

# **User-centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac Patients**

This thesis is submitted to the  
Auckland University of Technology  
in partial fulfilment of the degree of  
Master of Arts (Art and Design)

Rosemary Walkinshaw, 2008

## **Attestation of authorship**

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements”.

Rosemary Walkinshaw

2008

## **Ethics approval**

This project has obtained ethic approval 07/37 from the Auckland University of Technology Ethics Committee on 12th June 2007.

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## **Abstract**

Coeliac disease is an intestinal disorder, requiring patients to maintain a life-long gluten-free diet to ensure better health and reduce the risks of osteoporosis, intestinal lymphoma and other associated diseases. Patients must have access to clear information about the disease and about what foods are safe to eat, detect foods that contain gluten and make adjustments that need to be made to their diet. There is very little well designed information currently available for Coeliac patients. Eating out and shopping in supermarkets can become a nightmare. A User-centred Design approach was used to generate information and insights on the Coeliac disease and patients' needs to conceptualise, design and evaluate an information handbook that is both functional and pleasurable to use. Questionnaires, interviews and focus groups were used to generate empirical data that guided a participative design process before the evaluation of the handbook. This project consists of a handbook as practical work that represents the main body of applied research. The practical work and the exegesis constitute 50% each of the thesis value.

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## Chapter 1: Introduction

*“Rather than investigate form from an external perspective as shape or visual pattern, [we] regard form as a synthesis of what is useful, usable and desirable — that is, the content and structure of performance, human affordances, and product voice. In essence, form becomes a temporal phenomenon of communication and persuasion, as human beings engage with products”. — Richard Buchanan (2001), Design Research and the New Learning.*

Richard Buchanan, writing in 2001, highlights a changing perspective in design research away from form as the primary subject matter towards the investigation of what makes a product useful, usable and desirable. Without disregarding the importance of the designers need to know how to create visual symbols for communication, Buchanan asserts that visual symbols have no significant meaning unless they become part of the living experience of human beings sustaining them in the performance of their own actions and experiences (Buchanan, 2001).

This project utilized User-centred methodologies in order to engage with and understand the people for whom the design was intended. The insights generated from this process informed and guided the design with the aim being to generate an effective product that strengthened and supported users in their actions. The formal outcome of the design process (the ‘product’) was a handbook for newly diagnosed Coeliac patients in New Zealand.

### **1.1 The problem**

Coeliac Disease is an autoimmune intestinal disorder. A reaction to gluten damages the lining of the small intestine, which results in the malabsorption of nutrients. People diagnosed with Coeliac Disease must maintain a life-long gluten-free diet to ensure better health, reduce symptoms and decrease the

risk of osteoporosis, intestinal lymphoma and other associated illnesses. Diagnosis is confirmed by a biopsy of the upper section of the small bowel. In the past few years more gluten-free products have become more available in supermarkets. However gluten can be detected in many unlikely foods, so it is important that Coeliacs have access to clear information about what foods are safe to eat and adjustments that need to be made to their diet. If gluten is not totally avoided the patient will not heal and will continue to damage the villi in the intestine.

Designed information for Coeliacs in New Zealand is limited. Currently the Coeliac Society (NZ) has a handbook which is given to new members, however the structure and content is ineffective and difficult to use. This handbook is produced as an A4 ring binder folder containing 30 double sided pages of photocopied text, making the information very inaccessible. The handbook does not promote a pleasurable experience, and further adds to the frustration of the condition and its restrictions. There is a clear need for an information handbook that better suits patients' needs.

In 'Design for Patient Safety: A System-wide designed approach to tackling patient safety in the NHS' design is discussed as '... A structured process for identifying problems and developing, testing and evaluating user-focused solutions' (2003). Effective visual communications can enable complex and varied information to be understood easily and intuitively. However confusing and/or complex designs are often off-putting and distracting. In the case of a handbook, poor design could result in information that may not be read or may be misinterpreted. For someone who relies on information owing to a medical condition this could be misleading and potentially harmful to his or her health.

## **1.2 The process**

In order to design an effective handbook for newly diagnosed Coeliac patients that was useful, usable and desirable, it was necessary to establish empathy with those that would use the design. To gain this initial understanding empirical research was conducted in the form of interview and questionnaire. Based on the findings this research generated, a prototype was then designed before being evaluated by a focus group. As the design process was iterative, more adjustments were made to the design after the evaluation and testing with the intention to meet users needs, expectations and desires in the best way possible.

This project adds to the body of research-based evidence about User-centred design processes, but positions itself within a communication design/information design framework. The benefits of incorporating User-centred methodologies into communication design practices are still being explored by researchers, but it is acknowledged that the inclusion of these methodologies can help designers find appropriate ways to reach viewers (Forlizzi & Lebbon, 2002). This research project aims to support this belief.

## **1.3 Thesis overview**

This thesis forms the written component of this Masters project. The following is a brief outline of each of the chapters:

*Chapter Two* reviews literature relating to the background of the study, before discussing literature relating to User-centred design and Information design. Sources of inspiration are also discussed and how they influence the project.

*Chapter Three* outlines the research methodology used in this study

*Chapter Four* presents the key findings of the fieldwork and discusses what importance these results have for the design of the handbook.

*Chapter Five* details the concept design and development of a handbook for Coeliac patients. This chapter covers design criteria, the phases of the design process and the development of a prototype.

*Chapter Six* details changes made to the design as a result of evaluations and feedback. This chapter discusses further concept design and development, and outlines the final design.

*Chapter Seven* provides a summary, overall insights gained from the study and concluding statements.

## Chapter 2: Literature Review

This research focused on the relationship people have with information using collaborative design processes. This means working with people is part of the process through to establishing the outcome of the project. This human-centred approach to the design and implementation of the handbook was based on a variety of literature. This review discusses these areas of research and what influence the literature has had on the project.

This literature review is in three parts:

- 2.1 User-centred design
- 2.2 Information design
- 2.3 Sources of inspiration

### **2.1 User-centred design**

User-centred design is a design philosophy which although practised in many ways is fundamentally about revealing the needs, wants and limitations of an interface or document, and adapting the design so it can meet these limitations and be improved. User-centred design has been a recognised design process since the mid 1980s. It is often associated with computer technology and web based interfaces, however it is certainly not limited to this field alone. More recently, communication designers have started to become aware that incorporating User-centred design methodologies into their design processes enables greater potential to understand and reach the people that come into contact with the design.

There is a rich selection of research available about User-centred design particularly in the field of Interface/Interactive design. Most articles have mainly been centred on human-computer relationships. In the 1980s with the emergence of new computers, everyday people started to try to use computers

but found them difficult to use. Research into usability gave rise to new disciplines such as 'Usability Engineering'. Much research went into making computers and interfaces easier to use for everyday people. Researchers such as Hollnagel & Woods (1983) discussed 'Cognitive Systems Engineering' (CSE) which aimed to understand the complexities of human-machine systems. Patmore & Mahoney (2003) explored Internet usability and user experiences through creating pleasurable interfaces. Jakob Nielsen and Donald Norman are likely to be the most well known researchers in this field with their extensive discussions on Web usability with a focus on usable information technology. Norman also devised 'principles of design', which aimed to facilitate the designer's task to guide the design past a purely intuitive practice. Whilst users are seen as central to the part of the development process (Abrams, Maloney-Krichmar, & Preece, 2004), most of the emphasis in this field is on usability alone. Although the theory involved in these processes should not be dismissed, this research acknowledges that usability is only one factor in the overall involvement with people and the design in this project.

Within the engineering/materials and processes discipline, there is much more of a focus on user-needs analysis techniques and findings (Lindgaard, G; Dillon, R et al., 2005) and the incorporation of the idea of 'pleasure with products' which surpasses factors beyond usability (Jordan, P.W., 1999). Insight into user needs therefore becomes key to understanding positive aspects of the user experience.

The interest in people and their experiences is an attempt to broaden knowledge about users. This may be seen as a response from the design community which has become aware of the shortcomings of some User-centred design practices where the 'intended use of the design does not translate into

its actual use' (Redström, 2006). The belief that the insufficient knowledge about people plays a factor in inadequate design outcomes has led to a variety of new methods to generate better understanding.

Some of these methods, however, are not based around usability alone. Redström (2006) warns of the problematic nature of "over-determining use". He states: "we ... risk trapping people into a situation where the use of our designs has been over-determined and where there is not enough space left to act and improvise" (Ibid). His concern here is to do with designers not taking the complexities and subtleties of the actual use into consideration. He reminds us that in User-centred and/or Participatory design processes we are only dealing with abstract notions of use and experience. He also prompts us that objects are not used before they exist, therefore a person cannot be 'a user of an object' before it exists (p.129). From an epistemological point of view, this matter is important for designers to acknowledge, as it makes it clear there will most likely be "a difference between the intended use that governs the design process and the eventual use of the resulting design" (Redström, 2006).

These ideas signal a shift from the straightforward notions of usability design with efficiency in mind. Whilst clearly efficiency is one of the intentions of User-centred design, it is not the only objective. When involving people in the design process designers need to acknowledge that they are dealing with complex factors in human-object engagement. To simply design for usability (and therefore productivity in many cases) could potentially overlook some real user needs which would aid a more pleasurable interaction between person and product/object.

Participatory design methods can be used within User-centred design processes to take into account a

broader understanding of needs. Participatory design has its roots in both the U.S. Labour movement and the Scandinavian Industrial Democracy movement in the seventies, which established the rights for worker representation with workplace technology. The role of Participatory design was a mediating one, and scholars believed it empowered workers by accounting for their perspectives in design processes. Nieuwsma (2004) states that Participatory design scholars also saw an “opportunity to empower workers in ways that do not run directly counter to the authority of management”. Although grounded in computer information technologies, Participatory design methods are now being applied to other design disciplines such as architecture and product design.

Paul Nini (2005) discusses incorporating Participatory design methods within a graphic design framework. Nini suggests using the Participatory research method as a ‘part’ of the design process for conducting user or audience research, and to use it alongside other methods such as ‘Survey research’ and ‘Behavioural research’. On participatory research he states: “(it) can allow for a partnering with users to create communications that meet specific needs for particular contexts” (Nini, 2005). Nini also suggests that designing effective communications for audiences and users is “one of the most important contributions to society” and goes further to assert that “... this goal cannot be achieved without first making the step to identify and include those individuals for whom we design, so they may fully participate in the process of creating useful communications” (Nini, 2005).

In ‘From Formalism to Social Significance in Communication Design’ (2002) Jodi Forlizzi and Cherie Lebbon reiterate what both Nieuwsma and Nini have discussed. By including User-centred, interdisciplin-

ary methodologies within communication design practices, they state that: “When designer and viewer are actively involved in a shared dialogue, both become active participants in the creation and interpretation of the visual message. As a result, the designer is empowered, shifting from a decorator of messages to an agent who has influence on the social implications of delivering a visual dialogue” (Forlizzi & Lebbon, 2002).

In relation to this project, Participatory design methods in conjunction with empirical User-centred design methods, have been used as part of the research process to gain insight into the broader needs, wants and desires of the people using the design.

## **2.2 Information design**

*“The art and science of preparing information so it can be used by human beings with efficiency and effectiveness”*  
(Jacobson, 1999)

Information design is often multidisciplinary, drawing influences and processes from a range of fields such as computing, ergonomics, graphic design, typography, applied psychology and editing amongst others. It is understood that the discipline emerged as a response to people’s need to understand the information contained in such things as computer interfaces, forms, legal documents, signs and operating and assembly instructions (Walker & Barratt, 2007).

The belief that the origins of Information design coincide with the rich economy of 1914 America (Stiff, 2005) aligns to some of the needs mentioned above. Burgeoning companies during this time financially backed the research and development of graphical information materials for customer communication. Good communication in the form of signs, legal

documents, operating instructions and other forms ensure established brand values are maintained. Information designers responding to these needs still happen today, with the understanding that good Information design can lead to better efficiency within companies as well as customer satisfaction.

Alongside the financial support from commerce, the US Department of Defence has significantly contributed to the development and application of Information design. Walker & Barratt (2007) believe that Information designers “play a vital role in making complex information easy to understand and use”. This was certainly evident in the materials produced for the Defence Force post WWI; research into the area of operational diagrams was extensive. Complex operational diagrams needed to be understood quickly and effectively in training situations, and the Defence Force was prepared to provide the backing support to ensure objectives were met.

With this in mind, Stiff (2005) argues that the main impetus and driving force behind the development of design knowledge and of ideologies of design are the ‘purchasers of design’ (Stiff, 2005).

Today, Information design’s main role is still located and advanced within business situations. Effective Information design can economically benefit businesses, particularly through maintaining (and enhancing) brand values and customer satisfaction. Rob Waller elaborates on this:

“When a company conveys a vision of itself, there's promise and reality. The promise is delivered by promotional items; reality is often delivered by information design; and it's the quality of reality which leads to further business” (Waller, 1994).

Customer and business relationships can be complex. Effective Information design can be key to managing these relationships and ensuring optimum customer communication.

### **2.2.1. The relationship between people and Information design**

User-centred design practices are integral to Information design. Without considering the relationship that people have with the information produced, the purpose of the designed information becomes redundant. David Sless defines the role of an Information designer as such:

“Information designers create and manage the relationship between people and information so that the information is accessible and usable by people, and they provide evidence that the information is usable to an agreed high standard” (Sless, 2007).

Here, Sless emphasises that a relationship between people and the information occurs. This relationship can be evaluated to determine the success of the designed information. The main purpose of Information design is that the information will be used in order to help people achieve their goals. The ‘goals’ are contextual, and it is the Information designer’s responsibility to assess each situation, and all the factors that are likely to influence the design. This can be achieved by involving the people that would use the information in different phases of the design development.

Karabeg (2003) suggests “to design information, one would need to look at the culture, which is the whole within which information has the role”. Sless (2004) emphasizes the social role of Information design, stating that public documents are a matter of social agreement. It is clear therefore in relation to this project, that the designed information should

not be created in isolation. However, simply just including potential users in the process development is not enough. The role of participants in the design process must be defined and clarified.

Designed information, as already mentioned, is produced with a clear purpose in mind to help people achieve their goals. People must be included in the design process for the information to achieve its best results. However, an explicit understanding of these goals is needed, and systematic and directive methods must be implemented when involving people otherwise time and resources will be wasted.

When one designs information, they also design for 'goals'. However, it is helpful to maintain an awareness of how complex human-object relationships are to ensure the methods used to reach these goals are not too over-prescribed, and there is room for flexibility depending on the situation.

### **2.2.2. Information as a perspective**

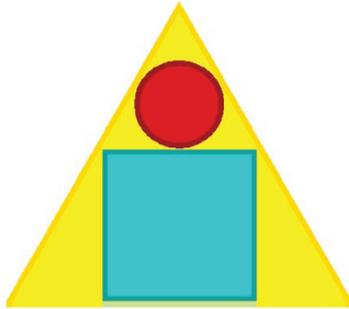
*"Information needs to provide a clear and correct perspective".*

(Karabeg, 2003)

Karabeg believes when designing information we should pursue the 'perspective'. He differentiates 'the perspective' from traditional informing in the way it can 'see through' an issue or phenomenon and therefore "create well-proportioned views, point out that which is essential and 'tell the whole truth'" Karabeg (2003).

In contrast, traditional informing usually favours factual truth, which can lead to focussing attention on 'spectacular events' and mass of detailed and precise information, which can be difficult to see through. In order to achieve a correct perspective, Karabeg believes the Information designer needs to allow for

the integration of diverse ‘views’. The Polyscopic information ideogram (Figure 1) represents this idea (Karabeg, 2003).



**Figure 1**  
Dino Karabeg (2003)  
The Polyscopic information ideogram

In the Polyscopic information ideogram, information is ordered into coherent scopes. According to Karabeg, a scope provides a “single angle of detail and angle of looking” Karabeg (2003). The Polyscopic model allows two diverse sets of information to become integrated. The square provides low-level information, which is precise and detailed information. This makes the information reliable. The circle represents a high-level view, which provides a larger picture. This allows for the person using the information to choose their own direction, and to make choices. Grounded on low-level precise and accurate views, the high-level information therefore becomes reliable. The two views balance each other out and work together.

Karabeg (2003) states that the purpose of the Polyscopic modelling is to “support the conscious choice of information”. He advocates that the importance of this is the role information plays as part of culture: “Information must be perceived as part of a larger whole, the culture. It must be created and chosen according to its role within the culture” Karabeg (2003).

Sless (2004) reinforces Karabeg’s ideas by asserting that the “new standards of public documents are a matter of ‘social agreement’”. These standards should not be decided alone by the designer, rather the designer should ‘guide the process of social decision-making’ by asking the following questions:

1. What is socially desirable?
2. What is the current performance of the document?
3. What is practically achievable?
4. What is socially acceptable?

All these questions focus our attention that the document/information material has a role as part of culture. Sless further reinforces Karabeg's concept of the Polyscopic information model, by stating that in order to produce documents of a high standard, we need to build new practises on the old (Sless, 2004). He believes that traditional, well-established practises should not be abandoned, but should be used 'as a bedrock on which new methods build'. Here, the necessity to integrate high and low-level information together is reinforced.

### **2.2.3 Integration of heterogeneous views**

"None of these traditional skills can be dispensed with in the new practices. It is the way in which the old and the new are unified that makes these results achievable in practice". (Sless, 2004)

Based on the literature covered, Information designers need to integrate heterogeneous views in order to portray a correct perspective. These views include the use of traditional processes as well as new ideas to achieve the best results.

Sless (2004) believes that traditional processes are the bedrock on which new methods are built. He lists these processes broadly as 'Writing', 'Designing', 'Editing' and 'Reviewing'. These processes are complemented with the new iterative, User-centred diagnostic methods.

With reference to Karabeg's discussion of ordering information, traditional and new processes fit into both high and low information scopes depending on what the process offers.

For example, for a document to achieve its purpose or goal, it must firstly be read (Sless, 2004). To encourage reading Sless states that the user needs

to perceive the document as 'credible'. Pettersson (2007) emphasises this by stating that: "High credibility sources exert a more persuasive influence on the receivers than low credibility sources. Receivers believe in a message of high credibility" (Pettersson, 2007).

The processes involved in achieving this attribute can be considered as 'low-level information', which are characteristically perceived as precise, authoritative and accurate. Traditional design processes involving typography and page layout can ensure that the material is legible and readable. Traditional writing and editing processes can employ structure, correct and clear terminology and general cohesiveness. Graphic design processes can ensure data is represented as understandable, clear and accurate.

New design processes ensure credibility by inviting feedback from potential users. The document can be evaluated and reviewed to assess its perception. This provides deeper insight into how the user really perceives the credibility of the material.

As already established, document/information material has a role as part of culture. Social relationships between organizations and the people who rely on that organization for information (e.g. a health provider and its patients) can be jeopardized if expectations are not met. Producing designed material that is aesthetically pleasing serves multiple purposes. Sless (2004) states that the importance of a document's attractiveness is about 'long-term satisfaction', enhancing 'the relationship between the reader and the document' (p. 26). The response a user has to the aesthetics of a document can add value and dignity to their task of reading (and therefore sustain reading) (Ibid) or conversely do quite the opposite. Zaccai talks of the role of aesthetics in design as such:

*“We need to understand that aesthetics is not simply a visual exercise, but rather the appropriate and harmonious balancing of all user needs and wants within technical and social constraints” (Zaccai, 1995)*

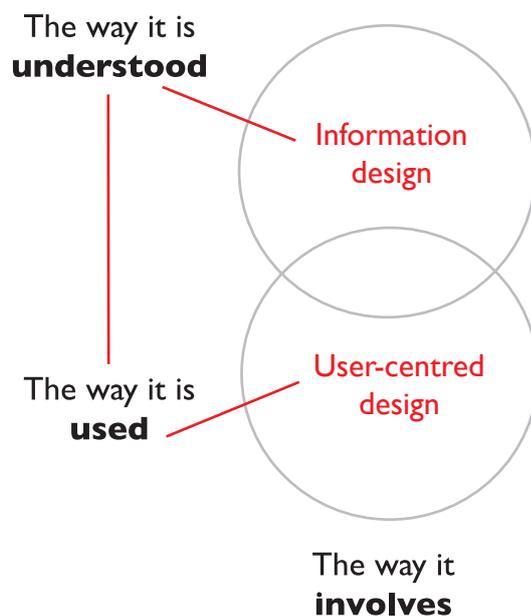
Aesthetics naturally fit within a ‘high-level information’ view. Traditional document design skills can be implemented as well as new processes. The combination of both traditional and new processes, along with the fact these views are founded on the more reliable, credible and authoritative low-level information means that information as a whole provides a more well-rounded perspective, allowing room for conscious choice.

### 2.3 Sources of inspiration

Alongside the body of theoretical research which guides this project, inspiration from visual sources have also been an integral research component. These sources have been categorised into three areas of influence. These areas surface out of the broader areas of study: Information design and User-centred design. Figure 2 represents this concept.

---

**Figure 2**  
Rosemary Walkinshaw  
(2007).  
Sources of inspiration  
NB: ‘it’ refers to the  
product, design or  
information material.



### 2.3.1 The way it is understood — Tufte and truth.

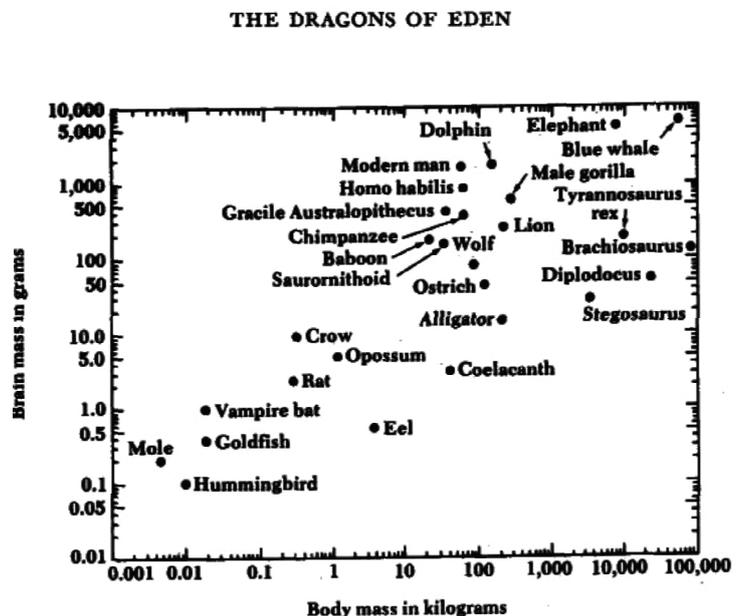
When it comes to visual communication, Edward Tufte is known by many as the primary authority on the presentation of information (AIGA, 2008). Labelled as ‘The Leonardo da Vinci of Information’, ‘The Strunk and White of graphic design and ‘The George Orwell of the Digital age’ (Smith, 2007), many designers, information architects, engineers and scientists alike admire and respect his work.

It has been quoted that Tufte’s ultimate goal is to “try and help people see better and more intensely” (Bonanos, 2007).

In his self-published books, Tufte tackles complex and/or confusing information. He provides case studies of redesigned examples which illustrate how his visual solutions make the information clearer, more user-friendly and more ‘truthful’. He believes that graphics can shape and distort our understanding of everything. He states: ‘bad graphics mangle the truth or lie outright by a myriad of design flaws’ (Smith, 2007).

Figure 3 shows an original version of a Brain Mass chart from Carl Sagan’s *The Dragon’s of Eden* which depicts the ratio of brain mass to body mass of 26 different species.

**Figure 3**  
Carl Sagan (1978)  
The Dragons of Eden. Brain Mass Chart

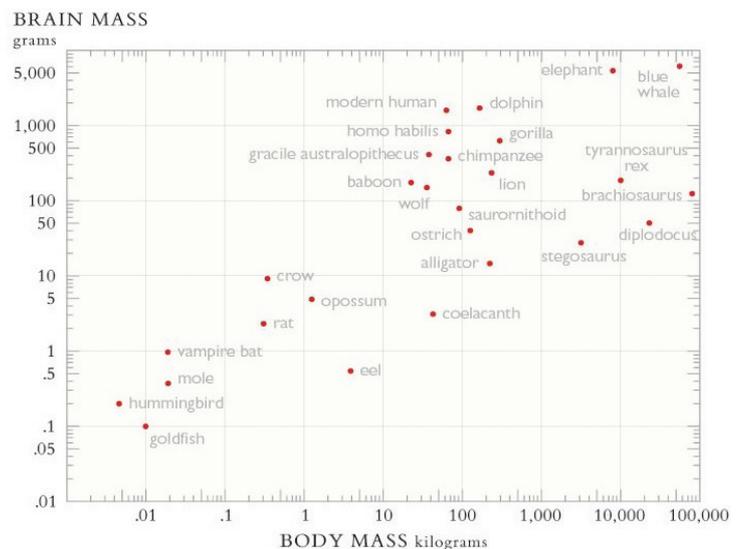


In one of his case studies, Tufte provides two examples of how design alterations can communicate this information more clearly, allowing less room for deception (Figure 4 and 5 overleaf).

To clarify the information Tufte adjusts the chart in the following ways:

1. The heavy black frame, which dominates the composition is removed and substituted for a grey frame, enabling the frame and the grid to recede.
2. Black is used for the logarithmic scale, which differentiates the scale from the other information, however the weight of the type and lines are reduced so the scale does not dominate.

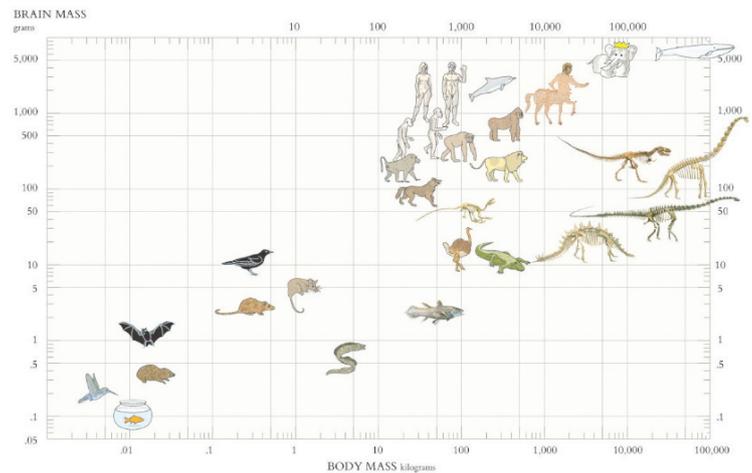
**Figure 4**  
Edward Tufte (2003)  
Brain Mass Charts  
(Version 1)  
Beautiful Evidence



In Figure 4, lines connecting data points are removed, and labels are spaced and adjusted to correct overcrowding and to avoid inappropriate visual connections. Red dots clearly cluster the information, amongst the grey type and grid lines. Label clutter is removed, but the labels are still there. Tufte states that: “Clutter is the failure of design, not an attribute of information” (Tufte, 2006).

In Figure 5 (overleaf) Tufte takes a lighter approach in the presentation of information. Figure 5 follows the same principles as Figure 4, but the graph has been redesigned to allow visual icons to be used as a

**Figure 5**  
Edward Tufte (2003)  
Brain Mass Charts  
(Version 2)  
Beautiful Evidence



replacement for the words which represent each species. He believes that “Visual problems should not be fixed by compromising the information”, and instead you should “fix the design” (Tufte, 2006).

Tufte’s views about how graphics can shape the understanding (or misunderstanding) of everything have raised concerns about how visual information should be represented in context of a handbook for Coeliac patients. Graphics which distort meaning or make the information confusing could lead to mistakes, which in the case of a person with Coeliac disease could cause unnecessary internal damage to that person’s intestinal lining.

On producing information that allows for a more truthful interpretation, Karen (Schriver, 1996) in *Dynamics in Document Design* adds to this approach:

*“Whether we call our audiences readers, users, customers or stakeholders they all want the same thing – to feel that someone has taken the time to speak clearly, knowledgeably and honestly to them”.*

### **2.3.2 The way it is used**

The representation of information in a clear and honest way is a very important element of Information design; it cements trust. The perception that the information is credible encourages reading (Sless, 2004).

Alongside encouraging reading, attributes that sustain reading are equally important for the information to be used to its full potential. Sless (2004) lists these attributes needed to sustain use of a document as:

1. Easy to use
2. Efficient
3. Productive

This section focuses on sources that have influenced the project in regards to function and use.

#### **Example 1: Royal Mail Instant Guide**

In 2002 Royal Mail required new reference publications for Post Office counter staff due to streamlining add-on services and the introduction of new prices.

Prior to its redesign, information was available to counter staff in the form of two separate reference volumes: an A5 ring bound Instant Guide and an A4 International Services Guide. In larger Post Offices, there was limited access to the International Services Guide ('Country Pages') (Boag, 2007).

Boag Associates were asked to improve access to this information. This was achieved by bringing the two volumes into one binder to keep all the information together.

To enable both guides to be used within the same folder, the A4 International Services Guide was reformatted and reworked to fit A5. Information was made easier to locate by breaking down the existing

Instant Guide into two sections. These were then wire-bound onto polypropylene fold out flaps, which meant they could be folded away when not in use to conserve desk space.

The redesign, as an integrated edition, cost Royal Mail £169,000 less in design and production costs than the previous separate versions. Alongside this, fewer look-ups and less time is needed (Boag, 2007) in order to send out a mail item due to clearer design and all information being contained in one edition. This design example had an influence on the conceptual development of the handbook concerning format, and how to integrate various sources of information in an easy to use, accessible way.

**Before:** Royal Mail International services covered in two separate volumes, one A5 and one A4



**After:** one A5 binder with fold-out sections

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### Figure 6

Boag Associates (2002)  
Royal Mail Instant Guide

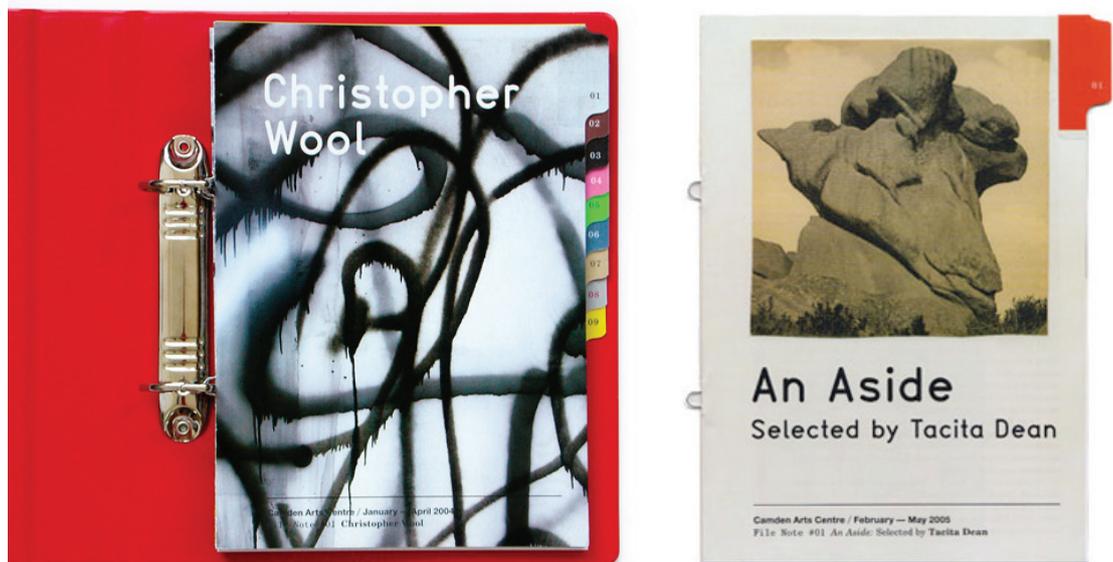
## Example 2: File Notes

As with the Royal Mail Instant Guide, this next example from graphic design studio Practice also deals with the question of how to integrate many sources together into a coherent whole.

File Notes is an ongoing project designed for the Camden Arts Centre. For every exhibition a File Note is designed as a supplement to the artists work.

Each booklet includes an essay about the artist, a biography, images of their work and a reading list. Each booklet can be collected separately or purchased as a set in the custom made ring binder.

The use of looped staples gives this document the flexibility to be read as individual notebooks on their own, or as part of a whole with the other tabbed sections. This choice of binding also enables content to be added to and removed (and revised) then replaced easily.



**Figure 7**  
James Goggin & Sara De  
Bondt, Practice (2004)  
File Notes

For this reason, File Notes is a source of inspiration for the project. The current Coeliac Society handbook that this project seeks to improve upon is in a ring binder so content can be replaced or added to easily. Information on Coeliac Disease and new food products is often changing, as research uncovers more information.

File Notes, with the utilization of looped staple binding and coloured tabs, presents an aesthetically pleasing, yet easy to use example that is also cost effective.

### **Example 3: COPD Academic Detailing Sheet**

Whilst both Example 1 and 2 demonstrate design focused on use, this next example is of particular importance to the project as it shows a visual outcome of a practiced User-centred process. This example (presented here still in its prototype stage of development), not only considers the question of use, but uses a design process based on a procedure developed by the Communication Research Institute of Australia (CRIA) to make sure the objectives of the document are being met. The procedure used also corresponds to Sless' list of attributes that are needed to sustain reading.

The example discussed is an evaluation and redesign of an Academic Detailing Sheet from the Alberta Drug Utilization Program. The sheet was produced to inform general practitioners about pharmaceutical drugs and their use in different situations (Frascara, 2007). The topic is Chronic Obstructive Pulmonary Disease (COPD). Figure 8 is an example of the sheet prior to evaluation and redesign. Figure 9 is the prototype developed by Frascara and Ruecker after evaluation.

The process included five steps out of seven that the CRIA usually use owing to time restraints. These steps included Scoping, Designing, Testing, Refining and Writing the final report. These steps enable product performance specifications to be developed. From this, criteria which benchmarks the prototype are produced, which is then tested and refined in an iterative way.

**SUMMARY OF CANADIAN THORACIC SOCIETY COPD GUIDELINES**

Chronic obstructive pulmonary disease (COPD) is a respiratory disorder largely caused by smoking. It is characterized by progressive, partially reversible airway obstruction, systemic manifestations, and increasing frequency and severity of exacerbations.

Smoking cessation is the single most effective intervention to reduce the risk of developing COPD and the only intervention that has been shown to slow its progression.

**Diagnosis**

A postbronchodilator forced expiratory volume in 1 sec (FEV<sub>1</sub>) of less than 80% of the predicted normal value and a ratio of FEV<sub>1</sub> to forced vital capacity (FVC) of less than 0.70 are both required for COPD to be diagnosed.

Most patients with COPD are not diagnosed until the disease is well advanced. Spirometry targeted at individuals who are at risk for COPD can establish an early diagnosis.

**Who Should Undergo Spirometry Testing to Detect COPD: A Decision Support**

- Smokers or ex-smokers 40 years of age and older
- Individuals with persistent cough and sputum production, with frequent respiratory tract infections, or with progressive activity-related shortness of breath.

**Evaluation of the COPD Patient**

Figure 1 shows a functional scale that is useful to assess shortness of breath and disability, and can assist in the evaluation of disease severity (Table 1).

Grade	Shortness of breath	Disability
Grade 1	Breathless with strenuous exercise	At risk (does not yet fulfill diagnosis)
Grade 2	Short of breath when hurrying on the level or walking up a slight hill	Mild
Grade 3	Walks slower than people of the same age on the level or stops for breath while walking at own pace on the level	Moderate
Grade 4	Stops for breath after walking 100 yds	Severe
Grade 5	Too breathless to leave the house or breathless when dressing	

Physical examination and chest x-rays are not usually diagnostic but are helpful to rule out comorbidities and complicating diseases. Arterial blood gases should be considered in patients with an FEV<sub>1</sub> < 40% predicted.

**COPD and asthma are fundamentally different and this diagnostic distinction should be made.**

COPD patients tend to have later age onset, a significant smoking history and slowly progressive symptoms over years. Patients with COPD never normalize their lung function.

Consider referral to a specialist when:

- Diagnosis is uncertain
- Symptoms are severe or disproportionate relative to the severity of air flow obstruction on spirometry
- Onset of symptoms is at a younger age (< 40 years).

Specialists can assist with the management of COPD patients who fail to respond to combined bronchodilator therapy, have severe or recurrent exacerbations, have complex comorbidities, require pulmonary rehabilitation, require assessment for home oxygen or may be candidates for surgical therapies.

*For complete guideline refer to: Can Respir J. 2003; May-Jun;19 Suppl 4:1214-654*

**Figure 8**  
Alberta Drug Utilization Programme  
Summary of the Canadian Thoracic Society COPD Guidelines

**SUMMARY OF CANADIAN THORACIC SOCIETY COPD GUIDELINES**

Chronic obstructive pulmonary disease (COPD) is a respiratory disorder largely caused by smoking. It is characterized by progressive, partially reversible airway obstruction, systemic manifestations, and increasing frequency and severity of exacerbations.

Smoking cessation is the single most effective intervention to reduce the risk of developing COPD and the only intervention that has been shown to slow down its progression.

**1 DIAGNOSIS**

**Required conditions**

A postbronchodilator forced expiratory volume in 1 second (FEV<sub>1</sub>) of less than 80% of the predicted normal value and a ratio of FEV<sub>1</sub> to forced vital capacity (FVC) of less than 0.70.

**Early diagnosis**

Most patients with COPD are not diagnosed until the disease is well advanced. Spirometry targeted at individuals who are at risk for COPD can establish an early diagnosis.

**Who should undergo spirometry testing to detect COPD**

- Smokers or ex-smokers 40 years of age and older.
- Individuals with persistent cough and sputum production, with frequent respiratory tract infections, or with progressive activity-related shortness of breath.

**2 EVALUATION OF THE COPD PATIENT**

The Medical Research Council Dyspnea Scale is useful to assess shortness of breath and disability, and can assist in the evaluation of disease severity.

**Assessing disability in COPD (Dyspnea scale)**

Grade 1 (none)	Breathless with strenuous exercise
Grade 2	Short of breath when hurrying on the level or walking up a slight hill.
Grade 3	Walks slower than people of the same age on the level or stops for breath while walking at own pace on the level.
Grade 4	Stops for breath after walking 100 yds.
Grade 5 (severe)	Too breathless to leave the house or breathless when dressing.

**Classification of disease severity**

COPD Stage	Symptoms
At risk (does not yet fulfill diagnosis)	Asymptomatic smoker, ex-smoker or chronic cough/sputum, but postbronchodilator FEV <sub>1</sub> /FVC > 0.7 and/or FEV <sub>1</sub> > 80% predicted
Mild	Shortness of breath for COPD when hurrying on the level or walking up a slight hill. FEV <sub>1</sub> /FVC < 0.7 and/or FEV <sub>1</sub> 60% to 79% predicted
Moderate	Shortness of breath causing patient to walk slower than people of same age on the level or stop after walking about 100 meters (or after a few minutes) on the level. FEV <sub>1</sub> /FVC < 0.7 and/or FEV <sub>1</sub> 40% to 59% predicted
Severe	Shortness of breath resulting in the patient too breathless to leave the house or breathless after dressing/undressing or the presence of chronic respiratory failure or clinical signs of heart failure. FEV <sub>1</sub> /FVC < 0.7 and/or FEV <sub>1</sub> < 40% predicted

Physical examination and chest x-rays are not usually diagnostic but are helpful to rule out comorbidities and complicating diseases. Arterial blood gases should be considered in patients with an FEV<sub>1</sub> < 40% predicted.

**COPD and asthma are fundamentally different and this diagnostic distinction should be made.**

**COPD patients tend to have:**

- later age onset,
- a significant smoking history, and
- slowly progressive symptoms over years.

Patients with COPD never normalize their lung function.

**Consider referral to a specialist when:**

- diagnosis is uncertain
- symptoms are severe or disproportionate relative to the severity of air flow obstruction on spirometry
- onset of symptoms is at a younger age (< 40 years).

Specialists can assist with the management of COPD patients who fail to respond to combined bronchodilator therapy, have severe or recurrent exacerbations, have complex comorbidities, require pulmonary rehabilitation, require assessment for home oxygen or may be candidates for surgical therapies.

**Figure 9**  
Jorge Frascara & Stan Ruecker (2004)  
Prototype for the new COPD

The case study (Medical Communications and Information Design) detailing all aspects of this study as well as the visual examples themselves was extremely useful in clarifying the methodology of the project and reassuring the processes effectiveness.

### 2.3.3 The way it involves

As already mentioned in section 2.2.2, information should be created and perceived as part of its role in culture, recognising the social role that information

can play. This example illustrates how, by utilising User-centred practices and involving people in the process, more effective communications and support tools can be established.

O'Donnell & Entwistle from the Medical School University of Aberdeen discuss what good medical information provide:

“‘Good’ information materials have the potential to enable people to participate appropriately in their health care. Depending on their focus and aims, they might for example, help people to engage in an informed way in discussions with health care professionals, to get involved in decisions about their care, and to take medicines in ways that are safe, effective and appropriate to their lifestyles.”

(O'Donnell & Entwistle, 2003)

A UK interdisciplinary team called RED attempted to address the complex social issues of supporting people with diabetes in Bolton to manage the disease effectively. By following a User-centred approach, RED attempted to look through the eyes of both end users and public services to understand why many people have difficulties in making lifestyle changes and carrying out effective self medication (Burns & Winhall, 2006).

RED's aim was to transform diabetes care, and empower patients to describe their needs. They recognised that a new kind of service and tools would be needed to achieve this.

Figure 10 provides an example of part of the overall outcome; a set of cards used as a tool to develop a personalised health care agenda. The cards were developed from initial focus group sessions. They can be used in a consultation to describe current life situations in multiple ways. The cards also work as a

tool for opening up dialogue about diabetes between two people (family, patient or care professional).

User research found that people with diabetes using the cards were able to speak more openly and honestly about how they were managing their health. Burns & Winhall (2006) conclude that the cards can “allow professionals to spend less time in diagnosis and more time developing a plan” (Burns & Winhall, 2006).

This final example was a great source of inspiration for the project. Firstly, it opened up the concept

of what form communication and Information design can be; effective Information is not necessarily the ‘traditional’ booklet with clear instructional graphics. Information should be designed according to what is revealed as the real needs of the user, and what would be most effective to meet those needs.

Secondly, this example is a reassuring case study of the potential outcomes of User-centred design. It is possible to help change behavior and improve the lives of others through creative, user-focused methods.



**Figure 10**  
Open Health & RED (2006)  
Self diagnosis cards for  
diabetes care

## Chapter 3: Methodology

Methodology is a term applied to the procedures and approaches used in an inquiry. This project utilized User-centred approaches to generate data that would provide insights to guide the practice-based component of this research. The focus of this project was to design a handbook for Coeliac patients that was useful, useable and desirable. In order to achieve this goal it was necessary to gain a deeper understanding of the people that would use the design. Empirical methods were formulated in this research to generate data that:

- Established an empathy with the user (understand feelings, attitudes and personal experiences associated with the disease and define issues Coeliac patients face)
- Formed a clearer understanding of the contexts in which Coeliac patients would use the design
- Established an idea/overview of current information material or support material available for Coeliac patients
- Evaluated how the designed material was used and assess if it met its purpose

Hanington (2003) and Sanders (2001) amongst others advocate that user-research begins in the very early stages of the design, including pre-ideation phases. Hanington suggests these early phases should be used to specify tasks and test ideas of 'product engagement and use'. The key in these early phases is to generate a broad contextual overview of the current document (how and why it is used).

This broad overview is an important phase in the design of documents. Many researchers have written about ways to include people in these early phases (Cassim & Keates, 2005; Frascara, 2007; Hanington, 2003; Sanders, 2001; Sless, 2004).

Frascara and Ruecker (2007) call this early stage of user research 'scoping'. They believe that scoping is an important first step in the process of designing information. Scoping defines 'product performance specifications', and provides the initial contextual overview of the product to decide how the document actually functions.

### **3.1 Pre-ideation phase**

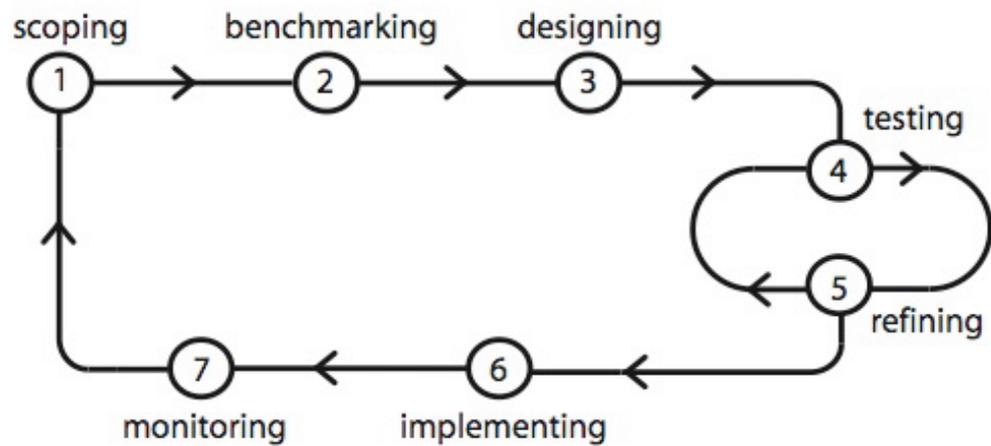
To generate this broad overview, empirical research using questionnaire and interview methods was implemented.

#### **3.1.1 Questionnaire**

The questionnaire aimed to seek information about experiences patients have had since they were diagnosed with Coeliac Disease. In order to achieve a non-biased result, members of the Coeliac Society were randomly selected from a range of locations around New Zealand in order to achieve an even-spread of responses. 167 people responded to the questionnaire (which is approximately 14% of the total members of the society). Questions were directed around their feelings and experiences adjusting to the gluten-free diet and any difficulties that they faced. The questionnaire then sought to establish what information materials patients require to guide their understanding of the disease, before asking questions directly related to the functionality and use of the Coeliac Society handbook.

#### **3.1.2 Interview**

Eight interviews were carried out to further broaden the researcher's understanding about users needs. The interviews were conducted on a one-to-one basis, which enabled the researcher to establish a rapport with each interviewee. Although the interviews addressed similar questions to that in the questionnaire, this method was able to draw out feelings and ideas that may not have been expressed



**Figure 11**  
 Jorge Frascara and Stan Reuker (2007)  
 ‘Scoping’ used as a first step in the iterative process

cations.

### 3.1.3 Collection and analysis of data

The final stage of the user-needs analysis was the collection and analysis of data. Data from questionnaires and interviews will be systematically analysed. Findings identified the needs of Coeliac patients. For a detailed analysis of the key findings please refer to Chapter 4.

### 3.2 Benchmarking

Journal articles, books and electronic sources provided the basis of the literature review. The literature review helped inform, contextualise and update the research with ideas and theories already being practised in the field. This information provided a benchmark for the design. The literature review also researched sources that inspired the designer, and therefore had an influence on the outcome of the design.

### 3.3 Design and evaluation

Pre-designs were developed after the user-needs had been established. Using heuristics, the pre-design phase was an attempt to consolidate the knowledge gained from the user-needs analysis. A list of performance specifications based on the data findings of the previous methods gave a guide for the designer to work to. The heuristic methods will follow a ‘trial and error’ approach and will require rigorous

questioning throughout the design process. Pre-conceptions will be addressed and continual critical questioning and reflection will be undertaken in this process.

Empirical methods were again used to evaluate the prototype. For the evaluation, focus groups took place. Following the feedback from the focus group more adjustments were made to the design so it better meets users needs. Heuristics were used when designing the handbook. It was intended that both methods were undertaken in an iterative manner. Interpretation and analysis was an ongoing process throughout the whole research project. Importantly, all analysis of data aimed to achieve a reflective viewpoint within a contextualised framework.

### **3.4 Interpretation and analysis of data**

The sole person transcribing the data was the researcher herself. There were three stages of the research that needed to be analysed:

1. Interview
2. Questionnaire
3. Focus Group

#### **1. Interview**

The first part of the interview analysis focused on key words and key concepts made by the interviewee. It explored connections and patterns based on the information gained as they talked through their experiences. Following this, the analysis focused on the transformation of the data by looking at and analysing the key words or ideas that were generated. These concepts were transformed into useful design criteria.

#### **2. Questionnaire**

Descriptive statistics were used to illustrate some of the basic patterns or features of the data in the study. This provided a useful summary in the study

of the participants' likes or dislikes and of their ideas of issues associated with Coeliac Disease. The descriptive statistics also showed how the participants perceive the current handbook available to them, and whether they believe the handbook is important.

### **3. Focus Group**

The focus group enabled the group to test whether the performance specifications established were reflected in the design. The focus group openly discussed perceptions and preferences, which were then analysed to inform and improve the final design of the handbook.

#### **3.5 Ethical approval and processes**

For a more detailed account of the methodological processes used in this research, including the sample questionnaire and interview questions please refer to the Ethics application in appendices A, B, C and D. For a detailed account of the transcripts of the interviews and focus group, please refer to Appendices F and G.

## **Chapter 4: Key findings (Results from fieldwork)**

This chapter discusses the significance of the research findings and their influence on the study. The chapter is divided into three parts. Part one presents key findings obtained from the questionnaire. Part two presents key findings of the interviews. Part three summarises the findings of the evaluation of the handbook, which took the form of a focus group.

Ethical approval to conduct this research was obtained on 9 July, 2007 (Ethics application number: 07/37). The Ethics application can be referred to in Appendix A. The application covers the reasons for involving participants in the study, the design of the questionnaire and interview questions, sampling procedure specifications, the type of information sought and the selection of participants.

### **Part 1**

#### **4.1 Questionnaire**

The questionnaire was designed to generate information about people's experiences with Coeliac Disease and the use of information material. Questions were designed to generate a contextual understanding. Qualitative and quantitative questions were included in order to employ a 'mixed method' approach (Trochim, 2006) and utilise the advantages of each method encouraging a wider variety of perception and insight.

#### **Part A: About you**

Part A of the questionnaire was directed towards identifying the demographic trend of the participants. These included questions about gender, age, ethnicity and language. These questions framed the contextual basis of the people that would use

the design. Although questionnaires were sent out to an equal number of both male and females in the Coeliac Society, most of the respondents were female (74%). A wide range of ages participated in the questionnaire, including under-16 year olds, but parents filled out these responses and stated this on the questionnaire.

Part A: Personal Information (About you)			N=Total Number of participants = 100%	
Questions	Information	N		100%
Gender	Male	42	N=164	26
	Female	122		74
Age group	0-9	9	N=163	6
	10-19	20		12
	20-29	11		7
	30-39	17		10
	40-49	31		19
	50-59	28		17
	60-69	28		17
	70+	19		12
Ethnic group	European/Pakeha	161	N=164	98
	NZ Maori	2		1.25
	Samoan	0		0
	Cook Island Maori	0		0
	Tongan	0		0
	Niuean	0		0
	Tokelauan	0		0
	Fijian	0		0
	Other Pacific	0		0
	Chinese	0		0
	Indian	0		0
	Other	1		0.75
First language	English	161	N=165	97.5
	Other	4		2.5

**Table 1**  
Personal information of questionnaire participants

The average age of respondents was 44.08 years. There were overwhelmingly more European/Pakeha respondents than any other group (98%). As the questionnaire was sent out to a random selection of Coeliac Society members, this indicates that most members of the Coeliac Society are from European

backgrounds. There were two New Zealand Maori respondents, and one Dutch respondent.

### **Part B: Coeliac Disease and you**

Questions in Part B of the questionnaire were designed to identify some of the factual details about the participant and their diagnosis. These questions ask whether the participant is diagnosed with Coeliac Disease, Dermatitis Herpetiformis or both, how long they have been diagnosed for and whether anyone else in their extended family has Coeliac Disease.

<b>Part B: Coeliac Disease &amp; You</b>			N=Total Number of participants = 100%	
Question 5	Information	N		100%
Diagnosed with?	Coeliac Disease	158	N=164	96
	Dermatitis Herpetiformis	0		0
	Both	6		4

**Table 2**  
Information about participants' diagnosis (Question 5)

Table 2 indicates that a majority of participants in the questionnaire are diagnosed with Coeliac Disease (96%) and only 6% have Dermatitis Herpetiformis (DH) as well. This indicates that some information could be included in the handbook about DH, but as only a small percentage would need to refer to it, it doesn't need to be extensive.

The average length of time that questionnaire participants have been diagnosed for is 8.27 years. This means that many participants in the questionnaire have been diagnosed for several years and are likely to be fairly knowledgeable about the gluten-free diet. This result may also explain later in the questionnaire why so many respondents do not use their handbook anymore, as several years have allowed time to adjust to the gluten-free lifestyle, and to understand information about Coeliac Disease.

Part B: Coeliac Disease & You	
Relation	Frequency
Mother	5
Father	1
Sister	8
Brother	5
Daughter	8
Son	6
Niece	2
Nephew	1
Grandson	1
Granddaughter	1
Aunt	3
<b>Female</b>	<b>27</b>
<b>Male</b>	<b>14</b>

**Table 3**  
Frequency of relations with Coeliac Disease (Question 8)

Table 3 shows the frequency of extended family relations with Coeliac Disease. 41 people responded to this question out of the total questionnaire recipients. Out of these responses, 27 had a female relation with Coeliac Disease (66%) and 14 had a male relation with Coeliac Disease (34%). Linked to the information produced in Part A, this indicates that there seems to be more diagnosed females with Coeliac Disease than males in New Zealand.

The second half of Part B (Questions 9, 10 & 11) asks participants questions on their perceptions of how often they would follow a gluten-free diet, how aware they think

they are about Coeliac Disease and how informed they think they are about gluten-free foods and the gluten-free diet. These questions allowed the participant room to comment at the end of each question allowing greater insight into the perceptions of respondents.

Part B: Coeliac Disease & You			N=Total Number of participants = 100%	
Question 9	Information	N	100%	
How often do you follow a gluten-free diet?	All of the time	137	N=164 83	
	Most of the time	26		16
	Sometimes	1		1
	Occasionally	0		0
	Never	0		0

**Table 4**  
Information about how often a gluten-free diet is followed (Question 9)

The multiple-choice scale in Question 9 indicated that 83% of respondents believed that they followed a gluten-free diet all of the time. However, the comments in Question 9 revealed that whilst most try to follow the gluten-free diet, they still make mistakes – usually when eating out. Only one person said they only follow the gluten-free diet ‘sometimes’, yet at least two suggested on the comments that they still eat gluten-containing foods regularly. When observing the comments alongside the multiple-choice

scale, it appeared that most people want to think they do follow a strict gluten-free diet, however this is not always the case – either due to ‘mistakes’ or because of conscious choice.

<b>Part A: Personal Information (About you)</b>		NB: For the complete list of comments on this question see Appendix E.
Question 9	Comments	
How often do you follow a gluten-free diet?	<ul style="list-style-type: none"> <li>• No point of being on a diet if you are not going to follow it</li> <li>• Strictly adhere to the diet</li> <li>• Minor mistakes sometimes</li> <li>• Try to stick to it all the time, but I’m sure some gluten gets through</li> <li>• I try as much as possible to follow a strictly gluten-free diet, although I find that when I eat out (family, restaurants) sometimes food is not completely gluten-free</li> <li>• I sometimes have a gluten containing goody</li> <li>• Except when going out to dinners, B’day parties etc</li> <li>• One item a day with gluten</li> <li>• Have become somewhat “tolerant” (not sure what damage has been done on the inside) – symptoms have become less severe</li> </ul>	

**Table 5**  
Comments about how often a gluten-free diet is followed (Question 9)

Question 10 revealed that a majority of respondents (71%) believed they are ‘very aware’ about Coeliac Disease, with 26% of respondents stating that they are ‘aware’. Only one respondent was ‘very unaware’. The amount of people that stated that they were ‘very aware’ could possibly be due to the length of

<b>Part B: Coeliac Disease &amp; You</b>			N=Total Number of participants = 100%	
Question 10	Information	N		100%
How aware do you believe you are about Coeliac Disease?	Very aware	118	N=164	71
	Aware	42		26
	Somewhat aware	3		2
	Unaware	0		0
	Very unaware	1		1

**Table 6**  
Information about how aware participants are about Coeliac Disease (Question 10)

time participants had been diagnosed who took part in this questionnaire (an average of 8.27 years), which is ample time to become aware of Coeliac Disease.

The comments section suggested that participants have made an effort to become aware by conducting their own research. There was also recognition that it takes time to learn about Coeliac Disease and gluten-free foods, and you learn as you ‘go along’.

<b>Part A: Personal Information (About you)</b>		NB: For the complete list of comments on this question see Appendix E.
Question 10	Comments	
How aware do you believe you are about Coeliac Disease?	<ul style="list-style-type: none"> <li>• Have read extensively on the topic – books and Internet and any other info that is passed on</li> <li>• Had it “all my life” so grown up with the diet and information</li> <li>• Lab background &amp; with family history have made a real effort to be aware</li> <li>• As informed as I can be. Always interested to hear about new research etc</li> <li>• My specialist gave excellent information and asked me to join the society. At first I refused but when I got less angry did join</li> <li>• You learn as you go along</li> <li>• Still learning about different hidden sources of gluten as I’m newly diagnosed - biopsy Nov 2006</li> <li>• Too early in the process to know all</li> </ul>	

**Table 7**  
Comments about how aware participants are about Coeliac Disease (Question 10)

Respondents of the multiple-choice section in Question 11 (overleaf) were not as confident of how informed they were compared to how aware they thought they were. Only 57% believed they were ‘very informed’, and 37% thought they were ‘informed’. This still indicated however, that most respondents believed they were reasonably informed. Only two respondents (1%) thought they were ‘not very informed’, and 8 people (5%) believed they were only ‘somewhat informed’.

Part B: Coeliac Disease & You			N=Total Number of participants = 100%	
Question 11	Information	N		100%
How informed do you believe you are about gluten-free foods & the gluten-free diet?	Very informed	93	N=163	57
	Informed	60		37
	Somewhat informed	8		5
	Not very informed	2		1
	Not informed at all	0		0

**Table 8**

Information about how informed participants are about gluten-free foods and the gluten-free diet (Question 11)

Part B: Coeliac Disease & You		NB: For the complete list of comments on this question see Appendix E.
Question 11	Comments	
How would you describe your feelings when you were diagnosed with Coeliac Disease?	<ul style="list-style-type: none"> <li>• The Coeliac Society and magazines are an excellent source of information and medical research. Also wonderful recipes, interesting articles written by Coeliacs throughout NZ</li> <li>• Dieticians and even doctors were not knowledgeable at first but my specialist was very helpful. I'm better informed now but still don't know much</li> <li>• But need to further research certain things which the information is not as readily available or is harder to find e.g. additive numbers and whether gluten is found in these additives and preservatives e.g. 450, 451, 452 etc</li> <li>• Self education is necessary</li> <li>• I could benefit more from information about food labelling and codes</li> <li>• Information more available than 10 years ago</li> <li>• Still learning</li> <li>• I believe my dietician could have given me more information</li> <li>• I am not a reader of what doesn't interest me. I need to become more interested</li> </ul>	

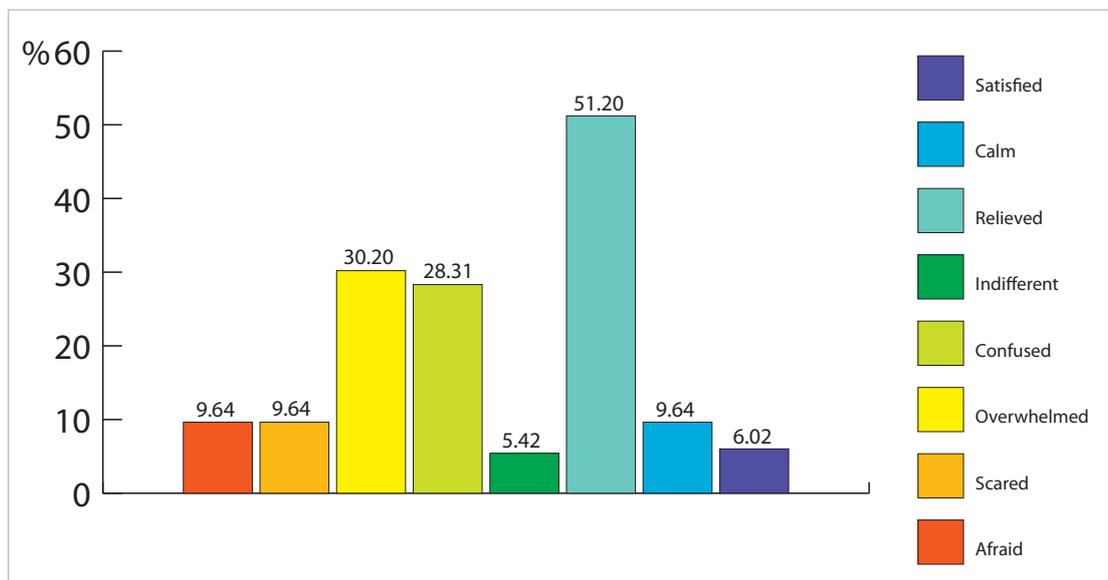
**Table 9**

Comments about how informed participants are about gluten-free foods and the gluten-free diet (Question 11)

The comments section of this question elaborated on this information by explaining how people were informed, why people chose to become informed, and areas they felt they thought they were lacking information in. The Coeliac Society of NZ was praised as a good source of information, whereas there was a general recognition that the information provided by dieticians was either minimal or not helpful. There was a general response from these comments that people needed to inform themselves through self-education, and some types of information were still found confusing, particularly additive numbers. One respondent stated that they did not read information they didn't find interesting, which is important to consider in the design of the handbook.

### Part C: Experiences with Coeliac Disease

Questions in Part C of the questionnaire were designed to enable participants to express their experiences with Coeliac Disease. These questions asked participants to describe their feelings when



**Figure 12**  
Feelings when diagnosed  
(Question 12)

they were diagnosed; to express how easy or difficult it had been changing to a gluten-free diet and what activities were impacted by this change.

Part C then went on to ascertain what feelings participants might share about having Coeliac Disease, before asking questions about compliance to the

diet. The last section of Part C focussed on the concerns participants may have when eating out. In Question 12 (Figure 12) just over half of the respondents (51.20%) stated that they felt 'relieved' when diagnosed. This was explained further in the comments with many stating they thought they may

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 12	Comments	
How would you describe your feeling when you were diagnosed with Coeliac Disease?	<ul style="list-style-type: none"> <li>• Annoyed!</li> <li>• With dramatic weight loss, severe cramping and diarrhoea I was convinced I had cancer</li> <li>• Angry, frustrated. I didn't have these feelings until I was 14</li> <li>• When a person has been unwell for some time it is a huge relief to finally know the cause</li> <li>• I had never heard of 'Coeliac' before being diagnosed</li> <li>• Shocked. I was 9 1/2 months pregnant when my 2 year old was finally diagnosed and was so worried</li> <li>• The diagnosis could have been much worse</li> <li>• Overwhelmed and indifferent especially when I knew what I could not eat anymore. Satisfied that my symptoms would stop with a gluten free diet</li> <li>• Relieved because I now knew what was wrong with me and that I could now get well</li> <li>• Because it explained why I felt so crappy and gave me a solution and control</li> <li>• Depressed</li> <li>• Mad, annoyed, unfair. I accept I have Coeliac disease, but still feel its unfair and still struggle with food to eat</li> <li>• Uncertain. Slightly overwhelmed and uncertain about what it would mean - what I would and wouldn't be able to eat</li> <li>• I was secretly hoping the diagnosis was wrong but my specialist has recently told me my biopsy was an open &amp; shut case I.e. it was very obvious</li> <li>• It was a very difficult time. I was sick and had never heard of Coeliac Disease or what gluten was</li> </ul>	

**Table 10**  
Information about how participants described their feelings when they were diagnosed with Coeliac Disease (Question 12)

have had cancer instead, or that it explained what was wrong with them and that there was a way to get well. 30.20% of respondents felt 'overwhelmed', and 28.31% felt 'confused'. These results are help-

ful guides for the design of the handbook as they indicate it should be designed with an aim to reduce confusion and the feeling of being overwhelmed. In the comments many had never heard of Coeliac Disease before, or knew what foods contained gluten, and what they would or would to be able to eat. The same percentage of people felt ‘calm’, ‘afraid’ and ‘scared’ (9.64%).

Feelings of ‘satisfaction’ (6.02%) and ‘indifference’ (5.42%) were the least expressed. In the comments

Part C: Experiences with Coeliac Disease			N=Total Number of participants = 100%	
Question 13	Information	N		100%
How easy or difficult has it been for you changing to a gluten-free diet?	Very easy	13	N=160	8
	Easy	48		30
	Neither easy or difficult	34		21.25
	Moderately difficult	47		29.5
	Difficult	18		11.25

**Table 11**  
Information about how easy or difficult participants found changing to a gluten-free diet (Question 13)

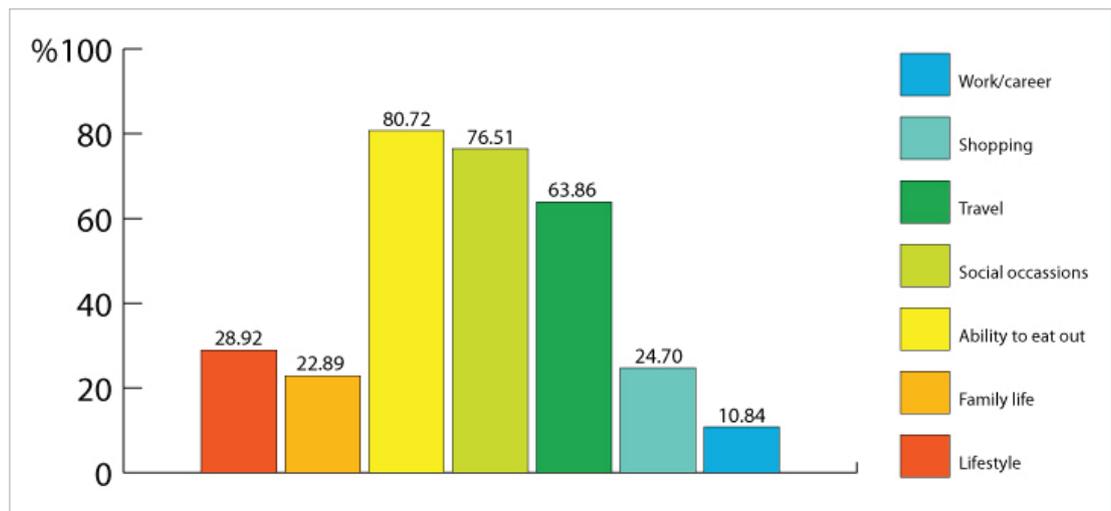
section many expressed that ‘it could be worse’ and some stated that they felt ‘angry’ and ‘shocked’. The results for Question 13 were fairly divided. Almost an equal number of respondents stated that changing to be gluten-free was ‘easy’ (30%) to the one’s that found it ‘moderately difficult’ (29.5%). Few people thought that changing to a gluten-free diet was ‘very easy’ (8%), and slightly more thought changing to a gluten-free diet was ‘difficult’ (11.25%). 34 respondents (21.25%) believed changing to a gluten-free diet was ‘neither easy or difficult’. These results indicate that approximately half the respondents believed the transition was reasonably easy, and half believed it was somewhat difficult. These results are clarified and explained by the comments respondents made in Question 13 (Table 12). Some state that changing to a gluten-free diet was very difficult, but in some cases this was due to being diagnosed at an earlier time when there were fewer

gluten-free products available. Many people commented that it was difficult at the beginning, but as they receive more information it became easier. These results suggest that the most difficult time for Coeliacs is when they are newly diagnosed. As they become more aware and informed the diet and lifestyle becomes easier. With reference to the design of a handbook, most people would benefit from this information when they are newly diagnosed. Information should therefore be focussed on this transition period.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 13	Comments	
How easy or difficult has it been for you changing to a gluten-free diet?	<ul style="list-style-type: none"> <li>• Initially difficult but as I had more information have found it easier</li> <li>• Once you gather all the info and understand labelling its easy</li> <li>• Easy because I was delighted I could do something to help myself get better. But on a practical level, it took a while to figure out exactly what/wasn't truly gluten free</li> <li>• The first year was the hardest</li> <li>• The lack of many GF foods and lack of labelling then was traumatic. Baking bread always flopped and ended up in the rubbish bin</li> <li>• Difficult when diagnosed as you could not buy anything ready-made in the shops then. Easy now except lunches when out</li> <li>• It was initially very difficult - took 6 weeks to see a dietician - too long</li> <li>• It was hard 11 years ago, but now it is easier</li> <li>• It gets easier each week since diagnosis</li> <li>• Living it away from the city made it more difficult because no specialist food was available. I didn't even know you could buy it</li> <li>• As an athlete, mother of a baby (now toddler) breastfeeding at the time and working part-time, found it difficult to get enough easy to reach carbohydrates</li> <li>• It was more difficult trying to explain to others why I kept refusing food</li> </ul>	

**Table 12**  
Comments about how easy or difficult participants found changing to a gluten-free diet (Question 13)

The results from Question 14 revealed that the activities that have impacted participants the most on a gluten-free diet are ‘the ability to eat out’ (80.72%), ‘social occasions’ (76.51%) and ‘travel’ (63.86%). ‘lifestyle’ (28.92%), ‘shopping’ (24.70%) and ‘family life’ (22.89%) were far less impacted by the gluten-free diet, and ‘work/career’ (10.84%) was the least affected.



**Figure 13**  
Activities that impacted participants on a gluten-free diet (Question 14)

117 people commented on this question in the questionnaire. Most of the comments were about eating out and social situations. There were many comments that a lot of restaurants do not have gluten-free food, or they serve limited items. Many responses also mentioned that there seems to be a general lack of understanding in restaurants and sometimes they get the food wrong. Comments related to social situations tended to focus on people’s perceptions towards a request for a gluten-free meal. Responses stated that people thought they were fussy, or that it was ‘just a fad’. Several people also mentioned that they feel awkward to ask for a gluten-free meal sometimes. In regards to travel situations, the main responses were about having to be more organised, having to think ahead and the difficulty of finding out where to locate gluten-free foods when away from home.

The responses in Question 14 (overleaf) highlight the difficulties Coeliacs have when eating out or explaining to people what their food requirements are. This feedback could be used to develop a tool (as part of the handbook) for people to use when eating out to make their situation easier.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 14	Comments	
Which activities have impacted you on a gluten-free diet?	<ul style="list-style-type: none"> <li>• Some restaurants/cafes don't serve GF food. Planned overseas travel may be postponed</li> <li>• Eating out: Being limited to a few items on the menu. Social Occasions: When someone else is cooking. Travel: Limited to deli/travel foods not many GF foods</li> <li>• Shopping takes longer - labels to read, prices high. Gluten-free food not always easily available when away from home</li> <li>• Because lots of restaurants or other people do not understand what gluten free &amp; therefore think you are being very fussy, but they don't realise what it can cause</li> <li>• Travelling is made difficult having to find out where to obtain GF food and what restaurants will provide GF food</li> <li>• Needing to inform people of dietary requirements. Travel requires more organization</li> <li>• Air NZ provides no GF on short trips eg pacific islands this is annoying and inconsiderate. Unable to find food in restaurants-it is always difficult eating at friends home</li> <li>• Unable to find GF food when out, confusion from other people or lack of understanding</li> <li>• Hard to find GF foods when eating out and feel awkward to ask sometimes</li> <li>• Always have to phone ahead for restaurants (weddings). Always have to have some of my own food for social occasions. Real pain. Many people can't be bothered. Think I'm fussy</li> <li>• Mainly through having to ring restaurant etc before going and having to explain to people who don't understand and think it's just a "fad". When I was first diagnosed even my doctors hadn't a clue about it. It is getting better now as through publicity more have learned about it</li> <li>• Not being able to go where my friends go and eat the same food they eat, so I feel different and left out</li> <li>• Always having to think ahead (travelling/eating out) no spontaneity</li> </ul>	

**Table 13**  
Comments on activities that impacted participants on a gluten-free diet (Question 14)

Part C: Experiences with Coeliac Disease						
Question 15: Please circle the number that best represents your answer						
Feelings associated with having Coeliac Disease	Participants who share these feelings					N
	All of the time	Most of the time	Some of the time	Rarely	Never	
Feel left out from activities with friends and/or family	4	2	51	55	48	160
	2.5	1.25	32	34.25	30	%
Feel different from other people because of Coeliac Disease	6	14	55	45	40	160
	3.75	8.75	34.5	28	25	%
Feel embarrassed to bring gluten-free food along to social occasions	10	16	41	36	60	163
	6	10	25	22	37	%
Feel angry about having to follow a special diet	6	9	45	42	57	159
	3.75	5.5	28.5	26.5	35.75	%
Feel that friends and/or family don't understand	1	9	55	28	66	159
	0.65	5.65	34.60	17.6	41.5	%
Feel that you can be healthy without having to follow a special diet	4	4	10	24	113	155
	2.5	2.5	6.5	15.5	73	%
Feel worried about the long term affects of not following a gluten-free diet	22	23	28	32	47	152
	14.5	15	18.5	21	31	%

**Table 14**  
Information about the feelings participants have associated with having Coeliac Disease (Question 15)

Question 15 was designed to enable participants to share the feelings they have about having Coeliac Disease. Most of the participants responded positively. A majority responded as never feeling embarrassed to bring food to social occasions (37%), never felt angry about having to follow a special diet (35.75%), never felt that friends or family didn't understand (41.5%) and never felt worried about the long-term affects of not following the diet (31%). A majority 'rarely' felt left out from activities with friends or family (34.25%). 73% never felt they could be healthy without having to follow a special diet,

indicating that in general participants understood maintaining a gluten-free diet was essential to their well-being.

When it came to ‘feeling different from other people because of Coeliac Disease’ a majority of responses said they felt this some of the time (34.5%), and many still felt left out from activities with friends or family some of the time (32%). A reasonably high proportion of respondents (34.60%) also indicated that some of the time they felt friends and family didn’t understand.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 15	Comments	
Comment about your feelings associated with Coeliac Disease?	<ul style="list-style-type: none"> <li>• Never worried because I do follow a GF diet. However if not followed, effects would be a concern</li> <li>• Always follow the diet, only embarrassed when certain people hassle my food</li> <li>• Used to feel angry, but only for the first year. Not worried, but its pretty obvious that one does need to follow GF diet</li> <li>• I am more confident now - but it was not always like that. Very frustrating for some years</li> <li>• I feel embarrassed to mention my new gluten free diet in new social situations eg visiting relatives for the first time since diagnosis or restaurants, new work situations (morning teas etc)</li> <li>• Only feel that friends and associates don’t understand. Family understands well</li> <li>• Sometimes feel bad about telling folk gluten-free if going to their place for a meal</li> <li>• Family and friends aren’t an issue so much as trying to explain it people I don’t know. Often there is a lack of understanding with strangers (restaurants etc). I would say that I feel bad ‘most of the time’ at work, conferences, visiting (part of job) travelling and eating out where it is part of a job function</li> <li>• Angry - maybe annoyed some of the time to most of the time. But feel it is denial and refusal to learn more about dietary needs</li> </ul>	

**Table 15**  
Comments about the feelings participants have associated with having Coeliac Disease (Question 15)

These figures are also reflected in the comments for question 15 (Table 15). The main point that was raised was feeling embarrassed having to tell people they are gluten-free, and feeling frustrated with lack of understanding. Some explained that they are never worried about the long-term affects because they know they follow a strict gluten-free diet. A couple of participants noted that they feel angry, or used to feel angry, about having to be on the diet.

Question 16 revealed that most of the participants (69.37%) believed their compliance to the gluten-free diet was very good, 24.37% believed their compliance to the diet was good and 5.65% of participants believed their compliance to the diet was reasonable. No participants in the questionnaire stated their compliance to the diet was poor, but one participant believed their compliance to the diet was very poor.

Part C: Experiences with Coeliac Disease			N=Total Number of participants = 100%	
Question 16	Information	N		100%
How would you rate your compliance to the gluten-free diet?	Very good	111	N=160	69.37
	Good	39		24.37
	Reasonable	9		5.65
	Poor	0		0
	Very poor	1		0.65

**Table 16**  
Information about how participants rate their compliance to a gluten-free diet (Question 16)

The results from Question 17 (overleaf) indicated that eating out had a significant affect on their compliance to the gluten-free diet. 133 out of 159 respondents (83.60%) stated that eating out affected them at least 'some of the time' to 'often'. Paying more for speciality gluten-free foods had the biggest effect on compliance to the diet, with almost half of respondents (48%) stating that this affected them often. Travel was another situation that had some affect on compliance to the diet, with 31% stating that it affected them fairly often.

Finding gluten-free foods in supermarkets, finding good gluten-free recipes and eating food containing gluten by accident did not affect compliance to the diet as much, but still had an affect at times. Staying in hospital had the least impact; 41% of respondents to this question said it 'did not affect them at all'.



The comments in question 17 (Table 18) reiterated that eating out could affect compliance and many either abstain from eating out or have to explain clearly to those preparing the food. Even after explanation, sometimes gluten is still contained in the food and eaten by the Coeliac by mistake. Not as many answered the question about staying in hospital (115 responses), and this was explained in the comments by many stating they had not been in that situation.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 17	Comments	
Please indicate situations that make compliance to the diet more difficult?	<ul style="list-style-type: none"> <li>• I end up doing a lot of cooking when people cannot guarantee a gluten-free meal</li> <li>• Do not as a rule eat takeaways</li> <li>• Used to be almost impossible to get food out or in the hospital but now most places can provide at least fruit or yoghurt</li> <li>• Have not experienced staying in hospital. Paying more affects me, but I don't opt for cheaper gluten containing products</li> <li>• Takeouts are very limited. Some supermarkets are better than others</li> <li>• Very hard to find cheap gluten wheat free flour. Too dear</li> <li>• Eating foods by mistake doesn't affect me often, but the effect is severe. Very difficult to travel - I travel around NZ with my job and often can't choose where to eat</li> <li>• Food labelling</li> <li>• Possibly I could inadvertently eat gluten because ingredients listed are not recognisable</li> <li>• Need to be upfront and always ask (esp. friends) re ingredients. I don't like doing it and avoid it if I can (eating out like that!) except with the ones who really try to go out of their way to help</li> <li>• Sometimes trust restaurants with mixed results</li> </ul>	

**Table 18**  
Comments about what situations make compliance to the diet more difficult (Question 17)

The price of speciality gluten-free foods affected participants often. Some stated in the comments that whilst it affects them, they do not opt for cheaper gluten containing foods. This indicates that whilst this situation had a large affect on people, it may not have affected compliance to the diet for all of the respondents. Finally, food labelling was commented on as affecting compliance to the diet. Poor labelling either made selection difficult or unclear, which can lead to 'accidental gluten intake'.

The comments in Question 18 (Table 19) mainly focussed on food labelling, needing greater awareness and better selection of gluten-free foods in restaurants and cafes, making products cheaper and pointing out the need to be organised. Several comments mentioned ways of checking additives in supermarkets, and respondents suggested a list of ‘allowed/not allowed ingredients’ in the supermarket. One other respondent suggested a ‘credit-sized card’ to take with you to restaurants to give to restaurant staff which explains what you can/cannot eat. Both these comments were directly useful for the design of the handbook.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 18	Comments	
Do you have any suggestions that you believe could help compliance to the diet?	<ul style="list-style-type: none"> <li>• A list of allowed/not allowed ingredients to check on packaging</li> <li>• Info about GF foods in overseas countries especially non-English speaking countries</li> <li>• Planning; ready food in freezer. Self control - remembering the consequences</li> <li>• Being organised, making own bread, cakes and biscuits. Informing other people when eating out at restaurant/friends place</li> <li>• Even better food labelling. Lower prices on some GF items. Explanation of additive codes on labels</li> <li>• Making a lot of products cheaper</li> <li>• Yes: A special credit size card outlining your need to avoid all gluten to use at restaurants</li> <li>• More education about gluten in the service providers</li> <li>• Having lots of ideas for packed lunches as this is my major problem</li> <li>• More gluten free food available for lunches at cafes</li> <li>• Labelling has improved, but some additives not well labelled. * Lack of understanding by restaurant staff</li> <li>• Educate yourself/read labels. Ask questions/double check all answers in restaurants and ask to see the chef if unsure</li> <li>• More detailed food labelling e.g. instead of stating “vinegar” should specify type of vinegar. Food handlers in restaurants should be better informed</li> </ul>	

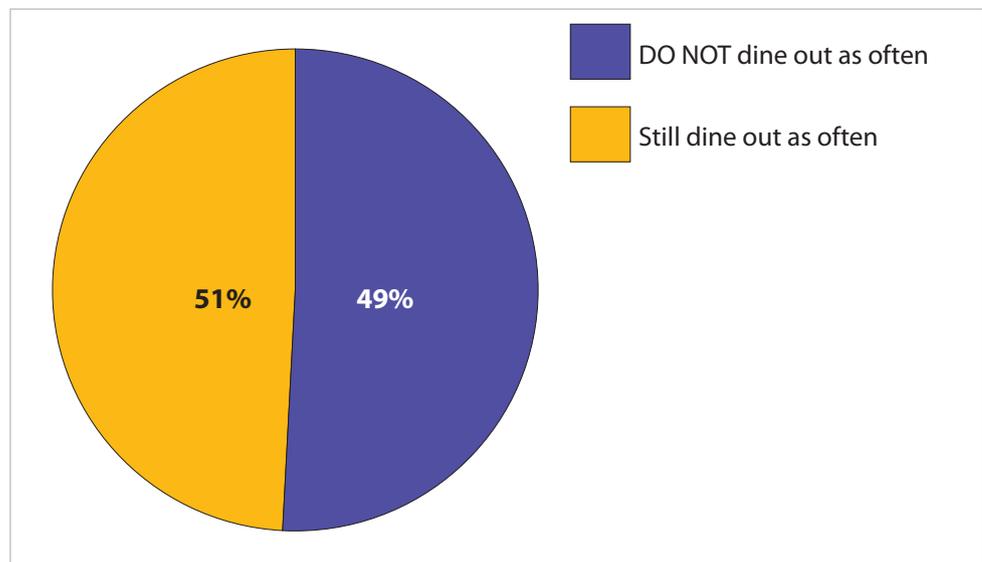
**Table 19**  
 Suggestions to help compliance to the diet (Question 18)

Question 19 (Table 20) asked participants how often they would eat out. 55 respondents (34.25%) stated they eat out rarely, however 36 respondents (22.5%) stated they still ate out once a week and 34 (21.25%) responded to eating out more than once a month.

Part C: Experiences with Coeliac Disease			N=Total Number of participants = 100%	
Question 19	Information	N	100%	
How often would you eat out?	More than once a month	34	N=160	21.25
	Once a week	36		22.5
	More than once a week	11		7
	Less than once a week	24		15
	Rarely	55		34.25

**Table 20**  
Information about how often participants eat out (Question 19)

This information is useful when viewed alongside the results of Question 21 (Figure 14), which shows that although a lot of people indicated they still dine out regularly, almost half (49%) of respondents now dine out less often, which is significant.



**Figure 14**  
Pie graph indicating whether or not participants still dine out as often now they are diagnosed with Coeliac Disease (Question 21)

Question 20 (Table 21) reveals that most people fall within the range of neither easy or difficult (40.5%) or difficult (37.45%) when finding places that serve gluten-free food. A small percentage (3.05%) found it very easy, and a slightly larger percentage (6.75%) found it very difficult. 20 people (12.25%) think it is easy to find places that serve gluten-free food.

Part C: Experiences with Coeliac Disease			N=Total Number of participants = 100%	
Question 20	Information	N	100%	
How easy or difficult do you find places to eat that serve gluten-free food?	Very easy	5	N=163	3.05
	Easy	20		12.25
	Neither easy or difficult	66		40.5
	Difficult	61		37.45
	Very difficult	11		6.75

**Table 21**  
Information showing how easy or difficult it is to find places that serve gluten-free food (Question 20)

105 people responded to Question 22 (Table 22 - overleaf), and there were common points that were raised. Many mentioned feeling frustrated and embarrassed. The frustration was usually linked with eating out, and the lack of understanding of those working in the food industry. Some people referred to the frustration they felt when they realised that some of the other health problems they were facing could have been avoided if they had been diagnosed earlier. A point that was raised often that led to frustration is the perception that people think Coeliac Disease is 'just a fad' or a 'trendy diet'. Many felt embarrassed when it came to ordering food or choosing places to eat, saying things like 'they didn't want to make a fuss'.

Air travel was also mentioned several times, particularly with reference to Air NZ not serving gluten-free foods on the Trans-Tasman flights. Some people positively commented that they feel so much healthier now they are on the gluten-free diet, and can still lead normal lives.

<b>Part C: Experiences with Coeliac Disease</b>		NB: For the complete list of comments on this question see Appendix E.
Question 22	Comments	
Please describe any other feelings, situations or events that you have experienced as a Coeliac patient which you find important in describing your experiences as someone with Coeliac Disease	<ul style="list-style-type: none"> <li>• Many places claim ‘gluten free’ food but have no understanding of the disease, therefore you can’t trust their ‘GF’ foods are truly GF</li> <li>• Lunches (esp. cafes) are difficult than evening dining</li> <li>• When people think it’s a fad or you are on a ‘diet’</li> <li>• Suffered two miscarriages due to coeliac disease</li> <li>• Find it slightly embarrassing when family make a separate dish when the whole meal could have been gluten free and just as nutritious</li> <li>• Sometimes feel embarrassed asking for Gluten free food eg checking of certain meals are gluten free and personally I don’t like making a fuss</li> <li>• I feel healthier with CD on a GF diet than ever before</li> <li>• I have been diagnosed for 44 years and have had a “normal” life-career I wanted - the “O/E” for 5 years and got married and had children, I think people newly diagnosed need to know it does not define you it is just part of you</li> <li>• Basically comments from other people who don’t understand Coeliac Disease and say comments like “Why do you have to be different” or “surely just a little sandwich or biscuit won’t make much of a diff” or a comment I’ve had quite regularly in my workplace “trust you to be difficult” or “we won’t be inviting you to our place for a meal!”</li> <li>• Flying- AIR NZ do not do GF to Aus/5hr and under flight time countries - difficult when travelling for work. Dining at friends houses</li> <li>• I feel I am putting friends to a lot more trouble and expense - and am sometimes embarrassed when they have tried to make something special for me - and it is still not suitable and I want to avoid it</li> <li>• I find it very difficult when I am served a ‘so-called’ gluten free meal at a restaurant that I know contains gluten. The chef and waitress/waiter ACT like they know what gluten is, where they really don’t have a clue</li> </ul>	

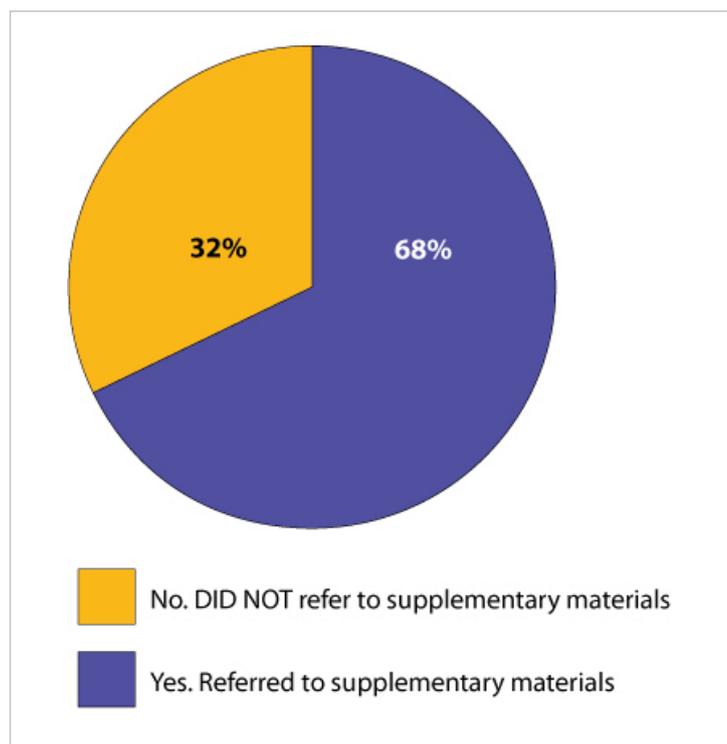
**Table 22**

Further comments on other feelings, situations and events associated with having Coeliac Disease (Question 22)

### **Part D: The handbook**

Questions in Part D of the questionnaire were focussed on assessing how useful the current handbook that the Coeliac Society provide is. It became apparent from some of the answers in this section that many members didn’t actually receive a ‘handbook’ from the Coeliac Society when they were diagnosed, particularly if they joined a while ago. This caused some confusion, and some participants decided to discuss the Manufactured Food Database (MFD) booklet instead, or left some of the questions

in Part D blank. This may have had some affect on the results, but regardless of this some useful insight was obtained about the current handbook and information materials to aid the design of a new one. Part D focussed on asking questions about information materials participants use. This included questions about the use of supplementary materials, where they seek information from, how often they would use the handbook and how useful this information has been. Part D then went on to ask about the quality of information, any pictures or diagrams that assisted understanding and how attractive participants thought the handbook was. Finally questions about how the handbook is used and stored were asked before a comments section asking for suggestions.



**Figure 15**  
Pie-graph indicating whether or not participants needed to refer to any supplementary materials other than the Coeliac Society handbook (Question 23)

Question 23 asked participants whether or not they needed to refer to any supplementary materials other than the Coeliac Society handbook. 68% responded that they did need to refer to supplementary materials (Figure 15).

The comments section outlined what the main supplementary materials were. The most referenced

supplementary material was the Internet. Alongside the Internet, people sourced information from Coeliac societies (New Zealand, U.K., Ireland and the Netherlands), cookbooks, libraries and hospitals. Specialists and dieticians were also referenced as providers of information sources, and some mentioned they received information from other Coeliac friends. A few respondents mentioned they sourced information from food manufacturers and health food companies e.g. Healtheries.

<b>Part D: The Handbook</b>		NB: For the complete list of comments on this question see Appendix E.
<b>Question 23</b>	<b>Comments</b>	
Did you have to refer to any other supplementary materials other than the handbook you were given by the Coeliac Society in your transition to the gluten-free diet?	<ul style="list-style-type: none"> <li>• Internet</li> <li>• Gluten free books, recipes books etc</li> <li>• Coeliac Magazine, Internet search, hospital/dietician info, friend's knowledge</li> <li>• Internet, Coeliac Society Netherlands, Coeliac Society Ireland, Southern Cross</li> <li>• Anything I could find e.g. books, library, Internet, hospital</li> <li>• Lots of cookbooks and shopping to see what's there</li> <li>• My niece in Canberra sent Australian information. Son got NZ information off Internet. Coeliac Link magazines. Libraries. Information from Prince Alfred Royal Unit lent by a friends - very good. Pharmacists are sometimes helpful</li> <li>• Dr. Rodney Ford's books and website</li> <li>• Notebook MFD</li> <li>• Printout from gastro dept (Mr HB Cook) ChCh hospital and dietician. Healtheries NZ</li> <li>• Medical journal articles, Internet articles, recipes etc</li> <li>• Info given by doctor, hospital Internet sources</li> <li>• I had other friends who were Coeliac that were very helpful</li> <li>• Newsletters from the society, Internet</li> </ul>	

**Table 23**  
Supplementary materials referred to alongside the Coeliac Society handbook (Question 23)

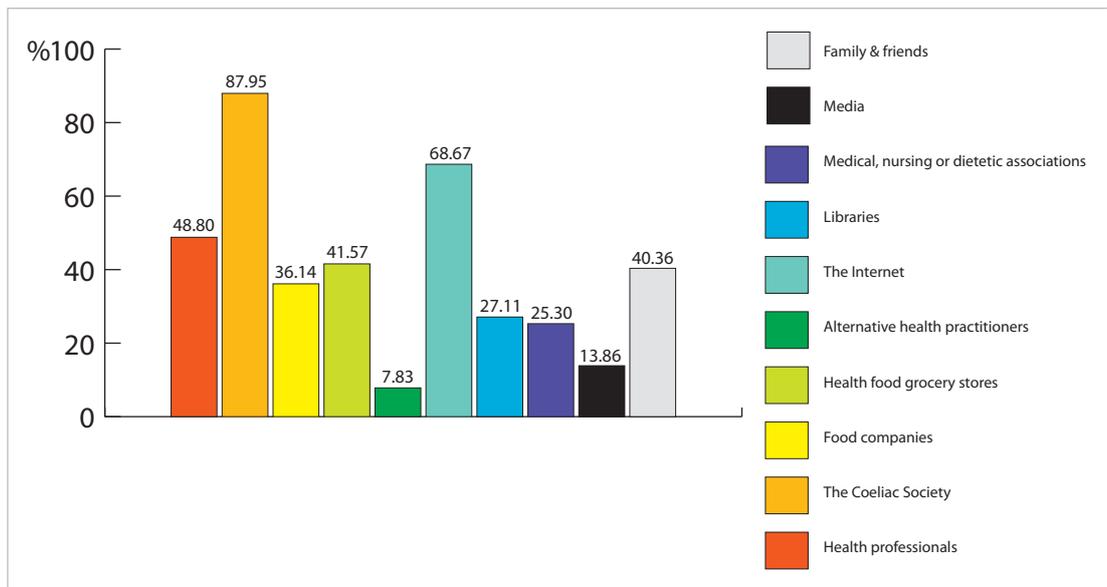
Question 24 asked participants to indicate how often they would use their handbook since receiving it. Over half (55%) of respondents in this question stated that they use the handbook rarely. This figure could be largely due to the function the handbook plays: an information and resource tool for the newly diagnosed. Those that have read the information and understand it may not need to use it later on.

Part D: The handbook			N=Total Number of participants = 100%	
Question 24	Information		N	100%
Since receiving the handbook how often would you use it?	More than once a month	20	N=140	14
	Once a week	13		9
	More than once a week	13		9
	Less than once a week	18		13
	Rarely	76		55

**Table 24**  
Information showing how often participants use the Coeliac Society handbook since receiving it (Question 24)

Question 25 (overleaf) asked participants where they seek information from on Coeliac Disease and the gluten-free diet. A clear majority of respondents indicated they seek information from the Coeliac Society, and 68.67% of respondents ticked that they seek information through the Internet. Only 48.08% indicated they seek information from health professionals, which is surprising given they must be diagnosed by a health professional in the first place. In the comments section health professionals were mentioned as not being 'that knowledgeable' about Coeliac Disease.

Only 7.83% responded saying they seek information through alternative health practitioners, and some commented that 'they often get it wrong'. Other sources of information mentioned were 'health magazines', 'bookshops', the 'MFD booklet and database', 'support groups' and 'food companies'.



**Figure 16**  
Bar graph showing where participants seek information on Coeliac Disease or the gluten-free diet (Question 25)

Part D: The Handbook		NB: For the complete list of comments on this question see Appendix E.
Question 25	Comments	
Where do you seek information on Coeliac Disease and the gluten-free diet?	<ul style="list-style-type: none"> <li>• Health magazines</li> <li>• Bookshops</li> <li>• I often ring the 0800 number on tin and packet products. Many companies will send out a list of their GF stuff</li> <li>• MFD database, MFD booklet</li> <li>• Support group</li> <li>• Doctors not always up on Coeliac. Coeliac Society provided me with information, but not as I would like, food companies not always honest or knowledgeable about their products. Alternative health practitioners are most informative, chefs, don't always have good understanding</li> <li>• The Coeliac Society Link magazine is also very helpful</li> <li>• Health food grocery stores often get it wrong so I no longer rely on them</li> </ul>	

**Table 25**  
Where participants seek information on Coeliac Disease and the gluten-free diet (Question 25)

Part D: The handbook			N=Total Number of participants = 100%	
Question 26	Information		N	100%
(Following from question 25) how helpful has this information been?	Very helpful	71	N=140	44
	Helpful	75		47
	Somewhat helpful	13		8
	Not very helpful	1		1
	Not very helpful at all	0		0

**Table 26**

Information showing how helpful the information mentioned in question 25 has been (Question 26)

Question 26 is linked to the information in question 25. The question asks how helpful has the information been that they have sought. Almost half of the participants (47%) stated the information was helpful, and 44% stated it was very helpful. 8% believed this information was somewhat helpful and only 1% said it was not very helpful. No one said the information was not helpful at all.

Part D: The handbook			N=Total Number of participants = 100%	
Question 27	Information		N	100%
(Following from question 25 & 26) how would you rate the quality of information you have received?	Excellent	33	N=158	21
	Very good	79		49
	Good	42		27
	Fair	4		3
	Poor	0		0

**Table 27**

Information showing how people perceive the quality of information mentioned in question 25 and 26 (Question 27)

From this information, Question 27 asked participants to rate the quality of the information received. Almost half (49%) believed the quality of information was very good, 27% believed the quality of information was good, 21% believed the quality of information was excellent, and only 3% believed the quality of information was fair. None thought the quality of information was poor.

Part D: The Handbook		NB: For the complete list of comments on this question see Appendix E.
Question 28	Comments	
What do you think could be done to improve the quality of information available to you about Coeliac Disease or gluten-free diets?	<ul style="list-style-type: none"> <li>• Nothing. I've had excellent advice &amp; assistance</li> <li>• I thought it was very informative</li> <li>• Society mags are excellent also handbook is also adequate</li> <li>• I'm pleased with the info I have received but did have to ask lots of questions and read lots of labels</li> <li>• Ingredients list of allowed foods</li> <li>• More basic information about food and numbers specifically</li> <li>• To be honest, it's dull and clichéd. The presentation is very dull. Which isn't to say I don't appreciate it, I do, but it's good to hear you are improving it! Make it interesting (informative) and well-presented material that doesn't look dull</li> <li>• Easier to read - better order</li> <li>• A list of food items, which contain hidden gluten, eg soy sauce</li> <li>• On labels - telling the numbers which have gluten or gluten free</li> <li>• A handy colour brochure chart with food suggestions to buy at supermarkets and code explanation of food additives etc</li> <li>• Write it in plain English and use up to date information</li> <li>• Simple pieces of long articles by professionals. More general rather than specific info re: baking: like replace flour with 1/2 tapioca flour and 1/2 fine maize cornflour and guar gum. No need for hundreds of recipes. Just use normal recipes with replacements</li> <li>• Information easy, more basic &amp; interesting</li> <li>• Explanation of thickeners. More help and follow up from dieticians</li> <li>• More information on the long term affects of NOT following diet</li> </ul>	

**Table 28**  
Comments about what participants think could be done to improve the quality of information available about Coeliac Disease or gluten-free diets (Question 28)

In general the comments in Question 28 mentioned the need for clearer labelling and explanation of additives. Some useful comments were given regarding redesigning the handbook. These included suggestions to make the content more interesting, easier to read (better order) and simplification of the information. Several people expressed they were very happy with the information as it was, but some added they still had to seek support and ask questions.

Part D: The handbook		N=Total Number of participants = 100%		
Question 29	Information	N		100%
Have you found any pictures or diagrams to be of assistance in understanding Coeliac Disease?	Yes	76	N=151	50.5
	No	75		49.5
	<b>Comments</b>			
<ul style="list-style-type: none"> <li>• The villi in the intestine and how they react with gluten</li> <li>• Gastroenterologist gave me several from the endoscopy and gastroscopy. It helped to see the damage</li> <li>• Only really pictures of villi - flattened and normal villi</li> <li>• Photo micrographs of normal and Coeliac affected villi</li> <li>• Diagrams of the digestive system with explanations of how villi worked</li> <li>• Pictures of damage to the villi. Why you can't absorb your food properly</li> <li>• Other specialist gave an excellent explanation of the disease using a diagram. This was useful with the visual results of the endoscopy</li> </ul>				

**Table 29**

Information showing whether participants found any pictures or diagrams to be of assistance in understanding Coeliac Disease (Question 29)

The responses for Question 29 were almost split in half. 50.5% said yes they had seen pictures or diagrams that helped their understanding, and 49.5% said they had not. Almost every comment for this question said that pictures and/or diagrams that were of assistance to them were of the villi in the intestine, and the damage that gluten causes to the villi (flattening). The only variation from this answer was one that mentioned a diagram of the digestive system, and a few others who saw the photographic results of the endoscopy.

Question 30 identified that most think that the current handbook is neither attractive nor unattractive. 26 people (19.70%) thought the handbook was attractive. However, this was contrasted by the same proportion of people (19.70%) that thought it was unattractive. Only 6.05% thought the current handbook was very attractive, and 5.30% thought the current handbook was very unattractive. These results indicate that although about half of respondents were indifferent about the appearance of the handbook, there is still a reasonable proportion of people that believe there is room to improve the visual quality of the handbook.

Part D: The handbook				N=Total Number of participants = 100%	
Question 30	Information		N	100%	
With reference to the handbook the Coeliac Society has provided you, can you rate on a scale from 1-5 how attractive or unattractive you believe the material is you have been given?	Very attractive	1	8	N=158	6.05
		2	26		19.70
		3	65		49.25
		4	26		19.70
	Very unattractive	5	7		5.30

**Table 30**  
Information showing on a scale from 1-5 how attractive or unattractive participants believe the old handbook is (Question 30)

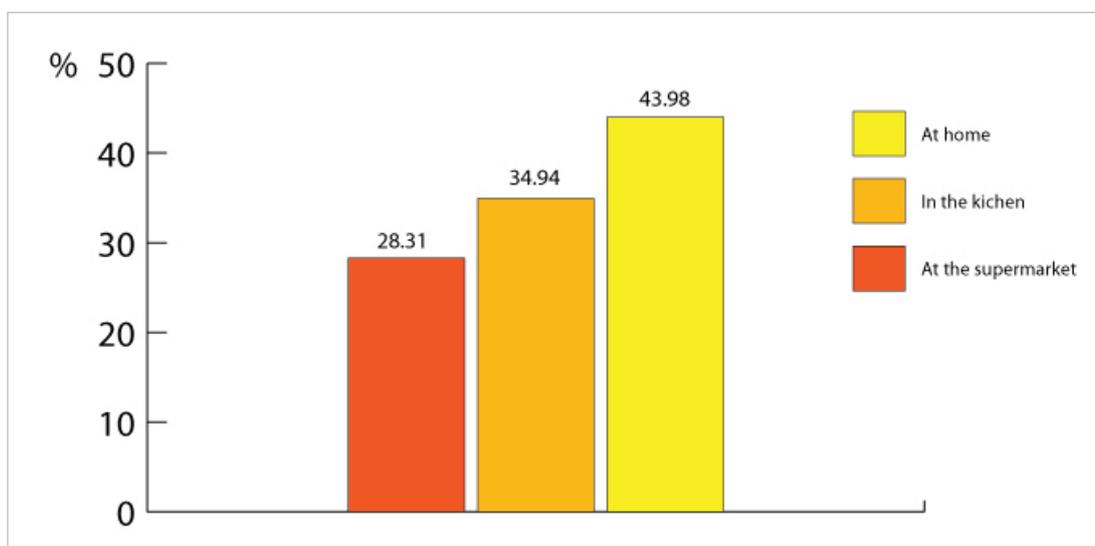
Question 31 (overleaf) asked participants to state how often they use supplementary materials other than the handbook to assist their gluten-free diet. 29% responded as rarely needing to refer to supplementary materials. 29 people (19.5%) said they needed to refer to supplementary material more than once a month and 30 people (20.25%) said they need to refer to supplementary material once a week. 24 people (16.25%) said they referred to supplementary material less than once a week, and the least respondents (22 people) said they refer to supplementary materials more than once a week. It should be noted that due to the wording of this question some people commented that they were a bit confused about the frequency scale. Despite this however, the table still reveals that supplementary materials are still being referred to occasionally, and by some on a regular

basis. This could correspond to earlier comments in the questions of ‘you learn as you go along’.

Part D: The handbook			N=Total Number of participants = 100%	
Question 31	Information	N	100%	
How frequently would you use supplementary materials other than the handbook to assist your gluten-free diet? (these materials may include gluten-free cookbooks, the Internet, The MDF database etc.)	More than once a month	29	N=158	19.5
	Once a week	30		20.25
	More than once a week	22		15
	Less than once a week	24		16.25
	Rarely	43		29

**Table 31**  
Information showing how frequently supplementary materials are used to assist participant’s gluten-free diet (Question 31)

Most of the respondents in Question 32 (Figure 17) indicated they use their handbook at home (43.98%). 34.94% stated that they use their handbook in the kitchen. The remaining responded that they use the handbook at the supermarket (28.31%). This figure may be slightly inaccurate due to many thinking this question was about the MFD booklet (as indicated in the comments section overleaf).



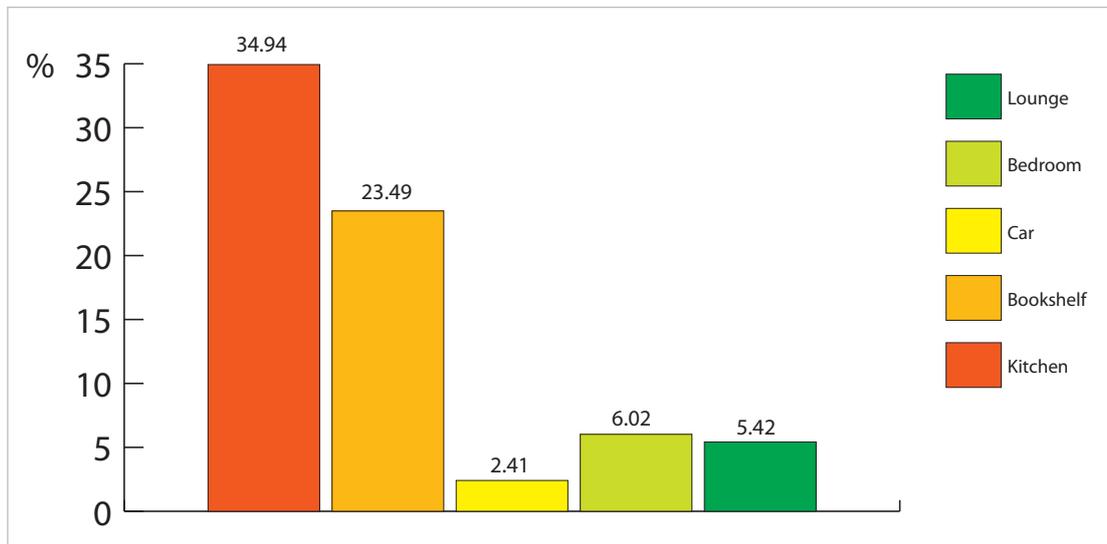
**Figure 17**  
Bar graph showing where participants use their handbook (Question 32)

The comments for this question (overleaf) revealed that many do not use the handbook anymore, either because it is out-of-date or because they feel they have learnt enough to get by without it. Those that still use it indicated that they often use it to share recipes or information with friends.

Part D: The handbook		NB: For the complete list of comments on this question see Appendix E.
Question 32	Comments	
Where do you use your handbook?	<ul style="list-style-type: none"> <li>• I do not use it anymore. Since the diagnosis of my daughter (before me) I have learned everything</li> <li>• Read it once. Outdated</li> <li>• I don't use it-out of date, not helpful anymore, as I am familiar with its contents-was helpful initially</li> <li>• Often share recipes with friends who want wheat free recipes etc.</li> <li>• Seldom refer to it now. Mainly used it when first diagnosed. Was certainly a good tool to have also, as information for other people</li> </ul>	

**Table 32**  
Comments about where participants use their handbook (Question 32)

Question 33 (Figure 18) asked participant to indicate where they store their handbook. This question was designed to assess format and practical for the design of the handbook. The majority of respondents stated that they store the handbook in the kitchen (34.94%), and some replied saying they store it on the bookshelf (23.49%). Only a few stated that they store it in the bedroom (6.02%) and lounge (5.42%), and the least stated they store it in the car (2.41%). The comments section (Table 33 - overleaf) added that people also store it in the cupboard, pantry and office.



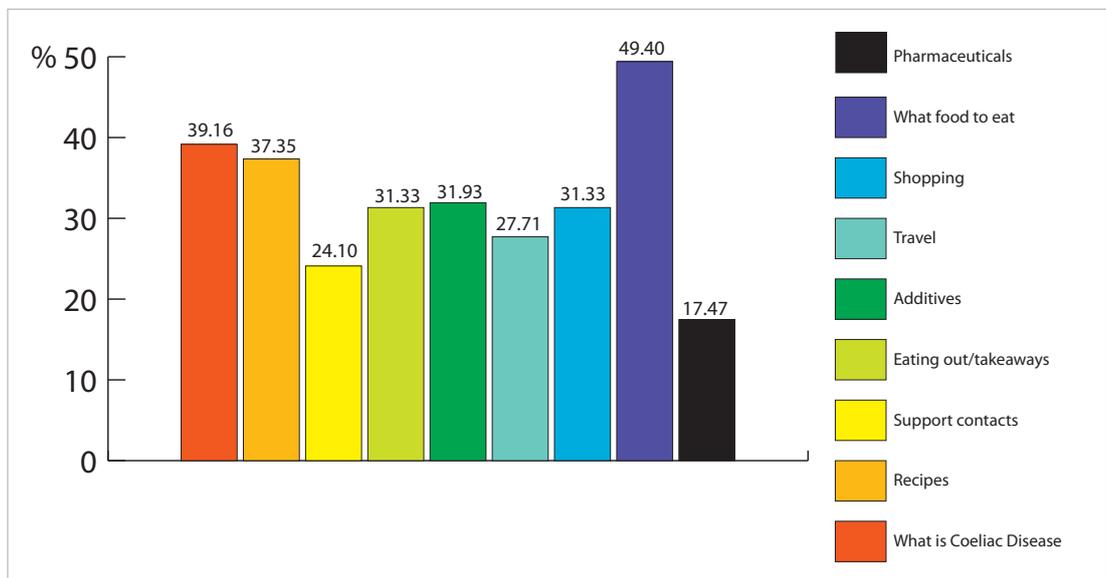
**Figure 18**  
Bar graph showing where participants store their handbook (Question 33)

Part D: The handbook	
	NB: For the complete list of comments on this question see Appendix E.
Question 33	Comments
Where do you store your handbook?	<ul style="list-style-type: none"> <li>• In a cupboard. Have not looked at it for years. Recipes are dated. The 2 recipe books I had to photocopy at the time are outdated too but at the time were helpful</li> <li>• Spare room</li> <li>• Hidden in a cupboard</li> <li>• Amongst other Coeliac material in the pantry</li> <li>• Home office</li> </ul>

**Table 33**  
Comments about where participants store their handbook (Question 33)

Question 34 asked participants to state what they believed the most important information in the handbook was. The information was overall ranked in the following order:

1. What food to eat (49.40%)
2. What is Coeliac Disease (39.16%)
3. Recipes (37.35%)
4. Additives (31.93%)
5. Eating out/Takeaways & Shopping (31.33%)
6. Travel (27.71%)
7. Support contacts (24.10%)
8. Pharmaceuticals (17.47%)



**Figure 19**  
Bar graph showing what participants believe is the most important information in their handbook (Question 34)

Part D: The handbook		NB: For the complete list of comments on this question see Appendix E.
Question 34	Comments	
What do you believe is the most important information included in the handbook?	<ul style="list-style-type: none"> <li>• Other Coeliac's experiences</li> <li>• I still use one of the recipes (pizza bases) from the handbook. Personal stories are great</li> <li>• The page to photocopy for school teachers is great</li> <li>• You simply must be able to recognize what additives are dangerous - if you can do that it's a breeze!</li> <li>• Knowing about additives is really important</li> <li>• All the information in the handbook is important to me</li> </ul>	

**Table 34**  
Comments about what participants believe the most important information in the handbook (Question 34)

In the comments section of question 34 (Table 34) some stated that they believed all the information was important. Several people said that other Coeliac's experiences were also important, which was insightful. Many commented on the importance to know about additives, and one mentioned that the page you could photocopy for school teachers was useful.

Part D: The handbook				N=Total Number of participants = 100%	
Question 35	Information		N	100%	
Can you rate on a scale from 1-5 how easy or difficult you find using the current handbook?	Very easy	1	18	N=132	14.75
		2	37		30.30
		3	46		37.70
		4	18		14.75
	Very difficult	5	3		2.50

**Table 35**  
Information showing on a scale from 1-5 how easy or difficult the handbook is perceived by participants (Question 35)

Question 35 was designed to reveal how easy or difficult participants thought the current handbook was to use. 46 people (37.70%) indicated they thought the handbook was neither easy nor difficult to use, and 37 people (30.30%) said the handbook was easy to use. The same number of people (14.75%) thought the handbook was very easy as those that thought it was difficult. Only 3 people (2.50%) responded saying it was very difficult. These results indicate that while many are satisfied with how easy it is to use the handbook, there is still room for improvement.

The final question of Part D asked respondents to provide any advice or suggestions about information material that people with Coeliac Disease may benefit from. Below are the key comments from this question.

Part D: The handbook	
	NB: For the complete list of comments on this question see Appendix E.
Question 36	Comments
Please write below any advice or suggestions about information material that Coeliac patients might find of benefit or need	<ul style="list-style-type: none"> <li>• New Coeliacs that I talk to just want a list of what they can't eat. Also additives that are gluten free</li> <li>• Food labelling most difficult thing to get head around. Updated lists in Coeliac Magazine of restaurants, cafes, health food shops etc. good when travelling. Please contact for support person to guide through early days</li> <li>• Make it more user-friendly</li> <li>• A list of Internet sources (websites)</li> <li>• The handbook would be more useful if bound as small booklet. It is full of good information, but I had forgotten about it</li> <li>• The only thing I find difficult is all the numbers on foods and I don't know what they all are. A list would be helpful</li> <li>• Diagrams and visuals of Coeliac Disease impairments, diagrams and visuals of results after gluten-free diet introduced, quotes from Coeliac (patients) persons on how their life is better and more healthier being on GF diet (positive info)</li> <li>• 1. More detailed additive information, 2. Lactose containing foods (or free of), 3. Contacts of outlets who sell gluten free breads (and lactose free!) - ready made</li> <li>• Personal stories about how other people (Coeliacs) have coped (adapted) to the diet - lunches, eating out, travelling etc. (I remember reading some in the handout, they're great; keep updated or have more)</li> <li>• A list of common foods at normal prices that are suitable to eat e.g. Oak baked beans, rice, fruit and veg, meat and fish</li> <li>• Up to date website advising of GF eating places around the country</li> <li>• The Coeliac Society magazine is the only resource I use now because it keeps me up to date on information relevant to Coeliac Disease</li> </ul>

**Table 36**  
Comments showing advice and suggestions about information material that may be of benefit or need to Coeliac patients (Question 36)

As with many of the other comments, many participants that answered Question 36 suggested they needed more information on additives and food labelling. A few suggested they would like to read about positive experiences of other Coeliacs. Some others suggested providing lists of eating places that served gluten-free food and of 'everyday' food you could buy that was not too expensive. There was

also suggestion of a list of what Coeliacs 'can and cannot eat'. Whilst many did not use the handbook anymore, they still praised the Coeliac Society for its support and noted that the Coeliac magazines were good.

### **Part E: Further comments**

Part E is the final part of the questionnaire. Part E provides a space where participants can write down any further comments they have relating to their experience with Coeliac Disease, or information that would help to design a better handbook. The key comments from this section are listed on the next page in Table 37.

Many responded to this section, providing useful insights. Comments that reoccurred frequently were to do with the format and presentation of the handbook. Participants indicated that they would like the handbook colour-coded with clear diagrams and visuals. Format was discussed by a few participants referring to the ability to add information into the handbook. The ring-binder was praised, and a suggestion to add pockets was mentioned by one participant.

Several mentioned that the handbook is really only of use to the newly diagnosed and that the re-design should be focussed with this in mind. One participant thought an Internet version of the handbook would be of benefit.

As far as additional tools/materials, one person suggested a wallet-sized card with additives on it, and another suggested a page you could photocopy and give to teachers to outline the child's condition. Similarly to this, one suggested a page that you could photocopy and give to restaurants.

In summary, most respondents in this section were positive about a redesign, and saw the use of the handbook as more than a document that would be read once, but a tool that could be used and adapted to different situations.

<b>Part D: The handbook</b>	
	NB: For the complete list of comments on this question see Appendix E.
Question 37	Comments
Please provide any further comments you may have relating to your experience with Coeliac Disease that would help me design a useful handbook	<ul style="list-style-type: none"> <li>• Colour-code the different sections for quick easy reference</li> <li>• Does current handbook have information for pre-school, primary etc so children’s teachers are more aware it is medical not just a diet by choice</li> <li>• Smaller and more portable, more attractive, more specific food/diet info. Updated regularly and sent out to members</li> <li>• Have a wallet size card with the additive codes on it</li> <li>• Don’t get too complicated about different tests. Clear diagrams help. Other folk’s experiences help. Keep on the positive side its easy to cope once you’ve worked it out</li> <li>• I think you have made a great choice to do this - well done. To have a professional looking document (currently looks amateurish - that’s not to be taken negatively!) would be great! Keep up the good work</li> <li>• Letting people know that it is not that bad to have CD and that they will far more healthier in the long run</li> <li>• Any handbook should include a diagram explaining the condition and some easy starter recipes</li> <li>• Most people only prefer to use this handbook the 1st year after diagnosis. I believe you should direct it to the newly diagnosed</li> <li>• Keep it simple, keep it positive and include recipes for things that people would normally eat. How to make stocks, hints on gluten free flour usage. I always use baking paper/ gladwrap because it sticks to everything!</li> <li>• Concise information with attractive sections/tabs for easy to find info</li> <li>• Need pictures to make easy to understand</li> <li>• Teaching how to recognise food additives is the key - then you can shop without a handbook. It is amazing once you start reading what’s in food - you find all sorts that you start avoiding and not just because of gluten!</li> <li>• I like the ring-binder format so I can add updates, recipes etc.</li> <li>• It would be really useful to have a photocopy-able page giving detailed instructions for restaurants or hosts as how to ensure food is gluten free.</li> </ul>

**Table 37**  
Further comments from participants  
(Question 37)

## **Part 2**

### **4.2 Interview**

The interview questions were designed to help participants describe their experiences with Coeliac Disease and the use of information materials. Participants were selected with assistance from the Coeliac Society NZ. Due to privacy reasons the Coeliac Society would not distribute any contact details of members, so the secretary of the society contacted some local members of the society herself who she thought might be interested in participating (all were living in North Shore City). Three interviewees were selected this way, two of which were young mothers with children that were diagnosed with Coeliac Disease and one member who was retired who had Coeliac Disease himself.

Four participants were involved from the Taranaki region. Contact was made to a Taranaki Coeliac Society support group member, whose details were listed in the Coeliac Society magazine. This support group member then contacted others in her group asking if they would like to participate in an interview, and three others as well as herself emailed me back saying they would like to participate. These interviewees lived in New Plymouth, Stratford, Patea and South Taranaki.

The final person allocated for the interview was from Auckland. He had also participated in the questionnaire. When the questionnaire was returned he left his contact details and a note saying he would like to assist further in the research. He was then contacted by email and agreed to be interviewed.

#### **4.2.1 Background of interviewees**

For anonymity reasons the names of the interviewees are not used, instead they have been abbreviated to I (for Interviewee) and allocated a number in the order their interview took place (e.g. I: 1, I: 2, I: 3 etc).

I: 1

Interviewee 1 is a mother of two children, one of which was recently diagnosed with Coeliac Disease. She lives in the North Shore, Auckland. As her daughter has only been diagnosed for three months, she talks in this interview with the perspective of a mother who is still learning about Coeliac Disease and having to care for a child who has just been diagnosed.

I: 2

Interviewee 2 is also the mother of two children, one who has been recently diagnosed with Coeliac Disease. She too lives in the North Shore, Auckland. Her son was even more recently diagnosed with Coeliac Disease, and has only been on a gluten-free diet for two months. Interviewee 2 also talks in this interview with the perspective of a mother who is still learning about Coeliac Disease and having to care for a child who has just been diagnosed.

I: 3

Interviewee 3 is 69 years old and was diagnosed with Coeliac Disease five years ago. He lives in the North Shore, Auckland. Interviewee 3 suffered ill health for many years when he was younger, and believes many of those earlier problems were related to Coeliac Disease. Interviewee 3 has a daughter and a granddaughter also diagnosed with Coeliac Disease. He insisted that his granddaughter also sat in on the interview, and she contributed briefly to the interview as well. The granddaughter (abbreviated in the summary as G: 3) was diagnosed with Coeliac Disease 10

months ago, and is still at school. Interviewee 3 talks about his transition to a gluten-free diet at a later stage of his life and his experience of this.

I: 4

Interviewee 4 lives in Remuera, Auckland. He is in his early 50s and was misdiagnosed with 'tropical sprue' during travel in 1980. Ten years later he was diagnosed properly with Coeliac Disease. Interviewee 4 travels a lot as part of his job, so talks in this interview about travelling on a gluten-free diet. He also discusses his perspective on 'eating out'.

I: 5

Interviewee 5 was diagnosed with Coeliac Disease 19 years ago. She lives and works on a farm in Patea, Taranaki. Interviewee 5 discusses what it was like adapting to a gluten-free diet in the 1980s in New Zealand, when it wasn't widely recognised. In the interview she also discusses the current handbook, and makes suggestions on it, before describing her experiences travelling with Coeliac Disease.

I: 6

Interviewee 6 is the Taranaki regional Coeliac Society support contact. She has an active interest in helping newly diagnosed Coeliacs in their transition to a gluten-free lifestyle. Interviewee 6 was diagnosed four years ago. She discusses in the interview how she was diagnosed and support material she received at the time, before going on to suggest ways the handbook could be improved.

I: 7

Interviewee 7 lives in Stratford. She has not officially been diagnosed with Coeliac Disease via biopsy, but her blood results were positive so she was advised by her specialist to go onto a gluten-free diet. Interviewee 7 is a nurse, and has a good understanding of the condition and the effect gluten has on the bowel.

She discusses the symptoms she had before going on the gluten-free diet before talking about how she adapted to the diet after her blood test.

I: 8

Interviewee 8 is also a nurse, and lives in rural South Taranaki on a dairy farm. Interviewee 8 also has an active interest in helping newly diagnosed Coeliacs transition to a gluten-free lifestyle, and is co-support contact for the Taranaki Coeliac Society. Interviewee 8 has been diagnosed with Coeliac Disease for about four years, and has two other sisters also diagnosed. In the interview she shows examples of her own collection of information materials, and provides suggestions for the re-design of the handbook.

#### **4.2.2 Structure of interview questions**

All interviews were loosely structured with the same interview questions in mind, however the interviews were directed predominately by the interviewee and what they wished to express. This flexibility was decided on in order to achieve the most insight possible into people's experiences and ideas for the handbook. This approach enabled some things to be brought to light that the interviewer could not have anticipated when writing the questions.

### 4.2.3 Interview results

The key points from the interviews are summarised in the table below.

1. Diagnosis	
Q: Who it was that was diagnosed and when?	
Respondent	Key comments
I: 1	<ol style="list-style-type: none"> <li>1. Daughter was getting skinny, but had a bloated tummy</li> <li>2. Went to the doctor for another bug, and doctor commented on her tummy</li> <li>3. Had an ultra-sound</li> <li>4. Thought it was 'Interception'</li> <li>5. Went to Starship Hospital and had another ultra-sound: wasn't Interception</li> <li>6. Saw a paediatric specialist, who said there was enough evidence to suggest Coeliac Disease</li> <li>7. Had a biopsy: confirmed Coeliac Disease</li> <li>8. Daughter diagnosed May 2007</li> </ol>
I: 2	<ol style="list-style-type: none"> <li>1. Son: May 2007 (2 months ago)</li> <li>2. Had pneumonia a year prior, and didn't come right</li> <li>3. Had vomiting and distended tummy</li> <li>4. Took to GP several times, but they said it was normal</li> <li>5. Took to a specialist</li> <li>6. Thought it was 'Abdominal Migraine'</li> <li>7. Put on medication for that</li> <li>8. After six weeks on medication there was no improvement</li> <li>9. Went back to GP and happened to mention cousin had Coeliac Disease</li> <li>10. Had a biopsy: confirmed Coeliac Disease</li> </ol>
I:3	<ol style="list-style-type: none"> <li>1. As a child diagnosed with spinal meningitis</li> <li>2. No strength through primary school</li> <li>3. When 63 years old had blood tests done to check for diabetes (family history)</li> <li>4. Extremely low in iron, so doctors were concerned</li> <li>5. Had a biopsy: confirmed Coeliac Disease 5 years ago</li> </ol>
I:4	<ol style="list-style-type: none"> <li>1. During travelling became sick &amp; ended up in hospital</li> <li>2. Doctors diagnosed 'Tropical Sprue'</li> <li>3. Diagnosed with Coeliac Disease 10-15 years later</li> <li>4. Realised that the 'Tropical sprue' was the first significant onset of Coeliac Disease</li> <li>5. Diagnosed with Coeliac Disease in the mid 1990s</li> </ol>
I: 5	<ol style="list-style-type: none"> <li>1. Felt like 5 months pregnant &amp; was very sick</li> <li>2. Had many blood tests taken, and procedures to remove urine and test</li> <li>3. First Coeliac Disease patient her doctor had diagnosed</li> <li>4. First Coeliac Disease patient the gastroenterologist had diagnosed</li> <li>5. Diagnosed with Coeliac Disease 19 years ago</li> </ol>

I: 6	<ol style="list-style-type: none"> <li>1. Had a hernia operation 6-7 years ago</li> <li>2. Was still unwell and feeling bloated</li> <li>3. GP's thought she was neurotic</li> <li>4. Changed GP</li> <li>5. Had biopsy: confirmed Coeliac Disease 4 years ago</li> </ol>
I: 7	<ol style="list-style-type: none"> <li>1. Went to the doctor anticipating she had cancer</li> <li>2. Diagnosed her with Irritable Bowel Syndrome (IBS), but had some blood tests done anyway</li> <li>3. Blood tests came back positive for Coeliac Disease</li> <li>4. Went on a gluten-free diet</li> </ol>
I:8	<ol style="list-style-type: none"> <li>1. Long history of diarrhoea &amp; kept losing weight</li> <li>2. Asked for blood tests</li> <li>3. Very anaemic</li> <li>4. Did a Coeliac Screen: = positive</li> <li>5. Had biopsy: confirmed Coeliac Disease 4 years ago</li> </ol>

## 2. Experiences living with Coeliac Disease

### Q: Can you tell me about your experiences living with Coeliac Disease?

Respondent	Key Comments
I: 1	<ul style="list-style-type: none"> <li>• Took a long time to see a dietician to advice her what to feed daughter, so had to do own research</li> <li>• Worried that what she was feeding her may contain gluten and make it worse</li> <li>• Daughter goes to day-care, takes her own food</li> <li>• Finds it a lot of hard work managing her daughters diet as well as looking after a baby</li> </ul>
I: 2	<ul style="list-style-type: none"> <li>• Son was really sick before diagnosis, but now is so much better</li> <li>• Adjusting to the diet was a huge shock, but now fitting into it well</li> <li>• Keep running into people that can share similar experiences</li> <li>• Son adjusted well to the diet</li> <li>• Thinks the diet is a lot more expensive</li> <li>• Gets confused by conflicting information</li> </ul>
I: 3	<ul style="list-style-type: none"> <li>• Very sick as a child &amp; lacked strength</li> <li>• Once diagnosed realised it wasn't such a bad thing to have: if you look after your diet you are fine</li> <li>• Has a lot more energy now</li> <li>• Uses a card at restaurants to explain to the chef what he can and cannot eat</li> <li>• Granddaughter: feels better, but at school friends tease her</li> </ul>
I: 4	<ul style="list-style-type: none"> <li>• Has made mistakes as he has learned, but takes a fairly relaxed approach to the diet</li> <li>• Dining out: doesn't find difficult or embarrassing, just makes sure he blatantly asks questions about the food</li> <li>• Travels often: does not find travel difficult, but thinks airlines give 'garbagey meals'</li> <li>• Has never struck him as a problem</li> </ul>

I: 5	<ul style="list-style-type: none"> <li>• Believes in making slight adjustments to your lifestyle and not making a big thing out of it</li> <li>• Doesn't take chances when dining out, and doesn't think there is anything wrong in asking questions</li> <li>• Travel: easy (in Asia)</li> <li>• Thinks it's neat how people now take quite an interest, whereas years ago people thought she was on a fad diet</li> </ul>
I: 6	<ul style="list-style-type: none"> <li>• Understanding that something was wrong was very emotional</li> <li>• Financially horrendous</li> <li>• Found the social implications hard</li> <li>• The other illnesses that go along with it: Thyroid, Asthma, Arthritis, Eczema (these may be less likely if you diagnosed earlier)</li> </ul>
I: 7	<ul style="list-style-type: none"> <li>• After diagnosed came home thinking "oh my god!"</li> <li>• Had a nurse friend who she knew was also diagnosed who helped her out</li> <li>• Believes it's important to talk about it with others</li> <li>• Struggled with hidden gluten in things like MILO</li> <li>• When travelling makes sure she is prepared</li> <li>• Finds a lot of places fairly accommodating, but some still make mistakes</li> <li>• Noticed a big increase in health: has energy she hasn't had since a teenager</li> </ul>
I: 8	<ul style="list-style-type: none"> <li>• Learnt how to adjust to a gluten-free diet initially from her cousin that was diagnosed</li> <li>• Always rings ahead when going out for a meal</li> <li>• Joined up with another local Coeliac, and ran a support group for Coeliacs</li> <li>• Thinks the adjustment to a gluten-free diet is hard work initially, but the health benefits are worth it</li> </ul>

<b>3. Information materials</b>	
<b>Q: What information materials did you use to support you?</b>	
<b>Respondent</b>	<b>Key Comments</b>
I: 1	<ul style="list-style-type: none"> <li>• Conducted own research</li> <li>• Joined the Coeliac Society and received information and cook-books from them</li> <li>• Dietician provided some information including an A4 booklet outlining Coeliac Disease which categorised things that contained gluten, that had low traces of gluten, did not contain gluten etc. (5 categories)</li> <li>• The Dietician also gave information on lunch examples: like salami sticks (quick-grab items)</li> <li>• Thinks too much information (e.g. lots of brochures) can be overwhelming, and end up just getting filed away</li> <li>• Talking to people is really important to get information</li> </ul>
I: 2	<ul style="list-style-type: none"> <li>• Conducted own research on the Internet</li> <li>• Dietician was really useful: gave lots of ideas</li> <li>• Joined the Coeliac Society: think they have been great</li> <li>• Talks to people</li> <li>• Didn't think that the GP wasn't able to pass on much information, and didn't know much</li> <li>• Thought information from the paediatrician was great</li> <li>• A friend who was already diagnosed gave her information (places that sold gluten-free food etc.)</li> <li>• Still gets a bit confused with contradictory information, so often picks things that actually say gluten-free and rings food manufacturers</li> </ul>
I: 3	<ul style="list-style-type: none"> <li>• Reads labels</li> <li>• Wife helps choose food and cooks</li> <li>• Joined the Coeliac Society</li> </ul>
I: 4	<ul style="list-style-type: none"> <li>• Uses the Internet predominately for information</li> <li>• One meeting with the dietician and everything else he knows is self-informed</li> <li>• Likes to read the Coeliac Society magazines, particularly the scientific parts with clinical research</li> </ul>
I: 5	<ul style="list-style-type: none"> <li>• Got books from libraries</li> <li>• Looked through medical books with her doctor</li> <li>• Joined the Coeliac Society</li> <li>• Went to a dietician, although she didn't find her advice very helpful</li> </ul>
I: 6	<ul style="list-style-type: none"> <li>• Initially was not given ANY information from specialist and looked up her own health dictionary to find out what it was</li> <li>• Talked to people who were already diagnosed</li> <li>• Joined the Coeliac Society</li> <li>• Mainly used the Internet for research. Thinks Southern Cross website is good</li> <li>• Cookbooks and pamphlets</li> <li>• Started a support group so people could get together to talk about it and share information and ideas</li> </ul>

I:7	<ul style="list-style-type: none"> <li>• Got information first of all from a nurse friend who was already diagnosed</li> <li>• Used the Internet as the main way of getting information</li> <li>• Joined a local support group</li> <li>• Dietician was not very helpful</li> </ul>
I: 8	<ul style="list-style-type: none"> <li>• Didn't get to see a dietician until 6-7 weeks after diagnosis, but had a cousin who was diagnosed so learnt what to do</li> <li>• Cousin provided information on where she got her food from, and her handbook she was given when she was diagnosed</li> <li>• Saw a dietician, but wasn't given a lot of information</li> <li>• Used the Internet for information</li> <li>• Joined the Coeliac Society</li> <li>• Joined the local support group</li> <li>• Collected anything she could find to share with group: pamphlets, brochures, packaging etc.</li> <li>• Became part of Awareness week</li> <li>• Group invited guest speakers to speak about gluten-free food</li> </ul>

#### 4. The handbook

##### Q: What suggestions do you have for the redesign of the handbook?

Respondent	Key Comments
I: 1	<ul style="list-style-type: none"> <li>• Thinks you need something little - a quick summary page or booklet – not the whole folder to give to people that your children stay with often. Included in this brief booklet would be: <ul style="list-style-type: none"> <li>→ A description of what Coeliac Disease is</li> <li>→ What gluten has done to the bowel</li> <li>→ How long it will take to recover</li> <li>→ 2nd part: everyday food you can have (i.e. lunch examples)</li> </ul> </li> <li>• “What I ultimately needed at the beginning...like ‘Where do I buy this stuff from?’”</li> <li>• Information about the disability allowance</li> </ul>
I: 2	<ul style="list-style-type: none"> <li>• Information about the child's disability allowance</li> </ul>
I: 3	<ul style="list-style-type: none"> <li>• A card to give to the waiter for the chef which outlines what you can't eat</li> </ul>
I: 4	<ul style="list-style-type: none"> <li>• Believes the handbook is really helpful for people in the first two to three years</li> <li>• Emphasise Coeliac Disease as a positive thing (doesn't even consider it a disease – calls it an allergy/condition)</li> </ul>
I: 5	<ul style="list-style-type: none"> <li>• Initial reaction: needs to be more colour</li> <li>• Needs to be more interesting</li> <li>• Emphasise that it is a journey; a learning curve – but it's positive</li> </ul>
I: 6	<ul style="list-style-type: none"> <li>• Start with basic ideas: <ul style="list-style-type: none"> <li>→ What you need to change in your pantry (things you can do straight away)</li> <li>→ Things that are going to catch you out</li> <li>→ Adjust normal recipes using cornflour and rice flour</li> </ul> </li> <li>• Make it more user-friendly <ul style="list-style-type: none"> <li>→ Different coloured paper</li> <li>→ Make sections more easy to find by colour coding</li> </ul> </li> <li>• Make it less boring</li> </ul>

I: 6 (cont.)	<ul style="list-style-type: none"> <li>• Ring-binder is good: you can add to it</li> <li>• Put additive numbers on a credit-sized card</li> <li>• Restaurant cards &amp; travel cards are good</li> <li>• Has to be a working document (with handbook updates in the magazine)</li> </ul>
I: 7	<ul style="list-style-type: none"> <li>• Initially you want to know what you can and can't eat, what Coeliac Disease is, what's got gluten in it and what doesn't</li> <li>• You need to know about the traps: marmite, MILO etc.</li> <li>• Pantry essentials and no-go's</li> <li>• Younger ones may find an online chat-room good. I would check a website that updates where to eat regularly</li> </ul>
I: 8	<ul style="list-style-type: none"> <li>• Pictures of the gut and damage gluten does to the villi</li> <li>• Design a beginning edition: "Sometimes too much information can be harmful"</li> <li>• Don't need to tip out pantry at the start: "they need to work out for each meal of the day that they have got something there"</li> </ul>

**Table 38**  
Key comments from the interviews

#### 4.2.4 Interview summaries

There was a very positive response to the interviews, and the interviewees involved were very generous with their time and willing to talk in great depth about their experiences with Coeliac Disease. Owing to this however, some of the interviews ended up dominated by stories of the interviewees diagnosis, rather than suggestions to help the re-design of a useful handbook. Still, some very valuable information and insights were established. The key findings are explained below.

#### **1: Diagnosis**

Every one of the interviewees expressed that it took a significant amount of time after they first started having symptoms until they were actually diagnosed. For some, this took years and years. All felt very unwell before going on the gluten-free diet, and although some of the symptoms were similar, they also varied between each individual. In most cases, the patients were misdiagnosed initially, and when their health did not improve they had to go back for further testing.

## **2: Experiences living with Coeliac Disease**

Two of the interviewees had pre-school children diagnosed with Coeliac Disease. For one it was a huge shock to begin with. Both expressed confusion to do with foods you can and can't eat. One was really worried she was feeding her child the wrong foods and making her health worse. One of the mothers said her child had adapted to the diet really well and understands that he can't eat gluten. The other mother was not so sure her child did understand, but said she was very young. This mother also stated it was really hard work learning and adapting to the gluten-free diet when she also had a baby to care for.

The rest of the interviewees had Coeliac Disease themselves. Both of the men, and one woman were really positive about the transition to a gluten-free diet. They were not embarrassed to be bold enough to ask waiters at restaurants if they could have gluten-free food, and took a fairly relaxed approach to the diet on a whole. One said it "wasn't such a bad thing".

The sixth interviewee expressed that it was a very emotional time for her after her diagnosis. She found the social implication hard, the financial implication "horrendous" and was angry she had not been diagnosed earlier as she now had other health problems that were related, and could have been avoided if she had been on the diet from an earlier age. This interviewee set up a support group in order to share information to help other Coeliacs like herself, and is really passionate about sharing beneficial information.

The sixth interviewee was overwhelmed to begin with, but had good support from friends that were diagnosed, and now is happy as she has lots more energy and feels healthier. The final interviewee also

spoke positively about the long-term benefits, and plays an active supporting role to help others with Coeliac Disease.

### **3. Information materials**

Almost all the interviewees expressed they received little (if any) information materials from their GP or specialists when they were first diagnosed. The two mothers with pre-school children diagnosed thought their dieticians were really helpful; however the other interviewees didn't seem to agree about this.

Most of the interviewees conducted their own research, mainly through the Internet. All of the interviewees joined the Coeliac Society, and some mentioned they were really helpful, either through providing verbal support, lending cookbooks or through the information they produce in the Coeliac Link magazine.

A few of the interviewees have stressed the importance of support networks. Two of the interviewees helped set up a support group. This group enabled information to be shared and discussed.

### **4. Handbook suggestions**

There was an emphasis from some of the interviewees that the handbook is mainly useful for the newly diagnosed. With this in mind, the handbook should firstly cover the basics. This should be information to start a newly diagnosed Coeliac off, tell them what they can and cannot eat etc. One suggested this could be in a separate little booklet so she could give it to family or friends, but several stressed the importance of the handbook being in a ring binder format so it could be added to and updated when necessary ("a working document", as one said). One person mentioned having an online resource that could be updated frequently.

Also associated with the handbook being about the basics was the point made by a couple of interviewees that too much information can be “too overwhelming or dangerous”. The people that expressed this suggested that it was more important to give people basic information rather than making them overwhelmed with content.

Finally, several stressed that the information should be positive. Rather than focussing on the negative side of Coeliac Disease emphasise the positive health benefits of being on the gluten-free diet.

Overall the interviews were of great value to the research. Ideas were brought up that the researcher would not have anticipated, and what people’s real information needs are was clarified.

### **Part 3**

#### **4.3 Evaluation of handbook (focus group)**

Unlike the interview and questionnaire methods, participants in the focus group are encouraged to interact with other members of the group. In this way, ideas and points-of-view are explored, discussed, debated in ways not achieved in the reasoned responses that are generated from interview questions.

The discussion in the focus group session can stimulate a variety of different forms of communication that sometimes can tell researchers more about what people really experience. These forms of communication may include jokes, anecdotes, teasing and arguing; all important for revealing dimensions and understanding not achieved by the more traditional methods (Kitzinger, 1995) of survey and interview.

The intended outcome of the focus group was to seek evaluation and feedback on the new handbook

prototype that the researcher had designed. The feedback would be used to evaluate whether criteria was met from previous research findings, and to establish any changes or modifications that needed to be implemented before the final design.

#### **4.3.1 Focus group composition**

Five people agreed to participate in the focus-group session. Between four to eight people is considered to be the ideal group size (Kitzinger, 1995). The group was “naturally occurring” – although not everyone in the group knew each other they were connected in some way to another in the group (e.g. brother, friend or flatmate). The participants selected represented a range of the study population. Gender was mixed (two female participants and three male). Participants came from different backgrounds and all but two had different jobs. The ages ranged between 23 and 32 years old.

Before starting the session all participants signed a consent form as required by the Auckland University of Technology ethics committee.

#### **4.3.2 Background of participants**

For anonymity reasons the names of the focus group participants have not been used, instead they have been abbreviated to FGP (Focus Group Participant) and to differentiate, between them they have been allocated a number (e.g. FGP: 1, FGP: 2, FGP: 3 etc).

##### **FGP: 1**

Focus Group Participant 1 works as an administrator for a charity. She is 23 years old. Although she herself does not have Coeliac Disease, she has a reasonable amount of knowledge as both her parents have been diagnosed, and one also has Crohn's Disease (which is often an associated illness). Her boyfriend also suffers from allergies (dairy and eggs). FGP:1 likes to travel, and lives with FGP:2.

FGP: 2

Focus Group Participant 2 lives with FGP:1. She works in sales. Focus group Participant 2 is 29 years old. None of her family or friends has Coeliac Disease, but has heard about gluten-intolerance and would like to know more.

FGP: 3

Focus Group Participant 3 is a biology graduate who now works in the outdoor industry as a Seasonal Instructor. He knows few people with Coeliac Disease, except for the researcher. Focus Group Participant 3 is 28 years old.

FGP: 4

Focus Group Participant 4 is a medical Graduate, who is now undertaking his Masters studies in Medicine. He is the brother of FGP: 3. He has a solid understanding of the condition, and has undertaken research on Coeliac Disease. Focus Group Participant 4 is 26 years old.

FGP: 5

Focus Group Participant 5 is 32 years old. He has an aunt with Coeliac Disease, and also lives with someone who has Coeliac disease. Owing to this, he has a good awareness of Coeliac Disease, what gluten is and what food Coeliac's can and cannot eat. Focus Group Participant 5 is friends with FGP: 3 and works alongside him in Outdoor Education. Focus Group Participant 5 was the quietest one in the session, but did contribute some thoughtful feedback towards the end of the session.

### **4.3.3 Focus group session plan**

In the development of the new handbook design, the researcher aimed to provide an accessible information support for newly diagnosed Coeliac patients. Based on the findings from the questionnaire and interviews, the researcher developed the following criteria that the new handbook had to meet:

1. The handbook should be for newly diagnosed Coeliacs, and focus on 'the basic information', so to not overwhelm with content
2. The handbook should be in a format that can be updated and added to easily
3. Information in the handbook should reflect a positive attitude towards Coeliac Disease, yet still outline symptoms and the importance of maintaining a gluten-free diet for life
4. The handbook should include clear information about additives and food labelling
5. The handbook should be colour-coded with diagrams and visuals
6. A wallet-sized additive card should be included in the handbook
7. The handbook should include stories of other Coeliacs' experiences
8. The handbook should be easy to read, easy to use and quick to find information

The aim of the focus group was to seek evaluation and feedback on the new handbook prototype based around the above criteria. In order to encourage communication amongst participants the focus group session was conducted fairly casually. The group took place in a comfortable setting, with refreshments. To begin with participants sat in a circle. After introducing themselves to each other the researcher, who was facilitating the session, explained what the purpose of the session was before handing the group the old handbook. The reason for the group looking through this handbook first was

to understand what resources are in place already for Coeliacs in New Zealand, and to consider this alongside the modifications the researcher had made in the prototype. After participants had viewed and discussed the old handbook, the new prototype design was passed around and discussed. The last part of the focus group session took on a more structured approach with the researcher asking questions. The questions asked were adapted from earlier questions posed in the questionnaire about the original handbook. The reason for asking these particular questions was to evaluate whether or not the new design was a significant improvement on the old handbook.

#### **4.3.4 Key findings**

From the transcription of the session, key findings have been summarised in the following tables. These have been divided into parts according to the structure of the session as follows:

- Part A: Key comments of the discussion around Handbook 1 (the old handbook)
- Part B: Key comments of the discussion around Handbook 2 (the prototype)
- Part C: Key comments from individual questions

Part A	
Handbook 1 (the old handbook)	
Respondent	Key Comments
FGP: 1	<ul style="list-style-type: none"> <li>• What? This is horrible! You got sent this?</li> <li>• I give up. I'm dyslexic and honestly, there's just too much information here. If I got this I wouldn't read it. There's no colour or pictures at all</li> </ul>
FGP: 2	<ul style="list-style-type: none"> <li>• There are a lot of pages of type!</li> <li>• There is a lot of information</li> </ul>
FGP: 3	<ul style="list-style-type: none"> <li>• Ha! Are you serious? Is this really what members pay to get? I'm sorry, but I don't know if I can be bothered reading this either</li> <li>• You know, it looks like they just went onto the net and pulled off loads of information and photocopied it off</li> <li>• Anything you do will be an improvement on this!</li> </ul>
FGP: 4	<ul style="list-style-type: none"> <li>• It appears that there may be some good information in here, but it's really badly laid out. There's no colour and so much type</li> </ul>

**Table 39**  
Key comments from Part A of  
the focus group session

In general, all participants seemed very disappointed with the current handbook. They thought there was too much information, and they couldn't be bothered reading it. One participant was shocked that this handbook was what paying members receive.

After participants had viewed and discussed the original handbook, the new prototype design was passed around and discussed. The key comments of each participant have been taken from this conversation and tabled on the next page.

Part B	
Handbook 2 (the prototype)	
Respondent	Key Comments
FGP: 1	<ul style="list-style-type: none"> <li>• I really like the colour, and these tab things</li> <li>• I like how these sections are in a different colour. It makes it clear when each section begins and ends. I think it's also good that important words are also in the same colour as the sections. It all ties in. The colours really good</li> <li>• I like these diagrams</li> <li>• Hey, this is cool. You can go to this website and get travel cards. That would be so handy. That's a good thing to include</li> </ul>
FGP: 2	<ul style="list-style-type: none"> <li>• Your eyes jump to the place you want to read. It's well broken up</li> <li>• What I really like is the handy hint, reference summary thing at the end of each page – I think that works really well</li> <li>• I do really like the bits down the side saying what section you are in</li> </ul>
FGP: 3	<ul style="list-style-type: none"> <li>• This is something I'd like to receive if I paid membership</li> <li>• This food label information is interesting. That's good, how you would see the label on the packaging</li> <li>• I really like this Further Information section. There's a place to read more if you want to, but also points to where to go for more information. That's really good. I like that. I wouldn't have thought about travel, and I imagine many other Coeliacs wouldn't either until they were in that situation</li> <li>• These cards are cool</li> </ul>
FGP: 4	<ul style="list-style-type: none"> <li>• It's stylised, but it shows what people need to see. You see, here's the bowel. That's where the damage happens (in reference to a diagram)</li> <li>• Some things could be worded differently - I don't think there's anything wrong with a casual statement – it makes it feel like it's real – like real people actually have Coeliac Disease. Only, you may want to think about another quote. It may look unprofessional</li> <li>• It's very accessible. It's basic, but it's got all the information that a Coeliac patient needs to know without being overwhelming</li> </ul>
FGP: 5	<ul style="list-style-type: none"> <li>• The bits telling you what the next page say are really useful</li> </ul>

**Table 40**  
Key comments from Part B  
of the focus group session

Overall, the comments about the prototype were very positive. Some of the participants became excited about certain aspects of the design such as the colour, cards and handy hints. Participants had no trouble navigating their way through the handbook, and thought it was well laid out in clear sections. A couple of participants really liked the Further Information section, and the notes on where to seek more information throughout the handbook.

One participant stated that it was very accessible. He noted that it was basic, but not overwhelming.

### Part C: Key comments from questions

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 1	Comments	
How helpful has this information been?	<ul style="list-style-type: none"> <li>• Very helpful – definitely. I think it is very helpful</li> <li>• I think it is very accessible. I think anyone could pick this up, read it and understand it. The pictures are good – they would be helpful. They are stylised, but make sense. You don't really want to see the medical photographs of the inside of your bowel either do you? It's not very pleasant for people to look at, and to be honest, I don't think it would help to explain it as well as these</li> <li>• I think it's very helpful. Basic, but to the point</li> <li>• Very helpful. For sure</li> </ul>	

**Table 41**  
Key comments from Part C of the focus group session (Question 1)

All participants in the focus group stated that the information was 'very helpful'. One participant elaborated saying it was 'very accessible' and the pictures were helpful.

Everyone that responded to this question agreed

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 2	Comments	
How would you rate the quality of information given to you ?	<ul style="list-style-type: none"> <li>• It's very good</li> <li>• It seems considered and well designed. You have picked out information that is needed to explain Coeliac Disease, but you have also omitted unnecessary or confusing information</li> <li>• I really like that you can jump from section to section. It makes it easy to use, and not confusing</li> <li>• I think the quality is very good</li> </ul>	

**Table 42**  
Key comments from Part C of the focus group session (Question 2)

Two participants said they thought the quality was very good. One participant referred to how the sections have been organised and said it was not confusing. One participant said it was well designed, and confusing information had been omitted.

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 3	Comments	
Do the pictures and diagrams assist your understanding of Coeliac Disease?	<ul style="list-style-type: none"> <li>• Yes</li> <li>• Definitely. They help for sure</li> <li>• Yeah they do</li> </ul>	

**Table 43**

Key comments from Part C of the focus group session (Question 3)

that the pictures did assist their understanding.

There was not much discussion about this question.

This could be partly to do with the way the researcher worded it as a closed-ended question, and that there had already been discussion earlier about the pictures and diagrams.

All the participants agreed that the handbook was

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 4	Comments	
How attractive do you think the material is? (on a scale from 1-5)	<ul style="list-style-type: none"> <li>• 4</li> <li>• 4</li> <li>• 4: it's attractive and practical</li> <li>• 4 out 5. It's not overly pretty and flowery which is good. It's information about a disease – you don't want it to be too pretty. You want it to provide information.</li> <li>• It's not about being pretty I don't think. But it still looks good</li> </ul>	

**Table 44**

Key comments from Part C of the focus group session (Question 4)

attractive, most awarding it 4 out of 5. Two participants discussed that being 'pretty' was not the point of the handbook, but it still looked good.

This question produced surprising comments.

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 5	Comments	
If you owned this handbook where would you store it?	<ul style="list-style-type: none"> <li>• In the kitchen</li> <li>• I think kitchen too</li> <li>• I'd keep it in the kitchen, but I would prefer it if it was less bulky. To be honest I don't like the ring binder</li> </ul>	

**Table 45**  
Key comments from Part C of the focus group session (Question 5)

Although everybody agreed that the kitchen would be the ideal place to keep the handbook, this question started up a debate on the format of the handbook. One person stated that she thought the ring binder was too bulky, and another thought that the ring binder didn't look professional. The participants spent quite a while discussing this, and three decided that if it were spiral bound it would look better. One participant disagreed, reminding others that the handbook had to be added to. He believed that "the look" of the handbook wasn't what was important.

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 6	Comments	
How easy or difficult do you think this handbook is to use?	<ul style="list-style-type: none"> <li>• I think it's pretty easy</li> <li>• The sections make it easy to find what you need</li> <li>• Each new section is in bold – also it's easy to find what you want in each section too</li> <li>• I think it's not too complicated. It's a really good starter pack for someone who is recently diagnosed</li> <li>• I also think that the simple stuff makes you feel happier about it</li> <li>• It's not too much. It doesn't freak you out</li> </ul>	

**Table 46**  
Key comments from Part C of the focus group session (Question 6)

All participants thought the handbook prototype was easy to use. It was commented that the sections made it easy to find what you need. One participant stated that it was a good starter pack for someone who was recently diagnosed. And two people mentioned the feelings they have with it, saying it would make them feel happier about their diagnosis and it wouldn't "freak you out".

Participants confirmed that the information of most importance was "what Coeliac Disease is" and "what to avoid". Both these sections were easy to find

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 7	Comments	
What do you think the most important information is in the handbook?	<ul style="list-style-type: none"> <li>• What Coeliac Disease is</li> <li>• What to avoid – what you can't eat</li> <li>• It covers all bases</li> <li>• It points to places you can find out more information</li> </ul>	

**Table 47**

Key comments from Part C of the focus group session (Question 7)

straight away. Other comments included that “it covered all bases” and that it pointed to ways you could find out more information if you needed to.

Part C: Questions		NB: For the complete list of comments on this question see Appendix G.
Question 8	Comments	
How positive is the information in the handbook?	<ul style="list-style-type: none"> <li>• Simple layout makes you feel happier</li> <li>• Colour is positive</li> <li>• Quotes from people could work, but need to be revised</li> <li>• Easy to use, so doesn't add to stress</li> </ul>	

**Table 48**

Key comments from Part C of the focus group session (Question 8)

The last question in the focus group session checked whether or not the handbook portrayed a ‘positive’ attitude towards Coeliac Disease. Comments were that the simple layout and ease of use made you feel happier and less stressed. The colour was praised as making you feel better about the disease. The quotes in the handbook were thought to be a good idea, but it was thought they needed to be revised.

#### 4.3.5 Results and recommendations

Overall, the response to the prototype was very positive. All participants preferred the new handbook to the original, and thought the changes were very good. As a whole, participants thought that the prototype was very easy to use, included good information and was not too overwhelming for someone who was newly diagnosed.

Some participants however were unsure about the format of the prototype. Some suggested that a ring-binder looked unprofessional. The issue of format was debated amongst the group, and one participant still thought the format of a ring binder was neces-

sary. It was pointed out that some pages to write your own notes on would be useful.

Further recommendations that were made were mainly to do with proof reading. It was agreed that some sentences and quotes needed to be worded differently, and spelling mistakes corrected.

The insights produced by the focus group were very useful. Some of the discussion led to some surprising remarks that the researcher had not considered, and also reaffirmed that the researcher's design decisions were appropriate. Balanced with the findings from the questionnaire and interview, the focus group tapped into experiences and attitudes that were integral to the overall understanding of user interaction with the information.

## Chapter 5: Concept Development and Practical Design

This chapter discusses the concept development and practical design of a new handbook for Coeliac patients. The initial empirical research (questionnaire and interview) identified that there was room for improvement in the design of the handbook.

This chapter has been divided into three parts:

5.1 Design approach

5.2 Design process (phase one)

5.3 Design process (phase two)

### 5.1 Design approach

The design of the new handbook erred on a safe approach to design rather than an experimental one. This approach was decided at an early stage owing to the purpose of the handbook: a guide to support newly diagnosed Coeliac patients. Design concepts were developed with consideration of the health repercussions that could occur if a Coeliac did not adhere to a strict gluten-free diet. Therefore the role of design in this project was to assist adherence to the diet and to ensure patients had a good understanding of the disease through clear communication.

In *Information Design for Patient Safety* (Swayne, 2005) the National Patient Safety Agency (NPSA) recognises the key role design plays in delivering healthcare products, and has recommended action for identifying opportunities for improved patient safety through effective use of design. Swayne identifies that although there is a widespread assumption that human error is inevitable, there is little awareness of the extent design-related factors impact on “user-error” (Swayne, 2005).

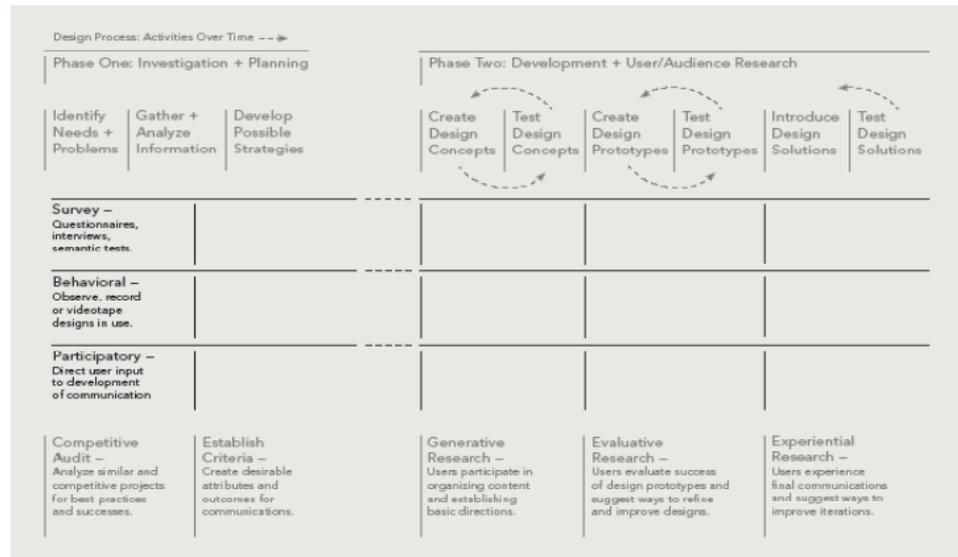
With this in mind, the style of this project was focussed on problem solving rather than an act of self-expression. Any design decisions had to consider the seriousness of the health implications involved, and what impact design-related factors may have on human-error.

Nini (2005) reminds designers of the danger of focussing purely on individual expression: “...by focusing so strongly on our own interests and agenda, we run the risk of excluding or alienating those for whom the communications we develop are intended” (p.9). Although heuristic methods were integral to this phase of the project, all design decisions were balanced with an understanding of patient issues and needs.

It should be noted however that not all patient issues and needs focussed around safe eating. The results from the empirical research defined a list of performance specifications beyond safety issues. These specifications included usability issues, aesthetic concerns and emotional needs. The specifications are detailed in section 5.2.1.1 of this chapter.

## 5.2 Design process (phase one)

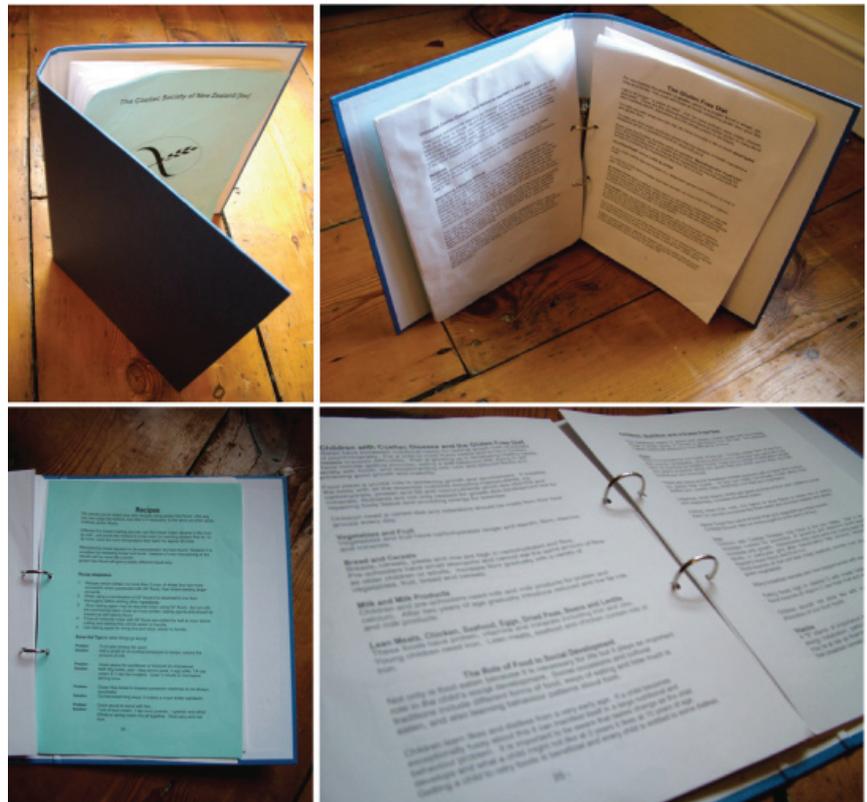
According to Nini the basic design process can be broken down into two phases. The first phase focuses on the investigation of the design problem and strategies to address the problem. The second phase concentrates on developing design concepts, and further refining prototypes and solutions (Nini, 2005). The design process of this project follows this model. This is represented in figure 20 below.



**Figure 20**  
Paul Nini (2005)  
A model of the design process

### 5.2.1 Identification of needs and problems

This first step of the design process also aligns to what the Communication Research Institute of Australia (CRIA) refer to as Scoping (Frascara, 2007). Scoping involves users of the document in question with the purpose of obtaining information about the actual use of the document and the physical, perceptual and cognitive tasks that its use involves. Through this the designer can gain an understanding of the actual functioning of the document, and a list of performance specifications can be defined.

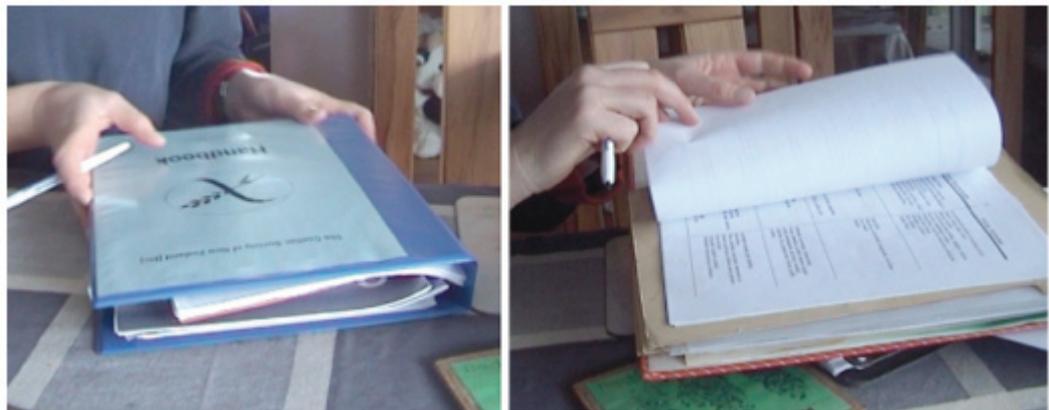


**Figure 21**  
Documentation of the old handbook

### 5.2.1.1. Performance specifications

Through the process of questionnaire and interview, information about the actual use of the document was collated (See Chapter 4: Key findings).

Observations of how people interacted with the old handbook were recorded for later reflection.



**Figure 22**  
Observation of actual use of the old handbook  
(Film stills from interview)

Based on these research findings the following performance specifications were devised:

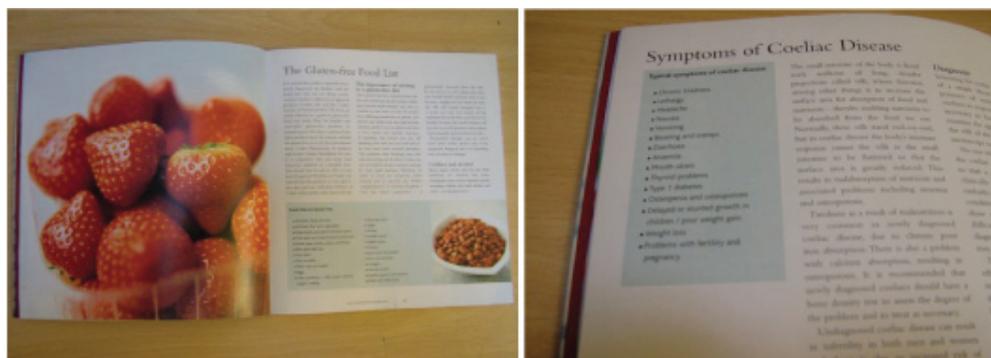
- The handbook should be for newly diagnosed Coeliacs and focus on “the basic information”, so as to not overwhelm with content
- The handbook should be in a format that can be updated and added to easily
- Information in the handbook should reflect a positive attitude towards Coeliac Disease, yet still outline symptoms and the importance of maintaining a gluten-free diet for life
- The handbook should include clear information about additives and food labelling
- The handbook should be colour-coded with clear diagrams and visuals
- A wallet-sized additive card should be included in the handbook
- The handbook should include stories of other Coeliacs’ experiences
- The handbook should be easy to read, easy to use and quick to find information



**Figure 23**  
Coeliac Society UK members resource

### 5.2.2 Gathering and analysing information

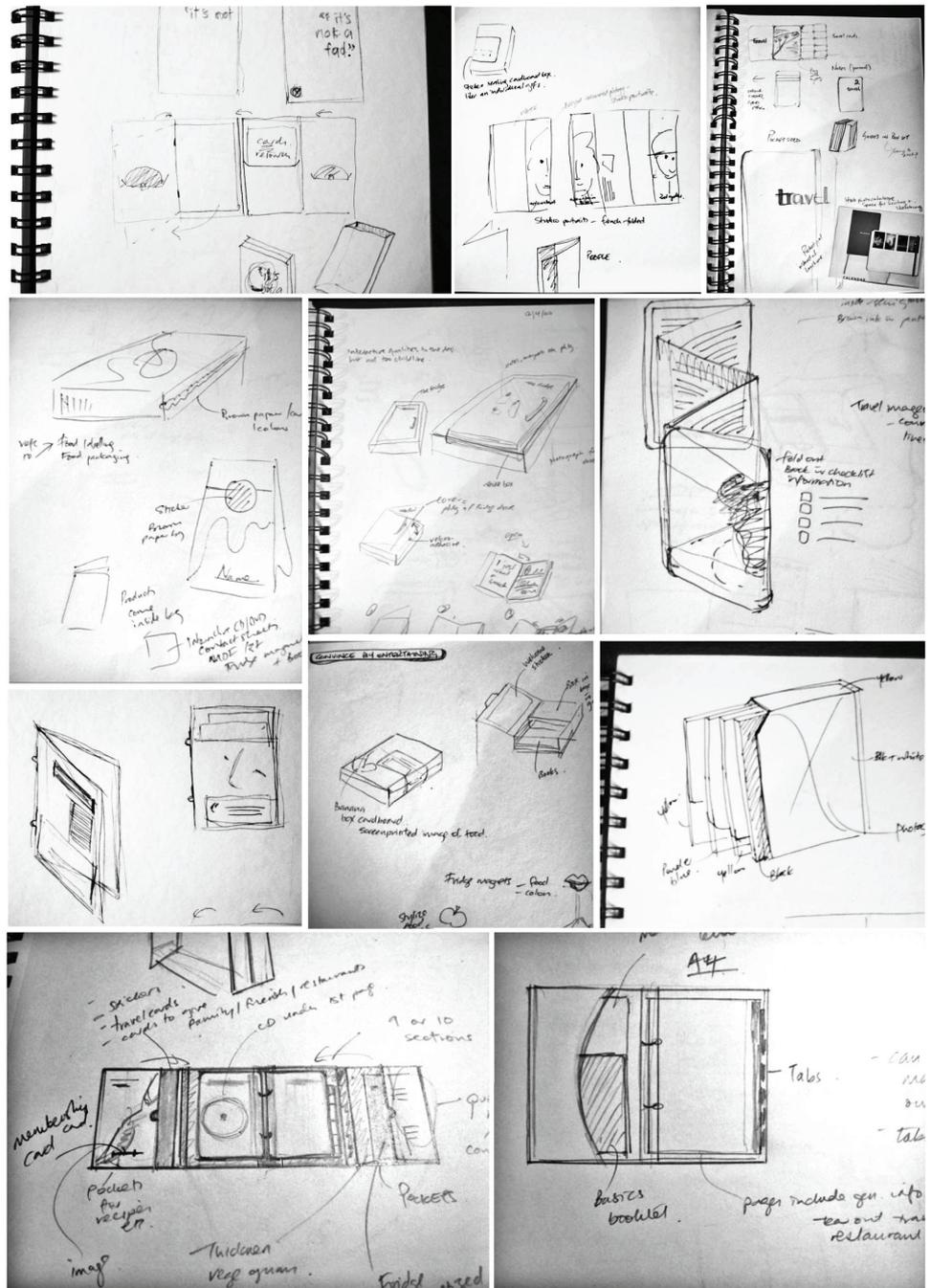
Alongside designing performance specification, analysis of other similar types of documents was undertaken. Such documents included the UK Coeliac Society resource, cookbooks about gluten-free eating and other information guidebooks. These provided a benchmark of what was already available for Coeliacs and also what other types of information handbooks and guides are on the market. Other sources of inspiration were also considered. These have been discussed in Chapter 2.



**Figure 24**  
Allen, Kearny & Coeliac U.K. (2004) Heathy Gluten-free eating

### 5.2.3 Development of possible strategies

As noted in section 5.1, heuristic methods (balanced with an understanding of patient issues and needs) were an important method in the concept development of a new handbook. Heuristics can be defined as educated guesses or acting on intuitive judgement. In this project sketches are used as a starting point to test ideas, to experiment with ideas and to develop new concepts.



**Figure 25**  
A selection of sketches from the early stages of idea generation

Figure 25 shows a range of sketches from the early stages of concept development. With performance specifications in mind these sketches considered ideas of format, accessibility and adaptability. Alongside this, ideas of how the handbook could be made into a positive experience were worked on, such as



**Figure 26**  
Brainstorming techniques used as a problem solving strategy alongside workbook sketches

novel ways to open the handbook and folding out pages. When reflected on, some of these ideas did not match the performance specifications at certain levels, so many were not developed any further than the initial sketch stage.

Alongside sketches, written strategies were considered. These ideas were quickly executed using brainstorming techniques, and

further developed into sketches again if considered a possibility for development.

### 5.3 Design process (phase two)

Phase two of the design process followed an iterative method of designing, testing, then designing again. Some of the initial ideas were developed into mock-ups, working models that could be played with to see if they worked. Further sketches were also used to test ideas for illustrations in the handbook and page layout. Alongside this, type and grid structures were explored. In the later stages of phase two more developed ideas (prototypes) were then tested by a focus group and evaluated.

#### 5.3.1 Explorations: Creation of design concepts

From sketches, some ideas were developed further in Adobe Creative Suite 3. Creating quick layouts in the desktop publishing application Indesign meant that ideas could be visualised with more clarity, and could then be printed to scale. This method enabled



**Figure 27**  
Explorations in page layout and format. The concept was printed to scale then tested for usability

the exploration and critique of typefaces, which could also be printed and considered for legibility and readability. Once printed to scale, obvious problems could be seen. In many cases the designer chose to move on to the next concept, rather than spending time trying to correct a concept that wasn't working at all. These methods of idea generation meant that several concepts could be considered in a short timeframe before arriving at a concept that was worth pursuing, and that best met users needs.

Alongside digital mock-ups, some ideas were created out of card to test format concepts (figure 28 -overleaf). Digital drawings of templates were created before constructing the mock-ups.

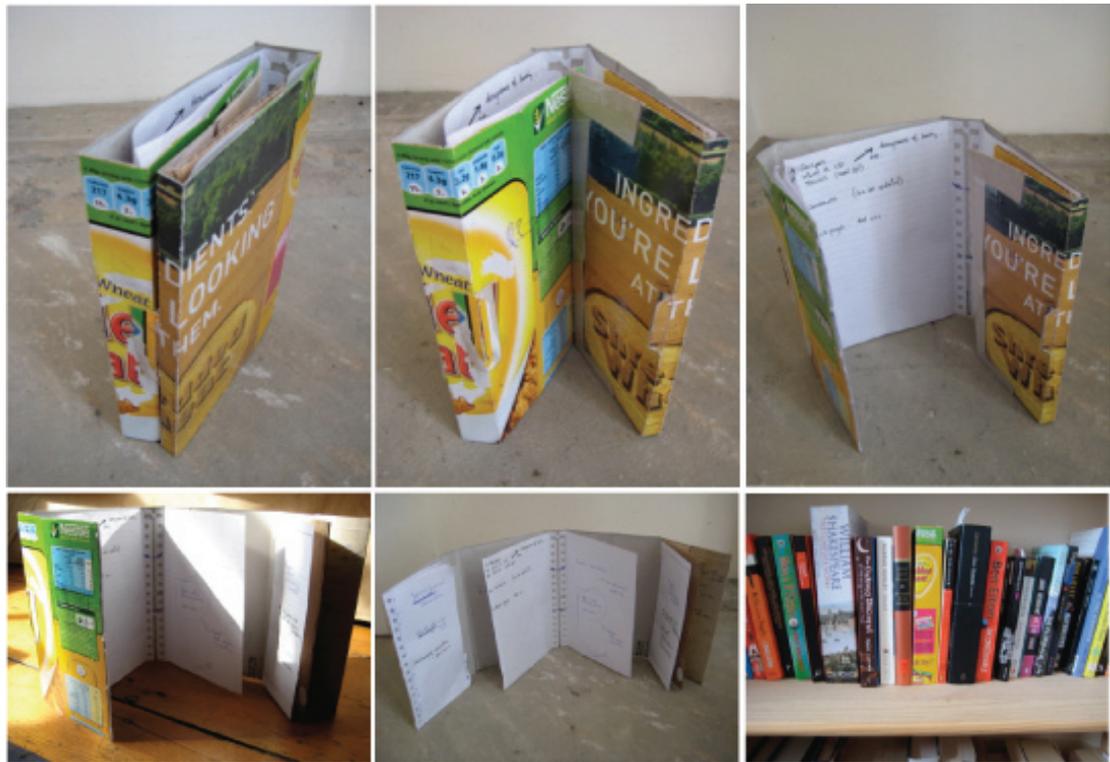
Testing these exploratory concepts highlighted some inappropriate design elements. For example in figure 27, one of the earlier mock-ups, it was identified that the rigid square grid was not the best format for the quantity of information that needed to be contained in the handbook. Testing out the cardboard mock-up (figure 27) revealed that the format was more complicated than it needed to be.

Peer feedback also ascertained that the

designer was placing too much emphasis on the format of the handbook, and other performance specifications were being ignored. This signalled a shift in design development, with the recognition that the handbook's use was actually in the content of the information.

### 5.3.2 Creation of design prototype

In order to reduce human-error and to provide clear, easy to use information, four different design-



**Figure 28**  
Explorations with cardboard mock-ups. Testing how it works and how it can be stored

related categories were identified as important areas of focus: Typography, Page layout, Illustrations and Colour. Each one of these categories was carefully considered in the design of the prototype. The following section of this chapter details these decisions.

### 5.3.2.1 Design categories

#### 1. Typography

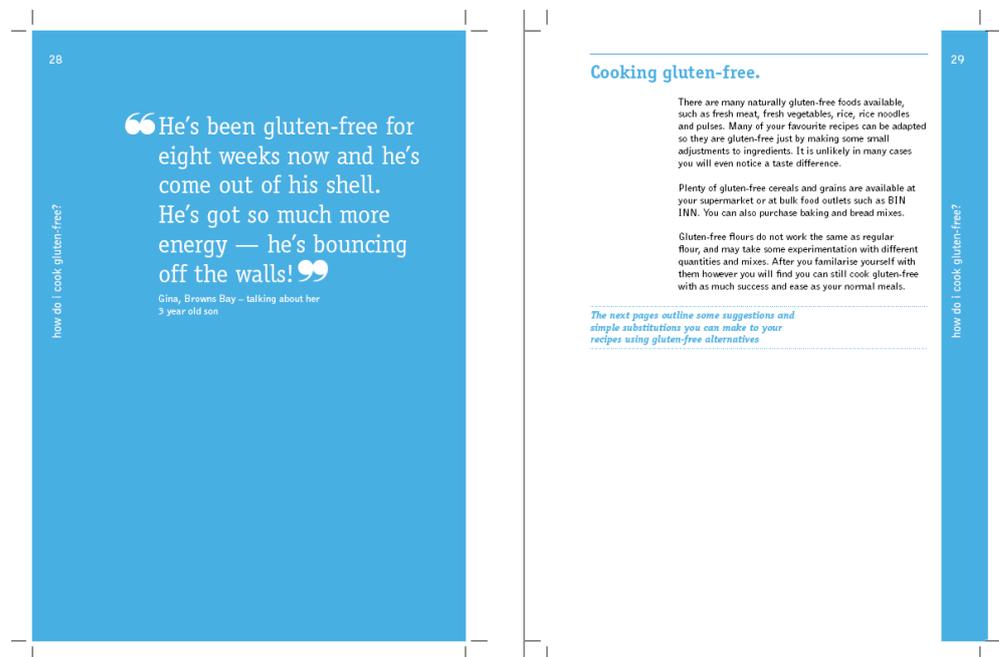
Feedback from the empirical research indicated that the old handbook was not always easy to read. The type was set in a single column that ran the width of an A4 page (see Fig 2). There were no visuals or colour to break up the blocks of type, so it was easy for readers to lose interest in the content. Occasionally different fonts would be used on certain pages, but these had no apparent purpose and looked like it was a 'default font'. Point-size in the handbook also varied within body type, confusing the eye as it jumped from one style to the next.

To add interest and variation and yet still maintain consistency, two fonts were chosen for the prototype: ITC Officina Serif and Bell Gothic BT. These fonts add variation through their styles (one is ser-

ified), but both have been designed to offer optimal legibility. ITC Officina Serif was designed by Erik Spiekermann and Ole Schäfer for office communication in 2000 (myfonts.com, 2008b), and Bell Gothic BT is a Bitstream version of Bell Gothic (designed by Chauncey H. Griffith), which was designed for telephone directories of the Bell Telephone Company in 1938 (myfonts.com, 2008a). Bell Gothic BT has been commended as a clear and easy to read font, and is a good choice for directories and catalogues (myfonts.com, 2008a). Bell Gothic BT was used for labels and the main body of type in the document, whereas ITC Officina Serif was used for headings, quotes and to provide tips throughout the document. The following example of a page spread (figure 29) illustrates an example of how the typography was designed to work in the document.

## 2. Page layout

The main objective when designing the page layout for the handbook was that Coeliac patients using the



**Figure 29**  
Screen shot of a spread from the prototype showing the use of type

handbook were provided with an easily accessible, clearly structured and aesthetically pleasing experience. Meggs (1992) in *Type & Image* states:

*“The designer combines visual signs, symbols, and images into a visual-verbal gestalt that the audience can understand. The graphic designer is simultaneously message maker and form builder. This complex task involves forming an intricate communications message while building a cohesive composition that gains order and clarity from the relationships between the elements”.*

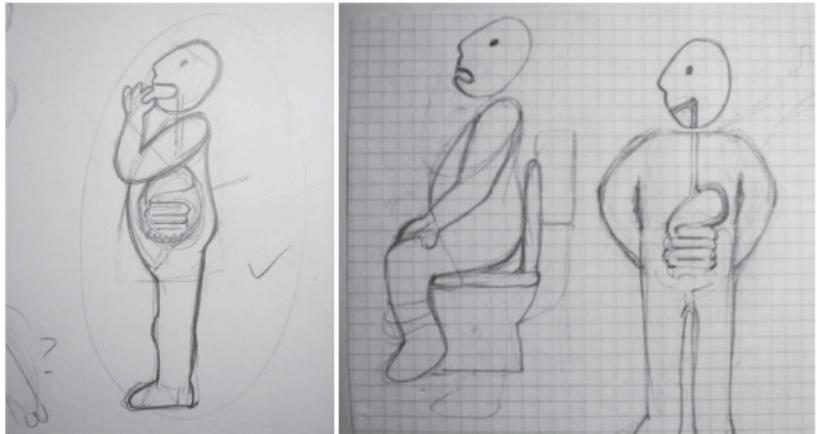
In order to achieve a cohesive composition, as mentioned by Meggs, a basic grid system was developed to help organise and establish relationships between elements in the structure (Greenzweig, 2006). The grid enabled the document to have overall consistency, yet maintained flexibility. The grid also enabled information hierarchies to be more clearly established.

Since the handbook had a purpose of delivering clear communication to Coeliac patients, it was critical that any important sections of information were emphasised. Swayne (2005) mentions the importance of utilising space in patient information designs: “Where pages are cluttered in text and images it may be difficult for a patient to recognise important information”. The inability to recognise important information can significantly increase the chance of error. Negative space was therefore used in the design of the handbook prototype to help draw attention to certain pieces of information and in turn emphasise it.

### **3. Illustrations**

Alongside the text, illustrations in the handbook have an important role. Illustrations are used to enhance the understanding of the text and to enable quick referencing of information. For this

reason the style and execution of illustrations had to be well thought out, as misleading visuals could confuse readers and lead them to make mistakes. A consistent style was necessary for illustrations. Many experiments into the style of illustrations were conducted in the earlier stages of research (see figure 30). These ranged from humorous, comical illustrations to serious realistic representations.

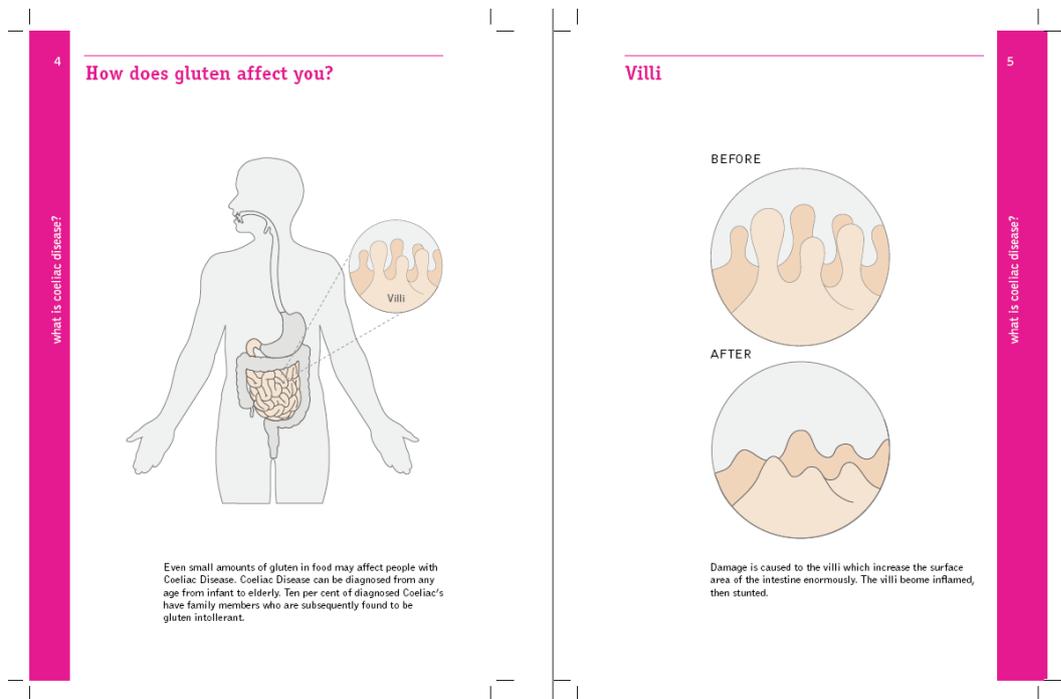


**Figure 30**  
Example of one of the styles of illustrations experimented with

When considering the feelings newly diagnosed Coeliac patients may be facing when first reading through the handbook, it was decided to develop illustrations that favoured clarity over humour. Illustrations of the human body were based on medical diagrams, so were precise in their detail. The illustrations were stylised, but not comical. Pictures of villi in the intestine were simple, so that the information was presented in an uncomplicated and clear way, so as to not overwhelm readers (see figure 31 - overleaf).

#### **4. Colour**

Colour differentiation was used to make different sections of the handbook stand out from each other. Colour also unified each section and made it simpler to quickly navigate through the handbook. Some of the colours were derived from research into other medical publications (e.g. the handbook uses Pantone 676 and Pantone 144 which are also used as part of the NHS brand colours for health publications). However, the colours themselves were meaningless, and were not supposed to represent any idea



**Figure 31**  
Screen shot of a spread from the prototype showing the use of illustration

or function in particular. This idea was advocated in *Information Design for Patient Safety* (Swayne, 2005) which reminds patient information designers that not all users will interpret colours in the same way (e.g. if the patient is colour blind).

Despite colour having no association to any particular meaning, the colour served as a tool to aid usability. Alongside this, the bright colours were chosen to liven-up the handbook and portray a positive attitude. The request for a ‘positive feel’ was a repeated comment in the questionnaire results.

### 5.3.2.2 Designing the prototype

The design categories discussed in 5.3.2.1 were used as the framework to guide the development and design of the prototype with the aim to create clear, easy to use information. However, this framework was not created in isolation to the performance specifications.

These performance specifications were considered in each step of the development so that the designer did not make decisions on a design based on their own agenda and aesthetic desires. Notes on how the prototype aimed to meet performance specifications

are listed below:

- The handbook was edited significantly making sure written information was clear, easy to read and not overwhelming
- The ‘basics’ were covered, and sections were ordered into what information Coeliac patients needed to know first
- Bright, happy colours were used to portray a positive attitude. Real quotes about people’s experiences were added throughout the handbook. All quotes had a positive but realistic tone to them
- Colour was used to differentiate sections and coloured tabs were designed to aid navigation and use
- Diagrams were clear, stylised and used to assist understanding. The diagrams had a serious tone but were not ‘gruesome’ or explicit, as some intestinal diagrams can be
- Typography, colour and layout assisted the readers experience with the handbook, and pointed readers in directions they could find more information
- Pages were designed to be hole-punched in the column so they could be stored in a ring-binder and updated and added to if necessary
- Clear information about additives and food labelling was included in the prototype, with a card to cut out and keep for future reference in supermarkets

Once the prototype was developed a copy was printed and bound in a temporary cover. This document was then presented to a focus group and evaluated (See Chapter 4: Key findings). A temporary cover was used for the focus group, which was also discussed.

Although the feedback offered in evaluation process was generally positive, some changes were suggested

for the final design. The insight generated from observing users experiencing the prototype in the focus group session proved invaluable. Their discussion and comments provided further understanding, which was needed to create a design solution that met users' needs better.



**Figure 32**  
Photographs of the prototype  
which was evaluated by the  
focus group

## Chapter 6: Final Design

The evaluation of the prototype revealed some key points that influenced further development and modification of the design. This chapter discusses these points and details what modifications were carried out in order to match user preferences better. To view the final outcome of the practical component of this project, please refer to the handbook.



**Figure 33**  
Photographs of the prototype being used, discussed and evaluated in the focus group session

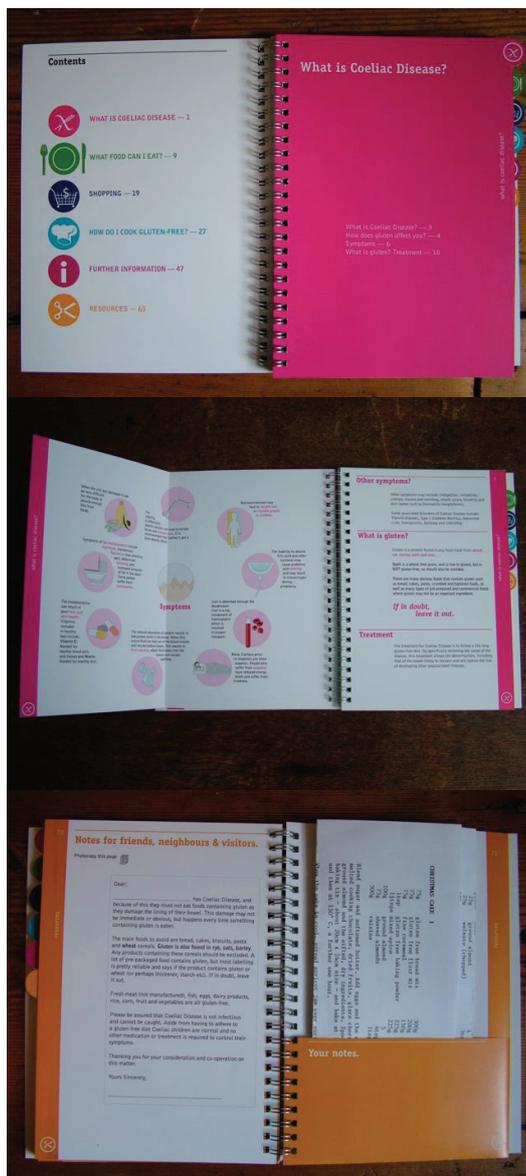
Although the focus group responded very positively overall to the prototype some of the participants were unsure about the format of the prototype. Several participants in the focus group considered the ring binder unprofessional looking and ugly. Suggestions were made to include pages to allow you to write your own notes, and making the handbook spiral-bound so it could lay flat when reading or writing. This topic concerning format of the handbook was hotly debated and almost caused an argument in the focus group. One person still agreed with the results of two interviewees who stipulated that they would like a ring binder so they could add more information.

The designer realised as a result of this discussion how much emotional response was generated from the format of the handbook. The fact that some had such intense dislike for the ring binder format meant that other solutions needed to be developed. As a result, a new cover and binding method was designed. To accommodate the desire to add information into the handbook a notes pocket was designed, as well as pages to write notes and recipes on.

In addition to the format, the focus group discussed whether quotes from people used in the prototype should be more considered. These quotes were revised to generate a more positive yet professional feel. The handbook was also proof read thoroughly and some sentences were edited to make better sense.

As well as feedback from the focus group session, two designers in Auckland gave feedback about the handbook. Both believed the handbook was running low on visuals in some areas. The prototype's minimal style was also considered too sterile.

Although the designer purposely designed the handbook with these minimal aesthetics with the intention to present information as clearly as possible, it was not her intention to generate these clinical associations. Considering this, the designer made some small adjustments to the design to make the layout and cover more interesting and slightly more playful. These included a set of icons that were created to represent and guide each chapter, a double-sided note pocket added at the back and a fold-out page to illustrate symptoms which replaced the 2 page spread previously designed.



**Figure 34**  
Modifications made to the design to add interest and assist with usefulness

## Chapter 7: Conclusion

The primary purpose of this research project was to utilize User-centred methodologies in design and development of a handbook for newly diagnosed Coeliac patients in New Zealand. In order to design a handbook that was useful, useable and desirable, the researcher believed it was necessary to create empathy for the people that would use the design. Empirical research methods were conducted to generate this understanding. Based on these research findings, a prototype was designed, which was then evaluated by a focus group before more design modifications took place.

### 7.1 Key insights

The following findings outline the key insights generated from the research processes.

#### 7.1.1 Data gathering (questionnaire and interview)

The results generated from the questionnaires and interviews indicated that although the Coeliac Society was praised as a good source of information for many patients, many have had to look further and educate themselves.

It was made clear through interviewing Coeliac patients that the old handbook was rarely used as it was too wordy and lacked appeal. The aim of this research was to design a prototype handbook that was informative, appealing, educative and user friendly.

#### 7.1.3 Evaluation (focus group)

The results from the focus group indicated that there was an obvious dislike of the old handbook and clearly something needed to be done to make the handbook more appealing and accessible.

There was a wide agreement that the diagrams and pictures helped their understanding of Coeliac Disease. The group unanimously agreed that the prototype design was attractive and useable.

There was a great deal of discussion over the use of a ring binder and in the end the focus group agreed on a spiral bound handbook as an alternative.

These results confirm that User-centred methodologies can generate an understanding about what users really need in a design. With a clear understanding of these needs, a designer has the ability to establish fresh specifications guiding the design process.

The evaluation results indicate that the designer was able to meet these needs and generate a positive and holistic response. In conclusion, the designer created a product that was useful, useable and desirable.

## **7.2 Issues arising from the research**

Although the results indicate that the aim of this research was achieved, this research study has highlighted some key areas of concern and issues to be discussed.

### **7.2.1 Length of time to generate data to assist understanding**

The user research conducted in this study was designed to be as rigorous as possible. The generation and analysis of the data was a lengthy and costly exercise. Although suited to this particular type of study some practical concerns were raised in relation to implementing User-centred practices outside of an academic framework.

The question of how to incorporate User-centred processes under tight time and budgetary restrictions should be a question communication designers ask. Although the question rests outside of this

study, further research and discussion on effective ways of generating empathy with audiences of communication design would be of great value.

### **7.2.2 Bridging the gap between user research and the design**

Whilst researching “customer valued quality” in the product development process, Buchanan (2001) observed that recently industrial organizations have made user-experience the focus of their business. Two significant outcomes became apparent early in the research: firstly, social science approaches and methodologies are key to generating insights to develop new products, and secondly, there is a distinct “gap” between the general insights of the social scientists and the work of designers.

Whilst this move towards User-centred practices is positive, the concern arises over the “gap” between the two disciplines. It was noticed in this research study the distinct shift in thought and practice between collecting and analysing data and designing the product itself. This “gap” would surely widen if the designer is relying on others to generate the data for them. If the information is not communicated well enough, it is possible the designer will not share the same level of empathy as the researchers of user-experience obtained. How to bridge this “gap” is a problem, which would require further research and investigation. Certainly further research and discussion into the methods and tools to bridge this “gap” is necessary.

### **7.2.3 In-depth response and critical evaluation**

The final concern generated from this research is to do with gathering critical feedback and insight in the evaluation process. Because this study focussed on the real people that would potentially use this design, none of the participants were formally trained in design or had experience in this field. Whilst this

was the intention, reactions and feedback from participants were only based on their initial responses generated from their emotions, feelings or first impressions.

It was agreed that all participants in the focus group were very positive about the prototype, but they were not able to articulate exactly why. The question raised by the researcher was how best to implement and stimulate the non-designers to critically analyse the design of the prototype handbook from a layman's point of view. Research suggests that everyone has something to offer in the design process.

Sanders (2002) states that:

*“It is the belief that all people have something to offer the design process and they can be both articulate and creative when given the appropriate tools with which to express themselves”.*

It is clear on reflection, that to facilitate critical analyses of a design process, the more participation and feedback that one has helps to widen the overall picture. This encourages fresh, new insight into developing improved, positive designs.

#### **7.2.4 Limitations of the thesis**

While considerable care and efforts have been put into the investigation, design and evaluation of the handbook, the thesis is not perfect owing to the limited time and scope of the study. For example, the focus group for the evaluation of the prototype handbook consisted of only five participants. These participants fell into a narrow age range, did not have Coeliac Disease themselves, and were chosen from within the researcher's peer group. Without time restraints a focus group consisting of Coeliacs with a larger range of ages and backgrounds would have been used for the study. Readers should use any data and information published in this thesis with caution, and by supplementing them with data gathered through their own research.

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Table 24

Information showing how often participants use the Coeliac Society handbook since receiving it  
(Question 24)

Figure 16

Bar graph showing where participants seek information on Coeliac Disease or the gluten-free diet  
(Question 25)

Table 25

Where participants seek information on Coeliac Disease and the gluten-free diet  
(Question 25)

Table 26

Information showing how helpful the information mentioned in question 25 has been  
(Question 26)

Table 27

Information showing how people perceive the quality of information mentioned in question 25 and 26 (Question 27)

Table 28

Comments about what participants think could be done to improve the quality of information available about Coeliac Disease or gluten-free diets (Question 28)

Table 29

Information showing whether participants found any pictures or diagrams to be of assistance in understanding Coeliac Disease (Question 29)

Table 30

Information showing on a scale from 1-5 how attractive or unattractive participants believe the old handbook is (Question 30)

Table 31

Information showing how frequently supplementary materials are used to assist participant's gluten-free diet (Question 31)

Figure 17

Bar graph showing where participants use their handbook (Question 32)

Table 32

Comments about where participants use their handbook (Question 32)

Figure 18

Bar graph showing where participants store their handbook

(Question 33)

Table 33

Comments about where participants store their handbook

(Question 33)

Figure 19

Bar graph showing what participants believe is the most important information in their handbook

(Question 34)

Table 34

Comments about what participants believe the most important information in the handbook

(Question 34)

Table 35

Information showing on a scale from 1-5 how easy or difficult the handbook is perceived by participants

(Question 35)

Table 36

Comments showing advice and suggestions about information material that may be of benefit or need to Coeliac patients

(Question 36)

Table 37

Further comments from participants

(Question 37)

Table 38

Key comments from the interviews

Table 39

Key comments from Part A of the focus group session

Table 40

Key comments from Part B of the focus group session

Table 41

Key comments from Part C of the focus group session  
(Question 1)

Table 42

Key comments from Part C of the focus group session  
(Question 2)

Table 43

Key comments from Part C of the focus group session  
(Question 3)

Table 44

Key comments from Part C of the focus group session  
(Question 4)

Table 45

Key comments from Part C of the focus group session  
(Question 5)

Table 46

Key comments from Part C of the focus group session  
(Question 6)

Table 47

Key comments from Part C of the focus group session  
(Question 7)

Table 48  
Key comments from Part C of the focus group  
session  
(Question 8)

## **Chapter 5**

Figure 20  
Paul Nini (2005)  
A model of the design process

Figure 21  
Documentation of the old handbook

Figure 22  
Observation of actual use of the old handbook  
(Film stills from interview)

Figure 23  
Coeliac Society UK members resource

Figure 24  
Allen, Kearny & Coeliac UK (2004) Heathy Gluten-  
free eating

Figure 25  
A selection of sketches from the early stages of idea  
generation

Figure 26  
Brainstorming techniques used as a problem solving  
strategy alongside workbook sketches

Figure 27  
Explorations in page layout and format. The concept  
was printed to scale then tested for usability

Figure 28  
Explorations with cardboard mock-ups. Testing how  
it works and how it can be stored

Figure 29

Screenshot of a spread from the prototype showing the use of type

Figure 30

Example of one of the styles of illustrations experimented with

Figure 31

Screen shot of a spread from the prototype showing the use of illustration

Figure 32

Photographs of the prototype which was evaluated by the focus group

## **Chapter 6**

Figure 33

Photographs of the prototype being used, discussed and evaluated in the focus group session

Figure 34

Modifications made to the design to add interest and assist with usefulness.

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## **Appendices**

### **Appendix A**

#### **EA8**

Application for Ethics Approval for Low  
Ethical Risk Research Projects

#### **EA8RA**

Self Assessment of Research Projects for  
Ethics Approval

#### **Memorandum**

Approval of application

**Auckland University of Technology Ethics Committee  
(AUTEC)**

**EA8**

**APPLICATION FOR ETHICS APPROVAL FOR LOW ETHICAL RISK  
RESEARCH PROJECTS**



***This form is only to be completed when its use is indicated by the EA8RA Risk Assessment. A completed EA8RA must accompany this form.***

***Please note that incomplete applications will not be considered by AUTEC. Please do not alter the formatting of this form or delete any sections. If a particular question is not applicable to your research, please state that as your response to that question.***

**A. General Information**

**A.1. Project Title**

User-centred design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients (working title)

**A.2. Applicant Name and Qualifications**

*When the researcher is a student (including staff who are AUT students), the applicant is the principal supervisor. When the researcher is an AUT staff member undertaking research as part of employment or a staff member undertaking research as part of an external qualification, the applicant is the researcher.*

Professor Leong Yap (PhD)

**A.3. School/Department/Academic Group/Centre**

Post-Graduate Studies

**A.4. Faculty**

Art & Design

**A.5. Student Details**

*Please complete this section only if the researcher is a student*

**A.5.1. Student Name(s):**

Rosemary Walkinshaw

**A.5.2. Student ID Number(s):**

0652751

**A.5.3. Qualification(s):**

BA (Otago)

**A.5.4. E-mail address:**

rose.walkinshaw@gmail.com

**A.5.5. School/Department/Academic Group/Centre**

Post-Graduate Studies

**A.5.6. Faculty**

Art & Design

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**A.5.7. Name of Degree:**

MA (Art & Design)

**A.5.8. Research Output**

*Please state whether your research will result in a thesis or dissertation or a research paper or is part of coursework requirements.*

The research will consist of an exegesis totalling 50% of output and practice-based work consisting of the remainder 50%.

**A.6. Details of Other Researchers or Investigators**

I will be working alongside the Coeliac Society NZ (Inc) to help inform the research process and to help develop communication material for New Zealander's with the disease. The Coeliac Society NZ (Inc) will not be involved as a researcher in this project, but they will provide feedback on design decisions.

*Please complete this section only if other researchers, investigators or organisations are involved in this project. Please also specify the role any other researcher(s), investigator(s) or organisation(s) will have in the research.*

**A.6.1. Individual Researcher(s) or Investigator(s)**

*Please provide the name of each researcher or investigator and the institution in which they research.*

Rosemary Walkinshaw, AUT.

**A.6.2. Research or Investigator Organisations**

*Please provide the name of each organisation and the city in which the organisation is located.*

Coeliac Society NZ (Inc)  
Byron Bay  
AUCKLAND

**A.7. Are you applying concurrently to another ethics committee?**

*If your answer is yes, please provide full details, including the meeting date, and attach copies of the full application and approval letter if it has been approved.*

No.

**A.8. Declaration**

The information supplied is, to the best of my knowledge and belief, accurate. I have read the current Guidelines, published by the Auckland University of Technology Ethics Committee, and clearly understand my obligations and the rights of the participant, particularly with regard to informed consent.

Signature of Applicant		Date
------------------------	--	------

*(In the case of student applications the signature must be that of the Supervisor)*

Signature of Student		Date
----------------------	--	------

*(If the research is a student project, both the signature of the Supervisor, as the applicant, and the student are required)*

## A.9. Authorising Signature

Signature of Head	Name of Faculty/Programme/School/Centre	Date
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## B. Methodological and Ethical Information

*When completing this section, the applicant is advised to consult AUTEK's Applying for Ethics Approval: Guidelines and Procedures, which is accessible online through <http://www.aut.ac.nz/research/ethics>.*

### B.1. Please provide descriptions of the following aspects of the proposed research:

#### B.1.1. The aim and background

**Aim:**

The focus of this project is to analyse, design and evaluate an information handbook for Coeliac patients.

**Background:**

Coeliac disease is an intestinal disorder, and patients must maintain a life-long gluten-free diet to ensure better health and reduce the risks of osteoporosis, intestinal lymphoma and other associated diseases. Patients must have access to clear information about the disease and about what foods are safe to eat, detect foods that contain gluten and make adjustments that need to be made to their diet. There is very little well designed information currently available for Coeliac patients. Eating out and shopping in supermarkets could become a nightmare. A user-centred design approach will be used to generate information and insights on the Coeliac disease and patients' needs to conceptualise, design and evaluate an information handbook that is both functional and pleasurable to use. Ethnography, interviews and focus groups will be used to generate empirical data to guide a participative design process and evaluate different versions of the handbook before it is printed for general use.

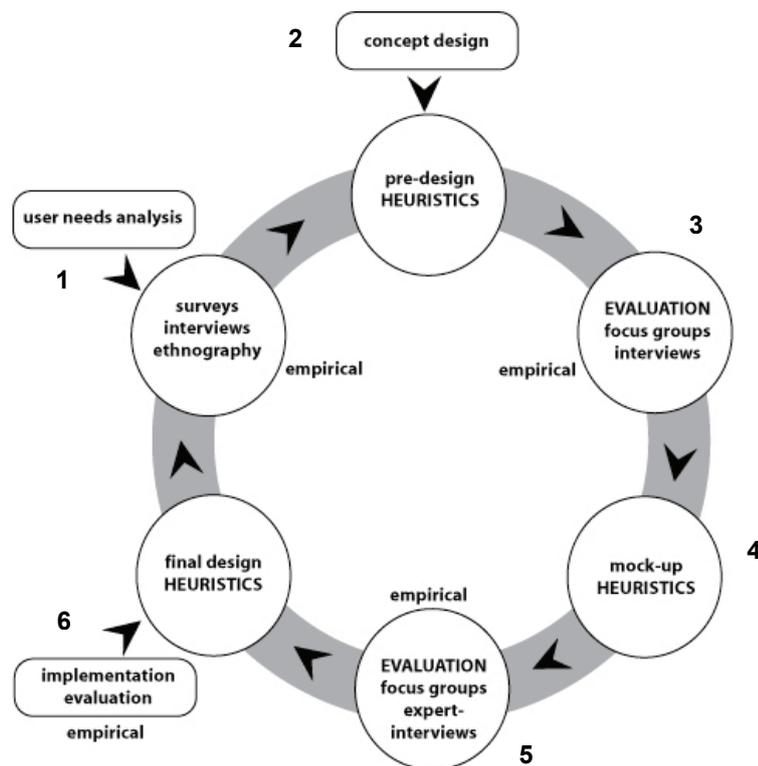
**Methodology:**

The focus of this project is to generate design solutions that support a contextualised design process and better meet user needs and design preferences. Working alongside The Coeliac Society (NZ), user research will be conducted to inform the design of a handbook for Coeliac patients. Both empirical and heuristic methods will be undertaken. Empirical methods will generally follow qualitative procedures. The research will aim to meet the following objectives:

1. Generate a deeper understanding of the user - (Understand feelings, attitudes and personal experiences associated with the disease, and define issues Coeliac patients face)
2. Generate a deeper understanding of the contexts in which Coeliac patients would use the design
3. Generate an idea/overview of current information material or support material available for Coeliac Patients
4. Evaluate how the designed material is used and assess if it meets its purpose (and make adjustments to the material based on these findings)

To meet these objectives, a user-needs analysis will firstly be conducted through a variety of research methods. These methods include questionnaire/surveys, interviews and ethnography (observations). These empirical methods will form the grounding basis for the design work that will take place afterwards. The diagram below (fig 1.) illustrates how these methods interrelate with the overall design objectives.

Fig. 1.



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### 1. User-needs analysis:

Once ethical approval has been confirmed, empirical methods will be used to generate a deeper understanding of the user and the contexts in which they would use the design. These methods are necessary in developing a more accurate representation of Coeliac experiences.

1.1 Questionnaires and interviews will address contextual factors (such as where the handbook is used and how it is used). Contextualization will aim to critically reflect on the 'social and historical background of the research setting'(Klein & Myer, 1999). Along with the intention of following a reflective practice, this helps build transparency in the process so that the participants involved can understand how the researcher has arrived at any insights or decisions.

The 'user-needs analysis' will also help define issues Coeliac patients face. This data will drive the design of the handbook. It is hoped that by using these methods the researcher will generate the necessary information to understand the problem and the issues involved. By looking at these factors, a factual and functional handbook will be designed to communicate information to meet the real needs of Coeliac patients.

The questionnaires will be administered to Coeliac patients. In order to achieve a non-biased result, members of the Coeliac Society will be randomly selected from a range of locations around New Zealand. It is hoped that around 110 people will respond to the questionnaire (which is 5% of the total members of the society) in order to achieve an even-spread of responses. Questions will be generated in order to better understand the life and issues of a person living with Coeliac Disease. The questions will be designed to try to understand the feelings, attitudes and personal experiences they have with their condition. Questions will also be directed at generating an idea of the current information and support material available to them.

The interviews will be administered to a smaller number of people (about 10-15 people). In order to generate a range of data the interviews will aim to involve committee executives of the Coeliac Society (NZ), nutritionists, endoscopy specialists and chefs.

### 1.2 Ethnographic processes

Ethnographic processes will be also conducted to gain further insight into the life and experiences of a person with Coeliac Disease. Video ethnography may be collected during observations as well as note taking. The participant observations will serve as a tool to analyse the rituals and culture of participants and they way they access information about Coeliac disease. It is intended that ethnographic processes will also be useful in determining the needs of the Coeliac patient by observing any frustrations or issues that arise (particularly in the handling of the current handbook and/or in other guiding material). The video footage and observational notes from the ethnography will remain completely confidential and not made public. The researcher will be the only one with access to this footage, and after the data has been transcribed and analysed it will be destroyed. The sole intention of the ethnographic processes is again to inform the researcher of issues that Coeliac patients may face (particularly with information material) and how a design could be implemented (or adjusted) to help the issues that Coeliac patients face.

1.3 The final stage of the user-needs analysis is the collection and analysis of data. Data from questionnaires, interviews and ethnographic observations will be systematically analysed. Findings will identify the needs of Coeliac patients.

## 2. Design and evaluation

2.1 Pre-designs will be conducted after user-needs have been identified. Using heuristics, the pre-design phase will attempt to consolidate the knowledge gained from the user-needs analysis. The heuristic methods will follow a 'trial and error' approach and will require rigorous questioning throughout the design process. Preconceptions will be addressed and continual critical questioning and reflection will be undertaken in this process.

2.2 Empirical methods will also be used to evaluate original concepts and then to evaluate the design. For the evaluation, focus groups will take place. Heuristics will be used when designing the handbook. It is intended that both methods will be undertaken in an iterative manner.

Interpretation and analysis will be an ongoing process throughout the whole research project. Importantly, all analysis of data must aim to achieve a reflective viewpoint within a contextualised framework.

The project outcome will be a handbook for those newly diagnosed with Coeliac Disease.

### **Interpretation and analysis of data:**

The sole person transcribing the data will be the researcher herself. There are four stages of the research that will need to be analysed:

1. Interview
2. Ethnography
3. Questionnaire
4. Focus Group

1. **Interview:** The first part of the interview analysis will focus on key words and key concepts that the interviewee has said. It will explore connections and patterns based on the information gained as they talk through their experiences. Following from this, the analysis will focus on transformation of the data by looking at, and analyzing the key words or ideas that have been generated, then transforming these concepts into useful design criteria.
2. **Ethnography:** Observations will be undertaken of the participants to analyse exactly how and why they access information and the way they handle things. These observations of the rituals and culture of participants will be critically analysed, so that their problems can be transformed into useful design criteria for designing the handbook.
3. **Questionnaire:** Descriptive statistics will be used to describe some of the basic patterns or features of the data in the study. This would provide a good summary in the study of the participants likes or dislikes, and of their idea of issues associated with Coeliac disease. The descriptive statistics will also describe the participants way of looking at the current handbook available to them, and whether they believe the handbook is important.
4. **Focus Group:** The focus group enables the group to test whether the participants have perceived the intention of the design accordingly. The focus group can openly

discuss difficulties, perceptions and preferences, which will then be critically analyzed to inform and improve the final design of the handbook.

**B.1.2. The number of participants that will be involved, how they will be recruited, any exclusion criteria that will be applied in their recruitment and how their privacy will be protected.**

In usability testing the research is usually qualitative. It is typical that the sample size is lower than quantitative research. The results will not be aiming for statistical validity, but verification of insights and assumptions based on observations. For the focus groups, field studies and usability testing the researcher will be aiming to have 15-25 people participate.

An exception to this is the questionnaire, which will be used to generate a contextual understanding and overview of people with Coeliac disease.

Currently there are over 2287 member of the Coeliac Society (based on membership figures 26/9/06). It is my intention to aim for responses from 5% of members of the society (110 people). As recruitment will be on a voluntary basis, a call for volunteers to participate in the questionnaire will be advertised in the Autumn issue of 'Coeliac Link' which is posted to all members. Members will then have the option to participate in the questionnaire online or to contact the researcher to send them the questionnaire by post.

The researcher will be aiming for an even spread of participants across the country. Participants will only be excluded if they do not have Coeliac Disease or a letter of recommendation from their specialist to follow a gluten-free diet (which is entry membership criteria to join the Coeliac Society). Also, participants will all be over the age of 16 years old.

The participants in the research will not have any names or other factors exposing their identity published for public readership. Participants will remain anonymous in the analysis and presentation of data. Information sheets and consent forms will be provided to participants detailing this. Data will be stored in a secure area.

**B.1.3. How the principles of the Treaty of Waitangi will be respected and implemented in this research.**

*Please provide evidence of appropriate consultation when this is needed.*

Although this project does not specifically target Maori, care will be taken to ensure cultural needs of all participants are addressed. Coeliac disease sufferers are mainly from Northern European decent, however more recently Indian populations have proven to be susceptible to the disease as well. This does not rule out the possibility of other ethnic populations who may participate in the research. Care will be taken to not discriminate in the selection of participants, but to encourage a broad sample frame. Furthermore, the principles of the Treaty of Waitangi will be upheld in respecting the decision of any ethnic population to not participate in the research or to discontinue at any time.

The researcher will maintain that appropriate cultural protocols are followed, and that the research will have mutual benefits for not only the researcher, but also the participants and the wider community.

Respect for collectives will be maintained by offering informed consent for collectives, with an acknowledgement of the collective ownership of information. The consent form will offer the aid of an interpreter to assist those that wish to have information clarified in their first language. Respondents will be given the choice to respond in Te Reo Maori if they wish, and will not be excluded for this choice.

**B.2. Please describe how, where and for how long the data and/or Consent Forms will be stored, as well as who will have access to them and how they will be destroyed.**

*If data and/or Consent Forms will be stored somewhere other than AUT, or will be stored for a period other than six years, please provide a justification for this.*

Consent forms will be stored on AUT premises. The storage facility will be provided and maintained by the Art & Design School. Consent forms will be stored for 6 years. As the researcher is an extra-mural student, the data will be kept at the student premises in a locked filing cabinet until the data has been analysed. Following the analysis the data will be promptly relocated to AUT premises to be stored in a more secure environment. The data will be stored separately from the consent forms and stored for 6 years.

**B.3. Please provide details of any funding that is being sought for this project.**

No funding will be sought after for this project. Personal funds will be allocated for research expenses, alongside the Coeliac Society's annual budget of \$3500 to cover costs of the handbook if it is accepted to be printed for general use.

*Please send one (1) electronic copy of this application form with electronic copies of the completed EA8RA risk self-assessment and copies of all Information Sheets, Consent Forms, Research Instruments, Questionnaires, indicative questions, interview outlines or any printed material that are being provided to participants and (1) printed copy (single sided, clipped not stapled) of this application form to your AUTECH Faculty Representative (see [http://intouch.aut.ac.nz/intouch/Ethics/knowledge\\_base/kb\\_sub.php?articleid=74&sectionid=31](http://intouch.aut.ac.nz/intouch/Ethics/knowledge_base/kb_sub.php?articleid=74&sectionid=31))*

*If you work outside a Faculty, then please send this application to:*

*Charles Grinter, Ethics Coordinator  
Wellesley Campus  
Room WA208, Level 2, WA Building  
55 Wellesley Street East  
Private Bag 92006  
Auckland 1020, NZ  
Internal Mail Code: RC*

**Auckland University of Technology Ethics Committee  
(AUTEC)**

**EASRA**

**SELF ASSESSMENT OF RESEARCH PROJECTS FOR ETHICS APPROVAL**



*Please note that incomplete applications will not be considered by AUTEC. Please do not alter the formatting of this form or delete any sections. Please answer all the sub-sections in section B.*

**A. General Information**

**A.1. Project Title**

User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients (working title)

**A.2. Applicant Name and Qualifications**

*When the researcher is a student (including staff who are AUT students), the applicant is the principal supervisor. When the researcher is an AUT staff member undertaking research as part of employment or a staff member undertaking research as part of an external qualification, the applicant is the researcher.*

Professor Leong Yap (PhD)

**A.3. Student Name(s)**

*Please complete this section only if the researcher is a student*

Rosemary Walkinshaw

## B. Assessment of Ethical Risk

The following sections will help assess the risk of your research project causing physical or psychological harm to participants and whether the nature of any harm is minimal and no more than is normally encountered in daily life.

Note: Student researchers are required to review the completed form with their supervisor.

### B.1. Risk of Harm

B.1.1. Does your project involve situations in which the researcher may be at risk of harm?

~~Yes~~ / No

B.1.2. Does your project involve use of a questionnaire or interview or other research process, whether or not it is anonymous, which might reasonably be expected to cause discomfort, embarrassment, anxiety or psychological or spiritual harm to any or some participants?

~~Yes~~ / No

B.1.3. Does your project involve processes that are potentially disadvantageous to a person or group, such as the collection of information, images etc. which may expose that person/group to discrimination or criticism?

~~Yes~~ / No

B.1.4. Does your project involve collection of information of illegal behaviour(s) gained during the research which could place the participants at current or future risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships?

~~Yes~~ / No

B.1.5. Does your project involve any form of physically invasive procedure on volunteer participants, such as the collection of blood, body fluid or tissue samples, exercise regimes, physical restraint or physical examination?

~~Yes~~ / No

B.1.6. Does your project involve the administration of any form of drug, medicine (other than in the course of standard medical procedure), or placebo?

~~Yes~~ / No

B.1.7. Does your project involve physical pain, beyond mild discomfort?

~~Yes~~ / No

B.1.8. Does your project involve the intentional recruitment of participants who are staff or students of AUT. (Note: section 6.1 of AUTEK's *Applying for Ethics: Guidelines and Procedures* provides an exception for audit or evaluation purposes only)?

~~Yes~~ / No

B.1.9. Does your project involve any AUT teaching which involves the participation of AUT students for the demonstration of procedures or phenomena which have a potential for harm?

~~Yes~~ / No

B.1.10. Does your project involve participants who are in any sort of dependent relationship to the researchers?

~~Yes~~ / No

**B.2. Informed and Voluntary Consent**

**B.2.1.** Does your project involve the use of oral consent of participants rather than written consent?

~~Yes~~ / No

**B.2.2.** Does your project involve participants who are unable to give informed consent?

~~Yes~~ / No

**B.2.3.** Does your project involve your (or your supervisor's) own students as participants (Note: section 6.1 of AUTECH's *Applying for Ethics: Guidelines and Procedures* provides an exception for audit or evaluation purposes only)?

~~Yes~~ / No

**B.2.4.** Does your project involve the participation of children aged 8 years or younger?

~~Yes~~ / No

**B.2.5.** Does your project involve the participation of children aged sixteen years or younger where parental consent is not being sought?

~~Yes~~ / No

**B.2.6.** Does your project involve participants who are in a dependent situation, such as people with a disability, or residents of a hospital, nursing home or prison or patients highly dependent on medical care?

~~Yes~~ / No

**B.2.7.** Does your project involve participants who are vulnerable (e.g. the elderly, prisoners, persons who have suffered abuse, persons who are not competent in English, new immigrants)?

~~Yes~~ / No

**B.2.8.** Does your project involve the use of previously collected information or biological samples for which there was no explicit consent for this research?

~~Yes~~ / No

**B.3. Privacy or Confidentiality**

**B.3.1.** Does your project involve any research about organisational practices where information of a personal or sensitive nature may be collected and where participants may be identified?

~~Yes~~ / No

**B.4. Deception**

**B.4.1.** Does your project involve deception of the participants, including concealment and covert observations except in a public place?

~~Yes~~ / No

**B.5. Conflict of Interest**

**B.5.1.** Does your project involve a conflict of interest situation for the researcher (where the researcher has more than one role or interest e.g. teacher/researcher, treatment provider/researcher, employer/researcher? (*Financial interests in research outcomes, sponsorship, etc. should be declared here*))

~~Yes~~ / No

**B.6. Payment to Participants**

**B.6.1.** Does your project involve payments or other financial inducements (other than koha, reasonable reimbursement of travel expenses or time, or entry into a modest prize draw) to participants?

~~Yes~~ / No

**B.7. Procedural Issues**

**B.7.1.** Does your project involve a requirement by an outside organisation (e.g. a funding organisation or a journal in which you wish to publish) for AUTEK approval?

~~Yes~~ / No

**B.8. Other Issues**

**B.8.1.** Does your project involve any ethical issues which may mean that the research is not low risk, other than those mentioned above?

~~Yes~~ / No

*If your answer was yes, please briefly describe the issues involved.*

**C. Applying for Ethics Approval****C.1. If your answer to ALL the above questions is 'No'**

*Please complete the EA8 application form for low ethical risk approvals and send it together with this completed self-assessment to your AUTEK Faculty Representative. If you work outside a faculty, please send them to the Ethics Coordinator who will forward them to the AUTEK Faculty Representative in the most appropriate faculty for the subject matter of the research.*

**C.2. If your answer to at least one of the above questions is 'Yes'**

*If you have answered 'Yes' to one or more of the above questions, you will normally need to submit a full EA1 application form to AUTEK, through the Ethics Coordinator. You may wish to consult your AUTEK faculty representative or the Ethics Coordinator before submitting a full application, however, if you consider that the reasons why you responded 'yes' do not take the research out of the low ethical risk category.*

For further advice, please contact:  
 Charles Ginter, Ethics Coordinator  
 Wellesley Campus  
 Room WA208, Level 2, WA Building  
 55 Wellesley Street East  
 Private Bag 92006  
 Auckland 1020, NZ  
 Internal Mail Code: RC

## MEMORANDUM

### Auckland University of Technology Ethics Committee (AUTEC)

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To: Leong Yap  
From: **Madeline Banda** Executive Secretary, AUTEC  
Date: 20 June 2007  
Subject: Ethics Application Number 07/37 **User centred design: the investigation, design and evaluation of an information handbook for coeliac patients.**

---

Dear Leong

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by a subcommittee of the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 7 May 2007 and that I as the Executive Secretary of AUTEC approved your ethics application on 12 June 2007. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 9 July 2007.

Your ethics application is approved for a period of three years until 12 June 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through <http://www.aut.ac.nz/about/ethics>, including when necessary a request for extension of the approval one month prior to its expiry on 12 June 2010;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/about/ethics>. This report is to be submitted either when the approval expires on 12 June 2010 or on completion of the project, whichever comes sooner;

It is also a condition of approval that AUTEC is notified of any adverse events or if the research does not commence and that AUTEC approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTEC for approval before that change is implemented.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at [charles.grinter@aut.ac.nz](mailto:charles.grinter@aut.ac.nz) or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



Madeline Banda  
**Executive Secretary**  
**Auckland University of Technology Ethics Committee**

Cc: Rosemary Walkinshaw [rose.walkinshaw@gmail.com](mailto:rose.walkinshaw@gmail.com), AUTEC Faculty Representative, Design and Creative Technologies

## **Appendix B**

Information sheets and consent forms to participate  
in the research project

# Participant Information Sheet



For questionnaire

## Date Information Sheet Produced:

15 March 2007

## Project Title

**User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients** (working title)

## An Invitation

I would be delighted if you were able to assist me in my study by participating in this survey. My name is Rosemary Walkinshaw. I am currently undertaking a Masters degree in Art & Design at the Auckland University of Technology. I am doing a project on the design of an information handbook for Coeliac patients.

You are invited to take part in this questionnaire survey about your experiences living with Coeliac Disease. I am currently a design student and I also have Coeliac disease myself. I am gathering information that will help me design a handbook for Coeliac patients as part of my Masters of Art & Design studies. I am particularly interested in defining what issues Coeliac patients face, and determining where and how the current handbook is used. The questionnaire is designed to help you describe your experiences with Coeliac disease and the use of information material. It asks you to describe your experiences with Coeliac Disease and social activities (such as eating out) and then asks you questions on support material you have used to aid your understanding of the disease. Your participation in this research is entirely voluntary, and you do not have to answer all the questions. You may withdraw from your obligations to partake in the research at anytime without penalty. Please note that completion of the questionnaire will indicate your consent to participate.

## What is the purpose of this research?

The purpose of this research is to generate design solutions that better suit user needs and design preferences. This research will contribute towards the fulfilment in a Masters of Art & Design.

## How was I chosen for this invitation?

All participants for this questionnaire are members of the Coeliac Society NZ.

## How will my privacy be protected?

No material that could personally identify you will be used in reports on this study. The questionnaire will be read by the researcher only and destroyed after successful completion of my Masters at the end of 2007.

## What are the benefits of being involved in this research?

It is hoped that this research will directly benefit Coeliac patients and the Coeliac Society itself by contributing to research and design solutions that better support Coeliac patients needs in regards to information material.

This version was last edited on 11 July 2006

**What are the costs of participating in this research?**

There are no direct costs involved except for your time. The questionnaire should take about 20 minutes for you to complete.

**What opportunity do I have to consider this invitation?**

Participation is voluntary. However, your input and feedback will greatly aid the research.

**How do I agree to participate in this research?**

The completion of the questionnaire will indicate that you agree and consent to participate in the research study. If you wish to take the questionnaire away with you, please insert it self-addressed envelope provided and post it back to me within 10 days. No stamp will be required.

**Will I receive feedback on the results of this research?**

If you would like to receive a summary of the results of this research please write your address in the section provided on the questionnaire. These will be posted out to you once the research has been completed.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), 09 921 9999 ext 8604

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), 921 9999 ext 8044.

**Whom do I contact for further information about this research?*****Researcher Contact Details:***

Rosemary Walkinshaw, [rose.walkinshaw@gmail.com](mailto:rose.walkinshaw@gmail.com), ph: 021 104 7430.

***Project Supervisor Contact Details:***

Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), ph: (09) 921 9999 ext 8604

Approved by the Auckland University of Technology Ethics Committee on 12 June 2007, AUTEK Reference number 07/37.

This version was last edited on 11 July 2006

# Participant Information Sheet



## For Interview

### Date Information Sheet Produced:

15 March 2007

### Project Title

**User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients** (working title)

### An Invitation

You are invited to take part in an interview by answering questions about your experiences living with Coeliac Disease. I am currently a design student and I also have Coeliac disease myself. I am gathering information that will help me design a handbook for Coeliac patients as part of my Masters of Art & Design studies. I am particularly interested in defining what issues Coeliac patients are facing, and determining where and how the current handbook is used. The interview questions are designed to help you describe your experiences with Coeliac disease and the use of information material. Your participation in this research is entirely voluntary, and you do not have to answer all the questions. You may withdraw from your obligations to partake in the research at anytime without penalty.

### What is the purpose of this research?

The purpose of this research is to generate design solutions that better suit user needs and design preferences. This research will contribute towards the fulfilment in a Masters of Art & Design.

### How was I chosen for this invitation?

All participants for this interview are members of the Coeliac Society NZ. This is an open invitation and participation is voluntary.

### How will my privacy be protected?

No material that could personally identify you will be used in reports on this study. The interview transcripts will be read by the researcher only and destroyed after successful completion of my Masters at the end of 2007.

### What are the benefits of being involved in this research?

It is hoped that this research will directly benefit Coeliac patients and the Coeliac Society itself by contributing to research and design solutions that better support Coeliac patients needs in regards to information material.

### What are the costs of participating in this research?

There are no direct costs involved except for your time. The interview should take about 30 minutes for you to complete.

### What opportunity do I have to consider this invitation?

Participation is voluntary. However, your input and feedback will greatly aid the research.

This version was last edited on 11 July 2006

**How do I agree to participate in this research?**

You will be required to sign a consent form to participate in the interview.

**Will I receive feedback on the results of this research?**

If you would like to receive a summary of the results of this research please write your name and address on the consent form and these will be posted out to you after the results have been recorded.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), 09 921 9999 ext 8604

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), 921 9999 ext 8044.

**Whom do I contact for further information about this research?**

***Researcher Contact Details:***

Rosemary Walkinshaw, [rose.walkinshaw@gmail.com](mailto:rose.walkinshaw@gmail.com), ph: 021 104 7430.

***Project Supervisor Contact Details:***

Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), ph: (09) 921 9999 ext 8604

Approved by the Auckland University of Technology Ethics Committee on 12 June 2007. AUTEK Reference number 07/37.

This version was last edited on 11 July 2006

# Participant Information Sheet



## Focus group

### Date Information Sheet Produced:

15 March 2007

### Project Title

**User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients** (working title)

### An Invitation

You are invited to take part in a focus group to discuss a series of concepts that I have designed to enable me to gauge a sense of your likes/dislikes and how easy or hard you find the concept designs to use. I am currently a design student and I also have Coeliac disease myself. I am gathering information that will help me design a handbook for Coeliac patients as part of my Masters of Art & Design studies. I am particularly interested in determining what problems you might face using the design and what your visual preferences are. Your participation in this research is entirely voluntary, and you do not have to answer all questions or partake in all activities. You may withdraw from your obligations to partake in the research at anytime without penalty.

### What is the purpose of this research?

The purpose of this research is to generate design solutions that better suit user needs and design preferences. This research will contribute towards the fulfilment in a Masters of Art & Design.

### How was I chosen for this invitation?

All participants for the focus group are members of the Coeliac Society NZ. It is an open invitation and participation is voluntary.

### How will my privacy be protected?

No material that could personally identify you will be used in reports on this study. The focus group observations and transcripts will be read by the researcher only and destroyed after successful completion of my Masters at the end of 2007.

### What are the benefits of being involved in this research?

It is hoped that this research will directly benefit Coeliac patients and the Coeliac Society itself by contributing to research and design solutions that better support Coeliac patients needs in regards to information material.

### What are the costs of participating in this research?

There are no direct costs involved except for your time. The focus group sessions will take about 45 minutes of your time.

### What opportunity do I have to consider this invitation?

Participation is voluntary. However, your input and feedback will greatly aid the research.

This version was last edited on 11 July 2006

**How do I agree to participate in this research?**

You will be required to sign a consent form to participate in the focus group.

**Will I receive feedback on the results of this research?**

If you would like to receive a summary of the results of this research please write your name and address on the consent form and these will be posted out to you after the results have been recorded.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), 09 921 9999 ext 8604

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), 921 9999 ext 8044.

**Whom do I contact for further information about this research?**

***Researcher Contact Details:***

Rosemary Walkinshaw, [rose.walkinshaw@gmail.com](mailto:rose.walkinshaw@gmail.com), ph: 021 104 7430.

***Project Supervisor Contact Details:***

Prof. Leong Yap, [leong.yap@aut.ac.nz](mailto:leong.yap@aut.ac.nz), ph: (09) 921 9999 ext 8604

Approved by the Auckland University of Technology Ethics Committee on 12 June 2007. AUTEK Reference number 07/37.

This version was last edited on 11 July 2006

# Consent Form

For interview



**Project title:** User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients (working title)

**Project Supervisor:** Prof. Leong Yap

**Researcher:** Rosemary Walkinshaw

- I have read and understood the information provided about this research project in the Information Sheet dated 15 March 2007.
- I have had an opportunity to ask questions and to have them answered.
- I understand that the interviews will be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- Do you wish to receive a copy of the report from the research (please tick one):  
Yes  No

Participant's signature:  
.....

Participant's name:  
.....

Participant's Contact details (if appropriate):  
.....  
.....  
.....  
.....

**Approved by the Auckland University of Technology Ethics Committee on 12 June 2007.  
AUTEC Reference number 07/37.**

# Consent Form

For focus group



**Project title:** User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients (working title)

**Project Supervisor:** Prof. Leong Yap

**Researcher:** Rosemary Walkinshaw

- I have read and understood the information provided about this research project in the Information Sheet dated 15 march 2007
- I have had an opportunity to ask questions and to have them answered.
- I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.
- I understand that the focus group will be video/audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.
- I agree to take part in this research.
- Do you wish to receive a copy of the report from the research (please tick one):  
Yes  No

Participant's signature:

.....

Participant's name:

.....

Participant's Contact details (if appropriate):

.....  
.....  
.....

**Approved by the Auckland University of Technology Ethics Committee on 12 June 2007.  
AUTEC Reference number 07/37.**

## **Appendix C**

Proposed interview and focus group questions

## Proposed interview Question Guide

1. Can you tell me about your experiences living with Coeliac Disease?
2. What difficulties do you have following the gluten-free diet?
3. What information materials do you use to support yourself on the gluten-free diet?
4. Where do you obtain these support materials?

### **Existing Coeliac Society handbook questions:**

5. How well do you feel this handbook is supporting you?
6. How often do you use it?
7. Do you value the handbook?
8. What importance do you place in the information in the handbook with respect to your health and lifestyle?
9. How easy can you find the following information?
  - a) Gluten-free flour choices
  - b) Information on travel and dining out
  - c) Recipes
  - d) Symptoms
  - e) Healthy eating
  - f) Information about what Coeliac Disease is
  - g) How to treat the disease
10. How well do you understand the:
  - a) navigation and b) terminology of the product?
11. Which aspects of the handbook do you find valuable?
12. Do you have any concerns about the information?
13. What changes do you think could be made to make this handbook more useful for you to use?  
(Wish list for what the handbook should do).

## Focus Group (guiding questions)

Small groups will be given concept mock-designs (or pre-designs) of the handbook and will be watched as they interact and use them. Guiding questions will be asked such as:

1. How easy do you find this to use?
2. Do you find this visually appealing?  
(if not/if so, why?)
3. Do you have any difficulties in understanding the information? (e.g. is the information too complex etc.).
4. Is the information clear? (i.e. easy to follow?)
5. What are your ideas for improvement?
6. a). What things would you like changed?  
b). Least changed?
6. Where would you keep this handbook?
7. Would a pocket-sized handbook suit you better?

## Appendix D

Questionnaire (sample)

# Questionnaire survey for the design of an information handbook for Coeliac patients



## Project Title

**User Centred Design: The Investigation, Design and Evaluation of an Information Handbook for Coeliac patients** (working title)

I would be delighted if you were able to assist me in my study by participating in this survey. My name Rosemary Walkinshaw. I am currently undertaking a Masters degree in Art & Design at the Auckland University of Technology. I am doing a project on the design of an information handbook for Coeliac patients.

This questionnaire will take about 20 minutes to complete. Your participation will contribute to the design of a handbook for Coeliac Patients who are members of the Coeliac Society (NZ).

The questionnaire is designed to help you describe your experiences with Coeliac disease and the use of information material. It asks you to describe your experiences with Coeliac Disease and social activities (such as eating out) and then asks you questions on support material you have used to aid your understanding of the disease. Your participation in this research is entirely voluntary, and you do not have to answer all the questions. You may withdraw from your obligations to partake in the research at anytime without penalty.

The information you provide on this form is confidential. No material that could personally identify you will be used in reports on this study. The questionnaire will be read by the researcher only and destroyed after successful completion of my Masters at the end of 2007.

Please note that the completion of this questionnaire will indicate your consent to participate.

Please complete this questionnaire and return by inserting it in the self-addressed envelope provided and post it back to me within **10 days**. No stamp will be required.

**PART A: PERSONAL INFORMATION (About you)**

**1** Gender (please tick)

1a.	Male	<input type="checkbox"/>
1b.	Female	<input type="checkbox"/>

**2** How old were you at your last birthday?

2a. Age .....

**3** Which ethnic group or groups do you belong to?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
European/Pakeha	<input type="checkbox"/>
NZ Maori	<input type="checkbox"/>
Samoan	<input type="checkbox"/>
Cook Island Maori	<input type="checkbox"/>
Tongan	<input type="checkbox"/>
Niuean	<input type="checkbox"/>
Tokelauan	<input type="checkbox"/>
Fijian	<input type="checkbox"/>
Other Pacific	<input type="checkbox"/>
Chinese	<input type="checkbox"/>
Indian	<input type="checkbox"/>

Other: (specify)

**4** What is your first language? (please tick)

4a.	English	<input type="checkbox"/>
4b.	Other	<input type="checkbox"/>

(Please specify).....

**PART B: COELIAC DISEASE & YOU**

**5** Are you diagnosed with? (please tick)

5a.	Coeliac Disease	<input type="checkbox"/>
5b.	Dermatitis Herpetiformis	<input type="checkbox"/>
5c.	Both	<input type="checkbox"/>

**6** How long have you been diagnosed?

6a. Month .....  
6b. Year .....

**7** What year did you join the Coeliac Society of NZ?

7a. Year .....

**8** Is anyone else in your extended family diagnosed with Coeliac Disease?

(Please tick)

8a.	Yes	<input type="checkbox"/>
8b.	No	<input type="checkbox"/>

8c. If yes, who? .....

8d. Are any of these listed people members of the Coeliac Society?

(Please tick)

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

**9** How often do you follow a gluten-free diet?

Please tick

All of the time	Most of the time	Sometimes	Occasionally	Never

Comment: \_\_\_\_\_

---

**10** How aware do you believe you are about Coeliac Disease?

Please tick

Very aware	aware	Somewhat aware	Unaware	Very unaware

Comment: \_\_\_\_\_

---

**11** How informed do you believe you are about gluten-free foods and the gluten-free diet?

Please tick

Very informed	Informed	Somewhat informed	Not very informed	Not informed at all

Comment: \_\_\_\_\_

---

**PART C: EXPERIENCES WITH COELIAC DISEASE**

**12** How would you describe your feelings when you were diagnosed with Coeliac Disease?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
Afraid	<input type="checkbox"/>
Scared	<input type="checkbox"/>
Overwhelmed	<input type="checkbox"/>
Confused	<input type="checkbox"/>
Indifferent	<input type="checkbox"/>
Relieved	<input type="checkbox"/>
Calm	<input type="checkbox"/>
Satisfied	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

Comment: \_\_\_\_\_

**13** How easy or difficult has it been for you changing to a gluten-free diet?

Please tick

Very Easy	Easy	Neither easy or difficult	Moderately difficult	Difficult

Comment: \_\_\_\_\_

**14** Which of the following activities has impacted you on a gluten-free diet?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
Lifestyle	<input type="checkbox"/>
Family life	<input type="checkbox"/>
Ability to eat out	<input type="checkbox"/>
Social occasions	<input type="checkbox"/>
Travel	<input type="checkbox"/>
Shopping	<input type="checkbox"/>
Work/career	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

Example of how these activities have impacted on you: \_\_\_\_\_

**15** Below is a list of feelings associated with how some people may feel about having Coeliac Disease. Please indicate whether you share these feelings by *circling* the number that best represents your answer.

	All of the time	Most of the time	Some of the time	Rarely	Never
Feel left out from activities with friends and/or family	1	2	3	4	5
Feel different from other people because of Coeliac Disease	1	2	3	4	5
Feel embarrassed to bring gluten-free food along to social occasions	1	2	3	4	5
Feel angry about having to follow a special diet	1	2	3	4	5
Feel that friends and/or family don't understand	1	2	3	4	5
Feel that you can be healthy without having to follow a special diet	1	2	3	4	5
Feel worried about the long-term affects of <i>not</i> following a gluten-free diet	1	2	3	4	5

Comments: \_\_\_\_\_

\_\_\_\_\_

**16** How would you rate your compliance to the gluten-free diet?

Please tick

Very good	Good	Reasonable	Poor	Very poor
-----------	------	------------	------	-----------

**17** Below is a list of situations that may make compliance to a gluten-free diet more difficult. Please indicate if any of these affect you by *circling* the number that best represents your answer.

	Affects me often			Does not affect me at all	
	1	2	3	4	5
Eating at restaurants or take-outs	1	2	3	4	5
Socialising	1	2	3	4	5
Travelling	1	2	3	4	5
Staying in hospital	1	2	3	4	5
Finding gluten-free foods in supermarkets	1	2	3	4	5
Paying more for specialty gluten-free food (or/ opting for cheaper gluten containing foods)	1	2	3	4	5
Finding good gluten-free recipes	1	2	3	4	5
Eating foods containing gluten by accident	1	2	3	4	5

Other situations: \_\_\_\_\_

---

**18** Do you have any suggestions that you believe could help compliance to the diet?

Suggestions: \_\_\_\_\_

---

**Coeliac patients have to be careful about eating out. The following questions address some of these concerns:**

**19** How often would you eat out?

Please tick

More than once a month	Once a week	More than once a week	Less than once a week	Rarely

**20** How easy or difficult do you find places to eat that serve gluten-free food?

Please tick

Very easy	Easy	Neither easy or difficult	Difficult	Very difficult

**21** Now that you have been diagnosed with Coeliac disease do you still dine-out as often?

Yes	<input type="checkbox"/>	(Please tick) <input checked="" type="checkbox"/>
No	<input type="checkbox"/>	

**22** Please describe below any other feelings, situations or events that you have experienced as a coeliac patient that you find important in describing your experience as someone with Coeliac disease?

---

---

---

---

## PART D: THE HANDBOOK

**23** a. Did you have to refer to any other supplementary material other than the handbook you were given by the Coeliac Society in your transition to a gluten-free diet?

Yes	<input type="checkbox"/>	(Please tick) <input checked="" type="checkbox"/>
No	<input type="checkbox"/>	

23b. If yes, what was this material? .....

**24** Since receiving the handbook how often would you use it?

Please tick

<input type="checkbox"/>				
More than once a month	Once a week	More than once a week	Less than once a week	Rarely

**25** Where do you seek information on Coeliac Disease or the Gluten-Free diet?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
Health professionals	<input type="checkbox"/>
The Coeliac Society	<input type="checkbox"/>
Food companies	<input type="checkbox"/>
Health food grocery stores	<input type="checkbox"/>
Alternative health practitioners	<input type="checkbox"/>
The Internet	<input type="checkbox"/>
Libraries	<input type="checkbox"/>
Medical, nursing or dietetic associations	<input type="checkbox"/>
Media	<input type="checkbox"/>
Family & friends	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

**26** (Following from question 25) How helpful has this information been?

Please tick

<input type="checkbox"/>				
Very helpful	Helpful	Somewhat helpful	Not very helpful	Not helpful at all

**27** (Following from question 25 & 26) how would you rate the quality of the information you have received?

Please tick

Excellent	Very good	Good	Fair	Poor
-----------	-----------	------	------	------

**28** What do you think could be done to improve the quality of information available to you about Coeliac disease or Gluten-free diets?

Suggestions: \_\_\_\_\_  
 \_\_\_\_\_

**29** a. Have you ever found any pictures or diagrams to be of assistance in your understanding of Coeliac Disease or the Gluten-free diet?

Yes	<input type="checkbox"/>	(Please tick) <input checked="" type="checkbox"/>
No	<input type="checkbox"/>	

29b. If yes, please describe what these were and how they assisted your understanding?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**30** With reference to the handbook the Coeliac Society has provided you; can you rate on a scale from 1-5 how attractive or unattractive you believe the material is you have been given? (Please *circle* the number that best represents your opinion)

Very attractive					Very unattractive	
1	2	3	4	5		

**31** How frequently would you use supplementary materials other than the handbook to assist your Gluten-free diet? (these materials may include gluten-free cookbooks, the Internet, The MDF database etc)

Please tick

More than once a month	Once a week	More than once a week	Less than once a week	Rarely
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**32** Where do you use your handbook?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
At the supermarket	<input type="checkbox"/>
In the kitchen	<input type="checkbox"/>
As reading material at home	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

Comments: \_\_\_\_\_

**33** Where do you store your handbook?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
In the kitchen	<input type="checkbox"/>
On the bookshelf	<input type="checkbox"/>
In the car	<input type="checkbox"/>
In the bedroom	<input type="checkbox"/>
In the lounge	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

**34** What do you believe is the most **important** information included in the handbook?

<i>Tick all that apply</i>	<input checked="" type="checkbox"/>
What is Coeliac disease?	<input type="checkbox"/>
Recipes	<input type="checkbox"/>
Support contacts	<input type="checkbox"/>
Eating out/takeaways	<input type="checkbox"/>
Additives	<input type="checkbox"/>
Traveling with Coeliac disease	<input type="checkbox"/>
Shopping	<input type="checkbox"/>
What food to eat	<input type="checkbox"/>
Pharmaceuticals	<input type="checkbox"/>
Other	<input type="checkbox"/>

Specify: .....

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**35** Can you rate on a scale from 1-5 how easy or difficult you find using the handbook? (Please *circle* the number that best represents your opinion)

Very easy					Very difficult
1	2	3	4	5	

**36** Please write below any advice or suggestions about information material that Coeliac Disease patients may find of benefit or need

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**PART E: FURTHER COMMENTS**

**37** Please make any further comments you may have relating to your experience with Coeliac Disease that would help me to design a useful handbook

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**THANK YOU FOR YOUR TIME  
COMPLETING THIS QUESTIONNAIRE**

If you would like to receive a summary of the results of this research please write your address in the section below. These will be posted out to you once the research has been completed.

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## Appendix E

Questionnaire comments

## Qualitative information from Questionnaire (actual).

### **PART B: COELIAC DISEASE & YOU**

#### **9. How often do you follow a gluten-free diet?**

- Occasionally if there's a packet of sauce with wheat I might have a bit
- The odd slip up
- Strictly adhere to the diet
- As much as I know and am able
- Minor mistakes sometimes
- No point in being on a diet if you are not going to follow it
- I might taste the odd corner of a biscuit but never a whole one!
- It's essential, I also have osteoporosis
- If not I suffer for it
- I do not suffer sore stomachs
- Follow a strict GF diet
- Mostly friends/restaurants are good un food prep - have been 'odd' mistakes
- I try as much as possible to follow a strictly gluten free diet, although I find that when I eat out (family, restaurants) sometimes food is not completely GF
- Need to be on a completely GF diet for life
- I can consciously make a decision to eat gluten. Sometimes you are not always 100% sure the food you eat is GF - i.e. restaurants
- Hard to tell sometimes
- Ignore traces of gluten or on some product line
- I occasionally take a chance on a product labelled as "processed with machinery that also processes wheat products"
- If I don't within 20 mins cough up mucous
- Sometimes discovered later it contained gluten
- Very careful to not eat any gluten
- Except when going out to dinners, Bday parties etc

- Occasionally I will 'risk' food e.g. a sauce I cannot confirm ingredients if made especially by a friend. Only OCCASIONALLY though
- Unless unknowingly I eat something with gluten
- I sometimes have a gluten containing goody
- Never cheat. Not worth it
- One item a day with gluten
- Try to stick to it all the time but I'm sure some gluten gets through
- 95% of the time with occasional transgressions
- Although I can get away with an occasional treat such as an ice-cream cone, but I keep it rarely. I can also eat oats
- As a mum of 4 kids I am easily tempted especially preparing food for them that I can smell but can't eat
- Only time I eat gluten is by accident
- I can eat anything but not wheat and gluten
- A very small amount of gluten causes vomiting and diarrhoea
- Have become somewhat "tolerant" (not sure what damage could be done on the inside) Symptoms have become less severe
- I have vivid memories of what I was like before - that keeps me on straight & narrow

#### **10. How aware do you believe you are about Coeliac Disease?**

- As still get caught on some items.
- Read all food labels, research etc.
- Mum is very aware - 2yr old not so aware just yet
- Have read extensively on the topic - books and Internet and any other info that is passed on
- Still learning about different hidden sources of gluten as I'm newly diagnosed - biopsy Nov 2006
- My specialist gave excellent information and asked me to join the society. At first I refused but when I got less angry did join. You learn as you go along

- Have made efforts to read up
- Done a lot of research via the internet
- I have read lots of medical information from the Coeliac Society
- Had it "all my life" so grown up with the diet and information
- For the rest of my life this is my eating lifestyle
- I am Aust citizen and also belong to the society
- Lab background & with family history have made a real effort to be aware
- I am still confused about the blood tests or some situations e.g. one brother has 3 children with CD but neither himself or his wife has tested positive. Also about long-term implications of CD
- Very careful when eat out. Read labels when not sure
- Too early in the process to know all
- But learning
- Definite denial. If I am 'clean' then small gluten makes me sicker. SO I eat gluten and have lesser symptoms
- As informed as I can be. Always interested to hear about new research etc.

## **II. How informed do you believe you are about gluten-free foods and the gluten-free diet?**

- Get confused as to why 150C is gluten-free even though derived from wheat
- All still new to me
- Through mother
- Still some debate on some foods
- Except for lines that have hidden gluten e.g. going tramping I thought I would take Raro packets, however reading the ingredients it has wheat in it and many other products like rice risotto one would think would be gluten free
- But need to further research certain things which the information is not as readily available or is harder to find e.g. additive numbers and whether

gluten is found in these additives and preservatives e.g. 450, 451, 452 etc.

- Still unclear about spirits e.g. gin
- Having a son born with it I've always been careful
- Dieticians and even doctors were not knowledgeable at first but my specialist was very helpful
- I'm better informed now but still don't know much
- I have been on the diet since age two, so it is a way of life
- I am filling this out on behalf of my daughter who has coeliac disease. The Coeliac membership is in her parent's names. As a parent I would consider my answers to both no. 10 and 11 as very informed and very aware
- I am completing this as the parent of a 5 year old girl diagnosed with Coeliac Disease
- I was a home science teacher
- Am always ready to learn more
- Again, have attended many association meetings - done own research - lots of cookbooks!
- Do get confused about a few things
- Always searching for new GF foods
- This is difficult as a lot of the time it changes
- I often refer to the list when shopping and have gained a lot of information from other coeliac at society events. I am now aware of small changes in my health when I have eaten "small" amounts of gluten
- Have to stay well
- The Coeliac Society and magazines are an excellent source of information and medical research. Also wonderful recipes, interesting articles written by Coeliac's throughout NZ
- My mother who cooks my food is more informed than me about a GF diet
- Support from wife
- Support Coeliac group library books
- Self education is necessary

- I could benefit more from information about food labelling and codes
- Information more available than 10 years ago
- Still finding my way around the supermarkets
- Still learning
- Some grey areas e.g. maltodextrin
- Foods could/should be labelled more clearly
- Still learning things everyday
- I believe my dietician could have given me more information
- Still learning
- My mother organizes my diet, but I am aware
- I am not a reader of what doesn't interest me. I need to become more interested
- A case of survival. Though makes it difficult when bought items aren't clearly marked and when 'safe' items change
- I am still not sure about the part flavourings and colourings play

## **PART C: EXPERIENCES WITH COELIAC DISEASE**

12 How would you describe your feelings when you were diagnosed with Coeliac Disease?

- Too young to know
- Annoyed!
- Annoyed. Calm but been trying to avoid positive diagnosis for years
- At last a reason for my loss of weight and possibly for headaches
- Had weight loss
- Mildly angry for a time. That I had been treated as a neurotic woman for years by male doctors
- I knew something wasn't right
- I was only one year old
- With dramatic weight loss, severe cramping and diarrhoea I was convinced I had cancer
- Don't remember. I was a baby: 13 months old

- Annoyed and frustrated that this could happen to a child of mine
- I was diagnosed only when they were testing for other illnesses I have. What ever makes me
- Better I don't mind
- Disappointed couldn't eat what he wanted
- Had no specific Coeliac symptoms but had Giardia from travelling which I was not recovering from
- Which led to tests revealing coeliac disease.
- I was pregnant at the time, often having had 2 m/c and was told coeliac could have caused the m/c
- When a person has been unwell for some time it is a huge relief to finally know the cause
- I can't remember when I was diagnosed
- Because at last I knew why I was feeling poorly.
- Angry that the diagnosis took decades. Allergy specialist missed coeliac disease. When became sick
- 2 years later was glad it turned out to be only coeliac disease and not cancer etc.
- I had never heard of "Coeliac" before being diagnosed
- I was only 7 and Mum took charge
- Very run down-easily fixed
- Relieved that I knew why I was sick but confused until I came to grips with the diet
- Because I'd never heard of coeliac disease before
- Unsure
- The diagnosis could have been much worse
- Relieved that there was a reason for all my problems
- Shocked. I was 9 1/2 months pregnant when my 2 year old was finally diagnosed and was so worried
- About her due to her weight loss and long time of being un-diagnosed
- Was very unwell, had had numerous tests
- Astonished
- Until diagnosis one thinks the worst e.g. cancer.

And unlike diabetes for example, Coeliac has a complete 'cure' avoid gluten

- Answer to life-long problem
- Was being tested for bowel cancer-problem disappeared when I went gluten free.
- A little uncertain because I hadn't heard of it.
- Overwhelmed and indifferent especially when I knew what I could not eat anymore Satisfied that my symptoms would stop with a gluten free diet
- Hadn't heard of it before
- Too young
- I was symptom less except for anaemia and osteoporosis. Diagnosed by bloods and bone density tests after a fall on my wrist on a bush walk. Endoscopies confirmed Coeliac
- I was not quite 3, so didn't really know what was going on, nor the impact of it. Don't even actually remember it
- I went for 2 years with all sorts of tests and specialists visits before being diagnosed. I didn't have any symptoms my son had
- Afraid etc re: diet. So confusing then
- Expected/resigned
- I had been ill for years and no one seemed to be able to do anything about it
- Relieved because I now knew what was wrong with me and that I could now get well
- We have had other allergies in our family (dairy, eggs, peanuts, fish) but I have found adjusting to GF the most challenging
- I had been hospitalised after my 3rd child was born. Acute folic acid def, anaemia, blood transfusions - suspected leukaemia. Finally diagnosed 2 years later
- Upset
- Relieved to have a diagnosis for my problems that I could/would recover. Overwhelmed by new diet and social implications
- I was only 15-18 months old, but my parents felt the above feelings

- It made such an immediate change to my health it became such an easy thing to live with
- I was 7. I don't remember really. Probably upset about the upcoming biscuit shortage
- My parents and I were relieved that we finally had a diagnosis for my ongoing health problems
- Diagnosed as baby then re diagnosed recently. Feelings of frustration/anger - the doctors thought I had grown out of it
- It's great to know instead of having antibiotic symptoms like hay fever sinus flu like symptoms
- Better than the cancer they were looking for
- Concerned
- I had never heard of Coeliac Disease when I was diagnosed so had to find out in a hurry
- I had been unwell for sometime and it was good to know what caused it
- I refuse to worry about things I have no control over and just get on with coping with the situation. I did find it rather frustrating when the only advice offered from the hospital nutritionist, to whom I was referred to, was 'read labels on food packages in the supermarket' (!!!) and also, the Privacy Act, which prevented the divulgence of names of others in like condition, who could be of assistance. My wife and I solved the latter by leaving our name and telephone number with the hospital pharmacy for passing on to any coeliac who called to collect a prescription - this was when the hospital pharmacy dispensed gluten free flours - and contact was achieved and helpful information received
- Depressed
- Because it explained why I felt so crappy and gave me a solution and control
- I was 6 years old at the time
- It explained why I had diarrhoea all the time
- It was good to know what was wrong with me
- Already had Type 1 diabetes so this 1 year later was...

- Mad, annoyed, unfair. I accept I have Coeliac disease, but still feel its unfair and still struggle with food to eat
- Anxious, scared. I was too young as I was only 18 months old, but my parents were
- Upset. I love food and felt a strict diet such as this would limit my enjoyable food experiences
- I was very glad to be told I could stop these symptoms and become well again just by following a diet. For some time though however, getting to grips with food additives was confusing
- Unhappy
- Relieved but I found it all a bit daunting until I got my Coeliac Society book
- Glad to have a diagnosis, but unsure of where to obtain GF products
- Relieved to know why no energy, stomach aches, all things go with Coeliac
- Sad due to food no longer able to eat
- Confused with food content, overwhelmed at how I just have it now and not sooner
- Concerned. Concerned about diet constraints
- Back in the UK they had diagnosed me as a hypochondriac
- Because I thought it could have been something worse I should have picked up the symptoms because of my son, but never thought of it
- I had been sick for over a year before Dr's diagnosed me - constantly queasy
- Just glad there was a reason I'd been ill
- Could be worse
- Couldn't believe I couldn't eat food that I'd eaten all my life. Asymptomatic - found it difficult to believe they could be doing me harm
- Diagnosed at 18 months old
- Grandmother died from cancer they think was caused from years of undiagnosed coeliac disease so all the family got tested. I had no symptoms (mother) but my levels of the test were really high

- I was secretly hoping the diagnosis was wrong but my specialist has recently told me my biopsy was an open & shut case I.e. it was very obvious
- Relieved to know what my problems had been but not happy as changes in my life I faced
- Disbelief. No symptoms until osteoporosis appeared
- Angry, frustrated. I didn't have these feelings until I was 14 at senior school
- Took 15 years to be diagnosed, having been wrongly diagnosed with pernicious anaemia, cancer, irritable bowel syndrome
- I was unwell for a long time but couldn't figure out what it was
- Too young - only 16 months old - parents relieved but confused
- Relieved there was a reason for being sick for 1 year, Disappointed I couldn't carry on eating as I knew all my life. I thought there would be a "pill" - a quick fix - maybe 3 months - heal and carry on.
- Uncertain. Slightly overwhelmed and uncertain about what it would mean - what I would and wouldn't be able to eat
- I'm glad I didn't have something more serious
- It was a very difficult time. I was sick and had never heard of Coeliac Disease or what gluten was
- Annoyed
- Relieved because there was a remedy for my problem. Confused about what was going to survive on. Vindicated - couldn't just take up the coast on family trips without knowing where the toilets were. We travelled from toilet to toilet. I always felt I was spoiling everyone's fun

### **13. How easy or difficult has it been for you changing to a gluten-free diet?**

- I already cook from scratch so its just a change of ingredients

- Mainly for wife re: cooking and baking
- I don't know anything else
- A two year old is hard to keep happy even without the disease
- At the there were not as many GF options.
- Sister and husband are chefs so we had a lot of help with recipe changes
- It's just being aware of the food I eat and also being organised, can't just grab a sandwich in town anymore
- Initially difficult but as I had more information have found it easier
- Once you gather all the info and understand labelling its easy
- Just completely changed my diet. Hospital dieticians were not helpful
- You have to think every meal so carefully.
- It has taken a while to sort out which foods to buy and convenience foods/travel/car trips and going out with a nearly 3 year old most difficult - just have to always be with snacks on board
- I felt so much better - suffered when I slipped up. It took about 6 months till I learnt to say no to food that contains gluten
- Easy because I was delighted I could do something to help myself get better. But on a practical level, it took a while to figure out exactly what/wasn't truly gluten free
- Really need to make home pantry basically gluten free - am also a vegetarian, so that has complicated eating out
- The first year was the hardest
- If I was diagnosed now I would tick easy - labelling and information is now hugely better
- At first I lost a lot of weight as no snacks available then and I didn't know how to make them until later
- Again too young
- As Nathan my sun was diagnosed 40 years ago
- I knew nothing about gluten or what it was in

- I enjoy what is essentially healthy eating
- The lack of many GF foods and lack of labelling then was traumatic. Baking bread always flopped and ended up in the rubbish bin
- Initially there weren't many products in NZ but this has completely changed over the years
- Driven by work situation (Mktg Manger of Food co.) and also required to travel/dining out
- It was initially very difficult - took 6 weeks to see a dietician - too long
- At first I resisted following a strict diet, but my health did not satisfactorily improve. Family/ friends find diet difficult to adjust to so don't invite me or make silly comments or don't have suitable food
- It has been easy because I was young. Also my mum has been responsible for my food
- Rely on my wife's cooking
- Huge shopping. Supermarket product changes and ingredients for meals - shampoo (some have wheat)
- Difficulty initially sourcing recipes and ingredients while feeling ill
- It has become easier to obtain gluten free food nowadays
- I adjust easily to situations and take control eg do the cooking and baking
- This was only in the first year. Now it comes naturally
- Way easier than 22 years ago when Dad was diagnosed
- Because I was 6 years old I ate whatever my parents gave me
- Probably much easier for a young child than a grown up
- Labelling is better now than when first diagnosed, more variety now also expensive
- One daughter, now 45, diagnosed at 9 so used to coping. 2 other children strongly suspect (ex husband has DH)

- Also milk protein lactose & soy intolerant
- Food very expensive, no taste, bland. Very restrictive
- Parents helped
- Much easier since biopsy diagnosis. Eligibility to join Coeliac Society
- You have to reorder your whole eating
- It was hard 11 years ago, but now it is easier
- It gets easier each week since diagnosis
- The only times I struggle are social occasions and sometimes travelling
- I had never overeaten bread - never ate it at night cause I knew it made me sick
- Family support/acknowledgement helps
- Concentrate on a diet of fresh food. Not processed
- Very easy at home, just cook gluten free baking etc.
- Gets easier all the time
- Having to change to different food and missing favourites
- Not all foods obtainable in one shop, hard for a person with a disability
- Difficult at the time to find foods palatable for a 2 year old. So many products now available and I'm much more used to adapting recipes
- Although it was difficult at the time, it is now my accepted way of life
- Because mum and my brother were already on the diet
- Still struggle with some things
- I am learner
- As an athlete, mother of a baby (now toddler) breastfeeding at the time and working part-time, found it difficult to get enough easy to reach carbohydrates
- Having a 5 year old diagnosed at the same time made it harder I think
- Been on one my whole life and didn't know anything else

- I am finding it hard especially as when I do eat gluten I rarely suffer symptoms, perhaps if I did I would be a lot stricter
- Living it away from the city made it more difficult because no specialist food was available. I didn't even know you could buy it
- Previously a vegetarian. Major food changes
- Easy when you feel so much better, having suffered for 15 years and got down to 45kg's
- I feel so much better sticking to the diet
- Difficult when diagnosed as you could not buy anything readymade in the shops then. Easy now except lunches when out
- It was more difficult trying to explain to others why I kept refusing food
- I haven't found it too much of a big deal - just got on with it
- It took a long time to be confident in all aspects of shopping, cooking, baking etc.

**14. Which of the following activities has impacted you on a gluten-free diet?**

- It's hard to find nice food out
- Have to make sure/f food available or take my own which is a nuisance
- Not yet comfortable with restaurants, have found even high class restaurant served me noodles on a dish requested to be gluten-free
- Some restaurants/cafes don't serve GF food. Planned overseas travel may be postponed.
- Have to choose where to eat. Shopping takes longer
- Need to eat BEFORE going out sometimes
- Label reading; positive as I now realise the "crap" in pre-packed items. Always have a "stand-by bar" in handbag!
- Travel; have to eat at more expensive places as no cheaper options GF. Have to "search" for places to eat. Kindergarten, school cooking classes

- Can't eat food at parties, at school would make food then watch other people eat it
- Everyone's eating and nothing for me. Things look nice but I can't eat them. People want to know why you don't want to eat
- Being from a small town with limited supply of gluten free foods
- Birthday parties, dinners out are difficult
- As a pastor attending functions with food I frequently find I can eat nothing
- Unable to totally relax unless you totally ignore all food on offer; and sometimes feeling a bit embarrassed at having to explain
- Eating out: Being limited to a few items on the menu. Social Occasions: When someone else is cooking. Travel: Limited to deli/travel foods not many GF foods
- I find it embarrassing saying I'm coeliac and can't eat anything on the table e.g. sandwiches, cakes, biscuits etc.
- I presume you mean 'negatively impacted. Impact is: not knowing what is in the food
- Especially Italian restaurants CD impacts on all the above but is a problem if you let it become one
- Not always able to eat out mainly for breakfast or lunch
- More planning needed; others need to be involved in my diet now
- Shopping takes longer - labels to read, prices high. Gluten free food not always easily available when away from home
- Because lots of restaurants or other people do not understand what gluten free & therefore think you are being very fussy, but they don't realise what it can cause
- I have to organise my food (explain to cooks, bring food in chillybin, double check food, make sure others do not contaminate and/or eat my food)

- A lot of restaurants still don't do GF meals/  
baking
- Ability to eat out at restaurants has got better,  
family meals still a struggle if I go to their place
- Don't enjoy eating out-restaurants continue to  
get it wrong, as do family. Sad but true
- Eating is a major activity in my life. Most social  
occasions involve food. Lunch is the hardest  
time; everyone else can purchase something from  
the bakery
- Careful where I go and finding restaurants and  
cafes that can cater for me
- Travelling is made difficult having to find out  
where to obtain GF food and what restaurants  
will provide GF food
- None, all OK
- Don't trust some restaurants others give you a  
very bland meal
- B'day parties - I make a GF dish. Travel O/seas  
- take a lot of food in case. Pit stops while out,  
cafes not much available. Sometimes it's hard to  
trust a sign in a café declaring it is GF. They may  
not be using the right ingredients
- Eating and having to learn to cook gluten free
- Ability to eat out. I love going to cafes but 99%  
(at least!) of the food has gluten in, but I still  
go and enjoy the coffee, and now I have lots  
of gluten free cafes I know and use. Ditto for  
restaurants. And I have travelled overseas quite a  
few times since being diagnosed, but have had no  
problems accessing GF food
- Restaurants much better than 5 years ago
- At conferences not providing gluten free food
- Generally can not eat finger food at social occa-  
sions
- Nothing impacted
- Everyone having to accommodate and work  
around me when choosing to go out. Or they  
feel bad when having no food that I can eat on  
work functions

- Needing to inform people of dietary requirements. Travel requires more organization  
Being told gluten free only to find now
- I need to ask questions when dining out. I travel a lot and need to have my "I can not eat ..." in many languages. Gluten free food is more expensive
- I usually stock up on bananas. Airlines good at providing meals but sometimes nothing on board. Sydney airport NO gluten free food. Because we eat rice and curry with Sri Lankans usually can eat something. Church teas etc need to take own cookies or fruit. Others are scared what to feed you at first. I usually say I can't eat flour - can eat most other things
- Aussie trip. Didn't find they catered for Coeliac's in cafes at all well. Difficulty in NZ as per above but no where near behind the 8 ball as my Aussie experience
- Have to plan ahead more and are more limited in where we can eat out
- Too many foods that other people do not realise have gluten in them.
- Air NZ provides no GF on short trips eg pacific islands this is annoying and inconsiderate. Unable to find food in restaurants-it is always difficult eating at friends home
- The need to involve others
- Need to forward plan all meals as you cannot be guaranteed a GF meal
- I worry about getting enough food or eating the wrong food when travelling
- Fatigues wanting to sleep and itchy skin
- We have to take our own food to most places we go - it's daunting for other families to host us for meals, however cafes/restaurants are so much more aware of providing GF options (they are not so good at dairy, egg and GF items!!)
- Carrying food with me when travelling overseas. Eating something that appeared OK and wasn't

Not being able to get lunch during a bus trip

- Often having to go without
- Went to Europe last year - a bit difficult. No point going for takeaways/Chinese
- Finding a bread substitute and GF foods to suit then (at first) - took a long time to come right - in other words, made mistakes with foods and suffered consequences
- You have to choose from what is available. Not always a choice
- Travel tricky in some places, need to be prepared. Loss of spontaneity
- Unable to find GF food when out, confusion from other people or lack of understanding
- Family don't like substitute flours and too expensive
- Inconvenience to self and others; having to be different
- Eating out is decided on who can provide GF food
- Can't eat previous favourite foods at home or out. e.g. Xmas cake, birthday cake etc.
- Must plan ahead before eating out, travelling in NZ, only travel overseas to English speaking countries, don't eat out for breakfast - hard to find lunch places
- At my pottery groups pot luck meals I can only eat food I take myself
- Kindy or school participation can be restricted (eg school camp or class parties)
- Very difficult to eat out - sometimes have to turn down invitations to dinner etc
- MY GF diet restricts me when going to restaurants or cafes
- Hard to find GF foods when eating out and feel awkward to ask sometimes
- Food wise eg expense and totally setting up pantry and travel everyday gluten food and outlets
- GF lunches out are hard to find. Restaurants are becoming more aware now

- Only to the extent of needing to be enquiring and cautious about food
- Financially because eating gluten free is and can be very expensive. I always have to spend extra time planning, preparing and shopping before I travel, social events
- Picnics, camping and travel a bit more difficult, but not too bad
- Many eating-places simply leave out gluten containing parts of a dish rather than providing a substitute. Light lunches seem to be restricted to salad or soup. When travelling I take my own food to be on the safe side, also it's cheaper. Shopping takes longer when you have to read labels
- Birthday parties, school activities
- School and cooking activities at school and at camps
- Family life until everyone knew what contained gluten and able to prepare GF food
- Food shopping takes longer - family have healthier diet - socially friends often come to café of my choice
- Health 100% improvement but always need to be very careful when travelling or eating out i.e. make sure food is 100% GF
- Always have to phone ahead for restaurants (weddings). Always have to have some of my own food for social occasions. Real pain. Many people can't be bothered. Think I'm fussy
- Always having to think ahead (travelling/eating out) no spontaneity
- As a child being excluded from birthday parties, sleepovers and the 'just a little bit won't hurt' attitude
- Avoid going out. Eat the same 'safe food' all the time. Take it out on other family members who aren't coeliac
- Have to ask about food availability, explain to people

- School- in cooking, in social occasions. People have to go to a special effort
- Eating out is difficult, finding substantial healthy food on the run is difficult, not being able to partake in most morning tea, nibbles or drinks "shouts" is difficult
- Travel can be very frustrating...trying to find decent food that satisfies. Social- obviously the awkwardness of refusing someone's gift
- You go out and have to go through the menu. Lots of places you can't even go to-deserts very limited
- Travelling with husbands catered business trips
- Work social functions and eating out awkward
- None of the rest of my family has CD so I am the only one who eats differently
- Work social functions and eating out awkward
- Go to social functions things, especially when nothing gluten free to eat. You don't need to eat, but you feel cheated nothing to eat
- The impulse buy is harder. Parties - having to take plate all can share, shopping takes longer: always looking for new things
- Takes longer to shop as all ingredients need to be checked. Social organizations - you usually have to take own food supplies i.e. Birthday parties, food trips
- Husband not keen on taste of GF food. When eating out or at social events too many foods not GF
- Some cafes and restaurants seem reluctant to know about this - others happy to listen
- Get fed up of eating salad when I'm out
- People saying it will be alright to eat it, just this time
- Buying lunch to takeaway has been very difficult
- Have to think ahead more about meals - especially as I flat with other people
- Christmas parties, birthday parties, school BBQ's etc, not much at McDonalds or any cafes

- Never sure eating out if it is GF also restaurant staff not sure what's in a dish
- Can't just have what hosts offer you without a thought
- Mainly through having to ring restaurant etc before going and having to explain to people who don't understand and think it's just a "fad". When I was first diagnosed even my doctors hadn't a clue about it. It is getting better now as through publicity more have learned about it
- Can't find anywhere to eat out
- Food more expensive; inability to access convenience GF foods means having to put more time into being organised re food availability and working week lunches, breakfasts & snacks are difficult
- Running out of energy quicker, instant foods become what you wish for - in my time there was nothing
- Others have to be informed
- Going to friends for tea. I have recently been to 2/3 places for an evening where there was zilch I could eat so I gave in and ate pizzas, bread buns etc which resulted in me getting depressed that I wasn't as strong as I thought I was
- Sporting trips/school trips - wasn't able to attend
- Vegetarian lifestyle had to change; eating out - no fast food - limited selection - travel many countries unaware
- School camps/sporting trips. Student accommodation/halls of residence. Parents had to purchase a small freezer to have in my room at the halls of residence (ChCh) - parents couriered frozen meals to me
- Friends are less inclined to invite us to their home for dinner as not sure what to cook. Tend to now go out for dinner instead. Family very understanding with 1 (out of 2) daughters diagnosed as well
- Not being able to go where my friends go and eat the same food they eat, so I feel different and left out

**15. Below is a list of feelings associated with how some people may feel about having Coeliac Disease. Please indicate whether you share these feelings by circling the number that best represents your answer.**

**Comments:**

- Always follow diet but would love to not have to
- Never worried because I do follow a GF diet
- However if not followed, effects would be a concern
- Always follow the diet, only embarrassed when certain people hassle my food (Mums perspective)
- Aunt & father had bowel cancer, which is a high risk factor of an undiagnosed coeliac
- I am meticulous about my diet so I do not worry about it
- I follow the diet. You just have to get on with it
- Never feel worried, because I will follow the diet for her until she is old enough
- Actually being vegetarian is far more of an issue for me re concerns re omega 3, B12 etc.
- Last comment does not apply, as I am very conscious about the diet
- I am not worried
- Used to feel angry, but only for the first year. Not worried, but its pretty obvious that one does need to follow GF diet
- Coeliac Disease does require a special diet, but I feel I can be healthy on that diet. But I do follow a gluten free diet quite strictly
- As a coeliac for a long time it has ceased to concern me, I don't mind carrying food, asking questions, telling people
- I am more confident now - but it was not always like that. Very frustrating for some years
- Additional restrictions due to lactose intolerance makes it harder
- I feel embarrassed to mention my new gluten

free diet in new social situations eg visiting relatives for the first time since diagnosis or restaurants, new work situations (morning teas etc)

- As I "grow up" I can handle it better because I can understand it more and explain it to others
- People usually understand
- Some people appear insulted by me saying "I can't eat" although I try to explain why always
- Not too hard to follow GF diet, and it's healthy
- I always try to follow a GF diet
- I am proud of being coeliac and am sure my diet is gluten free
- \*5 = because never consider not eating GF. Feel too sick.
- Follow diet BECAUSE of the long-term effects
- I would NOT take the risk of not following a GF diet
- Only feel that friends and associates don't understand. Family understands well
- When I was younger I felt most of these but now I'm fine
- After 10 years I have found it easier to explain my refusals of food. Also there is increasing numbers of people on all sorts of special diets so there is an increased awareness and acceptance in many social occasions. A huge plus (for me!) was about 2 years ago when my sister, brother, plus 4 nieces/nephews were diagnosed. Family had always made an effort for me before then, but now we make all our combined meals GF!!
- Family have been supportive - my husband is a diabetic and a daughter has trouble with wheat, fat & dairy
- Sometimes feel bad about telling folk gluten free if going to their place for a meal
- Some people presume that you will get better and can stop diet
- With ref to the last question- I know what the long term effects would be but I am not worried as I will be following the diet

- As I do follow diet well I don't need to feel worried
- I don't think I worry enough about possible consequences
- I often don't experience symptoms if I transgress, but I daren't let myself not follow the regimen prescribed, because I'd be angry with myself if serious symptoms/problems arose, although it is inconvenient
- There are a lot of things in life worse than to have Coeliac
- Angry - maybe annoyed some of the time to most of the time. But feel it is denial and refusal to learn more about dietary needs
- I still make mistakes which cause symptoms and I think about the long term effects
- I used to eat out 3x a week, now its 3x a year
- Family and friends aren't an issue so much as trying to explain it people I don't know. Often there is a lack of understanding with strangers (restaurants etc). I would say that I feel bad 'most of the time' at work, conferences, visiting (part of job) travelling and eating out where it is part of a job function

**17. Below is a list of situations that may make compliance to a gluten-free diet more difficult. Please indicate if any of these affect you by circling the number that best represents your answer.**

**Comments:**

- Sometimes trust restaurants with mixed results
- Don't know if I have eaten foods containing gluten by accident. But I cannot say never
- She did become angry when it takes us time searching for suitable places to eat when travelling e.g. South Island West coast on recent holiday
- Haven't tried eating out yet

- I end up doing a lot of cooking when people cannot guarantee a gluten-free meal
- I'm sure that many food manufacturers get it wrong and claim food to be GF when it isn't
- Possibly I could inadvertently eat gluten because ingredients listed are not recognisable
- Staying in hospital - only once, but I was shocked that GF food was not available/and not offered as a menu option. I would have expected greater awareness of special dietary needs in a hospital of all places. Eating Gluten food by accident - this happened on quite a few occasions at restaurants/cafes - staff each time said the food was GF and it wasn't. On one occasion I actually complained to the health department (I have severe vomiting if I eat gluten, so I felt pretty pissed off). AMAZINGLY they said I was the first person to ever complain about false labeling/gluten free food that contained gluten. They didn't really know what to do. They investigated the shop, which denied responsibility. I actually forwarded a sample of the food to the Health Dep, but they didn't test it for gluten. I think if more Coeliac's complained when falsely sold supposed 'GF' items it would be a good thing. The GF food industry is growing bigger by the day, but there is some rubbish out there - bad food and food that is incorrectly labelled. I think if food premises want to sell GF they need to be aware of the responsibility involved. If they make sloppy mistakes, a coeliac customer can be made ill. There should be consequences for businesses.
- Do not as a rule eat takeaways
- I travel a lot. The only big problem is Air NZ meals on the Tasman
- Used to be almost impossible to get food out or in the hospital but now most places can provide at least fruit or yoghurt
- Sporting places never have GF foods
- Need to be upfront and always ask (esp. friends)

re: ingredients. I don't like doing it and avoid it if I can! (Eating out like that) except with the ones who really try to go out of their way to help

- Difficult in work situations. I work in a variety of schools - often changes. Often need to explain at a m.tea why not eating 'party foods' as it looks like a 'social rejection'
- Poor labelling on food means we sometimes leave food out just because we aren't sure if it is GF
- Still don't know if Indian food is GF or not. Trying to ask an Asian cook if their dishes have flour is near impossible
- Often forget to bring lunch to uni - but can't really buy stuff that's filling and healthy and GF there
- It annoys me that some restaurants don't have any GF choices
- Being insulted for asking "no gravy or sauces please" and drawing a blank stare when enquiring about wheat flour etc used for thickeners
- I rarely eat it by accident - then it's just day/night feeling bad, so no major problem
- Over cautious so leave rather than risk
- Have not experienced staying in hospital. Paying more affects me, but I don't opt for cheaper gluten containing products
- At school when my friends swap lunches. I haven't been in a hospital since I was diagnosed as a Coeliac
- If I go to a persons place I don't know well I don't tell them about my diet and just eat what they give me
- Never opt for cheaper gluten containing foods. Mum is great at finding GF recipes
- Hard to read ingredients on wrapping or packets
- Takeouts are very limited. Some supermarkets are better than others
- Socialising-friends/family who don't realise what GF is and make me special dishes containing gluten

- Food labelling
- Very hard to find cheap gluten wheat free flour. Too dear
- Staying at friends - have to take own supplies
- Hate being "singled out" and having to explain at a restaurant. Or not being able to eat anything on the menu (takeaways or restaurants with no trained chef)
- Eating foods by mistake doesn't affect me often, but the effect is severe. Very difficult to travel - I travel around NZ with my job and often can't choose where to eat
- My wife does the cooking mostly

**18. Do you have any suggestions that you believe could help compliance to the diet?**

- A list of allowed/not allowed ingredients to check on packaging
- Info about GF foods in overseas countries especially non-English speaking countries
- Be prepared if you can
- Planning; ready food in freezer. Self control - remembering the consequences
- Be prepared and always have food with you
- Being organised, making own bread, cakes and biscuits. Informing other people when eating out at restaurant/friends place
- More informed community. If they don't know they can't help
- More awareness in the community, wider range options at supermarkets and when eating out
- Even better food labelling. Lower prices on some GF items. Explanation of additive codes on labels
- All foods that are not GF to have it written on packet etc.
- Get organised beforehand, get informed, accept the diet
- Making a lot of products cheaper

- Better labelling on all products without having to know what codes to look for
- All manufactured food should be labelled gluten free if it is. It is pointless checking a database as ingredients always change. Manufacturers should then have to change the label if key change to ingredients
- Belief that it will help. Willpower
- To go without is better than eating incorrectly - and it wont hurt you-
- More labelling of foods on gluten free
- Having a standard and/or making food manufactures labelling easier to see if there is gluten in the food. Needs to be more companies declaring if the food is GF and need a guarantee that declaring on the label that the company has complied
- Good information about foods. Naming specific foods and grey areas such as glucose
- Be happy that you can do something positive to help yourself be healthy
- I have learned that if you are unsure about food don't eat it. A trained chef is ok but some cooks do not appreciate the effects of gluten
- No issues for me
- Live in Asia!
- If Gluten Free food was cheaper.
- Feel so much better on the GF diet.
- Read labels. Use rice vermicelli instead of pasta it tastes better than GF spaghetti etc. Make sure chapattis are made with rice flour
- A cookbook specifically for packed lunch!
- Make your own bread
- More lunch options in cafes and restaurants.
- Yes: A special credit size card outlining your need to avoid all gluten to use at restaurants
- More publicity
- Clearer labelling on packaging
- A wider variety of products available on prescription as it is expensive and we don't all have the

time to bake

- There is no choice so I just get on with it
- In doubt leave it out
- Give your friends gluten free flour mix and instruct them explicitly re Coeliac Disease diet. It's amazing how recipes can be copied (ordinary to GF)
- Eat foods that are clearly identifiable. The more complex the more ingredients used, the more risk is involved
- Eating out guides. GF on restaurant menus
- The need to constantly be aware and not feel embarrassed to ask
- More financial help - labelling improvements
- Improved layout of the GF food guide booklet - frustrating trying to find foods in it
- More awareness for general public
- Availability of GF foods, but it has improved a lot recently. Restaurants could do a much better job of identifying GF food. If I find a GF restaurant I go back
- Cafes etc that provide GF food sometimes contaminate it due to ignorance i.e. putting GF biscuits beside non-GF ones on the same plate!
- Wider education - hospitals, rest homes. I have been given regular food in hospital, even though condition made aware
- GF food prices are too high
- I wish companies wouldn't label their products so ambiguously!!
- Having a good mum who looks after me
- More education about gluten in the service providers
- More restaurants showing GF choices. Better labelling on food
- Settle down - get on with it
- To train people in the food industry (restaurants) what gluten is all about
- When in doubt leave it out, or call the food manufacturer

- More chef/café training
- There should be information available to a newly diagnosed patient straight away. I had to wait several weeks to see a dietician and the local library had no books. Now computers have info, which helps but not everyone is aware it is on computer
- It would be helpful if food manufactures producing a product that is GF could say so on the packaging
- Know the effects in body of a little or larger amount of ingested gluten has on immediate and ongoing health
- More gluten free food available for lunches at cafes
- Clear label of gluten free (no gluten) as opposed to low gluten (>1%)
- Dedicated area in supermarkets for GF foods. All food companies being asked to replace wheaten cornflour with maize cornflour. Many products could be GF.
- Compulsory labelling
- Manufacturers listing ingredients more clearly. Restaurants and cafes offering a small selection of GF food
- Don't give up trying recipes to get gluten free versions of favourite foods
- Having lots of ideas for packed lunches as this is my major problem
- Better labels on food at supermarket
- Knowing the consequences of not eating the following diet. Keeping people around informed
- More awareness, compliance and choices by restaurants and food providers (i.e. cafes)
- Continued improvements in food package labelling!!!!!! Bread-development of a nice one that doesn't take so long to bake for yourself.
- Make GF food the same price as other foods
- Food labelling
- Labelling GF foods with international colour/

label

- Educate people on what could happen if don't comply with diet. Damage it does to body
- I am able to cope
- Making prices closer to the equivalent gluten containing food. Having gluten free food placed in one special place in the supermarket
- More public awareness that Coeliac D is a disease not a fad
- Availability of more GF food especially in small towns
- Book available in big print or recipes in big print
- Manufacturers stating whether a product is gluten free or not
- Just be aware of foods at bbq's and pot luck functions
- Labelling has improved, but some additives not well labelled. \* Lack of understanding by restaurant staff
- Yes remove gluten from all processed food
- I need to be more aware
- Be nice to have a gluten free only cookbook that does not also include wheat free, dairy free etc
- Focus on whole natural foods; add spices
- Join Coeliac Society. Get their quarterly magazine. Enjoy baking own bread, biscuits cake etc
- Not really
- Labelling of food
- Read all labels carefully and don't be afraid to ask questions
- Better food labelling. Better knowledge/labelling at restaurants
- Suggesting to manufacturers to use different flours instead of gluten ones
- Don't be afraid to ask for ingredients and leave if they can't accommodate your diet. Embarrassing, but better than getting sick!!
- Educate yourself/read labels. Ask questions/ double check all answers in restaurants and ask to see the chef if unsure

- Cost, Special section for GF in supermarkets, Advertising
- Clearer labelling in food and better awareness in restaurants
- Better labelling
- Greater awareness in community especially in terms of 'no gluten'. It's difficult to put trust in others when they are ill-informed
- Read a lot! Shop around
- When in doubt go without
- More restaurants/cafes offering gluten and dairy free food
- More detailed food labelling e.g. instead of stating "vinegar" should specify type of vinegar. Food handlers in restaurants should be better informed

**22. Please describe below any other feelings, situations or events that you have experienced as a coeliac patient that you find important in describing your experience as someone with Coeliac disease?**

- Occasionally being able to help others
- I react when eat food with gluten so always have to be careful, wish I didn't sometimes. More restaurants are becoming aware but sometimes treated as a nuisance when ask what is in food
- School camps - very difficult. In the end provided all the food just to make it easier. This is from primary to college level. At college they seemed more willing to accommodate and pay for food!!! Intermediate offered to pay us back when they realised after the event it was a 'medical' condition not a dietary whim!!! Luckily, as you can tell, she has no bad memories or feelings about any nasty experiences
- I'm not normal. Why is it that I can't ever get over it? If my body cells renew each year why am I not getting better?
- Many places claim 'gluten free' food but have no

understanding of the disease. Therefore you can't trust their 'GF' foods are truly GF

- It is easy to become a little angry at the lack of understanding and limited menu items
- When away from home (even at work etc.) you cannot generally get gluten free 'fast foods' (e.g. takeaways, sandwiches, rolls etc.) i.e. lunchtime food, snacks from cafes etc. unless the more expensive sit down items or non-satisfying salads etc.!
- I dine out as often but I can't eat at the same places. Make sure the waiter knows what GF is and not just wheat free
- When people think it's a "fad" or you are on a 'diet'
- Lunches (esp. cafes) are difficult than evening dining
- Suffered 2 m/c due to coeliac disease
- Range of food available has improved over the years but it is still very expensive
- Failure of some airlines eg Air NZ to provide GF meals on trans-Tasman flights. Good knowledge of GF held by many trained chefs. Increasing understanding of such dietary needs in the wider community
- It was very frustrating to organise the diagnosis of my Downs Syndrome brother in the Netherlands, as other health issues made diagnosis more difficult (biopsy not an option), and information is difficult to obtain from his caregivers as to an update on his progress. I wonder how many intellectually handicapped people are not diagnosed because they do not communicate their problems (although the symptoms are there)
- Not sure what you mean? Attending coeliac meeting/ Health Expo's etc.
- Eating out - most difficult when meals are finger food
- Sometimes feel embarrassed asking for Gluten free food eg checking of certain meals are gluten

free and personally I don't like making a fuss.

- Find it slightly embarrassing when family make a separate dish when the whole meal could have been gluten free and just as nutritious
- Most people/restaurants etc believe that gluten is just in flour. They have no idea how many foods it is in and in how many guises. Hence, often when dining out you find extra gluten containing food on your plate e.g. recently for me soy sauce and mayonnaise on a salad
- The best restaurants for dining out as a coeliac are indigenous: Chinese, Japanese, Thai, Mexican, and Indian. They tend to use pea flour or corn etc.
- At funerals when I cannot eat what is provided
- Also some afternoon tea meetings
- Much more healthy now gluten free
- For a child's mother it is constant thinking of what snacks to take everywhere and getting my 2 3/4yr old to trust new foods. At home with the food she knows she is fine, but out of the routine/food she knows will take some learning. Life is made easier by foods declaring that they are GF but sometimes I don't allow food that I'm not 100% sure has no additives etc to contain gluten. This cancels out foods sometimes at cafes for instance that might be OK. Sometimes chefs for example think GF only means using GF flour but don't think of the other ingredients - i.e. lack of knowledge
- I used to have hot chips at any takeaway place thinking they were OK. But then I read KFC's food allergy booklet and learnt that even without seasoning they still contain gluten - so now I have decided to stay completely away from chips
- I was happy when I got my diagnosis because I finally had an answer to my health problems. Something that made sense. And the funny thing is, I've never been a 'bread' fan, but growing up I used to get into trouble for not wanting to eat

it. Finally I have a forever-legitimate reason for refusing to eat it :)

- I feel healthier with CD on a GF diet than ever before
- Very hungry and frustrated when in a situation out or at someone's house with nothing gluten free. (And haven't had time to go to a specific shop to buy GF food) Would have been easier if bakery had something. Sometimes you don't feel like biscuits or pre-packaged shop GF stuff. Something hot, savoury, freshly made is hard to get and upsetting at times. Always have to think of something in advance
- Sometimes other people don't realise how important it is for Coeliac's to adhere to a GF diet- some people think its just a fad and don't realise how uncomfortable I feel if I eat gluten inadvertently or they don't realise the long term risks of not adhering to GF diet
- As I was not diagnosed till age 34, I now have some long-term affects eg osteoporosis.
- Waiters don't seem to understand the difference between cornflour and wheat cornflour. Some have no idea what a Coeliac is
- I was a teacher and at morning tea once a week for 10 years never had morning tea.
- Bloating motions make for difficulty in flushing in European type toilets. Smelly flatulence. Can be awkward until one gets the diet right. Some folk think your diet is just a fad especially if you're like me and don't have symptoms of diarrhoea and vomiting
- I have been diagnosed for 44 years and have had a "normal" life-career I wanted - the "O/E" for 5 years and got married and had children, I think people newly diagnosed need to know it does not define you it is just part of you
- A good healthy diet. Makes travelling difficult at times
- Lunches at out of town working meetings where

food is served at the meeting. Social meetings outside of home, e.g. a recent quiz evening to raise funds for a herception patient. Also cafes - some very good and specialise others hopeless. You tend to know the ones that specialise and therefore go to them as you know they cater for Coeliac's

- I often meet family or friends for coffee or lunch. There are very few lunch choices out there. It means when we eat out it is always at the same places. I have found that any eating place that is run by Asians (and there are plenty) never even try to cater for Coeliac's. They appear to be incredibly ignorant and often rude
- Conveying to health practitioners unusual symptoms that occur after diagnosis. Eg. Took 18 months for Doctors etc that the coeliac disease created other food problems eg fructose and lactose
- Basically comments from other people who don't understand Coeliac Disease and say comments like "Why do you have to be different" or "surely just a little sandwich or biscuit won't make much of a diff" or a comment I've had quite regularly in my workplace "trust you to be difficult" or "we won't be inviting you to our place for a meal!"
- Some people think it's all in the mind
- Often staff say something is GF but they do not know about thickeners, stock, soy sauce etc
- Initially I was embarrassed to ask at restaurants but this has got easier with more awareness
- 1. Diagnosis - symptoms showed for years, but diagnosis took ages. 2. Understanding all the terms for starches and to take it for granted they contain gluten unless stated (I find the numbers code handy but I was only given one this year). 3. I found a small book by Rita Greer (Diets to help "Gluten and wheat allergy") very informative approx 6-8 years ago. Had it not been for this book I would have still been making mistakes with glu-

ten containing additives like "starch", modified starch, corn starch, thickener, binder and many of the numbers

- People you have not heard about Coeliac Disease or Gluten free diet
- Flying- AIR NZ do not do GF to Aus/5hr and under flight time countries - difficult when traveling for work. Dining at friends houses
- Frustration a lot of the time eg co-workers eating many different foods in front of me and knowing I can't. (It's not deliberate, but can become annoying)
- I feel I am putting friends to a lot more trouble and expense - and am sometimes embarrassed when they have tried to make something special for me - and it is still not suitable and I want to avoid it
- The need to be assertive - the biggest risk is people who think they know what they are doing but don't. Sometimes they can be offended when asked are you sure?
- Feeling ostracised at social events with other males because I can't drink beer. Feeling 'judged' by my peers as I'm also dairy intolerant
- When you receive information that is incorrect about GF status of food (eg a muffin) you trust that info and eat something in good faith and get very sick (vomiting). You feel angry about your disease and people's ignorance (i.e., they think it won't really matter, after all how much could it really hurt?)
- Work places situations can be hard, either with customers (I.e. having to explain that you can't eat what you have been offered) or to good old staff morning tea. Overall the health benefits far outweigh the downsides. I think the amount of people going on the 'trendy' wheat free diet maybe trivialising CD. Sometimes I think when you tell someone you are on a GF diet you get a reaction like you are on an Auckland based diet

trend

- Often you will ask "Is this gluten free" and they'll say yes, but when you ask more questions it turns out its not, but its embarrassing to ask and sometimes people get angry/annoyed/offended
- Some people follow a wheat free diet by choice. But people don't understand that I don't have a choice about following a GF diet
- Q17, plus having to travel distances to different retail outlets for products. Some supermarkets start having good GF sections but overtime sell out or cease altogether or distribute amongst normal stock - harder to find
- Frustrated to find out that the diet was the treatment for coeliac disease. I was first diagnosed as a baby in 1938, but managed to cope with the wrong foods until 2000. Unfortunately because I didn't absorb calcium and other vitamins etc I have very porous bones and am on medication for life with osteoporosis and a damaged gut. Any other medical problem i.e. thyroid, miscarriages etc can be traced back to having coeliac
- Uncertainty when going into social occasions whether gluten free food will be available
- Am very aware that a non-Coeliac's perception of what is and what isn't gluten free is often flawed
- I find it very difficult when I am served a 'so-called' gluten free meal at a restaurant that I know contains gluten. The chef and waitress/waiter ACT like they know what gluten is, where they really don't have a clue. I have learned to be careful in restaurants where chef & waitress/waiter ask me if rice and potato are OK to eat
- Feel way healthier eating GF- so any hassle is worthwhile
- At school/camps/guides
- Being widowed about the time I was diagnosed with Coeliac Disease and with little culinary experience I was at loss on how to manage. A talk with a dietician helped a little with what to eat

and what not to eat - but no help on how to cook the damn stuff. However, over time I have adjusted and can prepare a reasonable meal for myself

- Some people thinking you are just on some fad diet and not understanding eating gluten is a medical condition, some waiters not knowing what gluten is - they say it doesn't contain sugar or something like that
- Feel weary of some waiting staff when they recommend foods - often don't really know what gluten is in. Often feel hungry when out over lunchtime. Drink more coffee often to 'fill me up', dislike attention when ordering a meal out
- Always ring ahead of time and find out about GF food they serve when going to a restaurant
- The biggest problem is that people avoid asking you to dinners etc, as it's so much extra work for them. They are afraid of making you sick too. Definitely a feeling of loss/sadness/missing out. At a social occasion with tables groaning with fabulous food but not one thing for me to eat. People assume I will bring something. Just sometimes it would be nice to have a choice. The few people that have remembered and taken the trouble make me feel more loved!
- Requesting a dish on the understanding that is GF and then on arrival it has ingredients that are obviously containing gluten (e.g. noodles on a chicken salad). You feel 'a pain' when you say it is not GF and you need to reorder. Frustration at the food knowledge of some places
- Ignorance of people in food industry is frustrating. Difficult especially at lunch time
- Going to a restaurant, they gave me a highlighted list of the menu that was GF. Then I noticed written at the bottom of the page it said the highlighted items contained gluten-not what the waitress was reading out to me. She apologised. Then they said the item I picked had a pastry decoration on top-they said they would leave it

there for decoration and I could give it to my husband. I was newly diagnosed so wasn't aware of cross-contamination at the time

- When I work late the boss often shouts tea, which is very often pizzas!
- Attitude of a person who thinks 'it is all in your mind' when taking GF food for a shared meal or social occasion
- People think that you are being difficult or fussy
- School camp, catered situations, eating out, foreign countries, grandparents initially
- Eating at home is easy as my partner is very supportive and we enjoy cooking so do not mind using substitute ingredients, being adventurous with ingredients or cooking sauces/stocks etc from scratch. Eating out frustrates me. Having to explain my situation to people who don't know me frustrates me. The perception that to be on a GF diet is a fad and "cool" frustrates me. No longer being able to enjoy food and drink I used to love frustrates me. On the flip side, I'm relieved/ I found out about my disease before it caused major health issues
- Carbohydrates when travelling/lunching out- sometimes it is incredibly difficult to find carbs (apart from fries which have lost their appeal). It can happen at breakfasts when travelling too. You can find yoghurt and fruit, but after some time the need for carbs can become quite overwhelming. Otherwise I'm glad to have this disease as opposed to almost any other I can think of!
- I get fed up explaining why I can't eat 'morning tea' > I never ate it anyway but people want to know why
- Most people at cafes/restaurants are very helpful and will try there best
- No difficulty
- People at social occasions are often insistent about you trying their food and make you feel its

just easier to comply. Its hard to be strong if you feel you may hurt someone's feelings

- Some people confuse CD with gluten intolerance & think it's a "fad". People never say to a diabetic - 'go on - it won't hurt you to miss the diet, but some feel that gluten free is just a fad so get over it
- School occasions - get sick of explaining to everyone
- School lunches are more difficult. Temptation is break GF diet. Buying lunch at school is now right out. Hard adjusting to GF bread as I am not into grainy breads
- Cost!!!! Expensive to eat out. Understanding by cafes, restaurants not able to take snack to favourite café so don't have to change
- Restaurants often helpful if you ring ahead
- Lunchtime cafes etc more difficult
- Air travel outside of NZ can be difficult even though requests are made for GF diet - and must be prepared to take food with you. With new regulations - I haven't travelled since they were introduced to know how these would affect me. Will do so in December
- Initially relevant info from Coeliac Society was helpful and important
- Sometimes eating out you feel fed up with explaining your allergy - at one restaurant a member of staff who knew me stopped the kitchen from deliberately putting a gluten containing product in my food - they didn't understand that it wasn't a fad weight loss diet, but a real food allergy. Needless to say I didn't go back and I often wonder about other times I've accidentally eaten gluten when eating out??!!
- People saying "it's the in thing now to be gluten free"
- We need to be very alert to recognise the possibility of gluten in certain foods and ask what is in it. If in doubt leave it out! Valentines and other

smorgasbord places are useful. When I was first diagnosed I went to the library to borrow books on the subject. When I finally got to see a dietitian I knew more about CD than she did, which was very little. That is how things were 14 years ago

- Travelling overseas, not sure of what you are allowed without regarding food
- Most restaurants are becoming aware of the problem and offer alternatives. Cheap takeaways is a killer a lot of 'food fillers' being wheat products
- I find takeaway GF foods very difficult to find especially in outer town areas. Perhaps a leaflet aimed at takeaway places could be worthwhile.
- Going to birthday parties – types of chips, lollies, food that is required. Parents usually buy GF options when informed
- Most people do not realise how serious being a Coeliac is, it is hard to explain that it is different from being off wheat for a particular ailment i.e. headaches. Coeliac is a lifelong disease that you are always going to have. It is also worrying thinking about the long term effects. As a young person I know that the less casual I am about a GF diet now the worse the long-term effects could be. Also very hard when you feel so well and don't have many symptoms when you eat gluten. I recently had a friend who knew I was Coeliac bring me around a freshly baked loaf of bread!! (It was NOT GF). I was good for the first day and didn't touch it even though I was cutting it up for the family but lost it on the 2nd day when there were two bits left and everyone was at school/work, so...I ate them and then felt bad, leading to depression
- To take part in simple representative netball tournaments or school camps/trips is too much stress to organise food available for myself while I am away

- See q.14
- Yes most people help me. But some time know deaf few has coeliac disease. I am not sure!
- Dinner at friends house soon after diagnosis. Assured me no gluten in dinner, but 20 mins later both ends (vomiting, diarrhoea). Very embarrassing and never been invited to that friend's place for dinner since. Still good friends, but eat out or at my place. Lunch a big problem, especially when you see absolutely nothing in a cafe you can eat. I know now to check beforehand, or take my own bread/panini for them to fill
- Difficulty in getting to toilet/conveniences (due to traces of gluten in system - often have emergency calls). Finding clothing to accommodate and expanding waist line due to "bloating" if there were traces of gluten in food, chefs not always understanding where gluten is in their products
- None that really come to mind
- Supportive wife and family made compliance with gluten free diet much easier
- That not eating food provided by a host feels anti-social and rude. However asking them to provide gluten-free food poses a risk, also places stress in people. I've found it better to be rude and bring my own food - it's often embarrassing
- Frustrated sometimes
- More café style eating-places are becoming aware of gluten free products. I take pleasure in finding even one product I can have. I have found restaurants in town who adapt recipes and I find I stick to the same restaurants and the 'same orders'
- Getting stale crackers in hospital because they couldn't find anything. Going on holiday
- Limiting socially

## **PART D: THE HANDBOOK**

**23. a. Did you have to refer to any other supplementary material other than the handbook you were given by the Coeliac Society in your transition to a gluten-free diet?**

**b. What was this material?**

- Internet
- Gluten free books, recipes books etc.
- Information on internet and from dietician
- List for health-dietetic people
- We were never given a handbook 16+ years ago. 16+ years ago things quite different.
- Dietician
- Internet
- Dietician. Coeliac Magi etc.
- Specialist info
- Internet
- Don't recall
- Coeliac Magazine, Internet search, hospital/dietician info, friend's knowledge
- Internet, Coeliac Society Netherlands, Coeliac Society Ireland, Southern Cross
- Magazine is useful
- Magazines, recipe books
- Interested in a wide range of information
- Don't know what handbook you are referring to
- Internet by my lovely loving wife
- Internet
- Internet, library books
- Read heaps of material. Can't remember specific names
- Anything I could find. Eg books, library, Internet, Hospital
- A cookbook which explains things a lot clearer
- Very wide variety and materials from a very wide variety of sources!
- Internet for recipes and mainly ingredients
- Dietician, Internet

- Info from hospital dietician
- Presume you mean handbook of availability of GF foods. Mainly used Internet sources.
- What handbook?
- Dietician, medical journals
- Books, recipes and information i.e. coeliac disease
- My niece in Canberra sent Australian information. Son got NZ information off Internet
- Coeliac Link magazines. Libraries. Information from Prince Alfred Royal Unit lent by a friend - very good. Pharmacists are sometimes helpful
- Not given handbook back in the 60's - if I was I can't remember
- Do not remember getting a handbook. Got 2 recipe books that were helpful
- Session with hospital dietician. Other books.
- Internet, library books
- Internet
- Yes, nutritionist from hospital
- I don't have the handbook currently
- I did not transition to GF in NZ - Not applicable
- Internet
- Dr. Rodney Ford's books and website
- Anything I could find
- Rita Greer's book 'Gluten & Wheat allergy'
- Books purchased
- Friends info/internet
- Lots of cookbooks and shopping to see what's there
- Anything that was available
- Notebook MFD
- Dietician
- MFD database
- Dr's advice, Internet research
- Website searches, Coeliac Soc video. Library books, hospital info - anything we could get our hands on!!
- Material from dietician
- Info material from dietician

- Wasn't given a handbook
- Internet
- Have not got one
- Cooking books
- Ingredients list in Australia where I was living at the time
- My mum and info from companies
- Printout from gastro dept (Mr HB Cook) ChCh hospital and dietician. Heatheries NZ
- Material form dietician
- Never received a handbook
- www.glutenfree.com. The gluten free diet by Rawcliffe Hames. The American Coeliac Society
- Coeliac mag and recipe books
- I don't recall receiving a handbook in 1999. I received 2 excellent free recipe books and a magazine
- Medical journal articles, Internet articles, recipes etc.
- Internet
- Website, Coeliac magazines lent by a friend
- Coeliac Society UK, Coeliac Society Australia. I didn't get a handbook
- Internet sites
- Websites
- Internet sites
- I don't think I ever received a handbook
- General books
- Internet, GF cookbooks, stuff from dieticians at hospital
- Library, internet, Dr Gluten book
- Internet, library books
- Dietician, paediatrician, anything I could get my hands on
- Dr Gluten website, several other books and cookbooks
- Leaflets from hospital dietician eg listing 'cereals' that are OK and other products in lots of OK or not OK
- Internet site- MDF

- Internet sites
- Internet and speaking to support group leader
- Stuff from Starship, internet, cookbooks etc
- Can't recall receiving a Handbook
- Supplied by dietician
- Internet
- Internet research
- Info given by doctor, hospital internet sources
- Books of GF kids, recipe books and internet
- But had previous knowledge because of my son
- Websites & specialists
- Library
- Cookbooks, web recipes
- I had other friends who were coeliac that were very helpful
- Don't remember receiving a handbook. Attended all meetings and got a lot of info from dietician and online
- Newsletters from the society, internet
- Resources from dietician, books about coeliac disease
- Library books
- Saw a dietician. Researched on the net
- Whatever I could get my hands on
- Recipe books, info from dietician
- Internet, medicines

**25. Where do you seek information on Coeliac Disease or the Gluten-Free diet?**

- Dietician at my work, ask her re: latest information
- Other coeliac people I know in the community.
- Bookshops
- Health magazines
- Gastro enterologist Auckland to check ingredients (toothpaste, alcoholic drinks) last resort (more expensive and not always knowledgeable). Trusted Internet sites only. Dietician (she learns a lot from me). Daughter (recipes and products). Pharmacist

- I often ring the 0800 number on tin and packet products. Many companies will send out a list of their GF stuff
- Health magazines
- Heath food grocery stores often get it wrong so I no longer rely on them
- Don't actively go looking. Read food labels significantly more, before being diagnosed had seldom read a label
- Books that I might buy
- MFD database, MFD booklet
- My best information came from family, one of who accessed a hospital dietician immediately and from that I found out there was a Coeliac Society. I would have floundered for weeks without that
- Food labels
- Other people with Coeliac's
- MDF database
- Support group
- Have it 'sussed' now
- The coeliac Society Link magazine is also very helpful
- In magazine
- Sorry I can't help you here. I never had a handbook. Don't think the society had them 14 years ago
- Coeliac magazine
- Food labels
- Dr's not always up on coeliac. Coeliac Society provided me with information, but not as I would like, food companies not always honest or knowledgeable about their products. Alternative Health practitioners are most informative, chefs, not always have good understanding
- Local coeliac society support group
- Wife

**28. What do you think could be done to improve the quality of information available to you about Coeliac disease or Gluten-free diets?**

- Nothing very satisfactory
- Bigger labels on food packaging
- It's a long time since I received info so not sure
- Ingredients list of allowed foods I.e. 150C as it seems to appear in the database allowed products
- I would purchase the MFD booklet for her if it were more specific, not filled with the obvious e.g. juices
- Nothing it's been excellent
- More public awareness as a lot of people don't know what it is
- Nothing, but I've been on this diet for so long I don't need to do any research etc.
- It's all pretty good just have to be cheaper and more available in café's etc.
- Info on packaging "Gluten Free"
- Where food is available
- The monthly magazine is excellent
- Food additive codes need frequent re publication
- Education of medical profession. Treatment by gastroenterologist. Public funding of coeliac society
- I feel that by belonging to the society I have gained more info than not belonging
- More basic information about food and numbers specifically
- I would love to find one decent book about it. Doctors don't know much/anything
- In general the information is improving all the time with research
- Integrating the info. I knew where to find a lot of things but others may not
- Make info more readily available for others who are non-coeliac e.g. businesses, shops, café's and supermarkets

- Put all good info in one place (like the cookbook intro in Eat Well, Live Well)
- To be honest, it's dull and clichéd. The presentation is very dull. Which isn't to say I don't appreciate it, I do, but it's good to hear you are improving it! Make it interesting (informative) and well-presented material that doesn't look dull.
- Greater comments on additives (eg maltodextrin) as well as comments on specific brands
- Nothing- I think I have enough information.
- A list of food items, which contain hidden gluten, eg soy sauce
- Although I recognise it is difficult for families with very young children with CD I think that for adults there should be much more positive spin on how easy it can be and how good for you. Most of the material takes the angle of making the most of a bad thing rather than saying how good it is
- On labels - telling the numbers which have gluten or gluten free
- Less adverts and more information in Coeliac Link magazine
- Clarify the difference between soy, Soya (i.e. nothing) and Soya sauce (contains gluten)
- I get a good service
- If the larger companies could put out full lists of their products I've written to some and had good replies.
- A specific section in library that is easily accessible
- Best pricing guide
- A handy colour brochure chart with food suggestions to buy at supermarkets and code explanation of food additives etc
- The booklet needs to include a larger variety of processed foods as these are the tricky things to buy
- A recipe book which has recipes tested by normal kiwi families. Lot's of the recipes aren't all

that nice or reliable

- I find the articles in the Coeliac Link VG - just keep them coming
- That mixed info is conclusive. I find mixed messages between different sources
- If you are sporty it can be tricky keeping energy levels up
- Needs to be more extensive, covering loopholes Coeliac's are faced with and consequential mistakes in eating gluten containing foods
- More awareness and a separate department in supermarkets
- As suggested earlier, improve the indexing of the booklet
- More symptoms described that relate to CD (as the symptoms vary a lot)
- I think it's OK - knowledge of the disease appears to be
- Write it in plain English and use up to date information
- Perhaps a section going over misunderstood issues - eg. Oats
- Once a year Coeliac Support day
- Better labelling such as 'suitable for a gluten free diet'
- I thought it was very informative
- Much has been done since I was diagnosed as Coeliac in 1984
- Just be kept up to date with any new developments
- I think its good
- Clearer labelling
- Maybe a TV programme to educate not just us, but public etc
- Simple pieces of long articles by professionals. More general rather than specific info re: baking: like replace flour with 1/2 tapioca flour and 1/2 fine maize cornflour and guar gum. No need for hundreds of recipes. Just use normal recipes with replacements

- More precise info, more authority, less folklore
- GP's need to be better informed and have information on support groups i.e. Coeliac Soc
- More NZ cookbooks or info
- Csoc handbook: too longer line length, column measure to text, not easy to read
- Compulsory allergen declarations on food
- Explanation of thickeners. More help and follow up from dieticians
- More condensed place for people that are first diagnosed
- More information about the coding on food labels and hidden ingredients containing gluten
- Opportunity to talk to someone from the Coeliac Society. Drs and dieticians do not know about living GF, and it would be great to have the disease explained, current data, and testings - someone who has a specialised interest
- Don't have conflicting info: e.g. 'oats'
- Food labelling
- More emphasis on healthy eating rather than just gluten free
- More information on the long term affects of NOT following diet
- It is very helpful
- The coeliac Society could email any new information to its members
- Too new to comment. But certainly with not living in a main centre access to many GF products is restricted
- In different media. Paid people other than medical persons
- Society mags are excellent also handbook is also adequate
- More information at a Childs level for them to understand also classmates
- At this stage I am quite happy with things
- I don't know
- With the net it can be hard to know what to believe

- The print size could be larger
- Not much
- Getting more manufacturers to subscribe to our MFD booklet
- More vegetarian recipes shopping lists
- Make general public more aware of Coeliac Disease
- Don't really know - sorry
- Get shops to better advertise that they stock gluten free produce
- I'm pleased with the info I have received but did have to ask lots of questions and read lots of labels
- Information easy, more basic & interesting
- What all the 'numbers' are in common terms i.e. Thickener 415. What number is cornflour or wheat flour etc without chemical names
- I would like more information about oats from the Coeliac Society. The internet is full of conflicting info - miss oats
- Easier to read - better order
- Nothing. I've had excellent advice & assistance
- Now well informed and just require snippets to keep up to date

**29. a. Have you ever found any pictures or diagrams to be of assistance in your understanding of Coeliac Disease or the Gluten-free diet?**

**29b. If yes, please describe what these were and how they assisted your understanding?**

- Coeliac Handbook
- The villi in the intestine and how they react with gluten
- Diagrams provided by dietician. Pictures/diagrams from consultant
- Diagrams of the intestine before and after a gluten-free diet
- An English book - coping with Coeliac Disease. Excellent way to understand text and diagrams

demonstrating the damage done to the villi of the small bowel

- Maybe the flattened villi to realise the severity of condition in bowel. Made sense it would take so long to recover from gluten exposure.
- In the original diagnosis the picture of healthy and non healthy villi
- From doctors/specialists (esp. Bob Anderson's presentation)
- Local Coeliac meeting when a doctor is the speaker
- Initial diagnosis pics of the villi and intestine and the effect gluten has on these
- Specialist showed pictures of diseased villi
- Small intestine change diagrams
- These were "power point" diagrams from Dr Bob Anderson's presentation at the society AGM in Dunedin 3 years ago
- On the Internet
- Gastroenterologist gave me several from the endoscopy and gastroscopy. It helped to see the damage
- Pictures of what happens to our small intestine.
- Only really pictures of villi - flattened and normal villi
- Photo's from my biopsy and diagrams drawn by my gastroenterologist helped explain the villi etc
- I guess the standard diagram which shows an outline of a body and indicates where the damage occurs is useful
- Pictures of the intestine and how gluten damages this
- Seeing endoscopy films
- Photo micrographs of normal and coeliac affected villi
- Information from Australian Coeliac Link articles. Leaflet put out 3 or 4 years ago - sent out with Coeliac Link magazine
- Picture of intestinal villi before and after GF diet
- Recognition of visual and my own physiology. e.g.

villi and function of small bowel and functions.  
Biopsy and diagnosis - images of endoscopy and  
consultation with specialist

- Like to see more GF clue price tag labels in grocery shops
- Dr. Rodney Ford's books
- Text books from years ago. As a home science teacher my prior knowledge was a great help both in the physiology of the disease and nutritional requirements
- Villi I duodenum. But this only relates to what gluten does. The real problem is understanding the pitfalls and learning to read labels carefully.
- The graphics showing the small intestine and the effects of the disease
- Stomach lining - medical diagrams - see in medical materials from Dr's and on internet
- The handbook and signs on packages for food
- Simple diagrams of the intestine so you can understand what a healthy one looks like and how gluten damages the villi
- Information I received from Christchurch hospital
- From the gastro dept ChCh hospital - the visual is always better than description verbally
- Pictures of damaged villi were helpful in my earlier understanding
- My doctor drew me a picture of what was happening to the villi in my intestine when I consumed gluten
- Villi atrophy and resultant effect on digestion
- Diagrams of the digestive system with explanations of how villi worked
- The local dietician at the hospital gave some children's info about the diet using pictures, photo's of "good" food etc
- Picture of villi (in handout)
- On labels some things have wheat in a circle with a cross through it and some gluten containing products have a picture of wheat

- Pictures of the colon villi that are damaged or flattened - easy to visualise
- Pictures supplied by the gastroenterologist at the hospital
- Photos of DH on the Internet, which made me realise, I had it! Had been treated by a specialist for adult acne when in my 20's!! Mine on back-2nd daughters on bum, son around neck and behind ears. Ex on head
- Pictures of what happens inside (villi) when gluten is consumed
- A) Pictures showing badly damaged villi (leaky gut) in a newly diagnosed Coeliac. B) The transformation to healthy villi (gut) once on a totally healthy GF diet. Very simple, but effective
- Pictures of damage to the villi. Why you can't absorb your food properly
- Labelling at supermarkets with large colourful stickers so that you don't have to read the back of products
- Drawing that the gastro specialist made of my intestine
- The picture of gluten affected villi opposed to healthy villi
- Specialist drew picture of what had happened to the villi in my intestine. I could understand that very well. BUT doesn't help questions like? How soon will they regrow? If I have some gluten (even a little) or get symptoms, does that mean they are flattened again so quickly?
- The duodenal biopsy! Quite a shock to see how badly damaged it was
- I am a Dr so have good understanding anyhow
- Pictures of the intestine and flatten villi
- Internet - showed what the damage looked like
- Especially explaining to others the impact of gluten on villi in the GI tract
- Before and after diagrams of small bowel
- Pictures of bowel with villi flattened by gluten
- Inside stomach picture

- Dr T Smith - Gastroenterologist from Hamilton - spoke at a gathering of members - 2 years ago. A great help to understanding the disease
- Regarding absorption from the intestine of nutrients, villi being flattened
- Interactive English website - from memory
- Found info in Dr's office about Coeliac and how it affects me
- Comparisons between healthy coeliac patients intestine linings
- Small booklet/leaflet from gastroenterologist when diagnosed. Diagrams of linings of intestine showing villi and wearing down caused by gluten intake
- When my specialist showed me a photo of my gut and actually showed me the damage that had been done
- Seen photo's in coeliac magazine of small intestine showing effects of gluten
- I saw a lot of coeliac food etc
- Initially to understand the pathological process of CD
- Picture of lower bowel showing the effect gluten has on the villi. Even the slightest amount of gluten can affect the villi all over again.
- The villi (over 10 years ago) how it affects the digestive
- Pictures of villi in the bowel and how they become stunted by eating gluten
- Other specialist gave an excellent explanation of the disease using a diagram. This was useful with the visual results of the endoscopy

**32. Where do you use your handbook? Specify:**

- Don't think I have it anymore
- Initially I used it all the time at the supermarket
- Don't use it at all - in fact can't even find it!
- I do not use it anymore. Since the diagnosis of my daughter (before me) I have learned

everything

- Read it once. Outdated
- Very handy
- I don't use it-out of date, not helpful anymore, as I am familiar with its contents-was helpful initially
- Travelling - MFD book
- Only really read it once when I first received it
- Virtually never now.
- Supermarket but it can be timely looking up products when you can't find it in the book because you're not sure what category it fits into
- Often share recipes with friends who want wheat free recipes etc.
- Seldom refer to it now. Mainly used it when first diagnosed. Was certainly a good tool to have?
- Never use it. Do not find it very useful. Prefer to read labels at the supermarket
- I don't. It's not much help to me. I have learnt from experience which foods to avoid and still check labels each time using the motto: if it doesn't state gluten free - don't use it
- Don't use handbook anymore
- Hardly use it
- I only used the handbook initially now I carry the GF MFD booklet in my handbag and refer to it 2-3 times a week
- Handbag (MFD)
- I don't use it. I rely on manufacturers food labels
- Never after the first look
- To check additive no's
- Never! The MFD booklet is essential to carry shopping
- Very rarely nowadays
- We don't have a handbook - never got one
- Rarely use it
- Never
- I use the recipes the most
- I used to take it to the supermarket with me when I was first diagnosed (MFD)

- I don't need to use my handbook now
- At Woolworth's or New World
- Initially used in supermarket and kitchen. After a month or two we don't need to use it anymore
- Don't have one. Didn't understand it 10 years ago
- To be honest, at the time of filling in this survey I haven't looked at the handbook for many years (probably since being diagnosed) and therefore can't comment on this
- Don't use handbook - misplaced it
- Also, as information for other people
- In the MFD book, categories are weird i.e. looking for marmite and peanut butter was under nuts and jam under sugars. They should be under spread

### **33. Where do you store your handbook?**

#### **Specify:**

- Handbag take it everywhere with me.
- Study
- In handbag
- Office
- In handbag
- In a cupboard. Have not looked at it for years. Recipes are dated. The 2 recipe books I had to photocopy at the time are outdated too but at the time were helpful
- In office or in handbag
- In my folder of relevant material
- In my handbag
- In my bag -MFD
- Spare room
- Hidden in a cupboard
- In my wife's handbag
- In my handbag
- Needs an index - hard to use
- My handbag
- In my wife's shopping bag
- Handbag

- Have loaned mine to a wheat intolerant friend who can't get the book
- In the recipe book section
- I don't look at it
- Amongst other coeliac material in the pantry
- Pantry
- Sometimes in my handbag if going out for groceries or dinner
- Handbag
- Handbag
- Office
- Carry MFD notebook in my handbag
- Home office
- In handbag
- Kept with the cookbooks
- Or in handbag when shopping
- Take out when shopping
- Computer room - office
- In my handbag
- Handbag
- Misplaced it
- N/A do not own one. Not presently a member of the Coeliac Society
- Upstairs on a shelf
- In my handbag
- Folder is kept in bedroom, MFD book kept in my purse

**34. What do you believe is the most important information included in the handbook?**

**Specify:**

- I would have never thought of pharmaceuticals if I hadn't read it here
- All info in this handbook is important, as you have to understand the whole Gfree scenario for being a coeliac
- I don't recall any info on pharmaceuticals. It would be great if medicines had to have GF labels on

- Products available
- Whoa! Is there a different handbook from the availability book? I don't recall and of this
- Other Coeliac's experiences
- All were important
- I am always looking for new dine out places for my son to eat at
- I still use one of the recipes (pizza bases) from the handbook. Personal stories are great
- All new Coeliac's should have as much information as possible
- Recipes: list of some books & put up web addresses: 100's of recipes, Additives: an additive book address: NZ Food Safety Authority [www.nzfsa.govt.nz](http://www.nzfsa.govt.nz) 0800 693721; what food to eat: A table with 3 columns: OK, Forbidden, Traps; Warning about eventual cancer risk if not following diet. Handbook long gone. Can't remember. New Coeliac's need contact numbers of other Coeliac's in their area. Fellow Coeliac's have so much helpful info
- I don't have the handbook
- The page to photocopy for schoolteachers is great. It is useful that the recipe pages are a different colour
- This is what I think about the magazine
- Knowing about additives is really important
- All very important and interesting. Loved the forms/explanation to give to school/friends
- Referred to all contents initially
- Support contact very poor in this area. Would be nice to meet other Coeliac's
- All the information in the handbook is important to me
- All of it very useful at time of diagnosis
- You simply must be able to recognize what additives are dangerous - if you can do that it's a breeze!
- I don't remember any of this information being in the book - only products and manufacturers

- How to live a relatively normal life with a gluten free lifestyle
- All information important. Sorry not used for several years. Used when diagnosed 10 years ago

**36. Please write below any advice or suggestions about information material that Coeliac Disease patients may find of benefit or need**

- New Coeliac's that I talk to just want a list of what they can't eat. Also additives that are gluten free
- Takeaway/eating out advice-they suggest Asian which Chinese has soy (gluten) and Thai marinades and coats meat in flour before stir frying - suggested questions to ask a food supplier so you can be sure a product is truly GF
- Food labelling most difficult thing to get head around. Updated lists in Coeliac Magazine of restaurants, cafes, health food shops etc good when travelling. Please contact for support person to guide through early days
- I think the CD magazine is really helpful
- In England the handbook is written under each supermarket, the listings of the foods are not done all over, this needs to be addressed
- Starches can contain traces of gluten (although tests cannot find gluten). The check ups for osteopenia/osteoporosis, bowel cancer, diabetes, arthritis, thyroid etc is very important. Multiple allergies are possible. The check ups for malabsorption problems is of utmost importance (one a year). The biopsy before the diet is an important issue. Easy/ cheap recipes are welcome. Take supplements when needed. The issue of cross contamination is important. There is an additives booklet available from Food Standards-Australia/N.Z (very good). A lot of travel agents do not know about meals, which

cater for multiple allergies (which I have). It is important to check medicines and cosmetics and alcoholic drinks. A list of ingredients that contain gluten is very helpful especially when you have to inform others. Gluten intolerance (negative tests) is a possibility. How to wean a baby on solids when there is a family history of allergies and or coeliac disease. Multiple health problems can confuse the health professionals, as symptoms may be typical. Buy a freezer and chillybin, stock non-perishable GF foods

- Its not so much the new diagnosed coeliac but it's the doctors /practice nurses all need to be educated with more material. I work in a medical centre and they are all asking me about info and up to date knowledge that I gather from meetings etc.
- Suppliers of GF goods are very helpful e.g. Crombie and Price in Oamaru. Also Heatheries, Orgran and Freedom Foods. They are the experts who have great recipes and dietary advice. Tell people they should be pleased
- Keep it simple
- Make it more user-friendly. Need more info about DH. I have recently developed a rash that I think is related, but I'm not sure
- A list of internet sources (websites)
- The handbook would be more useful if bound as small booklet. It is full of good information, but I had forgotten about it
- Maybe listing it in just brand names eg Pams-list all gluten free items. Watties-"so on".
- The biggest plus for me is that my wife enjoys cooking and experimenting with gluten free recipes. To be a coeliac and a poor cook could be quite difficult
- Elderly like me may not be computer literate. Coeliac Society cannot fully cope with all enquiries. Some areas have good societies, others meet in inaccessible spots. A good specialist who

puts you in touch is great is a great help

- As earlier - be positive - quote from others who have had full and normal lives and achievements
- The only thing I find difficult is all the numbers on foods and I don't know what they all are. A list would be helpful
- Advise new Coeliac's to ring and ask for help if they need it. Coeliac society member are all very willing to help new members
- Other possible reactions to other food groups and the symptoms to look for eg fructose and lactose difficulties
- Diagrams and visuals of coeliac disease impairments, diagrams and visuals of results after gluten free diet introduced, quotes from Coeliac (patients) persons on how their life is better and more healthier being on GF diet (positive info)
- Need more brands and eating out info
- 1. More detailed additive information, 2. Lactose containing foods (or free of), 3. Contacts of outlets who sell gluten free breads (and lactose free!) - ready made.
- More advertising on TV or perhaps a national week on TV
- A list of common foods at normal prices that are suitable to eat eg. Oak baked beans, rice, fruit and veg, meat and fish
- That they might have secondary intolerances because of the CD
- Personal stories about how other people (Coeliac's) have coped (adapted) to the diet - lunches, eating out, travelling etc (I remember reading some in the handout, they're great; keep updated or have more)
- Common pitfalls eg Additives, food produced in countries with lax labelling laws etc
- Stock lists of GF food, GF takeaways, how to test for the disease in children
- Applying for benefits; you do not get this advice from your doctor/or specialist & Work & Income

certainly don't give it freely

- 1 on 1 explanation to settle with the acceptance of the disease and walk you through - supermarkets and changing lifestyle
- Get a wife like mine!
- A really good recipe for gluten free bread made I a bread maker
- Not doubt the handbook has been updated, but the one I received "Help! I've got Coeliac Disease" had no recipes, which would have been helpful for newly diagnosed coeliac. It contained 8 pages
- I only became aware of a Coeliac Society handbook when my daughter in Wellington, made contact with Bakels, reference their gluten free bread mix source in Hawkes Bay. In their response, they sent a pack of bread mix to me, plus several of their own bread making recipes and a number of pages from the Coeliac Society's handbook. However, from early on in my coeliac journey, I firstly adapted some of my wife's favourite cake and biscuit recipes - willing to experiment with quantities and the addition of other ingredients to achieve satisfying gluten free equivalent - and then secondly, made up my own recipes. Of course, there is an occasional failure, but the satisfaction of achieving tasty results and sharing them with other Coeliac's, is hugely rewarding. I have not found the preparation of gluten free meals at home, or when we are in our daughters home in Wellington (she is very supportive and makes sure the ingredients are gluten free), to be a problem
- Up to date website advising of GF eating places around the country
- Maybe another handbook with info on pharmaceuticals that are GF
- Devise a bit for dieticians to hand out to coeliac patients, including useful phone numbers, books, GF food stores etc. Lists of Coeliac friendly

doctors. Still few doctors who are good at diagnosing Coeliac's. Dr Tapper from Invercargill is Coeliac and said the disease is very common. Most Coeliac's are misdiagnosed many times. I had 60 years of being sick including 25 years on indigestion tablets!

- Types of CD-diagnosed by biopsy, blood test or other means or self diagnosed by diet
- Like the list of sympathetic restaurants etc
- New research likely to be of interest such as the enzyme to take when dining out
- Hidden gluten in products. What not to get caught buying in error
- Additive information. Soy sauce in ingredients to what extent can we eat it
- More specific information about the child disability allowance. We missed out on it for 4 years. A big heading about it would have helped, and distinguishing the fact it wasn't only for food. I thought it was the same as the adult prescription benefit (maybe I am just dumb)
- Information on labelling i.e. Sugar content in GF foods
- Impact of not following diet, testing of relative. Emergency food - i.e. what to have on hand info GF food is available
- Odd things gluten is found in eg Milo, rice bubbles, marmite, raro, jelly, tender basted chicken
- Info regarding small benefit available from Social Welfare regarding extra cost due to being Coeliac? Disability Benefit
- Be vigilant in reading labels on all products
- The coeliac society provided all the info I required
- The coeliac society magazine is the only resource I use now because it keeps me up to date on information relevant to Coeliac Disease
- Once again the Coeliac Society magazine. Attending local group meetings can be very

helpful too. This way tips and recipes can be exchanged

- The internet has a lot of useful material on it
- List of places in NZ that have GF food -restaurants etc
- Additives and food codes
- Vital to stick to a totally gluten free diet or can result in cancer of stomach or bowel (good reason!)
- Learn about which food additives you should avoid and be ruthlessly strict with yourself. Recognise that wheat is not the big "saviour" - my family far prefer many of the gluten free meals I cook (especially pasta) as it is much lighter and digests very easily. Quinoa pasta (by Coronilla) is fantastic!! This plant is grown at high altitude in harsh conditions
- Support groups - regular meets. I think I need an 'AA' group - Gluten Eaters Anonymous Group to help me go straight
- Substitution of GF flour in recipes and how easy this is (e.g. mixing flours available from BIN INN rather than buying expensive GF flour mixes. Good information on nutritional GF flour that is available (e.g. millet, soy, buckwheat) and how easy it is to use this in baking
- Cafes that serve genuinely gluten free food i.e. carefully prepared without contamination by geographical area.
- Information on what happens in a gluten reaction and ideas on how to lessen affects if gluten is consumed by accident
- Getting GF food on prescription. Eligibility for child disability allowance. General rules for adapting non-gluten free recipes to GF

## **PART E: FURTHER COMMENTS**

### **37. Please make any further comments you may have relating to your experience with Coeliac Disease that would help me to design a useful handbook**

- Warn of the cost per year to be a Coeliac. Estimated, I believe, to be a min of \$5000!
- This is all new to me
- Colour-code the different sections for quick easy reference
- Does current handbook have information for pre-school, primary etc so children's teachers are more aware it is medical not just a diet by choice
- Handbook hard to find things. Could the handbook (manufactured food list) give a scale for other foods that may contain minimal amounts of gluten?
- Filled out by mother. More help for young kids lunches. Maybe another copy of basic outline of the disease to give to family
- The most helpful item is the manufactured food list from the CS, although it is quickly out of date
- So long since diagnosis and can't remember getting handbook and can't recall how helpful it was.
- Just read all labels carefully. If in doubt leave it out. Natural homemade / home grown is best
- Smaller and more portable, more attractive, more specific food/diet info. Updated regularly and sent out to members
- You must point out that there seems to be huge variations in people's conditions and needs. The coeliac condition is still not fully understood. Other digestive conditions seem to be related and occur in wider families (eg chohn's disease, other food allergies)
- When you are sick and do not get a diagnosis, change doctor, ask for (another) referral, never

give up, consider multiple problems. Inform the non-coeliac that have to deal with Coeliac's so that they do a better job at diagnosis, care and cooking. Get your offspring and their offspring, your sibling's parents and grandparents tested. Talk about it when needed to those who want to/can listen. Concentrate on the solution. Feeling bad is a waste of time. Find people who are willing and capable of accommodating your dietary needs. Do not trust everyone, your worst enemy is the person who thinks he/she knows it all but doesn't. Double check your travel meals and bring emergency supplies (not perishable). Stick up for yourself. Ask people to heat your GF meals that you brought with you (petrol stations often have microwaves. Eat plenty of fruit and pulses, drink lactose-free milk (lactose intolerance is a problem with many Coeliac's) - yoghurt and cheese and buttermilk are low lactose foods. A biopsy-proven coeliac gets a subsidy for certain foods. I have 6 allergies and 4 intolerances and I carry a list with all the names of the things that contain these allergants. If you have an allergic reaction to medication it may involve a whole group of medications (F. erythromycin - macrolides). Your pharmacist is your hero; he has saved me trouble a couple of times because he has my list on his computer and I ask him all the time to check. The worst thing that ever happened is that my GF meal was given to another passenger twice on the same flight; fortunately I saw what happened just in time to rescue my meals

- As I stated before I think that an up to date info package should be sent to all GP's/ nurses as they all seem to be in the dark about when to send people for biopsies and the importance to be diagnosed for gaining our NHI number
- Have a wallet size card with the additive codes on it

- 1. Define coeliac disease. 2. Follow the diet; it's healthy and good for your heart. 3. There are plenty of worse things you could have. 4. So much choice now than 7 years ago
- Handbook probably needs to be replaced every 5 or so years and sent to members. Also what to do when mistakes are made. Do you just see it out? When I do have a 'mistake' I suffer much worse than before. Can't stand up etc, so intolerance for me is far greater than before
- Type needed to be bolder and if possible larger
- Difficulties when following the diet following a heart attack with the GF diet.
- It needs to be able to take with you at all times.
- It's a bit confusing trying to find something in a hurry
- Alphabetical order. Not lists as long I.e. break down categories more, better font, and clearer headings, and have more companies contribute eg. Nestle, and state criteria for companies to be included I.e. need a reassurance that the food manufacturers comply (MFD)
- Eat Well Live Well - with gluten Intolerance (Murdoch Books Australia) - awesome book to read as intro explains Coeliac Disease in easy language
- Please make it look attractive. Also well indexed so that info is easy to find. Thank you! I look forward to viewing the results.
- A handbook with places to eat in alphabetical order by suburb and brief description of what they offer i.e. lunch or only cakes.
- I like the ring-binder format so I can add updates, recipes etc.
- Important to stress possible long term effects of coeliac disease if diet not adhered to. List gluten content in pharmaceuticals additives etc. List of snacks that are GF would be helpful-especially when travelling
- Don't get too complicated about different tests

Clear diagrams help. Other folk's experiences help. Keep on the positive side its easy to cope once you've worked it out

- A question and answer section, colourful user-friendly visuals
- The support material is very good
- I think you have made a great choice to do this - well done. To have a professional looking document (currently looks amateurish - that's not to be taken negatively!) would be great! Keep up the good work. Please send summary
- Add an envelope inside front or back to keep contact details or recipes or place to add own recipes
- More experiences with people travelling we hope to go next year but I am a little worried
- Hard to find what you are looking for
- I think the handbook is a great idea (don't know if I ever received one). After my GP diagnosed osteoporosis I think reminders of the long-term effects of the disease and early checks eg bone density need to be included. Many are unaware of these facts
- 1. The varied signs and symptoms of the disease,  
2. The way of diagnosis (tube puts people off) with blood test- for those with family members who suffer with some of the symptoms, but are inconclusive
- I had never heard of Coeliac Disease till I was diagnosed and it was through my rheumatologist investigating my anaemia
- It is hard to find your way around the basic food categories. Give basic explanation followed by more depth for initial skim and later in depth reading. Give some info for lactose intolerance as well as it is often a result of damage due to coeliac disease. Similarly with linked conditions.
- Good luck with your study, if you can change the booklet I will love you forever!
- Letting people know that it is not that bad to

have CD and that they will far more healthier in the long run

- Make available on the Internet or have an Internet version. You may want to talk to partners who live with someone with Coeliac Disease. May give you useful insight. Often they are motivated as much as the patient
- Helpful hints to parents of coeliac children especially babies. In our experience we had to cope with it for our young child and needed a lot of help as she was the first person in our extended family and we knew nothing
- Might be nice to have a section for kids to read
- It needs to have different sections for 1. Children, 2. Teenagers, 3, adults. There also needs to be a section for parents of children who are diagnosed with Coeliac disease (Mum's suggestion)
- Simple recipe adaptations. Brand names
- Any handbook should include a diagram explaining the condition and some easy starter recipes
- Always like to see new things. Good luck with your handbook
- A colourful children's explanation section would be valuable
- Most people only prefer to use this handbook the 1st year after diagnosis. I believe you should direct it to the newly diagnosed
- Please note that a child's view of coeliac disease is different from her parents. We are responsible for providing a 100% gluten free balanced diet at all times. This covers shopping, choices of places to eat out and her diet on school trips, guide camps, sleepovers and social occasions. A large percentage of choices we make for her she is not aware of
- I haven't attempted Part D - I haven't seen the handbook, or perhaps I never had one. I have no recollection of its use otherwise
- Would like to know what products are gluten free or "low gluten"

- This is really bad but I don't know what the handbook is! I assumed it was the very small MFD booklet. I love getting coeliac magazines and also occasionally use the MFD booklet but that's all I'm aware of. Will be interested to know if everybody else knows exactly what the handbook is
- Ref: to GF Manufactured food list. I use this little book always and carry around a tattered one in my handbook
- First thing is to educate doctors. I have found worse than useless. However you will only be addressing the few lucky ones that have been diagnosed. It is a very debilitating disease with many symptoms. CD is thought of as a negative, whereas it really is a positive. We are so lucky that we cannot eat all the rubbish that westerners eat. What we eat is healthy food on the whole. Re: presentation- tables are often easier to follow or bullets with short precise sentences. Pages for photocopying to give to school friends restaurants etc. A page with non-GF pharmaceuticals- a real trap. A page for showing friends/relatives/others with a simple clear statement: Name is not fussy. He/she has an autoimmune disease which some people call an allergy, its not- its Coeliac Disease. Gluten, which is wheat, rye, barley and oats, is poison to this person so it is essential that they eat GF food. Please ask for more information from them or their carers if you need help supplying food for them
- Better name is coeliac allergy. CD is not a disease, sickness. It's a condition or an allergy. People with CD or on a GF diet are not sick and are not patients
- Keep it simple, keep it positive and include recipes for things that people would normally eat. How to make stocks, hints on gluten free flour usage. I always use baking paper/gladwrap because it sticks to everything!

- A comprehensive list of resources e.g. a pack when you join the Coeliac Society. Yellow Pages guide to GF restaurants. An index more extensive. I am 12 years so I find it hard to locate vegemite for example
- Concise information with attractive sections/ tabs for easy to find info
- Thank you for doing this research. I am really glad of your interest. I am extremely grateful to the Coeliac Society for the help got when I was first diagnosed, and they produce an awesome quarterly magazine. Without them, I would be ignorant of many things and I don't believe the medical profession has any resources to help. So the more research, the more headlines, the better. If I can assist you in another way please let me know
- I was overwhelmed when the boys were diagnosed- we had them on rice crackers until I could figure out what to feed them! Some of the foods listed in the shopping guide still made them sick (e.g. Skippy cornflakes). Some experiences like this and reassurances that things will get better would have been good to read about. i.e. others experiences in the manual
- List products i.e. Yoghurts altogether no matter what type, baked beans etc. List of common products
- Sorry I haven't been more helpful
- Bigger darker font
- How to change everyday meals - i.e. beef stroganoff, cheese sauce (i.e. use Edmonds cornflour) took ages to learn this one. I use to make paste with flour and try to add milk. No way now
- As fairly newly diagnosed Coeliac all info provided has been of help and still at learning curve phase so soaking up everything and don't feel "experiences" enough as yet to provide informed comment

- Double check with any airline you are travelling overseas with that your special request is noted and check it again when delivered to you. If the airline changes your flight on route, check the changed flight has taken note of your meal request
- I have answered questions based on "handbook" meaning Manufactured Food list booklet. When not at home, lunch and breakfast are more difficult to find than dinner
- A handbook is really only needed when you are first diagnosed. Keep food fresh and simple - continually pester your local café and build a relationship with them and they will eventually make the effort to make some gluten free food rather than "pies", "pies" and more "pies". I don't like the term 'gluten free diet' it sounds like a weight loss programme rather than a prescription for health
- Contents page, index etc Different sections in different colours i.e. recipes, medical info
- Definitely join the Coeliac Society. The biggest problem for Coeliac's is good bread recipes. I have one, which toasts well, freezes well. I have taken out of the freezer after 6 months and it was still good. Doesn't crumble. I got it from the CS magazine. But have changed it slightly. I will enclose a copy for you
- As I have been diagnosed for over 30 years hard to remember how I felt at the time - but the society was marvellous to call on
- The importance of sticking to the diet, alternatives, places to eat out
- Need pictures to make easy to understand, because I don't read very well, because I am deaf
- Teaching how to recognise food additives is the key - then you can shop without a handbook. It is amazing once you start reading what's in food - you find all sorts that you start avoiding and not just because of gluten!

- Stress to newly diagnosed patients that this is one of the very few diseases you can get that can be treated totally with diet - and no medication. I've never felt better!
- The recent introduction of Home to Hospital programme for prescriptions in Nelson has been fantastic and made ordering flour and pasta so easy
- Making sure user friendly for others family members (spouse) so they can be supportive and adapt as well
- It would be really useful to have a photocopyable page giving detailed instructions for restaurants or hosts as how to ensure food is gluten free. i.e. chopping boards, deep fryers, and utensils. Also the use of soy sauce etc and 'a little bit won't hurt'. Also it would be great to have a handbook for children for them to take to school etc. where coeliac disease is explained in age appropriate language and illustrated
- Pharmaceutical info would be handy
- I found the folder and information very useful when I started out. Now I only refer to the Manufactured food update
- Pictures of the food/labels/packaging

## **Appendix F**

Interview transcripts

## Interview 1

**I1 = Interviewee 1**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I1, thanks for taking the time to do this interview. If you could start by just telling me about who it was that was diagnosed and when and what the procedure was?

I1: OK. Well her name's [Name], and she turns three in three weeks time, but she was diagnosed back in May I think it was. Um, but what kinda happened in terms of the background was for the past 12 months she looked like she was losing weight – everyone kept saying 'gosh she's getting skinny', 'gosh she's getting skinny' and then she had this huge stomach and it was bloated and tight, and it looked like you could get a pin and sort of pop it. Umm, but the rest of her was sort of dwindling away. Um, so I went to the doctor with her for a bug for a bronchitis type bug not for her stomach at all – and we saw a different GP – not our normal GP- and they were the ones that said "Ohhh, is her stomach always like that?" and I said "well, yeh – it is", and he said "Oh well, it's probably nothing, but I think you should go and have an ultra sound because if it was my daughter I'd want to check out it was all OK". He couldn't feel anything and dada da.

So then I think it was the next week we went for an ultra sound and they thought they had found this other condition called 'Interception' which is where the bowel telescopes in on itself. But generally that's an acute problem, like the child ends up in heaps of pain, it's all a bit of an emergency, which

was nothing of what the circumstances were. But that led us to seeing a specialist in a hurry rather than having to wait a few weeks for an appointment. So we saw a specialist that afternoon, um and then he sent us off to Starship, um and then they re-did the ultra-sound and then said, “Ohh, no, it’s not Interception” Ha! But we stayed the night because they agreed she was showing signs of malnourishment and um, had obviously a big stomach, um, and they weren’t going to let us go until they had worked that out.

And then the next day she was actually – I stayed a couple of days because my baby was crook at the time too – but um, we were discharged with Ella and just followed up through the GP who had no idea what to do next because he was like “well they didn’t find anything”, so then we saw a paediatric specialist who just deals with kids and he checked her out and said “there is enough evidence to suggest she has a bowel condition like Coeliac Disease”. So he sent us off to a gastro paediatric gastroenterologist who then agreed there was enough evidence to go ahead and do a biopsy. So we did. Did the biopsy and it came back positive. So that’s the diagnosis!

R: Wow

I1: It didn’t actually – from what I’ve read- some people take you know, ages, years even to be diagnosed. But in the scheme of things it was only- once we started the ball rolling- it was only a couple of months with the investigations and then, yeh, she was diagnosed.

R: So what happened after she was diagnosed?

I1: Umm, what was the first thing that we did? I think the first thing was that we just went back to the specialist, and he gave us a better description of what Coeliacs disease was. He then referred us to

a dietician. Um, but I think that...that took ages....I dunno, like six weeks or something like that to get an appointment. So it was quite a long – I remember there was quite a long time between being told “yes she’s got this” and to the point where I was going to see someone who was gonna tell me how to feed her properly.

So I did, in that time, because everything that you feed them from the day you get told everything you’re feeding them you’re thinking ‘Oh my God, this is making it worse’ so I did my own research, and I joined the Coeliac Society that day, umm and looked on their website, I also just did other searches on the web as well. And, then I spoke to – left a message on the Coeliac answering machine then a lady rang me back, and put me onto- I think was it [name]? [Name], the Northshore lady?

R: yeh

I1: She rang me back and she was really good and gave me information, and then she sent me a letter with cookbooks and things to borrow and if I liked them, obviously, I could come in and buy them. So slowly I sort of- by the time I got to the dietician I kind-of knew. Yeh, what she told me was only pretty much what I already knew, but a couple of extra things with regards to ingredients to watch out for. Soo...

R: Did the dietician give you any material?

I1: Yes. She gave me a booklet, like an A4 booklet that outlined what Coeliac Disease was, but a lot of the booklet was about these five categories which was about products that contained – absolutely contained gluten, products which had very low traces of gluten, products that um, you know it had the five stages, so you could see very clearly which products

to stay away from and which products you could feed. So that was really good...cause some of them like malts and things like that, that I wasn't very familiar with. So that was quite good.

R: OK.

I1: So but I haven't really read it in depth because I actually lent it to my Mum because I had all this other stuff as well, and my Mum was sort of like 'well, I want to read something' so I gave her that, and I haven't had it back yet. So I haven't actually read it in huge detail. But it was just an A4 photocopied sort of handout. I could get it for you if you wanted to see it.

R: Thanks, but it's just good to know what...so it was just photocopied information...

I1: Yeh, like a whole heap of these sorts of papers (refers to the current Coeliac Society handbook). It wasn't a book as such.

R: So is your daughter at daycare?

I1: She's at preschool

R: Preschool...and how's that going for her?

I1: Well she only goes for three hours...for two sessions, so they don't actually have lunch....which is good. But they do have morning tea, and it's usually a piece of fruit and a biscuit, so she has a set lunchbox that I take her own equivalent biscuit or a muesli bar – whatever we've got...and give it to the teachers every morning. And she knows – like I told her she's not allowed what the other kids are having – unless its the fruit. And even when like they have birthday parties they often do like a lolly-pop, they wait until the end of the session, until I arrive, until

they give her anything to make sure it's alright. So actually it's worked out really well.

R: That's good. So as a parent, how did you find just trying to figure out everything for feeding your child?

I1: It's just heaps of work! Um, I think just because I've also got a baby – like if it was just me and Ella, I'd have more time. She's at that age where she is off at preschool and I have got time, but now that I've got a baby, you know there's heaps going on with that as well. So there's not much I find that is ready-to-go food. That a lot of it you have to make yourself. Or things like lunches and stuff are a tricky one, you can't just whip into a bakery and grab a filled roll when you're in a hurry somewhere, and if you're out and about you've always got to have your lunch box for her with all the stuff in it. And she had sort of got to the age where I could send her off to my Mum's, or my in laws, for the day or the night and not have to provide anything, but now I have to go back to making sure I've cooked a meal for her because I can't expect them to um, cook gluten free because they don't have all the right ingredients, and they aren't 100% familiar with all the little bits that can slip through.

R: So you sort of feel that you've got to keep ...

I1: (interjects) it's just heaps more work yeh. – At the moment – cause it's only new for us – it's only been, what? Three months? And I'm still waiting, I've got the - I bought the cookbooks that the Coeliac Society lent me and I've just ordered some more – just trying to keep things different all the time. So I'm still trying to learn what sort of things I can make and freeze.

There was a book that the Coeliac Society gave me that I ended up bringing back, they wanted some

feedback on it in terms of children.

R: Oh, OK

I1: A new book...and Ella loved being read it, but I think she was almost a little bit too young to truly understand some of it. Like she talks like she says 'gluten free' but I don't think she really registers what that really means. Like she doesn't constantly say 'Can I have this?' 'Has it got gluten in it?', she doesn't check it out beforehand...she's not quite there yet, cause it's new, and she's only just coming up three. But, for someone that was like four, I think that book would be perfect.

R: Is there anything you can think of as far as educating your family, if she was to go over and stay there?

I1: Yeh, I think like, cause the survey that you sent out, I think I wrote on there that folder you get when you join the Coeliac Society is cool but you almost need something little, not the huge bulk of the folder, but something little like a quick summary page or a couple of pages to give – and you need two or three copies – to give to the in laws and the people that your children stay with often.

(At this point a Coeliac Society volunteer who says that is already in the folder interrupts the interview... but they are referring to something different to what I1 is describing).

I1: It's probably in there is it? I haven't even seen it? But how much information is on there? (She reads the information that the volunteer gives her).

I1: Yeh, I think cause like my mum was like 'I need to know everything – in a quick...'. Well you know the little database books? They're really good.

Volunteer: Cause you can get that off the internet as well and print it off..

I1: Yeh, cause I found that really good. But you do have to be careful cause a couple of things I have found that are in the book, and suddenly I think – like Pascals Marshmallows for instance – I think they’ve just changed their recipe. And so, you know, I’d read the little book, told my mum a whole heap of products “I’m really surprised these don’t have gluten in them” Mum goes out and buys them all and suddenly its changed...and I’m like “no no no you can’t give that to her anymore”. So I think constantly as much as I’m learning and trying to update myself, you’ve got to repeat it to everyone else you know- cause they tend to buy a bag and lets face its gonna last about six moths with the number of times she goes there. So you’re almost better to say don’t buy anything I’ll just provide you with, you know when I make gluten free muffins, I freeze 1/2 of them and then split up the other 1/2 to give to the family to put in their freezers...and so um, things like that.

But they want to be independent and they want to feel I can drop [Name] off and they can make her something that’s gluten free, but...

I mean the dietician even said things to us like you know you have to buy a new toaster that’s got two separate slices for her and two separate for us, and I thought parents can’t be expected to be doing that. You can expect them to be going toasters...but anyway.... Getting back to the booklet!

That sheet that you showed me was good, but for my Mum anyway, she sort of felt she wanted to do – she felt she needed more information- and probably one of those little M – Manufacturing Food Database things would be quite handy to have.

R: What sort of information do you think she needs

to know?

I1: Um, to get her head around the condition she wanted a brief description of what it is and what it has done to the bowel already, and how long it was going to take to recover and things. And, the second part I guess was everyday foods, like I think it says the foods to avoid – but kinda what you can have – opposed to what – I mean it's good to know what to avoid as well, but some ideas for lunches for example.

(At this point a Coeliac Society volunteer interrupts the interview again...and hands I1 a piece of paper)

I1: (I1 addresses the volunteer) Oh yeh. OK. This is ...there is probably all this stuff around...Oh yeh.

(The volunteer misses the point again, so I1 dismisses the information and turns back to the interview).

I1: Like the dietician when I said to her 'lunches is a real tricky one', she got out a piece of paper and handwrote just a whole list of ideas that she's had with other children – like Salami Sticks – and you know, just a whole list of things that you could just whip into a supermarket and just grab rather than having to make ...something like that.

R: That's a good idea...

I1: ...for family would be quite....for children anyway. I mean it's different when you're an adult, cause you learn it yourself, and you don't ever get 'dropped off' to be babysat do you? You're always on your own and whereas...it's only gonna get harder I suppose with school, because a lot of the lunch ideas I do are heaty-up type of things, like leftovers and stuff, whereas at school in the tuck shop and stuff...I can't see how that's going to work! I'll work on that later!!

One more thing....like these types of products (refers to the brochure the volunteer gave her) there's probably always brochures that go with it but you actually end up with swarms of stuff.

R: It can be really overwhelming...and it just ends up getting filed away...

I1: ...and you don't go back to it. I found that a little bit about my...I mean I thought [Name] was fantastic on the phone for a while, and she was mentioning all these great products, and I remember sitting...it was at nighttime...and I'd just found out [Name] had it and I thought 'I don't even know these brands! I need a pen!'...you know, and it just flowed off her tongue, but after the conversation I thought 'Oh! I can't even remember any of those things!' (laughs). So you sort of go back to the beginning again and seek it out yourself and I'm sure if I rang her again now, like three months later, I'd be like 'well I've tried that one and OK now...you know...it would make more sense, cause it's sort of the same language. Whereas before, with all these brands...I'd never even heard of them before.

R: So, feedback from people is that, talking to people is really important as far as gathering information...

I1: Definitely. Like, where to go. That's what I ultimately needed at the beginning...like 'Where do I buy this stuff from?'...and then, the whole, like, Disability Allowance thing that was a bit eerie-fairy I got the impression that some people get it and some people don't get it, and it depended on who you sit with at the IRD...I mean Work & Income!...and stuff like that. And I thought well, that's a bit odd, surely if you've got it...the disease, then you should qualify irrespective of who you are – and my GP didn't know much about it either – and the prescription forms

for the bread – and yeh, you’ve kinda got to keep plugging away at it, cause for people, for them, it just gets lost and it’s not important – you know.

R: Thanks I<sub>1</sub>, that should be about it. You’ve given me loads of information, and I thank you for your time.

I<sub>1</sub>: Well, hope I could be of help.

## Interview 2

**I2 = Interviewee 2**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I2, thanks for taking the time to do this interview. If you could start by just telling me about who it was that was diagnosed and when and what the procedure was?

I2: Ok. I've been asked in today to talk about my son [Name], and he's three. He just turned three in May, and he was diagnosed with Coeliac Disease – well he had a biopsy on the 5th May, 4th May – so he's been gluten free for about two months now – it's July the 5th as you just said. And, about August last year he had a bout of pneumonia and ever since then he just didn't come right. He was just frail, and he just never recovered properly. Each month he'd have vomiting – he'd just vomit for no reason – then he's be fine, and that sort of carried on for about six weeks, just about to the day he'd vomit every six weeks, then be fine. Then month by month he got worse, and he had distended tummy...then six months after his pneumonia he started getting tummy cramps, so he's just be crying in pain, but it only usually be in the afternoons, then he'd vomit and he'd be fine.

So we took he to the GP several times, and they kept saying, “well it's normal for kids to get sore tummy's” and I was saying, “well it's not normal for them to vomit and things” and I knew something wasn't quite right, so from about 10 months he was so unwell, and he kept on getting worse and worse, so we went to the specialist, who actually diagnosed him with ‘Abdominal Migraine’, and they put him on

medication for that, and they wanted him to be on that for three months but after six weeks there was no improvement, and he was getting these cramps worse, and he was getting nausea, he was spending almost every afternoon with a vomit bowl, sitting on the couch. So we went back to my GP and said, “look, this medication isn’t working”, and I just happened to mention that I had a first cousin with Coeliac Disease, and so did my husband, so they did tests for Coeliac Disease and they were strongly positive. So about a month later he had the biopsy, which obviously came back positive with severe tissue damage to the small intestine. Um, so yeh, he’s been gluten free now for about six – eight weeks now and he’s been – probably took a good three or four weeks before I started noticing, we started noticing any difference, but he’s come out of his shell, he’s got so much more energy, he’s bouncing off the walls, he’s um, put on about two kg’s in two months. When I look back at photos’ - other people starting seeing he was going really pale and things – but I guess because I am with him all the time you don’t notice it as much, but looking back at photo’s just before he was diagnosed he looked shocking – pale and thin – and yeh, he’s just come in leaps and bounds – it’s just amazing the difference in him. Eh [Name]?

Son: yeh!

R: So your husband is Coeliac as well?

I2: No, no, my husband’s first cousin – and my first cousin has Coeliac Disease.

R: Oh right

I2: So yeh!! But I think if I hadn’t mentioned that, I think we’d probably still be in the dark. And luckily, I’m a nurse, and I sort of knew a bit about Coeliacs, so I thought I might mention it. But I sort of think

that if I hadn't mentioned it, we still wouldn't have found out.

R: So how have you adjusted to the diet?

I2: Well at first it was a huge shock – because we knew something was wrong all along – but still, when your child is sick – you know it was a big shock. But now that I know what's wrong with him, obviously it's manageable, and it's not life threatening, and we're fitting into it really well actually. It's actually a lot easier now than I thought it would be. I mean, there's obviously so many gluten free products on the market, and I don't know – I've done a lot of research on the internet and the Coeliac Society have been great, and I keep running into people, like the bakery the other day, I happened to ask if they did any gluten free bread, and this lady beside me said "Oh..is it ok if" and I wanted to look at the ingredients and she said "is it Ok if I have a look as well" and I said "my son's got Coeliac Disease" and she said "Oh so has my son!". And you know, I've run into quite a few – and since, I've been in contact by phone a few times and she's offered to give me recipes and things, and we seem to run into quite a few people who know someone with gluten intolerance or Coeliac Disease. So I've been quite surprised with people coming out of the woodwork with – that I never knew.

R: So when [Name] was first diagnosed, what sort of resources were you given to help your understanding?

I2: To be honest, the GP and things, I seemed to know a lot more than them. I didn't feel they had the right information for me. But the paediatrician was great he obviously - well actually – in the first year, just before Nico was diagnosed, while we were in the interim of waiting for the biopsy, a friend of mine's mum has Coeliac Disease and she gave me,

before we knew he had Coeliac obviously, and she gave me a list of places like, that she got her food from i.e produce and...

Son: Mum Mum!

I2: Oh that's a beautiful picture...that's lovely poppet

I2: and um, yeh she gave me a few names of places I could get gluten free food and that was so helpful, and although I didn't go out and buy anything then, it was just so helpful to know and I don't know...I mean I got the big folder from the Coeliac Society, and um, just talking to people really.

R: Thanks, that's great...

I2: would you like to speak to [Name]? ...[Name]... Now this is [Name], and [Name] you tell R how old you are.

Son: Three

I2: Good boy. And what have you got wrong with your tummy?

Son: Sore.

I2: But, what...you've got Coeliac Disease haven't you? Can you say that?

Son: cee -llee-acks diseze

I2: And what does that mean? You tell R it means you can't eat gluten doesn't it?

Son: No

I2: And it mean you have special food don't you? You tell R what you like eating?

Son: um, gluten free

I2: Gluten free that's right!

R: gluten free? And is that yummy?

Son: Yep! You talking to camera now.

I2: You talk to the camera, you tell the camera what sort of gluten free food you like. You tell it what you just had for morning tea. You had some chick pea chips didn't you?

Son: Chippy chips

I2: Have you tried those? They're really nice! Um, so yeh, [Name] actually adjusted really well, amazingly well for his age, like I say, he's only just turned three. He goes to day-care three times a week, and he takes his own special food. And if anyone offers him food – well people know not to generally – if people do, he always asks if it's gluten free, and whenever I give him food he asks if it's gluten free and say if we're all eating something that's not gluten free then sometime he quite likes to smell it and – but he knows he's not allowed it. He's been amazing in understanding that! And it still blows me away how intelligent they can be at this age. I guess cause he knows how sick gluten makes him.

R: Did it make you feel sick before [Name], did gluten give you a sore tummy?

I2: What did the gluten do to your tummy?

Son: Make it sick

I2: It made you sick a lot didn't it?

I2: Yeh, so he's adjusted really well. He's a really good

eater anyway, he loves fruit and veges, he eats pretty much anything. And we've had to see a dietician, which I would definitely recommend, she's been fantastic on helping us get his diet on track and things... and just giving us some ideas. Because when you're trying to feed someone else, I mean, I'm totally responsible obviously. And you know, at such a young age, you don't want to get anything wrong obviously, and yeh.

R: What was the hardest part you found? For instance was it food labelling? Or something else?

I2: Well, I still find it hard. So I stick to things I know, obviously I pick a lot of things that actually say 'gluten free' and I do use the Manufactured Food Database book. But I still get a little confused – like, I have read one of Dr. Rodney Ford's book and it sort of says things with certain numbers on them, may be wheat based – then I read the Manufactured Food Database and some things I've got in the fridge that I've been feeding him, it says in the Manufactured Food Database that he can have, but then it says in Rodney Fords book that he .....so you know, I've been doing a lot of phone calls and things to try and establish what to refer to, because you know it can be so confusing when you are told different things.

But I guess one of the things I find hard too is, not that it's a problem, but it's obviously a lot more expensive to buy gluten free foods, so if people don't really know this, you can actually apply for a disability allowance, so we're getting a disability allowance for [Name], and it's not means tested.

R: That's good to know.

I2: yeh, so I think it's fantastic. I think it's a Childs one obviously...I don't know...I think it goes until he's 16.

Son: Mummy!! Mummy!

I2: So I definitely recommend people look into that, because you're Paediatrician has to fill in a whole lot of details...

Son: Excuse me Mummy...

I2: Yes, darling

Son: (points to some biscuits on the table) That's not got gluten in it

I2: Oh good!

Son: Gluten Free!!

R: Well, thank you [Name] and I2 for speaking to me today. I really appreciate your time, and input into the research. I'll get back to you with the results.

I2: No problem. It was good.

## Interview 3

**I3 = Interviewee 3**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I3, thanks for taking the time to do this interview. If you could start by just telling me about who you are and when you were diagnosed, and what happened?

I3: Good afternoon, I'm [Name], I was diagnosed about five years ago with Coeliac Disease and I'd never heard of it. At four years of age, that would have been in 1942 I had terrible spinal meningitis and I was in hospital for three weeks, death bed for four days...I had all my funeral planned, and my days through primary school were um just sheer hell. I remember when I was in standard four, a young lassie from standard one gave me a hell of a thrashing and I had no strength to come back from it. Many a time I'd leave school midday and just go home and sleep and sleep, and well, we always thought it was meningitis, and the doctors were saying, 'no, meningitis shouldn't do that'.

And as I got into high school I joined a brass band. One year I was doing about 17 different rehearsals a week, I felt my chest expanding – I was playing a big brass. And I thought I had grown out of it, but I also did tramping, Mountain climbing, and I often used to wonder why, people I would go tramping with would go half way through the night and party, and I'd have to go to sleep.

Now, both my parents were diabetics, and consequently from that the doctors I was going to kept

a pretty good eye on me, and I've had more blood checks than a porcupine has quills. When I first started getting them I used to faint or collapse like any young men do, but I've had that many I just sit there watching it all draw off now. And ah, one day, about five years ago, when I was 63, the doctor called me in after one check and I said "I suppose you're gonna tell me I'm a diabetic" and he said "no I'm not" and I said "what's the problem" and he said "you've got no iron in your blood", and I said "well OK, what does that mean?"....and he said "well..." I don't know what he was talking about...a million mercuries or something like that. He said "a man has got anywhere from 20 - 200 is fine. If he's got anything over that he won't walk past a magnet. But in your case you are under 20". And I said "what am I?" and he said "you're under 9 - you're dangerously low". And I said "what can we do about it?" and he said "I'm going to find out why". So more checks - more blood checks - a colonoscopy proved nothing. Then had - what do you call it, a coloscopy? And after that I went and had a cuppa tea and a biscuit and the doctor gave me a gorgeous coloured photograph of my duodenum - this gorgeous pink colour and it was like I was looking down the barrel of a brass instrument, and I know what I'm talking about because I used to play one. And ah, it was a lovely pink shade with little white spots all over it and across the top of the photograph he had written this word 'Co - e - liac', which didn't mean a thing to me, I had never heard of it. So a few days later the doctor rings up and says I want to see you as soon as possible, and I thought, 'ah well, maybe we've got something'. Went around and saw him, and he said "you've got Coeliac Disease", and I said "OK what does that mean?" and he said "you've got to give up everything to do with wheat, oats, barley and rye". I was a bit brassed off. He said "can you do that" and I said "well, rye, well I'm fond of me drop of scotch and you gonna tell me to give that up" and he said "yeh".

So when me daughter found out the head office of the society was in Northcoate at the time, so I went in there and Carol approached me and she said “what do you want?” and I said “I’ve come to join up” and she said “you can’t” and I said “why not” and she said “you’re not a Coeliac”, and I said “well according to the doctor I am”. She said “you can’t! – you’re not a Coeliac!” she said “you’re not the right shape” and I said, “well I’d like to join up anyway”. So I joined up and about a fortnight or so later I got a phone call from the president. She welcomed me to the society and she said is there anything you want to know, and I said “I’m highly brassed off” and she said “why?” and I said “I’m told I’m not allowed to drink scotch” and she said “why?” and I said “well scotch comes from rye and rye is one of the things I have to give up”, and she said ‘well you can drink all the scotch you like” and I said “you just saved my life – because I don’t drink anything else, and scotch is the one alcoholic beverage that doesn’t contain sugar...and I’m rather partial to it – it’s a drop of blood from me ancestors”.

So anyway, I started reading all the labels, and my wife started reading all the labels with me, and we’ve come to the stuff that we can buy and can’t buy. There’s stuff that we don’t even bother reading the labels on anymore cause we know what’s in them. When we do the shopping me wife knows what to get. And one Christmas day, me daughter had made a Christmas cake and she thought well I’m going to have a piece of it, and I know jolly well I’m going to suffer after it – but it was a gluten free cake, and about two or three days later she said “I haven’t suffered from eating that cake” and I said “what do you mean?” and she said “well normally after eating something like that I’m pretty crook”, and she doesn’t eat bread, and I said, “well don’t you think you should go get a check and take the family with you”. So, she said “not a bad idea”, and took the

family, same doctor as I go to and both she, and my granddaughter here, [Name], have both been diagnosed with Coeliac Disease.

Now, if I've got to have something, I don't think Coeliac's is a bad thing to have – if you look after your diet you're fine. I realise now, looking back, that I was probably born with it. Because as soon as I went off my mother's milk I was very sick right through to... I just had no energy what-so-ever, and this is the thing apparently that zaps your energy. As you grow older you grow out of it, but then it comes back in later life. Now, I'm pleased that I discovered it, because I'm approaching 70 right now, ah mid life, and when I get older I don't think it's coming back, but if I look after my diet it's fine. So there's no problems. That's it.

R: Thank you. (Referring to his granddaughter) So, [Name], when were you diagnosed?

Granddaughter: Late last year

R: and do you feel better now?

Granddaughter: yep

R: How do you find being on the diet when you are at school and taking lunches and things like that?

Granddaughter: It's OK, but like, when all my friends have cakes and things like that, they come around and start teasing me and it's like – and I say “stop it” and they just won't stop it. Mrs [Name], she's the one who enrolled me my sister, I told her, and she comes up to my friends and just says “stop it” and it's just like...but now that most of my friends know I'm a coeliac they've stopped doing it, but like, one of friends, she comes up to me, and she's like “oh oh noodles...do you want some?” and I'm like “no I can't

eat them”. But it’s just like, really annoying. I’m like, “will you just stop that already”.

R: ..but it’s lucky you know now though rather than having to go through...

I3: Well that’s right. Since I’ve had it I’ve started baking. I wouldn’t even know how to fry and egg before, and I’ve started baking now and I’m rather enjoying it. I cook a lot of stuff that I like, see. And if you look around and OK...it may be more expensive...but there are a lot of other things you could have too that are a jolly sight worse than Coeliac Disease. As a taxi driver I used to run the dialysis patients in and out of hospital – three times a week they go in for a couple of hours a day, and they’re there to have their blood cleansed by a machine – kidneys and liver long since given up. And I think, well, I’m much better off than them. And if you look after your diet, good health is yours.

R: ...and you feel better since you were diagnosed?

I3: Oh yes! Yes! The doctor said to me I’d have much more strength. To a degree, getting older you find you lose a lot of...you can’t go so well...but I find I can go through the day pottering around the garden now, whereas I used to go out to the garden, potter around for about an hour and go inside and have a sleep. But I can go the day now...I still have me sleep, but I can go the day now.

R: Siesta! So what was the year that you were diagnosed?

I3: What was it now? It was about 2002.

R: 2002, right, and did they refer you to a dietician as well?

I3: Sorry?

R: Did your doctor refer you to a dietician?

I3: No! He just told me to give up all gluten food. The dietician I've got is my wife, and I don't think I could have a better dietician! She wants me around a little bit longer....

R: So, how did your wife go about educating herself about what foods contained gluten?

I3: Well, a lot of stuff she has is also gluten free – it's just a matter of expedience – but um, she makes sure she has gluten foods at least once a day - crumpet or a bit of toast for breakfast. Wheat in toast for breakfast. But that might be her lot. But when we go out, most of the restaurants we go out to now know that I am a Coeliac and they prepare for me.

R: would you have any advice for people trying to eat out?

I3: Yes! Go out! Don't stop going out! The society will have a card for you – take that card and show it to the waiter, and tell him what you want, and it's up to him to go out to the chef. And the chef will tell you what you can and can't have. As the president said to me...you will know within six hours that you've eaten something you can't have.

R: Has that happened to you?

I3: Never! No. I find most of the places are sympathetic and only too helpful – only too glad to help.

R: So you tell them up front – straight away

I3: Yes, you must tell them up front, and if you are suspicious about anything – forget it! Don't touch it.

If not, well suffering could be yours for two to three days after, and it's just not worth it.

R: Well, Thanks [Name] and [Name] for taking the time to do this interview. I really appreciate it.

I3: No problem.

## Interview 4

**I4 = Interviewee 4**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I4, thanks for taking time out of your day to meet me. Let's start by discussing when you first found out you had Coeliac Disease.

I4: It was during my travels. I had been in Asia. They thought I had a tropical disease and London had a tropical disease hospital, so I ended up in that. And in those days...and I never made the connection between the two, but they came out and said that I had 'tropical sprue' which is damage to the intestine and they said it had been caused by something – they didn't know what – some sort of food poisoning or whatever must have happened. And later on, about 10 – 15 years later when I had the Coeliac Disease diagnosed, I read more about it, and they said that sometimes it's called 'Coeliac Disease' or 'Coeliac Sprue' or called 'Non tropical Sprue' and then I made the connection between the two and then the specialist told me that the episode in 1980 was also the first significant onset of it. You know, it had hit me then, then I guess had eased off for a period of time. Although I was never fantastically; well...you could link back a series of things...and realise things were going wrong.

So what I now believe is that I had it about 20 – 25 – 27 years ago!, and it was misdiagnosed, just because people didn't know about it.

So I think just the sheer knowledge and awareness of the medical profession and the public is enormously

higher than what it was in the last two to three years. That's the impression I get.

R: How did you find the transition into a gluten free diet? Did you find it easy?

I4: Yeh, yeh. Umm...looking back at it, in the first year or two I'd have made a lot of mistakes food wise. Either because I got it wrong, or thinking that could have something or I might be able to have something and not. So I used to have this expression that 'something got through' – probably about half a dozen times a year. But now, I mean I take a pretty relaxed approach to it, but I wouldn't have had anything – I'm fairly sure I wouldn't have had any gluten for two to three years. Well, certainly not enough to affect me. Because in that time, as I've said to you before the interview, I've enjoyed a beer – I don't drink wheat beers, and I have recently worked out by checking on the Internet, that the things that have 'glucose syrup from wheat' I have those. So, a Mars bar, you eat a chocolate bar sometimes, so it had been saying previously 'glucose syrup' and I hadn't even been thinking what that was, but then about three years ago when Australian and New Zealand labelling got slightly better, this from wheat thing came out and I tested myself on that.

R: ...and you didn't react?

I4: No, it's not a problem. So, that was another one. So again, what I do first of all is go back on the internet, and someone there has gone back through and said - generally it's someone in Australia, and that's the place I listen to the most. I think that – the impression I get through the Coeliac Society and the view I hold is that Melbourne is the – Melbourne people are absolute top in the world in thinking about it and researching it, whatever. So I am pleased we live here rather than in the States.

I've travelled a lot in my work and when I'm in the States it's crazy! I don't know how Coeliac's get on there. They must live in fear.

R: Could you talk about travelling with Coeliac Disease?

I4: yeh well, Western countries, Australia...the restaurants...dinner is no problem because you can generally speak to, if you...

I've never had in 10 years or so ever had one dinner meal in a restaurant that went wrong, maybe two, and I realised it after two bites. Just the texture was wrong. So I generally find in New Zealand, Australia and in Canada and in the States in a better restaurant, they've got a better idea, but I haven't been to the UK since I've been diagnosed, but I imagine it's very good there too. Oh, South Africa, I've done a lot of work there and they were fine as well, you can get to speak to somebody and they probably know about it and by the time you speak to the chef, he knows what he's doing. If you have to actually ask to see a packet you can get to see the packet, if it's been packaged food. They're pretty good about that. And if in doubt, I have the simpler food or and it doesn't worry me. Better than eating it and it going wrong. And, I've travelled quite a lot in Asia, and there I do it by selecting foods that are probably right, and I probably take more of a risk, but on the whole the Chinese food and Asian food if they are using a starch is nearly always a potato starch or a tapioca starch and sometimes they say cornflour, and if you can finally get through to them and ask them if they have used wheat flour, they generally say 'Oh no, we would never use wheat flour' – so, I'm probably taking a bit more of a risk with Asian food – but – I eat fantastically well at dinners, and in a home situation my wife cooks superbly, and ah, we really, the only things – we just use rice flour for thickener and two types of pasta, and everything else is exactly the same.

I've gone through phases of making bread – I don't really bother anymore, and I go through phases of buying bread because I hang out for toast, so I really have very little bread. We make cookies – then again a mixture of rice flour and um, the baking mix. Generally about 1/2 and 1/2 and chuck it together. What else? The breads in New Zealand are garbage, despite every company here thinking they're doing it right, I'm yet to find a good bread...so if you want to make that feedback back to them! And there is a bread company in Melbourne, I work for a Melbourne company, and the bread there is fantastic – I've just forgotten the name – we've actually asked them if we can try and get it brought in here – they've got a great bread that you can get in Australia. I was eating it two days ago. But it lasts longer and toasts well- it's just a good bread. So, without exception all the New Zealand makers are way off the mark from what I've tasted.

So, um, I don't find travelling difficult! Ah, the only thing that bugs me is Air New Zealand – I travel on them so much, and most other airlines give you a pretty garbaggly but acceptable gluten free meal – and Air New Zealand, Trans Tasman – I don't mind saying this – because I have tried and tried with them to get them on their meal choice when they have a piece of chicken, and I say “don't put the bread crumbs on it”, but they just don't listen. But otherwise it's just not an issue. But I'm well informed, I guess that's one advantage I've got. I know what I'm doing. It must be harder for parents of young children, and they lose them out of their sight and kids make their own decisions – I accept it's harder – but for an adult, luckily I don't have a dairy issue, I don't have any other issues going on – it's just the gluten. It's absolutely easy – I think.

R: So you basically informed yourself through your dietician and the Internet?

I4: One meeting with the dietician and everything else is self-informed – Internet.

My wife used that food book thing for a while, but she wouldn't have looked at that for five, six, seven years I think.

So I think that that resource, and the handbook resource are probably really helpful for people in the first two or three years. My recollection was that I was still getting it wrong after two to three years. So I think there is a period of time, possibly, certainly two to three years and maybe as long as five years that would take a settling down and a normalising process to go on, but now I don't think about it.

And I don't have any embarrassment about checking, you know, reminding people that we're, you know, friends and family that might just forget. We remind them in advance if we are going to go out for dinner with them.

R: That seems to be an issue some people have – that they feel embarrassed at restaurants to ask...

I4: WELL...I'll blatantly ask! It's interesting, if I'm travelling somewhere with someone they get more concerned than I do. And if they think that the dialogue between me and a waiting person – a waiter – is not clear enough – the other person will burst in even more strenuously than I will. And you know, I'll sometime jokingly say "You've got to get this right otherwise I'll die" and focus a bit of attention – just joking. No, I can't see, it doesn't even cross my mind to be embarrassed asking a waiter, because it's absolutely critical. They should know what's in the food. Um, you go to restaurants that proudly announce that they have got gluten free dishes, which is OK, but probably about half the rest of them have gluten free as well – or can be made gluten free. So you can work out most of the time what's going on. Fortunately I don't ever have to eat couscous again in my

life, which is great! I don't have to wear it down my shirt, and all of that sort of stuff, so you can work it out from the menu pretty much.

But, ah, I just can't see what anyone would feel embarrassed. I guess people could be – but they should get over that pretty fast.

R: So, what sort of advice could you give to a person who has just recently been diagnosed as a Coeliac?

I4: Well that's interesting. It probably does take a bit of time to get used to it. And if – and again, I'm probably quite fortunate – I worked out fairly early that I was so much healthier all round. Just everything got better than it had been for most of my adult life. I've always seen it as a positive thing rather than a negative thing – it was never a problem. And now the things I can't eat, I just don't miss them at all. I don't hanker for them, get tempted one little bit – because the positive side of feeling well is so much better than some sense that I'm missing out on some piece of food. And so, I guess that's the best thing to see it as a good thing happening in your life.

And I think that's also evidenced because you hear so many people making choices to say they want to be wheat free, and you say, "well what do you mean by that?" and they say "well, a few times a year I go without bread for a week". ...Okkk... And they feel better from it. And somewhere else I read they say that gluten is a toxin, and it's potentially toxic to everybody but most peoples immune system have the ability to deal with that toxin. So if you start with the view point by saying "right so, gluten (primarily from wheat of course) is actually potentially poisonous to your system, then is that a good thing to have?".

I think we were already very fortunate as a family because pretty much every meal has got fresh vegeta-

bles in it, the meat we have is fresh meat – or frozen – most of the time if we making a sauce or a curry it was made right from the natural foods anyway. I mean we don't go overboard about it – but we're not using packeted food – very much. We're not having take-a-way's. I haven't had to have McDonalds for 11 years! Which is fantastic. So those things weren't an issue. They weren't part of our lives anyway.

I just think – it never struck me as a problem – I never liked the word 'Coeliac Disease' I think it's something – whether that can be worked on – it is a condition. It's an allergy, but it's a condition. The idea that it was a disease had never crossed my mind. It seems the wrong word. I know they say 'Coeliac' but...

So, if it's a subtle thing over time – if the society and people – just don't refer to it as a disease then, make it very much more open. That's my view of it. It's positive.

R: In front of you is the handbook the Coeliac Society provides new members. Can you comment about the information they provide you, and if it benefits you?

I4: I enjoy the societies magazine, and probably the main part I read is the scientific parts with the clinicians? Or whatever it is that they are doing with research, because, although I'm not hanging out for a cure, it does start to seem to me that there is something relatively close that will deal with it. And whether or not I bother to test it out or not... And the bit I probably don't dwell on are all the stories of people travelling off overseas with suitcases of food because it's never crossed my mind to do that. I've never taken anything. I mean if we go away for a weekend we'll take food that is reasonably suitable for me...but um...So it's never crossed my mind to dwell on the issue of thinking that I won't get food

there. And I work out, you know if I'm going to a French speaking place – I think the word is 'blé' – so I work out how to say 'wheat' and those things before I go somewhere if I can... to explain has it got those things in it – I learn a phrase.

So the magazine to me, is...I don't know...I mightn't be the right person to judge it by, but I look a little bit at the recipes, I don't look at all the travel bits, I'm very interested in the scientific, clinical side of it, and the awareness creation side of it.

But I think the society is doing a good job. Though I suspect it's a lot more grass-roots support because I've never gone along to the coffee things at all – maybe that's a bit of a lack of support for the society – but I recognise that there's people there that feel that that sense of support – meeting other people in those sort of situations – is really important, whereas that's never worried me at all.

I like recognition. Café places where you go in and on the counter they have a gluten free muffin or a gluten free piece of cake – I will always buy it, so they know to keep on providing it. And I always thank them for putting it in too, because I think that's the most important thing. Because I know they are going out of their way to take the risk to make a piece of almond flour cake – or whatever it is – orange cake – it always seems to be orange cake – and so they need support. So I always, even though its more expensive, will buy it, even if I don't eat it. I'd eat it.

So that's my bit.

R: Thanks so much [Name]! I'm sure this will be of use. Thank you for your time, and nice to meet you.

## Interview 5

**I5 = Interviewee 5**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I5, thanks for taking the time to do this interview. If you could start by just telling me about when it was that was diagnosed and the whole process involved?

I5: Well that was a long time ago – 19 years ago – and the health professionals at the time they didn't know anything, so we learnt about it together basically. I was my GP's first patients, and we had all the books out – and when I went to the gastroenterologist gentleman specialist at the hospital, I think I was one of his first too – I think I WAS his first too! So you know, it was a whole new learning curve for all of us, but everyone was quite happy to learn and me included. But there was no information out there really. I did join the Coeliac Society, which was great, but to be honest within about the next three I years I didn't belong anymore because the information that was sent out at the time was kinda scary and put me off! Then a friend said to me you're probably more likely to get run over by a car tomorrow anyway, you know. So I actually had a year off and I lost a bit of contact for a while there. But back in those days there wasn't any internet, it was very hard to get information. In fact, the only place I could find information was out of a nursing book at the Rotorua public library...and you know, it was more kinda their information, and the Coeliac Society did put out a handbook and to be honest I might even have that floating around, I'm not sure.

So it was very different to today, there wasn't really any support – so people today are a lot better off with the Internet, books and there's people out there to talk to and things like that.

R: How did you end up going to get diagnosed in the first place?

I5: Oh, I was very sick, and I changed doctors and he said I don't like what I read in your file could you come and see me, and when I was there I said "God, my stomach, I feel like I'm five months pregnant" and he went "Oh! Hang on a minute" so he got all his books out and wrote the name 'Coeliac' down and said "you look up in your book – what does your book say?" and we're reading our books together and it took 18 months of constant blood tests, and I went to the hospital and had I don't know how many vials of blood taken – they checked every vitamin and mineral in my body. Then I had to go and have zylos taken – I think it was called zylos – and they put it in one way and I had to spend all day and they took all my wee out and tested it. They stopped doing that about 10 years ago.

So, there was a change from thinking that my body was supposed to do as it's told, to suddenly having to stop and listen to your body – which you don't want to do when you're young really – and live between these lines, these invisible lines really don't you? So yeh. I can now say it's quite a learning curve really, it's just a little journey that you go on.

R: So for you, most of your research was through libraries mainly?

I5: I went to the library, yes. I didn't own a computer of course all those years ago, and the dietician I went to see at the hospital – she just told me what was wrong with me – and I didn't find her very helpful at

all, and then five years later I met another couple of people that had been to her and had similar experiences, so I never bothered with her again, because ah, we just didn't click. So um, in fact if anything she probably put me off, rather than help me.

So um, yes, it's been a long process, but you know, cause my new husband, we've now got step-children and his extended family, but everybody learns about Coeliac Disease – it's quite incredible. And I'm a person, I hate – I don't buy anything that doesn't have the ingredients written on the packet now. And I always encourage other people you know, and so when I go to other people's houses for tea I often forget to tell people – and people get quite cross with you – cause you live with it all the time, you kinda forget. And they go “well you didn't tell me!” and I go, “well it doesn't matter, I'm not here for the food” and I keep saying to myself “don't forget to tell people” Ha ha – cause people get cross!

R: Haha

I5: But it's neat, people say “well look I was at the supermarket and I noticed there was this (points to the 'Crossed Grain' logo) on the packets, and did you know you can get gluten free this” – and people take quite an interest. Whereas that was another problem years ago – you know my family thought that I was off on some fad, you know, even though I was very unwell at the time, and I was very thin – I was 7 stone something. People just thought “ah! She's off on some fad diet – nothing wrong with her really”. But you know if you had a broken arm, or if you were an amputee people would understand, whereas today everyone is quite accepting of it. Back then, it just wasn't accepted easily, and it took my family a long time – my extended family – and I had one friend and she rang up and said “come for tea” and she made an effort and went to the library

and found a recipe, and made stuffing out of rice, and I thought “wow – someone’s actually making an effort” – and she encouraged me actually to go and look for more cookbooks and things actually – there’s little inspiring things along the way that happen to you.

R: So how did you educate your family about what you had?

I5: Well I didn’t really, um, at all. It’s just taken them a really long time, it took them a very long time to get it I think, and I didn’t really educate them I think. Back originally too, you’d sit down and have some chocolate, which is OK, and they would be like “Oh, but you won’t have the bread for dinner – and you won’t have this and that”. You know, people just put all food and lumped it all together. So yeh, yeh. And my kids, like my son is now 20, my younger one, and he was 18 before he came home and said “Can we eat food like other people?” and I said “what do you mean? – can we eat food like other people”, “well yeah, we’ll start” – you know, and I thought well they know about it, and they’re aware of it, and because of that it’s made them a lot more accepting of other people, and other people’s problems, and illnesses and things, without them knowing – well they are boys – without them realising that that’s what they’re doing, but they’re um, it took them along time to click in and realise that we did eat slightly differently.

R: So your children don’t have Coeliac Disease?

I5: No, I’ve got one son and beer upsets his stomach terribly, and it’s a bit of a family joke if we have a get-together that Caleb will be sick tonight, he tends to do it inside peoples houses and their shoes and things like that! And I keep saying to

him, because you know when I was small my parents on a Saturday afternoon would have beer and lemonade – they used to call it a ‘Shandy’ - don’t know if you remember Shandy’s at all? And it used to drive me....you know every now and then I’d have a taste as a kid and my guts would swell up and explode, and he’s the same, he has a problem with beer – he probably has a problem with other things – but because the gluten in our family – you know they’ve been eating gluten free meals all their lives anyway, so if they do have a bit of a sensitivity it’s probably been kept to a minimum maybe – so – they should go for a bloodtest...

I worked in a hotel for five years, so everyone sort of knew, chefs always knew at staff dinners and things. Anytime someone came in, they’d be like “Oh! We already have someone here I’ll get her for you” you know “you’ve got to come talk to this lady, she’s a Coeliac”. It’s just amazing how everyone learns slowly. I mean it’s such an easy thing to accept and do these days, and it doesn’t have to be a problem. And when I was originally diagnosed – and it would be interesting to hear if others felt the same – the steps seemed to be very big steps, you know, and it took ages to get up them, but today, there is so much information, support and product – product was another thing you know – if I went out I used to just have plain meat and potatoes, and sometimes even that’s hard to get for you when you go out for dinner. Everyone accepts it now. It’s great.

R: If you were to be introduced to a newly diagnosed Coeliac patient, what advice would you give them?

I5: What would I give them...? I would say “you need to listen to your body” I think that’s really important. That, just because one thing works for one Coeliac, doesn’t mean it’s gonna work for another. I would say, you know, go to the Health Shop, check

out what's available, and also ask your doctor what you can get on prescription because there's more than just bread mix available as well. And have lots of rest, and just have a positive attitude about it – you know, it doesn't have to be a bad thing or a difficult thing – it's just your mindset isn't it. And you know, it's just a complete and utter learning curve. And that's how I look at it. And it hasn't really been a bad journey. It's just the way it is.

R: Just making slight adjustments to your lifestyle?

I5: Yes. Yes, and don't make a big thing out of it.

R: So as far as information resources available. What are your initial thoughts and reactions to current handbook?

I5: I would say for me, there needs to be more colour, even some cool little pictures, or something to break up the words. Because I'm one of those people who gets bored – you know – it doesn't make me interested instantly. Maybe a kids section – there is one in this particular one – but maybe a kids section that could explain things a little bit easier.

R: Can you think of any images that you found particularly helpful at the start to explain what happens?

I5: No, it was such a long time ago. I don't think there has been many images – that's kind of a hard one, whether it's just pictures of food, and just even colour. Breaking up bulk wording is key.

R: As far as the format of the handbook goes, what do you think about the ring binder?

I5: Um, bulky. That's what I would say. Um, just bulky. I mean, it's big enough so people can just pick it up, but I'm just thinking about storage. Because

I think, when you get this information, you hold onto it for many years, so I would say somewhere to keep it – you know. Cause I think, there’s so much information in here you wouldn’t read it all in a day and it’s nice to get it out for other people who aren’t Coeliac sometimes, and also you might want to look something up over the time, you know, a couple of years later you might want to get it out again. I would just think it’s a little bit bulky myself.

R: So, when you talk about giving information to other people, have you in the past given information to other people to inform them about what Coeliac Disease is? And what sort of information?

I5: Um, when I’ve had kids in my house and asked – I’d have to have a look, because I think it might still be the original one, and sometimes, I’ve got a few cookbooks that explain it. Sometimes I just quickly read it to remind myself that I’m telling things right and not going off the subject slightly. Sometimes I’ve bought things and they’ve had ‘what is a Coeliac?’ – sometimes I hold onto those sorts of things. We’ll be sitting around and I’ll be like “well here’s some information” so yeh. But other than that, it’s just telling people when people ask. Because when you go out to work and you have lunch with your work colleagues, you know, or you go out for dinner and suddenly they are like “Oh, well why don’t you?” – it’s really mostly just word of mouth to be honest.

R: How do you go about eating out, for instance at restaurants?

I5: Oh, I’m pretty disorganised – but I’m pretty good at it now. I always – I just don’t take chances. Cause it’s not worth it. Sometimes I actually watch the person – you know, have you asked the chef? – and I watch whether they go to the kitchen sometimes, it just depends on the person. If they hesitate, I think

are they going to tell me – are they going to make up a wee story here – because sometimes that does happen, or are they going to go out and find out. And if they don't come back out I always ask too. You know “did you ask the chef?”, but most people go out and ask and come back – well today they do. It's pretty good. You become seasoned at it don't you? I'm always quite careful really.

R: Some people that I've spoken to find that quite difficult or embarrassing.

I5: It is, but I've worked in a hotel for five years – I've been on the other side of the coin, I don't mind people asking me questions, and you know it's OK to say “sorry I don't know, I need to go and ask”. There's nothing wrong with saying that. And, you are absolutely within your rights to ask questions.

But like, 18 months ago I was in Rotorua, and we went to this little pizza place, and I said “Do you have gluten free pizza's?” and he said “Oh yes, you can have any vegetable you like on top of your pizza”, and I said to him “oh well, look, that's cool” and there was just no way I could eat anything in the restaurant, and I said “hey look, that's cool, but we've actually decided not to stay”. We've left restaurants not very often, but they were extremely busy, the guy had no idea, but that was cool though – we just went to the restaurant next door.

R: You can do that in Rotorua! There's so many restaurants!

I5: Yeh, that type of thing, but I don't have a problem with that, and as I say, I've run a restaurant, so I come from the other side and I don't mind.

R: Have you travelled much?

I5: Yes, I've travelled to Asia five times

R: How did you find that as a Coeliac?

I5: Easy. Language is a barrier, but rice and plain vege is easy. I took my children and my partner a month back packing in Thailand, so we got into this habit if the people didn't speak very good English, that we would all order different meals and which ever one was gluten free I ate. Generally it was the one that I picked, but occasionally one would come up and we'd go "well we don't know what's in that one – don't want to take our chances stuck in Thailand – we'll just swap around". And I think only once, I mean things were so cheap, we just ordered another meal, and the others picked on it.

R: Have you travelled elsewhere other than Asia?

I5: I've been to Australia and Australia was fine. Aeroplanes were really good. So yeh.

R: Was that through Air New Zealand?

I5: yeh, I've been through Air New Zealand and Singapore. Singapore was very good.

R: And did you just tell them in advance?

I5: Yes, Always. In fact it guarantees you a nicer meal often and a fresher meal! So it pays to kinda do that anyway!! People think, well I'll have one of those too!

R: Ok, as discussed before the interview, I am just going to get you to find something in the handbook for me so I can see how well it works. Could you locate for me the page that has 'Gluten free flour choices'

I5: Gluten free flour choices – OK. (picks up handbook and starts looking though the contents page)

Ah well...(reads out list)...I'm guessing we're going to 5 or 6 or not??

Not that page. This page...oh no that's not the page.

I didn't see it in the contents. It's a bit hard to find. Page 16 ...Oh there you go! Did I miss that? It was under 'healthy choices'!

Hmm. I think the little book that you get from the Coeliac Society – the MFD book. That is one thing I always have. I think, well I bought something the other day and I did actually look it up when I got home. It said on the back that it didn't have anything in it, but I wondered if it was in the wee book. So that is something that I do use and hold onto.

R: So do you just keep that in your handbag?

I5: No, no just at home

R: Do you use the MFD website?

I5: Um, I have looked once. But you know it's different for me, I been at this for quite a long time, and there's always new things, and I probably should have a look, but I feel confident enough.

R: Well, I've definitely used up enough of your time! Thanks so much Carolyn for your input and feedback. It will be of great help.

I5: It's been fun. Good luck for your project

## Interview 6

**I6 = Interviewee 6**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I6, thank you for taking the time to meet participate in this interview. If we could start off with you telling me about your experiences living with Coeliac Disease?

I6: Ok, my experiences of living with Coeliac Disease – probably for me, it was understanding that something was wrong. Emotionally it was huge. You have to deal with the fact that you have a disease that's life long. Obviously there's no drugs for it – it's a lifelong disease. Financially it's horrendous, as other people probably would have realised – which shouldn't be that way. And the social implications I have found particularly hard, when you go out for a meal with other people, restaurants tend to know no that if they aren't going to serve one person with Coeliac's then everyone else will go as well. I think more restaurants have become aware that they do have to cater for Coeliac's now, or anyone on a special diet or dietary requirements, because if they want a whole group to dine there then they have to deal with everyone's, um, dietary habits. And it's not easy for them either, and I accept that, but they do have to take some responsibility.

Um, the other experiences of living with Coeliac Disease for me, are the other illnesses that go with it. Like the Thyroid, in my case, Arthritis, Asthma and Eczema. So, the Thyroid I got first, the Thyroid disease, so in a way I think it's probably easier if you were diagnosed as a child because then you learn to

live with it, and that's how you are, and you are less likely to get some of those other diseases – you're not as susceptible to getting the other auto-immune diseases – so for me, particularly the other diseases that go with it. Cause, people say to me, "you've been diagnosed, you must be feeling so much better now", and I say, "no, in actual fact I'm not – I still have headaches, my Thyroid Disease is not going to go away, my Arthritis is not going to go away – none of those things are going to go away – they might improve a little bit – but they are still there".

R: When were you diagnosed?

I6: Four years ago.

R: And how did you end up getting tested?

I6: Right, mine was, I had a hernia operation about six, seven years ago, and then I was still having problems – I was getting bloated in the afternoon – just not feeling well, stomach pain – I was just totally unwell. So my GP suggested – I changed GP's – because my first GP basically thought I was neurotic, I had all of these complains but he couldn't pin point anything. So I actually changed GP's and my new GP was really, really good, and he suggested I go back to the specialist who did the hernia, so he did another endoscopy and he found the Coeliac's. Took the biopsy and found it. So simple as.

So, I had no idea what Coeliac Disease even meant – I couldn't pronounce it – I had no idea, none whatsoever.

R: How did they explain it to you?

I6: I got a letter from my specialist saying that I had Coeliac Disease and I should trail a gluten free diet for a month - and that was it! – So, so what? Gluten

free? What? I didn't know!

R: So you weren't given any material to explain what Coeliac Disease was, and how to eat gluten free?

I6: No information! No nothing! Yep. So the first thing I did was look up my health dictionary that I've got, my medical dictionary – my basic family one. The I found out what gluten was in, then I thought to myself, OK I'll go without my bread and all those sorts of things, but it was so much more than that!

Actually I was quite lucky when I think back, because one of the girls I worked with. She was a school teacher and I was a librarian, and she had had Coeliac Disease and had been diagnosed in South Africa, but she had been diagnosed as a child, so it was normal to her. But it took me a wee while to realise – to get to talk to her – to know that's what was wrong, and that's what I'd been diagnosed with. So she told me some of the basic things to start with. But it was a whole learning curve, and basically it was the Internet I suppose. I actually went and bought one really, really good book and it's called 'Wheat Free, Worry Free' – have you heard of that? – It's by Dana Corn, she's American, and she's the spokesperson for Coeliac Disease in America. Her son was diagnosed at three or four I think, and she's totally taken it on board, and her book's wonderful it's just got lot's of little chapters on what to avoid, what to do, how to go about when you eat out, what to do when you go away – all sorts of wonderful, wonderful information. A really, really good book.

So, that's what I did when I found out – I just had to read as much as I could and find out as much as I could, then start eliminating stuff. Reading labels.

R: So when did you join the Coeliac Society?

I6: I basically joined straight away, because once my GP, once he had got the letter from the specialist, he gave me details of joining the society – they had them at the doctor’s surgery. So otherwise I wouldn’t have known that they even existed.

R: So he basically relied on the Coeliac Society giving you information?

I6: Yep. They really didn’t know any more than I did. They did refer me to a dietician, but she didn’t know very much either ...so....

R: So, obviously one of the initial difficulties was that you didn’t know what foods contained gluten.

I6: Absolutely! Huge difficulties there. Because I think most people think of wheat and gluten, and they think of bread, cakes, pasta – some don’t even think of pasta, they say “I didn’t know that one” – bread, cakes and savouries – those sorts of things. But over the years I’ve found it’s all of the hidden things, and for me, the biggest one that people don’t know about is things that have got malt in them or malt vinegar. Because you are told you can have potato-based products, corn and rice, two that spring straight to mind are Cornflakes and Rice-bubbles, and everyone thinks that’s fine, but when you read the labels they are coated with malt. So, in another way, friends might make something for you – they might make a slice and think they’re OK because they’ve got Cornflakes in them, or it’s a Rice-bubble square, that will be fine for you, but they have used normal Rice-bubbles. So those are particularly difficult and personally, the one biggest thing I think people have to be aware of next to wheat, and the flour, is barley – all the things with malt vinegar in them. It’s huge. And people don’t realise that.

R: Do you notice quite quickly if you have eaten

something containing gluten?

I6: I do now, and I believe the longer you are without gluten the more intolerant you become. And I had a classic example about a year 1/2 ago, and I had an ice cream at half time, and I never even thought, and I ate this whole ice cream, one of those things with a cone, and right in the middle of the second half of the movie I just said “Shit!” and I thought “Oh god! I have just eaten an ice cream cone!” – didn’t even give it a second thought! And within, just over an hour, I had diarrhoea. Stomach pains and diarrhoea. And that’s the other thing that people don’t realise either – that you can get sick really, really quickly. Friends that don’t know what it’s like, find it very difficult, they say “Oh, you’ll be OK – it’s only a little bit – it doesn’t really matter”. But it does matter.

R: How to you explain it to your friends?

I6: Most of my friends now are really, really good, and aware, and if we do go out for tea or lunch particularly because that’s really hard, they’re really aware of it. And they just know – they know, maybe because I’ve been so involved with it and learnt so much about it, I’ve just passed that on. So they just know.

R: You mentioned before that you used the Internet, and the book that you just mentioned as well, but was there any other support materials that you used?

I6: Um, there were a few pamphlets that I picked up – Bin Inn in Stratford at the time was really good and they had some pamphlets, I know that one there (passes over a pamphlet) that Sanitarium one is a good one. That’s been revamped. Yeh, that’s ‘Eating for Health’ purely about Coeliac Disease. But they are putting another one out which is incorporating

Coeliac Disease and Diabetes in the same book.

R: There seems to be a link between Coeliac Disease and Diabetes.

I6: There still is. Very big link between Diabetes, Thyroid, Arthritis, Osteoporosis. Um, yeh, probably I would say the Internet. Southern Cross website, I think it is have a very good site for Coeliac Disease – well all illnesses. But it's quite well explained. And I guess if I didn't have the Internet, I would have relied probably on getting books from the library. And that's why we started the support group, because we felt, well I felt, it was really, really important for people who had Coeliac Disease to actually talk about it. And we used to share ideas, and new products that came out and were nice, or weren't nice or too expensive or whatever – at least we could all share that and we knew. So a support group I think is really, really good. But our support group folded, mainly because I moved out of town. But I think it's very, very necessary. The other thing that I do, as co-ordinator, is visit other families, when they have been diagnosed. Especially when they don't know anything about it, and they want to feed their whole family. If it's been a child that's been diagnosed, they come to me and say: "what do we do? – Do we have to change all our cooking? – Do we have to buy all this expensive food? – What do we actually do?". So that's why I devised that list of what you need to change in you pantry, some basic ideas - some things that are going to catch you out- and what I will generally do is go through it with the family with what they would normally eat in a week, and I help them adjust those recipes, by using cornflour, by using rice flour. Just by being really careful, by buying gluten free gravies, and perhaps yes using that for the whole family, but especially if it's a child who is diagnosed, I always say: "things like your bread and your cereal, which are really expensive – keep those as special

treats for the kids”. Don’t make them different, don’t make them try to feel different – try and change all the rest of your cooking – because it’s going to help the rest of the family anyway, and it’s not going to be horribly expensive to change to rice flour or cornflour. But keep the breads and things special for them. Because they are so dear.

R: at \$6 a loaf..

I6: Exactly! \$6.20 I’m paying at the moment

R: Community support seems to play a big part in supporting most Coeliac’s with Information

I6: Definitely

R: Aside from this, how did you think the handbook assisted you when you were first diagnosed?

I6: When I got it, it was good, because it had the magazines. I honestly have to admit that I haven’t used it for a long time, because I used it initially, but I haven’t used it since. Um, yeh it was OK. I think what you’re doing is good, because it can actually be updated. It can be made more user-friendly, and it can include – probably a lot more ideas – basic ideas – things like general family cooking from day to day. Lot’s more basic recipes – or just how to adjust things – how to know how much rice flour to use instead of flour when making a cheese sauce. I’ve got a really good chocolate chippy biscuit that’s a basic one, and it’s 1/2 of gluten free flour and 1/2 of rice flour – just knowing how to do those things.

And in the interim too, there just needs to be something too, like my pantry list, that they know they can do straight away. That it’s not going to cost a fortune, that they just need to make sure they’ve got gluten free baking powder, gluten free icing sugar,

at least one sort of gluten free baking mix – because there’s so many available now, which there weren’t four years ago – I think people, and like myself, tend to think it’s so huge, and it is really huge...

R: but there’s some basics...

I6: basics! You’re not going to fix it overnight. You’re not going to change to totally gluten free overnight – you have to think about it. But just some ideas of what to do. Ok, when I get the groceries next week, I’ll get white vinegar instead of malt vinegar so I know I’ve got that in the cupboard, or I’ll do away with all the tins of spaghetti in the cupboard and buy gluten free pasta instead. But don’t try and do it all at once, I think that’s what a lot of people try and do – the whole lot all at once – and it’s gonna cost me an arm and a leg. But you don’t need to do it, just gradually, as long as your basic things – like your bread has changed, your cereal has changed, you’re using cornflour and rice flour instead of flour for crumbing and all those sorts of things. And things are going to trip you up, they always do – I mean four years later I still get tripped up. But I just think, more help with ‘Ok this is what I should do’. Just try and change these few things, then in a months time try and change your grocery list to add a few more, and then a bit more, and then a bit more – and then it just becomes routine that that’s what you buy.

R: You mentioned earlier that you thought the handbook could be made more user-friendly. Could you elaborate on that?

I6: Well, I’m not sure if these dividers came with it or not. I wonder if I’ve actually put those in there myself – I can’t remember. Uh, even if it was just on different coloured paper – I find that that really works – if you had all your recipes on say blue paper, or something like that, and pantry requirements on

red paper, or something like that, then I think it would be far easier to find your way around. It's actually probably a little bit hard because it's all - it's um - it's BORING!

Really, I shouldn't say that, but it's not set out how I would set something out. Yeh, I think colour coding the pages for different sections would be much easier.

Um, important things - it's probably not as important now - knowing you can buy gluten free flour on prescription. 90% of Coeliac's I know have no idea about that, and I only found by reading this and noticing it one day, but now Bakel's bread mix is available in the supermarkets - so it's not such a big deal now. Because I personally think it's the best product on the market - Do you use that one?

R: I have.

I6: Yeh, I personally think it's the best.

R: And I know a lot of members from the Coeliac Society use bakels.

I6: Yeh. So...

R: What about the actual content of what's in the handbook?

I6: Oh yeh, I think the actual content is very good. It does actually tell you what Coeliac Disease is, about the subsidies and benefits, and how to shop. Yeh, the content is very good, it's just boring! It needs to be spruced up a bit I think.

R: What about the format? The ring binder and the size of it?

I6: Oh, I think that's great, because I've added other

things to mine. I've got magazines in there that are important, pieces that I found from the internet are in here, um, yeh I think a ring binder is great. I know these pages are good too (refers to a plastic pouch she had used herself to hold information in her ring binder) – but you can do that yourself if you want to separate stuff. But no, I think a ring binder is great. I would definitely go with a ring binder.

I6: Information on travelling is another one. I don't know about others, but especially for International flights, make sure you check, double check and sometimes triple check that you are going to have gluten free food available. Since I've been diagnosed I've only travelled once. I went on a cruise, and the cruise was absolutely brilliant. I had ordered gluten free food, and when I got on board the boat they just advised me to check, and so I went along and checked with the bursar, and no I wasn't on the list for having gluten free food. So I was like, "great, I'm going to be on this ship for four days and I'm not going to be able to eat anything but fruit". But by actually going along and seeing the maître d' – or whatever he's called – that was fine. He got me on the list, I had my own waiter, he organised my meals every night, and it was absolutely fine. But always check! I'd booked it, but when you get on, still check. When I got on the plane to come home I hadn't checked – no food. It hadn't been done. So I don't know what had gone wrong. I'd ordered it. Whether the travel people mucked up, or whether they mucked up at the other end, I don't know. But it's not nice. And that day flying back I think by the time I actually got food I could eat it was something like 10 hours later, and that's just not OK. So on travel, that would be my best advice just check, check and double check.

And always have a little snack box. Especially if you aren't travelling overseas, a little plastic container

with a little bag of chippies, or some dried fruit or a nut bar. Always have that in the car. Always. Because you are going to get caught out somewhere.

R: How about dining out? Do you go to places you specifically know sells gluten free food?

I6: It's a combination. I will try to go there first. If I know the day before or two to three days before, I will ring first. Rather than just bowl in and say "I'm gluten free – I have to have gluten free – what are you going to do for me?" I will ring and find out first, and if they say "yes, that's not a problem, we'll adjust things for you", then as soon as they come to take my order, I explain to the waiter or waitress that I need a gluten free diet, I have already phoned, and can you please ask the chef what I can have tonight. That's generally what I do. When you are in a place that's somewhere different, and you are just going out for a meal, and you have no idea what the restaurant is like, I generally will just look through the menu, and see if there's something that can be adjusted. Like at lunchtime I'll have a steak sandwich without the steak- or a BLT without the – OH not without the steak!!! Sorry without the bread!! A BLT without the bread. So, I'll go through the menu first. And, if I don't think there's anything there, I'll just ask, and if they just can't do it I'll go somewhere else.

R: At that point, would you tell them you were gluten free, or would you just ask for it without the bread?

I6: No, I'd definitely say "I need my meal gluten free, that's why I'm asking to have no bread" and if there's wedges or something, then I'd say "I'd rather not have them, in case they have got flour on them, and if you are going to do me a salad, please don't put any dressing on it". And the different chef's I've talked to over the years, they've all said if they know right

from the start when they are preparing a meal, then they're fine. There's no point getting a meal dished up in front of you and saying "I can't eat that – take it away" – it's too late. As long as you are up front and tell them.

R: A lot of people have commented that many people react by saying "it's just a fad"...

I6: Oh for sure! My own family have said that! "It's just a fad diet and you'll get over it". And it's not, and that's what I have to stress to so many people, and they turn around and say "but it's so – 'modern' – you see all this gluten free food", and I say "no, it's not modern, it's just there's such an awareness now. I don't think more people are being diagnosed – well they are – more people aren't getting sick with Coeliac's. More people are AWARE that that's what they've got. Because the testing is now available, you don't have to have a biopsy, you can just have a blood-test taken to give an indication. People are more aware, and anything where people are aware and it's in their face they think it's a fad. But they will realise in ten years time that that stuff is still on the shelves, and there will probably be more of it. It's purely an awareness.

R: Can you think of any ways that could enhance that awareness?

I6: Anymore than what they are doing now? I dunno. It's quite surprising when you get a room of 80-90 people in a room and you ask how many have heard of Coeliac Disease or gluten free food – quite a lot of them have. So I just think with the awareness week they have once a year, items of food on the shelf... It's amazing once you are diagnosed how many come up to you and say "Oh! Guess what, I saw such and such on this shelf". "Thank you very much – I already knew about that – but thank you very much",

but they are quite aware of it. I don't know if they could do much more to make people aware of it. We are a minority, same as diabetics and other people, but I think it's pretty good. Perhaps the supermarkets could do a bit more? Um, especially some supermarkets need to have all their gluten free food together. Especially when you are out of town, and you go to a supermarket and you are just looking around the shelves going "where have they got the pasta?" or "where have they got the bread?" – but if it was all together, and you knew exactly that whole shelf end was all gluten free. A lot of supermarkets fall down too because they put organic food with gluten free. They think it's gluten free and a lot of it's not.

R: Did you use the little MFD handbook?

I6: I did when I first got it, I did. I don't tend to use it as much now. I always have it with me, but I don't tend to use it. Because I personally feel I know enough about labels to know what the labels are saying. But definitely for someone who is new, it's a great idea. Or, once you have got several copies, give it to a family member. It may be a year out of date, but it's not going to change that much. So give it to someone else in the family that might think "Oh, you know, my daughter or granddaughter or niece or whatever is coming, what can I give them to eat". At least if they've got a book then they know.

R: A lot of people have said that initially understanding food labelling is one of the hardest parts. Can you think of any advice?

I6: Extremely. Extremely. Well what I would like to see happen, but it probably won't in New Zealand because of the cost, is actually having the gluten free label on everything that is gluten free. Either the gluten free logo with a tick, or the wheat symbol with the line through it. But, I know I have

questioned that before, and it's a matter of cost. Because I think the Coeliac Society actually own that logo, and to put that logo on products costs a lot of money. So, I'm picking that's why probably a lot of companies don't do it. It's because it's going to make their packaging dearer, so it will make their product dearer in the long run. Yeh, I'm pretty sure I asked about this a long time ago – and it's that special Coeliac logo. I'm just looking at this (looks at a gluten free food advertisement) and it's got 'gluten free' with a tick beside it, which is fine, but if it was quite clearly stated on the front with a logo so you didn't have to read the label, unless you were allergic to something else as well.

But I think with all of the numbers people get quite confused, as there's all the colour numbers and all the additive numbers, and if people are aware of the thickener number – but that can be confusing too, because I know what it is, but lots of people forget!

R: And there's vegetable gum numbers as well.

I6: Definitely! It is very confusing, and because they have to do it now I suppose, cause there's no easy way around it.

R: So for you, it was just learning over time what those numbers were?

I6: Absolutely

R: Do you think that that a little card, or something that you took to the supermarket might help?

I6: Well, they used to have in the back of the Manufactured Food Database booklet a list of what the thickener numbers were. But they have taken it out of there. Something to do with the dieticians – I'm not sure why – there was in the back of the book,

what numbers were OK. So you had the book, and that was in the back as well, but there was definitely a reason why they took it out. But if they are introducing a membership card, which I think they are, putting a list of those thickeners on the back – the numbers you can have – would be a very, very good idea. I think a membership card, if they do bring that in is a very good idea.

R: What was the intention behind the membership card?

I6: Well I think that it was – people that I had talked to – it had more weight for them to go into a restaurant and say: “I am Coeliac, these are my requirements, what I do actually need”. I don’t think people wanted discounts for anything – but even if you went to a chemist out of town and you wanted some medication and you could show it and say “I’m a member of the Coeliac Society, can you please make sure any medicines you give me haven’t got any gluten in them”. I don’t know – it’s kinda like a little support thing I think, that you’re not just saying it. It’s not that people disbelieve you, it’s just you have a library card and things like that. I think it’s more than anything when you are out of town – or if you got sick and someone went through your wallet and found out you were Coeliac and would know what to do, or find out what to do.

R: Could it help in restaurant situations where people are embarrassed to explain?

I6: Definitely. They might be able to discreetly hand their card over and say these are my requirements, and no one at the table need to even know what your requirements are. It can be extremely embarrassing when you are sitting in a restaurant and have to say that to a waiter.

R: Have you know of the travel cards – the ones’ that explain you have Coeliac Disease in different languages?

I6: Yes I do.

R: Do you know of anyone who has used them?

I6: Yep, we’ve got a member in Hawera who went to Germany I think it was last year, and she asked me specifically to find out if there was anything available, and the Coeliac Society sent those to me, which I forwarded to her. She said they were brilliant – absolutely brilliant. Yeh, she went through several different countries in Europe, and they were fine.

R: Well, thank you, I think that’s about it....

I6: Oh! One more thing! I think what you are doing is really good, because I think it’s probably only time constraints that that they don’t...I mean it’s voluntary, the secretary is the only person who is paid, and I think a lot of people don’t realise that. Every other person who is involved up there is a volunteer, same as I’m a volunteer and giving my time to help people around here in our area. It’s probably just time. And if you don’t get feedback either then you don’t know. If no one said anything, the general consensus would be that everything in that handbook was fine. That there wasn’t an issue with it. I just think it could be a little bit more user friendly.

But it has to be like a working document. It has to be something that changes and evolves, and something new can get added to it or deleted, and then it’s purely a matter of saying to members that have already got it: “Take page such and such out and replace it with this”, which could go out with the Link – you know if there was something changed in

the handbook, there should be no reason why they couldn't pop a new page in here (refers the Link magazine) or just have a handbook update page in there, you know: "please delete page such and such and add this to it". Or something like that.

R: That's a good idea.

I6: I mean, if you are a member, you're going to get this (the magazine) anyway. Have a handbook update page in there. If necessary. I mean it may not always be necessary.

User-friendly I think it would be much better this way (points to ring binder), because then if people have then got ideas, or if they want to add information of their own, then they can slot it in the relevant place. If there is a separate section for recipes, then they can slot their own recipes in. I think this format really, rather than a book. If you want a book – you go and pay \$50 for a good book. And that's the other thing I suggest too, is that people don't go and rush out and buy a huge selection of recipe books and all of those things, because you end up going back to what you know how to cook anyway, and just adjust it. OK, my favourite is that Wheat free, Worry Free because it's got so much information in it, and it's very easy to read. You pick it up and can read a little chapter at a time if that's all you want to read, but don't rush out and buy all the books, because they are very, very expensive, and honestly, a lot of them you will only read once.

IF, you are going to buy one – the better one's I've found – there's an English one, I think the English one's are more to our way of food eating than American, and one of my favourite one's is actually written by a Coeliac. So, she knows.

R: Is that the Sue Sheppard one?

I6: Um, no, it's put out by the UK Coeliac Society. But Sue Sheppard is definitely Coeliac as well.

R: Wow! Thank you for all your input, advice and suggestions, and thanks for your time – I really appreciate it.

I6: It was great talking to you! I thought the interview went well. Good luck with your study!

## Interview 7

**I7 = Interviewee 7**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I7, thanks for taking the time to do this interview. If you could start by just telling me about when it was that was diagnosed and the whole process involved?

I7: I had gone to investigate what would have been long-standing incredibly loose bowel motions, and looking back now a host of symptoms I didn't realise I had. But my main thing was horrendous diarrhoea six, eight times a day. I'd gone thinking – I'd been under a huge period of stress – I'd gone thinking I was going get told I had cancer actually. Initially the biopsy showed I had a bit of Diverticulitis, they diagnosed me with Irritable Bowel Syndrome and I saw the registrar with the results and she said: "Oh, we might just do this blood test – you know, it's probably not worth it – but we'll try", so I almost didn't go and get that blood test done, because it was so casually offered. So I went and got the blood test and my results were slightly positive, so I saw the specialist to get my results and he just said: "well you are possibly Coeliac. You have a couple of choices from here. You can either go onto a gluten free diet, or you go and see a specialist – I can refer you onto someone else – and get a biopsy done and work it out from there". And I said: "well either way I am going to be trying a gluten free diet aren't I? Either I try it now – you know – if he says it's positive, I'm definitely on a gluten free diet, and if he says it's negative you're still saying it's worth trying a gluten free diet – so either way I'm on a gluten free diet".

Looking back, I probably wish I hadn't done it that way, I wish I had gone and got the gastroscopy because I don't know now whether I am gluten intolerant or if I am truly Coeliac. But, um, the thought of going back onto gluten for three weeks and going back onto all those other symptoms – I just can't face it. Maybe if I was on holiday or not working or something, but trying to cope with study and working and everything else – there's no way. There's no way I'm going back to the horror of that, and I'd be even more susceptible now cause I know now after three years there's foods that I was perhaps getting away with occasionally that I'm not now.

R: What are your main symptoms when you do eat gluten?

I7: Mainly – I get a dry slimy mouth, and that's usually my first indicator – actually I get a dry slimy taste and I think: "oh...what have I done?" I get diarrhoea, particularly around some foods – particularly anything malty. That seems to be one of my biggies. At the least, I will get incredible wind – just full of wind. I quite often get wheezy – I'm asthmatic – so I quite often get wheezy if I've eaten something I shouldn't have. I get aches and pains if I've goofed badly or cheated – you know, on myself. I'll end up with achy joint, aches and pains. Heaps of stuff that I didn't realise I was experiencing, that I haven't since I went gluten free. Incredible aches and pains, my asthma's heaps better since I've been gluten free, I don't get – wind was just a constant problem. You know, I'd be off tramping or doing exercise and I'd just be blowing off the whole time. Which doesn't make it very public. I remember sitting in a meeting, and I'd eaten sausage rolls for lunch, and the whole room could hear my stomach gurgling afterwards. Everyone was – and there was no mistaking it – there was just this rumble from top to bottom sort of thing. Fortunately not needing to let it out the

bottom end, but it was just gurgling. What else? Oh yeh, less headaches. More energy – and incredible amount more energy. I lost about 13 kgs.

R: Is that right?

I7: I was maintaining my weight on the diet I was eating, and going gluten free meant I lost about 13kg's. I've put a bit back on at this stage, but it's um, yeh it just fell off me.

R: Do you think it's because you eliminated the breads?

I7: Absolutely! I dropped a lot of the carbohydrates from my diet.

R: Do you still try to eat gluten free carbohydrates?

I7: Yep. I have a couple of bits of gluten free toast – the Vernerdi toast – for breakfast, and/or a gluten free cereal. I've found some pita breads that I can eat. They are very, very expensive – and the naan bread. If I have a “sandwich” at lunchtime, I'll eat the corn thins. So yeh, I try and keep – I haven't got my head around the pasta stuff yet. There's obviously something wrong in the way I cook the pasta! That's an experiment to come, but unfortunately I've got a teenage son living with me at the moment who won't eat pasta – or not that kind of pasta. I'm waiting for him to move out so I can start playing again.

R: So you didn't have the endoscopy, so what happened after you had the blood test and you were told to go on a gluten free diet? How did you educate yourself to know what was gluten free and what wasn't?

I7: OK. I came home thinking “Oh my God!” and I fortunately had a nurse friend who I had worked

with previously, whom I knew had been diagnosed, so I gave her a ring. And I'll never forget her opening words. They were something like: "you're at a point now, where everything you look at, you can't eat". And I was like "Yeah. My whole pantry is forbidden food! My whole eating style: pasta's, bread's" – bread was huge for me. Bread was, often toast for breakfast, sandwiches for lunch and quite often something - 'mince and toast' for tea – something like that. So, bread was a big part of my diet.

Um, she gave me some basics...she gave me what cereals she ate...

R: Your nurse friend?

I7: Yeh, my nurse friend, actually [Name]. Yeh, [Name] gave me the stuff that she had found. Things like the 'Simple' cereal. Get yourself some gluten free flour. And from there I went to the dietician, and she actually printed off the Manufactured Food Database for me, and gave me that, and from there, a lot of it was done searching the net. Making it known publicly that I was gluten free and people would be feeding in little bits of information to me. I'd be sitting in the café with a box – I might have taken in some rice crackers in for example – oh, that's another carbohydrate I eat a bit of too, and they'd be reading through it going "do you realise this has got such and such in it" and I'd be like: "no – I obviously didn't read that label properly". Learning to read labels – yeah. And then I actually joined the Stratford Coeliac group, and that was also good, because people would bring in packets of things, and Sharon had a lot of information. They would bring in a folder made up of the packets, and stuff you could eat. Examples of gluten free restaurants, and it's probably where I finally got my head around what numbers you can't eat of the food additives.

R: So that was through discussing it with the group?

I7: Discussing it with the group. People bringing ideas in – someone saying I got caught out.

I got caught out with MILO! That's something I have struggled with. As a rule I don't drink much – I don't drink coffee and I don't drink tea – so I had been drinking 'Lemon & Barley' in hot water or MILO. Both of which ... and I'd been gluten free for a few weeks, and decided at work one day to make myself a MILO. I hadn't even thought about it. I hadn't even stopped to think that it might have been in there, and had a really nasty reaction, then had to go back and sort of play detective, and that's when I actually read the MILO packet and discovered it's got malt in it.

So, yeh, those were the sort of...some of it's 'trail and error' – some of it's discovering what you can and can't – like I can't eat the white bread as a sandwich. I haven't yet found one of the white breads that I can eat as a sandwich. I would kill to have a gluten free sandwich! Yeh, but I just make do with the pita breads and naan's and that sort of thing.

R: So, the main way you learnt about your gluten free diet was talking to people, the Internet and your dietician?

I7: Um, I don't think the dietician was terrible helpful actually. Probably the main way was the Internet. I got on there and got a Coeliac book and had a flick through that. By the time I got to this – because I was kinda spending money on changing my entire pantry – this kinda came a little bit down the track for me. So, Internet searching, learning to read labels, and still goofing occasionally, because there's stuff hidden on the labels that – although over the last three years - I don't know whether I've got bet-

ter, or if there's more stuff on the labels, but they will often write in big letters 'Contains wheat', and that seems to be something that seems to have evolved over the last while. Yeh, probably the internet and talking to people. Talking to the guys in the Coeliac group, ringing Pip occasionally if I was stuck about something.

R: What advice would you give someone who had just been diagnosed gluten intolerant? What would be the first thing you would say to them?

I7: Ring somebody. Get hold of somebody who's been there. Because the supermarkets are a real challenge – shopping in them – particularly in the more rural areas. Um, yeh. Ring someone and talk to someone who has been there. And, um, Stratford Coeliac Society put out a little booklet, which I have given out to various people as well, and that just gives you the basic things you need in the pantry, and the really obvious 'what to avoid's' – so yeh, that would be my start.

It's not easy to live this way, and it's reasonably expensive, but the health benefits are worth it.

R: What's your experience travelling out of your local area with gluten intolerance?

I7: Some of it is – go prepared! I take snack food with me, I usually take rice crackers – call it my 'emergency box' if you like – so if I do end up at a catered lunch that has sandwiches, savouries and cakes, then I can at least go back to my room and have something to eat. I usually try and have some fruit with me, yeh. Sometimes if I'm going to something that I know there's not going to be anything much I can eat, then I'll have something before I go out. I guess to some extent that even works here.

Most places are pretty accommodating. I remember being in Tauranga at a wedding and getting sent into the kitchen to talk to the chef, so we could decide between us what I could and couldn't eat, and what was on the menu that he could modify for me. So most places have been pretty adjusting – pretty open to me saying “can you just give me fish without batter or crumbs”. Some of the places, I think, there's still not a very good understanding out there of what it is to be gluten free. Most people understand that you can't eat bread, but I've sometime found myself with a salad, and found they have done my fish without coating, but then they have put salad dressing on the salad. Like, poured it over, you know. And you look at it and think, now is that a gluten free one, or has that got vinegar in it.

Or they will make you a salad, and I had found some really neat little rice cakes and gluten free muffins, and then they will put a bowl of relish on the side, and I've got caught out with that a couple of times. You know, ordering gluten free, and assuming that whatever they give me is gluten free, and then the bowl of relish won't be. Yeah. So there's an understanding out there that you can't eat bread, or flour, but the knowledge isn't out there in restaurants and things like relishes and dressings and things aren't always gluten free.

R: So when you go out to restaurants or cafes, what to you do to inform them you need to eat gluten free?

I7: I usually pick something on the menu that I think is safe. I usually say to the waiter that I'm gluten free. And sometimes I say to the waiter, “look, I'm gluten free, can you just check with the chef what I can have?” That's worked quite well sometimes. I've gone some places, and they have said: “well, I'll talk to the chef and see if there's some-

thing he can come up with”. Um, it depends if I’m in safe company or in a big group – sometimes if I’m in a big group I will just quietly try to decide on the menu.

R: And take a chance?

I7: Take a chance, Yeah. Or if I’m – yeah I guess it depends on the crowd I’m with. Most of my friends now know I’m gluten free, so they are sort of watching out for me “Oh, that’s might be good for you Jenny – it doesn’t look like it’s got gluten in it”.

R: There are some restaurant cards that you can use to explain the gluten free diet to restaurant staff. Would you use something like that?

I7: I have got one and I haven’t used it. No. Yeh, I guess handing a card to a chef, who has then got to stop and read it, and then..yeah...

R: You would prefer to just verbalise?

I7: Yeah, just verbalise it. And sometimes I might just say if I get something I’ll just say “please keep my meal gluten free”. Or I’ve learnt now if I’m getting a salad, I’ll just ask for no dressing or can I check the dressing container. I mean I’ve had big bottles of dressing brought out from the back room - standing there reading labels at the table!! It’s quite good.

I got caught a while ago – at work. Every so often if I’ve got a bit slack, and haven’t taken a meal, I’ll eat wedges. And I’d be fine, and the staff put down a bowl of wedges in front of me, and I thought “they look pale today”, but I ate them, and I had a reaction that night. I sure enough – I went to her the next day and said: “those wedge – have you changed the brand?” and she goes: “Oh no! Oh yes we have!”.

Sure enough – out the back into the freezer and out she came. So yeh.

R: They were coated with flour?

I7: Yeah. Yep. Yep. And probably going back three years, I would have got away with that. But I'm far more sensitive than that.

R: The handbook that you have in front of you. You said before the interview that you had received that quite a while after you went gluten free...

I7: Yeah, about eight months later.

R: So, did you find it useful at the time?

I7: Um, no not really, because I had read most of it somewhere else. Yeah. I didn't personally because a lot of it I got elsewhere. Actually looking at that recipe adaptation (looking at information in front of her) – one thing I haven't done is tried a lot of baking gluten free – without gluten.

R: Did you bake much before?

I7: No, no. So it hasn't been a huge issue for me. I had various favourites that I did, but baking, not been a thing for a little while now.

R: Just looking at the handbook you have in front of you, do you have any ideas in how it could be modified to make it more useful for you? Or for newly diagnosed members?

I7: I guess there's quite a bit in here that – this is good reading – but initially you want to know what you can and can't eat. And that's straight up, with what Coeliac Disease is, what's got gluten in it, and what hasn't – is where I needed to start. You know,

like the 'traps' – vegemite and marmite, MILO – you know it took me a while to trig why I was still getting symptoms – and barley – you know, not even triggering that the barley – you know, yeh.

So, pantry essentials, and pantry 'no-goes'. Um, quite clear message, yeah, would be what I'd be looking for, yeah, thinks that are um, 'banned' if you like for want of a better word. No-go items – stuff to get out of your pantry.

R: So about making that initial adjustment from being able to eat gluten – to not?

I7: Yeah. And, um, yeah, the other thing is you can't do it over night. It takes a while to weed out the foods that do have gluten in them. And I certainly know I stopped eating bread to start with, but I still kept eating cereal, until I got my head around that I was totally, for me, totally change my diet – because so much of my diet had been based around bread.

R: Have there been any visuals that have helped your understanding? – I mean, you're a nurse, so perhaps...

I7: Yeah! Yeah! The picture of the villi has been – I could see all the villi of my gut all flattened off. I could see, I knew what the villi was supposed to look like, and see these little flattened off little – and for me it makes sense – you know, food would just go through me. I could eat stuff at breakfast time, and it would be out by the end of the day. You know, I'd eat it at morning tea time, and I'd have something for lunch – I might have a corn fritter for lunch – and by evening the corn would be through me. So stuff just wasn't being absorbed! How I kept my weight on I don't know! Way too regular – you know six, eight times a day! And it's gross, but for me it was bright yellow liquid – it was bile coming through. It was like I had permanent diarrhoea. And

to be honest, for the first time in a lot of years, and it's gross again, but normal bowel motions. I get up in the morning and I have a bowel motion.

That's the other thing that's changed slightly, I know if I've goofed, and I'll get symptoms – but I'll get constipated slightly. It's gone the other way. I remember being incredibly constipated as a young adult/teenager and looking back now I probably should have been – I mean I've coped with unusual bowel habits for a long, long time. And it was usually “you're at boarding school – you're not getting enough liquid”, and then it was “oh you've got babies and you're busy”, and as they got older I had a lot of stress with kids, so it was put down to stress. Um, so yeah, looking back it probably should have been done years ago. Years and years ago.

R: So you noticed an increase in health?

I7: Oh yeh! I had energy that I haven't had since I was in my teenage years. I don't need as much sleep. I'm out exercising again. I went in a woman's triathlon. My brother actually hit the nail on it's head and said “if you had said to me a year ago that you were going to do a triathlon, I would have laughed at you”. Cause I just dragged myself. That's the other thing, is the sense of tiredness that I no longer have. So I literally dragged myself around in the daytime. I'd drag myself out of bed, I'd drag myself to work, what I'd want to do, well I quite often did, when I got home was go to sleep. Go and have an hour's sleep, then I could face the evening. I would nap when my kids napped – yeah. Kids got used to me – you know, they would come off the school bus and mind me asleep in bed. You know, then I'd get up and get tea or something.

That's gone, and I'm 50 now – and I'm starting to lead the life I should have been living. So I'm out

riding, swimming, cycling, tramping again. Doing stuff that I wouldn't have had a hope in hell of doing.

That's a tricky one, going tramping!

R: Yeah. What do you do?

I7: Um, try and take heaps of cereal, try and take heaps of snack food. Make sure I've got fruit – but it's not easy. And I haven't really faced a two or three day tramp – I don't know how I'd go with that. Cause you know, you can't fill a bread roll and throw it in your backpack. So yeah – try and have a lot of snack type food.

R: I guess for evening meals, you could have something containing rice?

I7: Yeah. I did a five day trip down the Wanganui river and actually that was catered so that wasn't so bad. But lunch there became my problem. Because we were on a river, whatever we had almost ready, so what I did was cook up rice the night before and the next day just stir a tin of tuna or salmon through it. It wasn't particularly appetising, but it meant at least I didn't have symptoms. Having to pile out of a canoe half way down the river to ah – yeah.

And we were lucky on our course because we had a chef on board as one of the participants who was quite happy to modify meals and – we actually had a vegetarian with us as well – so between her being vegetarian and me being gluten free we actually did quite well. They cooked up a pumpkin one night – we had pumpkin – we actually got really spoilt. We had a pumpkin with us one night so we made a big bowl of pumpkin soup, and we had pumpkin soup the next day for lunch when everyone else had – I can't remember what they had – a spread of some kind. So it was a little bit tricky, but I didn't really

want to face rice for a few days after eating rice and tuna or rice and salmon at lunchtime. Yeah. But again, there's not a lot of – you can't just open a can – and the other thing I'm surprised about is a lot of the big companies haven't got on board with it. You know, Watties, Sanatarium – those sorts of places.

R: I wonder if more awareness was created there would be more out there?

I7: I don't know. It seems pretty strange. I mean Hubbard's have got one cereal out, which is excellent. Yeah. It seems quite strange that some of the bigger – Chelsea's brilliant, Edmond's – their products are labelled. But yeah. But some of the cereal manufacturers – and I can't help thinking it would reduce the price. If there was just one more line in a whole line of stuff, then the price may reduce. But 'Simple' making gluten free products – you know – their market's quite narrow.

That's the other thing – I don't know if you can put it into a booklet or not – is shopping in the supermarkets. More and more I have discovered, particularly around here, that they are not stocking gluten free items. Hawera now, I was being able to go and get my bread – and I could pick up a loaf a week of Venerdi, which is the one I have chosen to eat, and now I have to order in some six or eight loaves and freeze them.

R: Did they use to stock gluten free food?

I7: Stratford here, used to stock Venerdi bread and Dovedale – they've stopped – and for a while they got in all the pita breads and Naan breads – all the rolls and the buns and things – and that's the other thing, some of it's edible, and some of it I really struggled with. But I've noticed they have stopped now. Whether it's because it doesn't turn over

quickly enough. Some of the supermarkets now no longer have a gluten free section. The other thing that I quite often find is that gluten free and organic are mixed, and that's a trap. You go into what you think is a gluten free section, and you think "Oh, that looks good", and you get home and discover you have got organic, not gluten free – or they will be diabetic – you know, they haven't got their heads around what's gluten free. And I notice that in more and more of the supermarkets, they are just spreading their gluten free stuff through the shelves. I'm actually having to start really looking for the products.

R: Do you have any idea of how supermarkets could be more accommodating for people that need to eat gluten free?

I7: I guess going back to at least having a gluten free section would be a start. I don't know what the easy answer is. I do know there are more and more people living gluten free. I guess that's where they need to start being – to recognise that there are diabetics and there are gluten free needing catering to.

R: Did you receive the MFD book?

I7: Yep.

R: Did you use it?

I7: Occasionally. Invariably didn't have it with me when I was in the supermarket, so I'd be coming home and hunting through – yeah. Something I've managed to misplace.

R: Do you use the website that they have?

I7: Yep. Occasionally. Yep.

R: Would you use the website more than the MFD book itself?

I7: Um, probably not if I could find the book! Haha! At least I know the website's still in one place. That for me is, yeah – I'm probably not quite as organised as some. So for me, I know where the website is.

R: Yes, I guess that's can be a positive about websites – you can't lose the material! In regards to the format of the Handbook, what do you think about the format of the current handbook being in a ring binder?

I7: Yeh, I guess – it's always there. It's something you would put aside and – I know I have a wad of stuff something like this size (indicates about 15 cm with her hand), that I have printed out, got off sites. Printed out – some people were coming up from all over the show with websites to have a look at. I will say I haven't ordered a lot of stuff through it, but um, you know like online shopping type stuff – yeah. At least it gives you a place to start.

R: If there was an online space where you could talk to people that suffer form gluten intolerance would you use it? Like to post questions for example? Like an online support network.

I7: Possibly not now. Because I got the support I needed and went out and got out there and found it. So I don't know if I would have – but perhaps that's because I'm not into that chatty sort of stuff. But I could see some people would find it – particularly younger ones – would find it really good. To be able to chat. Particularly if it was like, free. Because there's an Australian one I found: Angela's Gluten Free dot something – but you actually have to pay to join. You can get the recipes, but you actually have to pay to join to find out a lot of other information. And to do the chat thing. So yeah.

R: The other thing could be a site that just gets updated regularly with new recipes or new advice on what supermarkets have this product for example. Would you check something like that?

I7: Yep. I would. Particularly if I'm travelling. It's quite nice to go somewhere and find out if there's particularly good restaurants, or a supermarket that I can actually get access to. To know that I could go to this, this or this restaurant.

R: Right I think that's probably about it ...

I7: Just another thing about eating out – eating on the run's pretty difficult. You know, like if you are needing a quick meal and you are out somewhere, and you need a quick meal prior to going somewhere else – you know, Maca's is out, KFC is out, Pizza Hut unless you happen to be in New Plymouth – is out – I mean Hell's pizza do a gluten free pizza which is to die for. I mean, even going to Maca's or KFC and getting a salad isn't safe because it's got chicken in it sort of thing, and to be honest, when you've been on this thing for a while you are saladed out too. Sick of salads!! Or chips!! You know.

The other thing I find difficult, is if you have been tie up at work, and it's really late and you need to get home in a hurry. You know, it's 8 O'clock you're home, you need to get a meal in a hurry, there's not a lot you can do that's quick and easy. I've discovered a couple of meals I can eat at the Chinese shop down here, but I'm kinda 'Chicken and Cashew nuted out' – or Stir fried rice is my other option. Yeah, so a limited selection of easy to eat, quick to have meals. Short of – if all else fails I will grab some hot chips, and again, it's not healthy stuff and you do get sick of – if everyone else is having take-away's – you think well, I'm eating chips.

R: And then some chips can be floured.

I7: They can!! And you know, that's the risk – it's a gamble. You know, you've been out on a working project some day – family – and someone says “well, we'll grab some fish & Chips for tea” – you know – so everyone throws in some money to grab some fish & Chips, and you think: “well, I'm eating chips, and I'm taking a risk here”. I mean, it's a risk that I will choose to take sometimes. The other thing is if I know that I'm not going to be at work the next day – if I've got a day off – then I will choose to gamble a little bit more, then if I do pay the price then at least I'm not trying to still cope with it at work as well.

R: Well, I think we can wrap it up there. Thank you I7 for doing this interview, and for your time and insight. I really appreciate it.

J: Not a problem. Good luck for your project, I hope it all comes together OK.

## Interview 8

**I8 = Interviewee 8**

**R = Researcher**

I introduce myself, and explain the project. The process of the interview is explained, and permission sought for videoing the interview. Consent is signed.

R: Hi I8, thanks for taking the time to do this interview. If you could start by just telling me about why you ended up going for tests in the first place, and the process of diagnosis?

I8: I had really just had a long history of diarrhoea, and I would go to the doctor, and they would say it was a bug. So they would do a stool sample, and it would come back negative, and it got to a point – this is over about three or four years, a long, long time – and then my Dad was diagnosed with cancer – prostate cancer, and he had it in the liver, and I was losing weight – I was spending all day on the toilet – and feeling lousy, thinking that I was going down the same track.

So I went to my doctor, and I said: “I want bloods and I want this, this and this” – not knowing what I was looking for – well, I thought I knew what was going to happen, but I wasn’t looking for Coeliac’s! And I was totally anaemic – I had no iron stores – and they said with the bowel history we should do a colonoscopy. So she referred me off for that, sent blood results through to [Name - Specialist], and he sent back a message saying: “I want a Coeliac screen on her”. So we did the Coeliac screen, which came back positive I was prepped for my colonoscopy! And so we went through and had the colonoscopy and the gastroscopy at the same time. Colonoscopy was fine; the gastroscopy was pretty nasty really! Yeah, there was just no villi at all on the gut – just

totally gone.

R: Did you get to see your images?

I8: No, I didn't, no. So yeah, that was about 2001 I think – no! 2004!

R: So you had been living with it for quite a while.

I8: Yeah. [Name] was born in 2001, and it was after she was born I just had this diarrhoea develop for no reason. But prior to that I'd had glandular fever then it went on and they said it was Chronic Fatigue Syndrome, then it went on and they said it was M.E – you know, lot's of little things that were there all the time. Yeah- so that was...

R: So you went from being told that you had to go on a gluten free diet, I guess, and from your diagnosis, what was the next step?

I8: They brought me a gluten free sandwich – he he he! At Southern Cross, and I was not impressed! Oh no! So I thought: “right, well bread's obviously out of my diet!” ha ha! What is Coeliac's Disease? I was thinking. And then a penny dropped, and I thought: “oh ! my cousin had talked to me about breads she couldn't eat!” – a long time ago – and she was diagnosed Coeliac ten years prior to me. And I got a lot of information from her – she sent me some books and things.

R: Did they send you to a dietician?

I8: I eventually got to a dietician – it was a good six, seven weeks later.

R: So, from being diagnosed, what advice did they give you straight away?

I8: Not a lot really! What was it? – Oh yeah, just that “you would be referred to a dietician and you needed to avoid bread and anything that has got ‘gluten’ in it”. But from memory, there wasn’t a lot of information given to me at that time. Once I had seen the dietician I then joined the Coeliac Society from that point I think it was. But in the meantime I had got a hold of [Name], and she had sent me down all her information: where she gets her bread from, where she gets her cereals from, and that sort of thing.

R: So you found out what to do through someone who was already diagnosed?

I8: Yeah, through someone who was already diagnosed really – yeah. I remember driving home from the gastroscopy, we called into Subway thinking “they’ll have gluten free stuff in there”. Haha! “what’s that?” they say!

R: Did you use any other resources to find out what gluten was in other than talking to other diagnosed people?

I8: Um, I think I just stumbled – just went a long my own way – Um, Internet. There was the society in New Plymouth. Cause in the meantime, Dad went on and died – like a week after I was diagnosed – so I had all this happening as well. So it was probably about May that I went up to New Plymouth with [Name] and had a meeting – I think it was about May – up there, and we decided we needed to have something locally – more central. And I think I might have had a newsletter posted out from the New Plymouth group. So yeah, sort of - my cousin – she’d bring food a long, for that time anyway, I probably wasn’t really thinking as to what else.

R: What were your cousin’s main suggestions?

I8: She actually did write me a letter which I have here somewhere... She said go to Brumby's – she would go to Brumby's at that stage for her bread – that was Hawera to New Plymouth! And there were speciality shops, like your health food shops and things, which had gluten free foods, but she also said that the supermarkets had as much available then as what the health food shops and that sort of thing. When she was first diagnosed, she said it was really hard – there was just nothing! Nothing around.

R: When was she diagnosed?

I8: She was diagnosed as a 16 year old. Yeah. Ten years prior to me, so around '93 – '94.

R: What do you do if you need to travel around the country or eat out?

I8: Ring ahead! Yeah. The spontaneity of OK let's just go out for tea – you can't really do that anymore. You get to know locally who will do the gluten free foods, but a lot of them will be “Oh, so you can't have the oil?” – you know! – they don't seem to be aware – or cheese – “can you cheese?” – Yes! So we were up in Auckland recently and I had to ring ahead to the restaurant and actually it was at Sky City - and they said “well you come down and we'll take you through what we've got”. So that was really good – yeah. So um, ringing ahead and making people aware I need um, special diet.

R: would you ever just turn up to a café and explain to them there – or would you always ring ahead?

I8: Um, sometime we would just turn up. But it's usually – being on a farm – we usually plan ahead for where we're going. And like, up in Hamilton, my two sisters are in Hamilton, and one of them is Coeliac, and she knows where “Oh pop into there,

they'll always have something, or something in the freezer". And [Name] down in Blenheim, my other sister, she's also a Coeliac, she knows down that way. We usually go the family areas anyway! And through the magazine they also have a list of eateries around New Zealand, who provide what – but that gets added to and taken off all the time.

R: So when did you join the Coeliac Society?

I8: At the time I was diagnosed – it would have been.

R: So, the handbook that you were given, how far after your diagnosis did that get to you?

I8: Um, I'm not 100% sure – maybe six, seven weeks?

R: Did you find it helpful?

I8: Initially I did. I went through and it gave me a lot of information like 'what is gluten' and 'where is it hiding' – um, a few bread mixes and tips, and that sort of thing. But then, I haven't really referred back to it recently. And then I've added to it with bits and pieces I've collected along the way, and sorted things – yeah.

R: Is that it there?

I8: That's the cover of it! So what I've really turned this into is the folder for the magazine, all the Link's and all the leaflet's that I've had – that I've picked up along the way.

I8: And then this bigger folder here – that's part of it here – 'Coeliac Disease', 'Gluten Free foods'. And then through work, I had to do – one of the nurses at work was doing a study on hereditary illnesses or something like that, and she said: "can I pick you?" So that was her little family tree.

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**Figure 35**  
Original Coeliac Society  
handbook folder being used  
to store Coeliac Society 'Link'  
magazines. (Film still)

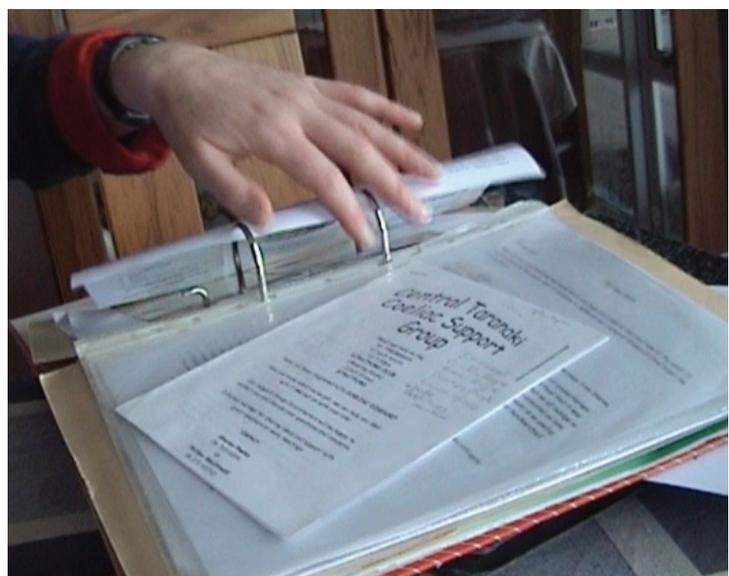


They are just bits and pieces that I have collected up along the way – Organic Matters, I think they are in New Plymouth. They came and talked to us at a Coeliac meeting one time. A book that [Name] started, we started to put together for our new Coeliac people. But I don't know if [Name] got any further than that.

I8: Just bits and pieces. Newsletters that [Name] – we would send out. I had an experience where I had some food sent up from the gingerbread man in Christchurch, and the pizza was all crumbled. It was a bad experience. So that was their letter back form my complaint – basically they were blaming it on the

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**Figure 36**  
Member's handbook that  
has been modified to meet  
their own and others needs.  
Showing image of a book  
made for newly diagnosed  
Coeliac's in their local area.  
(Film still)



courier, and they sent down a product voucher to use for next time. It's quite expensive to get mail order things in. Yeah, and really just bits and pieces.

We had someone come in and talk to us who was associated with Coeliac Diseases, an agenda of a meeting – yeah all sorts of bits and pieces.

R: So you got quite involved with the awareness week?

I8: Yeah. [Name] and I – there's the letter from [Name - Cousin] – that she sent down, and she also said “by the time she had an appointment with the dietician, she had learnt more about it than the dietician had!” um, so that was from her. So I sort of just got the handbook and intermingled it through-out.

Bits and pieces – that's all from the handbook here – and just bit's and pieces off the Internet.

R: How much would you say you have used the Internet overall for finding out about Coeliac Disease?

I8: Quite a bit. Yeah. Initially. Magazine – things in the newspaper from Awareness week I came across. Oh, and Mum found this “A new pill holds hope for sufferers”. Somewhere down in the South Island. And just bits and pieces, like Vicky my sister too, she emailed through to the Coeliac Society with a query on malt and deli ham, as well – so thee response back. So that's really all – bits and pieces. That's when we first started out group up – those people aren't there anymore – Deborah May Bread – these guys came and talked to us. Venerdi, he came down.

R: were they helpful?

I8: Yeah. He was good actually. I use his bread, cause

you can get it at the supermarket now. He was good yeah. Um, this is more from the handbook – from memory. This is all bits of product that’s around. I’ve got another book over there with recipes.

R: Were mainly collating all this information because you were co-running a support group?

I8: Part of a support group – but also for myself. Just so I could have it all together and go “this is what ...” you know, or someone might say “what does it mean to do this? – or that?”. So you can just show them the information, or, and particularly with two sisters with it as well.

R: So has advice from family been really important for you?

I8: Yeah. Well I was the first out of the three of us diagnosed, it was then [Name - Specialist] said: “If you have anyone in your family that is anaemic or with bowel problems, get them tested”, so both of these girls have been low iron all the time – anaemic. [Name] my youngest one, who is up in Hamilton, she was pregnant at the time – she had the blood test – it came back positive, [Name] had the blood test, it came back positive – scope positive. Jenny said: “I’m not even going to bother with the scope”. So she just decided to go gluten free from there-on in, and felt heaps better.

R: So, as far as feeling better, did you notice almost immediately a change?

I8: Pretty much. Yeah, I did. And the energy levels that came back – just, yeah – able to achieve more and no more sore tummy’s and being told I’m offensive! Haha!

R: So what advice would you give to a recently diag-

nosed Coeliac – I know you are actually seeing one this afternoon! – but would be the first thing you would advise them to do?

I8: Well, I don't think they need to tip their pantry out and bring everything in, they need to work out for each meal of the day that they have got something there. And it's going to take a while to find the foods and really adjust – you're cooking is totally different! – I've had some disasters!

Um, yeah – it's hard work initially, but for that bit of hard work, you feel so much better. At the end of it all. You don't want to go back – you can't afford to go back! – to what you were doing!

Like I said to him yesterday: "It's not easy initially – it's quite daunting – you don't know where to go, where to get your information from and that sort of thing".

R: How did he get your number?

I8: He had been to the dietician and she had my number, because [Name] and I were contact people, but it mainly all went to [Name]. He's the first person I've actually had ring me. So, I've had no one from South Taranaki contact me. I don't even know if he's made contact with the Coeliac Society or anything, but he's sounding quite lost.

R: You are a nurse, so you probably have a pretty good understanding of what happens visually to your intestines if you eat gluten –

I8: Yeah, with all the finger-like projections...

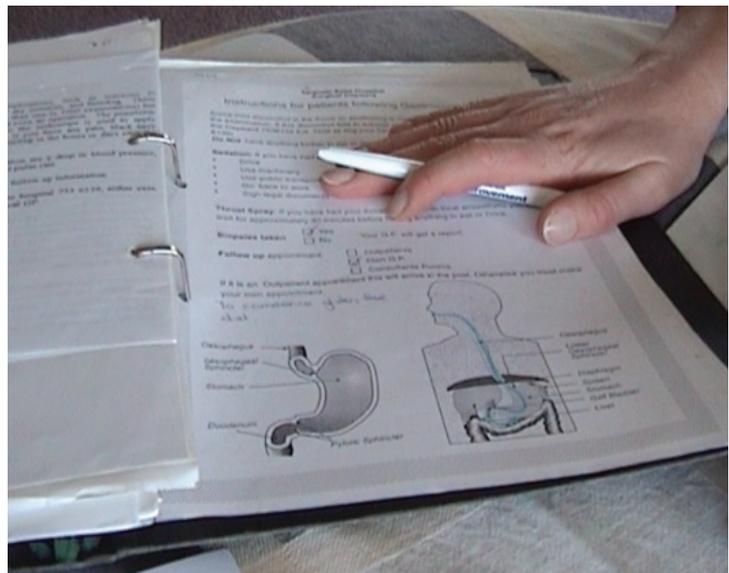
R: Have you found any images that have helped your understanding of Coeliac Disease?

I8: No, not really.

R: Can you think of anything that could improve the handbook?

I8: Oh! [Name] had something from when she had her scope!! This is her bit's and pieces... Coming from a nursing background, they say you have to have an endoscopy, so you know what that is, but for the people that don't – she had a little – you know, it showed the esophageus and down into your gut through a drawing, and where they are going to be looking into and that sort of thing. Oh here, basically explaining what they have done.

**Figure 37**  
Drawing given to patient after endoscopy to explain procedure. (Film still)



I8: That was obviously at Day Ward. It would be quite neat to see pictures of the gut damaged with gluten. Abnormal to the normal – what it should and shouldn't look like. It might help people to understand the absorption. Why people start losing weight, why people become anaemic – that sort of thing – because it's not able to absorb – cause they just can't!

I8: This is what she was given when she was diagnosed I guess (refer's to Cousin's folder). I don't know if there's was a Taranaki group at this stage,

because this must have been like the ink magazine – yeah, cause it says ‘Coeliac Society of New Zealand’. So the Link magazine must have come from these (referring to a photocopied newsletter).

R: Do you find the magazine useful?

I8: Yeah, I look forward to the magazines. They’re good.

But the main downside of Coeliac Disease is the cost! The cost of your food. \$6 for a little loaf of bread or a ‘brick’ as the kids call it!

R: So your family don’t eat your food?

I8: The meals I cook are all gluten free. The majority of the baking I do is gluten free, but their school lunches – they take their own sandwiches. Breakfast they do their own thing for cereal. But the main meals are all ... Other than breakfast, and sandwiches, everything else is gluten free – and they enjoy all my crackers and that sort of thing! So I guess they are sort of 50/50.

R: Do you think your kids understand what you have?

I8: Yeah, they will often say “has that got gluten in it Mum? Are you allowed that?” – or wheat- “are you allowed that wheat?” Yeah, they are probably more aware of...yeah, they have a reasonable understanding.

R: I have spoken to a couple of parents with kids that have Coeliac Disease, and that’s one issue – trying to explain it to them so they understand.

I8: Yeah. I think having lived with it already, the kids, should they go on and be diagnosed – which I think [Name], I don’t know, I think she might do –

they've already got that bit of insight into it.

R: And of course, they would have the support!

I8: Yeah!

R: Just one thing about the format of the handbook. It is interesting to see how you have added, and just kept adding – so as far as a ring binder format goes, would you think that was advisable, given the way you currently use it?

I8: Um, I think the ring binder is good, because you can just open things up and add things into it, rather than a fixed book as such.

R: The only thing is it's quite big ...

I8: The bulk!! Yeah, that's the other thing. But, I found it useful for me...

But there could be like a 'beginning edition' and... cause the other thing, when you are first diagnosed, you have people out there, the novices, who say: "you should have this" or "I've seen this". You have information, at times coming from all directions. And you are trying to digest as well what's going on. Sometimes too much information can be harmful.

They need to know the basics, and then get their head around the basics.

R: Thanks I8 for sharing all your resources with me, and taking time out of your busy day to talk to me! I really appreciate it, and you've given me some useful things to think about!

I8: Yeah...that's fine. Good luck for your project and keep in touch.

## **Appendix G**

Focus group transcript

## Focus group

For anonymity reasons the names of the focus group participants have not been used, instead they have been abbreviated to **FGP** (Focus Group Participant) and to differentiate, between them they have been allocated a number (**e.g. FGP: 1, FGP: 2, FGP: 3 etc**). **R = Researcher**.

The focus group session involved five participants (not including the researcher), and ran over a period of an hour and a half. During this time participants had to read over the information in the handbook, so dialogue was not continuously maintained for the whole period of time.

R: Welcome, and thank you everyone for coming. Make sure you help yourself to the food and drink provided. This is intended to be a fairly casual session, where you get to talk to each other to discuss and evaluate the handbook I have produced. I don't think everyone knows each other here, so if we could go around and introduce ourselves that would be great.

FGP:1: Hi I'm [Name]. I'm an administrator for a charity - YMCA. I used to work with [Name] and we talked about Coeliac Disease a bit because both my parents have it – and I'm used to allergies and food intolerances and stuff cause my boyfriend is allergic to dairy and eggs.

FGP:2: I'm [Name]. I live with [Name]. I work in sales. Um, I don't really know any people with Coeliac Disease and I don't have it. I've heard about gluten-intolerant people though, and wouldn't mind learning some stuff about it. I came with [Name] really, but think it could be fun.

FGP:3: Well I'm [Name]. Like [Name] I don't know

anyone really with Coeliac Disease – oh, except for [Name]! I'm a biology graduate, but now work in outdoor education as a seasonal instructor. I'm friends with [Name] and promised her I'd do this!!

R: thanks [Name]...

FGP:4: Hi I'm [Name]. I'm [Name]'s brother. He suggested I come along because I'm a Medical graduate, and he thought I might be useful in that way. He overheard me talking to my mate the other day about Coeliac Disease, and told me about [Name]'s project. So yeah, uh, hope I can help.

FGP:1: well that's an easy name to remember!

FGP:5: Right well, I think most of you guys know me... but I'm [Name]. I'm friends with [Name], and [Name] I guess – ha ha.

FGP:1: Hey!

FGP:5: So, anyway, [Name] got me and [Name] involved cause I live with someone who has Coeliac Disease – and we have adjusted all our meals to be gluten-free. Also, my aunty has Coeliac Disease, so all our Christmas meals have had gluten-free stuff for a while...so I guess I'm fairly familiar with Coeliac's and their requirements.

R: And finally, I guess to be fair! As you all know, I'm [Name], and I'm doing my Masters on User-centred Design. I have Coeliac Disease myself, and have worked with the Coeliac Society to generate user research for this project – and this is the last part – so I'm really happy you have all chosen to join in. So, I guess, let's get started!

R: Firstly, before we begin can everyone read through the information sheets I have given you, and

sign the consent forms. If you have any questions please ask.

\*Participants start reading the information sheet and sign consent forms

FGP:1: Do we have to put our address?

R: No, that's up to you. You can leave it off if you like

FGP:2: What about this bit – do I want a summary? I don't really...

R: You don't have to tick that if you don't want to.

\*Participants hand back consent forms

R: Ok, the purpose of this session is to evaluate the handbook I have designed. I'd really like to encourage you to talk to each other. I'm going to take a backward seat at the moment, and just 'listen in'. Please try to just talk to each other at the moment rather than me. We are going to have a look at the current handbook first, then the one I have designed. Later on in the session I'll intervene - I have some questions for you. Right, let's get started!

R: OK, now what I'm going to do first is let you look through the current handbook that the Coeliac Society sends out to members. There's quite a bit to look through in it, so we'll spend the next 10-15 minutes looking through it. The idea is to familiarise yourself with the material I have chosen to improve on before you look at mine.

FGP:1: OK, sounds good. I'm first.

R: Since there is only one handbook, maybe if we split up into two groups. [Name] and [Name], you

are already sitting together, so you can look through it together, and [Name] and [Name], you guys are already together too. [Name], I guess you can choose who you join in with.

FGP:1: What? This is horrible! You got sent this?

FGP:2: There are a lot of pages of type!

\*About 5 minutes later

FGP:1: I give up. I'm dyslexic and honestly, there's just too much information here. If I got this I wouldn't read it. There's not colour or pictures at all.

FGP:2: Yes, there is a lot of information...do you boys want to look?

FGP:3: Yeah, pass it over.

FGP:3: Ha! Are you serious? Is this really what members pay to get? I'm sorry, but I don't know if I can be bothered reading this either.

FGP:4: It appears that there may be some good information in here, but it's really badly laid out. There's no colour, as you said [Name], and so much type.

FGP:3: You know, it looks like they just went onto the net and pulled off loads of information and photocopied it off...

FGP:5: that's what it looks like.

\* FGP:3 chucks down the original handbook on the floor, without reading it.

FGP:3: You know [Name], anything you do will be an improvement on this!

R: OK, well, I'll now pass around the handbook I have designed. Just some points before you get started. This is a prototype, so the final version will be printed in better quality, so the colour and the paper will be better. The other thing is there are one or two places I have used something called 'placeholder type'. This means that the words aren't real, they start of with Ipsum Lorem, and this is used to just give me an idea of what the page will look like with type in it. I will put the real words in before it is finished.

I'm not going to interfere at the moment, and will sit back and let you discuss any ideas. Feel free to be critical and provide suggestions, as this is an evaluation. Ok?

\*The handbook is passed to FGP:1 & FGP:2 first

FGP:1: Oh, Oh! I can see colour! I haven't even got it and I can see colour. I'm going to like this I know it!

FGP:2: oooh. Look at this.

FGP:1 and FGP:2 spend the next 15minutes looking through the handbook, making comments and pointing out some errors

FGP:1: I really like the colour, and these tab things... though I'm guessing in the final one they won't be stuck on! Ha ha.

FGP:2: Yeah, your eyes kinda jump to the place you want to read. It's well broken up.

FGP:1: I like how these sections are in a different colour. It makes it clear when each section begins and ends. I think it's also good that important words are also in the same colour as the sections. Hmm...

it all ties in doesn't it...the colours really good.

FGP:2: Ooh! There's a typo: Note down that on page 9: what is gluten, 3rd paragraph, it says 'an dis' instead of 'and is'.

FGP:1: also on page 9, the end is repeated on the following section.

FGP:2: I'm really liking the look of it though. What I really like is the handy hint, reference summary thing at the end of each page – I think that works really well.

FGP:1: Yeah, I really like that too.

FGP:2: It's really well broken up isn't it?

FGP:1: Yeah – ooh...I like these diagrams. Look at this...

FGP:2: Oh yeah, that's cool. Oh, that makes sense now. Well, I didn't know that. This is a very educational evening isn't it!?

FGP:2: um, on page 31, this doesn't really read that well. You may want to think about rewording it.

FGP:2: Uh, page 36, there's a bullet point missing from 'remember'

FGP:2: Also, page 39, the paragraph on the Thai restaurant...spelling of sauce.

FGP:2: ...and page 45....it doesn't read well. You might want to change that.

FGP:2: I do really like the bits down the side saying what section you are in.

FGP:1: Hey, this is cool. You can go to this website and get travel cards. That would be so handy. That's a good thing to include.

FGP:1: I do like it - it's good. Ooh, this a bit odd (points to the restaurant cards) - oh no, I get it. Oh you pop them out for your wallet. No, I like it. Do you boys want to look?

\*The handbook is passed over for to FGP:3, FGP:4 and FGP:5, like the girls they spend the next 15 minutes looking through the handbook, making comments and pointing out some errors

FGP:3: AH! So this is what you have been working away on! Now, THIS is something I'd like to receive if I paid membership!

FGP:4: hmmm.

FGP:3: So, this is that placeholder stuff you were talking about. What were you going to say here?

R: Oh, sorry I forgot to mention...those bits on the section tile pages...they list what's in each section with page numbers. Like a break down of the contents page.

FGP:3: Ah, you see...yes, once you do that it will be good. That will help.

FGP:3: (talking to FGP:4)...so is this drawing accurate?

FGP:4: yes, I think it is. It's stylised, but it shows what people need to see. You see, here's the bowel. That's where the damage happens.

FGP:3: the bowel? It says duodendum?

FGP:4: Same thing.

FGP:4: Um...this could be worded differently though. This paragraph, it is a bit wordy.

FGP:3: Ok, now I'm thinking that we leave the proofreading until later. It's taking up heaps of time. I'm sure [Name] wants our overall impressions don't you? Or do you want it proofread. I can proof it for you later if you want?

R: Yeah, that would be good [Name]. Yes, let's stick to overall impressions. It does need to be proof read, but it's getting late.

FGP:2: Oh I'm sorry! I really thought you wanted it proofed.

R: No, no, don't apologise. Your suggestions were really helpful. It's just time is running on.

FGP:3: Ok, yeah, I'll proof it on Friday for you...I can see quite a few typos in it. Hey [Name]? We can sit down for an hour over fresh coffee.

FGP:4: Yeah, alright.

FGP:3: This food label information is interesting. Hmm – that's good, how you would see the label on the packaging.

FGP:5: I've talked to [Name] about this handbook before, and saw some stuff on her computer, but there's loads of stuff in here that I wasn't aware she was doing. Like, what the next page says bits are really useful. And the handy hints.

FGP:4: It's very accessible. It's basic, but it's got all the information that a Coeliac patient needs to know without being overwhelming.

FGP:4: Page 22 - that's quite a wordy statement.

FGP:3: yeah it is. Was this what someone actually said?

R: yes, it's a quote from an interview

FGP:3: It's just really badly worded.

FGP:4: I don't think there's anything wrong with a casual statement – it make it feel like it's real – like real people actually have Coeliac Disease. Only, you may want to think about another quote. It may look unprofessional.

FGP:3: See, this one, on page 58...that's really good. You know it's someone with Coeliac Disease saying that. But it's well worded. Anyway, I'll proof it for stuff like that later.

FGP:3: NOW! This is good. I really like this – this 'further information' section. There's a place to read more if you want to, but also points to where to go for more information. That's really good. I like that. I wouldn't have thought about travel, and I imagine many other Coeliac's wouldn't either until they were in that situation.

FGP:1: Yeah, I really liked that bit too.

FGP:3: Hey!? Look at these. These cards are cool. I'd get my handbook, skim through the pages and find those and cut them out straight away. Or! You could pop them out! How cool would that be?

FGP:4: yeah, they are actually a good idea.

R: Thank you for your comments and suggestions so far. We should now move on to the last part of this session. I'm going to ask you all as one group some questions. These were asked in the questionnaire to evaluate the original handbook, and it would be

interesting to ask these about the new one, to assess evaluate how successful the modifications have been.

R: Firstly, how helpful do you think this information has been?

FGP:2: Very helpful – definitely. I think it is very helpful.

FGP:1: I agree with [Name].

FGP:4: I think it is very accessible. I think anyone could pick this up, read it and understand it. The pictures are good – they would be helpful. They are stylised, but make sense. You don't really want to see the medical photographs of the inside of your bowel either do you? It's not very pleasant for people to look at, and to be honest, I don't think it would help to explain it as well as these pictures.

FGP:5: I think it's very helpful. Basic, but to the point.

FGP:3: yeah. Very helpful. For sure.

R: Ok, how would you rate the quality of information given to you?

FGP:3: I take it by quality, you mean how well designed it is...or how professional looking? It's very good.

FGP:4: It seems considered and well designed. You have picked out information that is needed to explain Coeliac Disease, but you have also omitted unnecessary or confusing information.

FGP:1: I really like that you can jump from section to section. It makes it easy to use, and not confusing.

FGP:2: I think the quality is very good.

FGP:5: You said that it will be printed in better quality and this will give a better impression of the quality of information.

R: Do the pictures and diagrams assist your understanding of Coeliac Disease?

FGP:1: Yes.

FGP:2: Oh, definitely, they help for sure.

FGP:4: Yeah they do.

R: How attractive do you think the material is?

FGP:1: On a scale from 1-5, I reckon a 4

FGP:2: Yeah, I think that too – a 4

FGP:3: Hmm

FGP:4: yeah, I think a 4 out of 5: it's attractive and practical

FGP:3: yeah, you are right. I think a 4 out 5 too. It's not overly pretty and flowery which is good. It's information about a disease – you don't want it to be too pretty. You want it to provide information.

FGP:5: It's not about being pretty I don't think. But it still looks good.

R: If you owned this handbook, where would you store it?

FGP:1 & FGP:2: in the kitchen!

FGP:2: ha ha! Yeah – in the kitchen. I'd put it in a drawer, so I could refer to it when I was cooking.

FGP:3: yeah, I think kitchen too.

FGP:1: I'd keep it in the kitchen, but I would prefer it if it was less bulky. To be honest I don't like the ring binder.

FGP:2: Yeah, ring binders just don't seem that professional do they? I would prefer it to be bound...by one of those spiraly thingies.

FGP:1: A loopy-woopy thingy-bob – that would be good

FGP:3: A loopy-woopy thingy-bob! Ha ha! IS that a real name?

FGP:1: you know what I mean!

R: This is interesting. The reason I decided to go with a ring-binder was because in my interviews I conducted last July, quite a few said they really like the ring binder because they want to add more information into it as they find it. Also, it allows the Coeliac Society to update pages.

FGP:2: One way you could do it though, is like in a diary...you know, it's spiral bound, but with blank pages for notes. I always make notes in columns when I am reading stuff like this.

FGP:1: Yeah, note pages would be good. I just think spiral thingy, cause then you could open the information flat.

FGP:3: yeah, if it's bound then the pages don't open properly, and through all the use it would get they would get damaged. I don't think it should be bound, but maybe a spiral binding could work.

R: There was another option as well, 'looped staples'.

FGP:I: What are those?

R: I'll show you an example

\*A booklet, which has been loop-stapled, is passed around

FGP:I: I don't get it

R: Ok, well, another option is to take each section and bind them with these loop staples. This means you could take a whole section out at a time, and take it with you – to bed to read, to the shop, whatever – and you don't have to carry around the whole bulk.

FGP:5: Yeah, they could work. They would look a bit more professional by being bound I guess.

FGP:3: I see a problem with this. I think the booklets would get too damaged. I don't think it's a good idea.

FGP:I: No, I don't really get why that's useful. I reckon spiral.

FGP:5: I can see what you are getting at [Name] and [Name] about the look. It would 'look' better bound. I think though that the 'look' isn't what is important with this handbook. If people with Coeliac Disease said they needed to add information, then you need to run with that.

FGP:I: Yeah, but you could have notes pages

FGP:5: Yes, but then you have to hand write information in don't you? What if you found something online and printed it off?

FGP:I: you could stick it in

FGP:5: Yes, but you would have limited pages. A ring binder allows you to put as much as want in. I don't know – I just think that it's all very well saying it would look better, but I just don't know if it would function better.

FGP:1: hmmm, well it's something to consider.

R: I will definitely consider your points. The next question is: How easy or difficult do you think this handbook is to use?

FGP:1: I think it's pretty easy.

FGP:3: Yeah. The sections make it easy to find what you need.

FGP:2: I'm just thinking – if I was just diagnosed, I would want to find out first of all how do I fix it? Like, if I have been to the doctors and they tell me I have an infection, I want to know how to I clear the infection – well, you take antibiotics. So, when I'm reading this, the first thing I want to know is how to I fix it (picks up handbook) – and look, there it is 'treatment'. That was easy to find.

FGP:1: Each new section is in bold – also it's easy to find what you want in each section too.

FGP:4: I think it's not too complicated. It's a really good starter pack for someone who is recently diagnosed.

FGP:3: You know, I really do like the handy hints. They are really good. ALSO, these bits about 'things that might catch you out' and food that you can or can't eat. That's really good. There's food in there I wouldn't have thought about. And if you were diagnosed you would be like, 'Ok so what can I drink?' and it shows you here...you can't drink beer

FGP:4: That is unfortunate

FGP:3: I also think that the simple stuff makes you feel happier about it

FGP:5: Yeah, it's not too much. It doesn't freak you out.

FGP:1: I really like the handy hints

FGP:3: so do I, and I'd have those cards in my wallet ready to go...

R: Ok one of the questions that was asked about the original handbook, is what do you think the most important information is in the handbook?

FGP:4: What Coeliac Disease is.

FGP:3: What to avoid. You want to know what you can't eat

FGP:2: I think all the information is good

FGP:4: It covers all bases really. I don't think it's missing anything out

FGP:5: And it points you towards websites etc to find out more information

FGP:2: Yeah. It gives you the information, but says where you can get more.

R: Finally, one last question – some of the research has pointed out that people want the information to be positive. Do you think the handbook portrays this?

FGP:3: Well, those quotes you have used – at the beginning of sections. Some of those are good, but some could be worded better. It's good to include

people's thoughts though.

FGP:1: The colour is really good.

FGP:3: The cards are good too. Like I said before, the simple stuff – it makes you feel a bit happier, and like Rich said...what was it?

FGP:5: it doesn't freak people out.

FGP:3: yeah – ha ha.

FGP:1: I think it's easy to use as well. Why I think that is important, is if you were just diagnosed and you got loads of information that was hard to use it would make you more stressed out.

FGP:3: Yeah. That's good. I like it. I like it [Name].  
Just fix those quotes.

R: Well, thank you everyone for your insights and feedback...and all your positive comments. This took a bit longer than I anticipated, so thank you for your time. I guess there was a lot to read through!

FGP:3: I'll proof read it for you on Friday alright?

R: Thanks [Name] – look, I really appreciated everybody's contribution. Please feel free to eat some more...it's all gluten-free food by the way. Thank you, really, this has been very helpful.

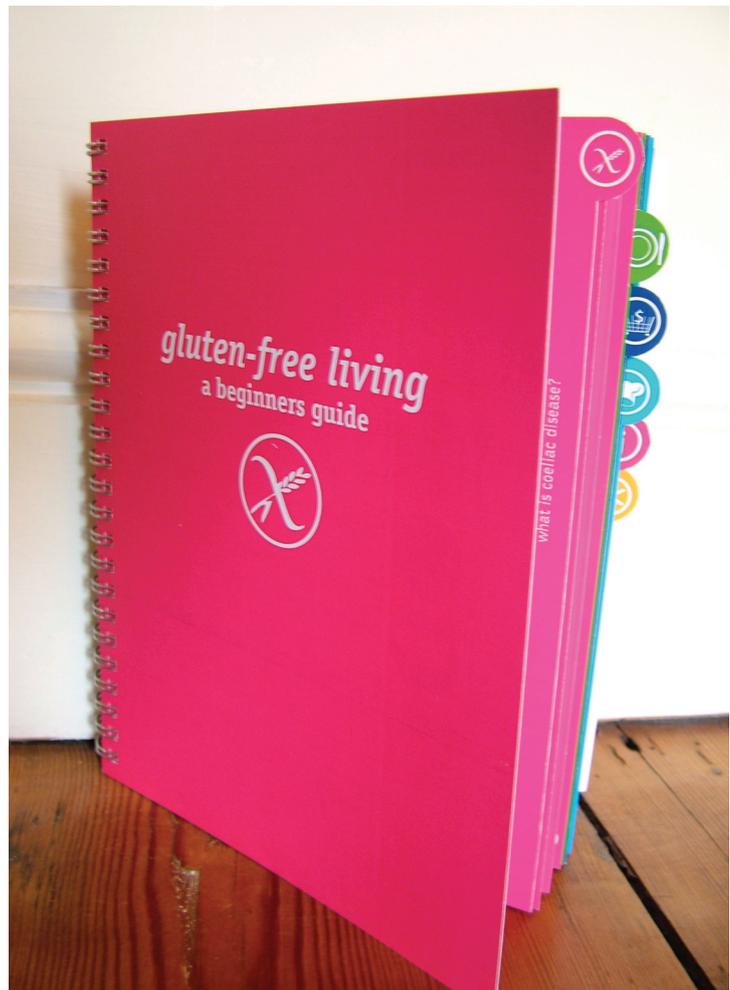
FGP:1: That's fine, it's been fun.

FGP:3: Yeah, and good to see what you've been up to for all this time!

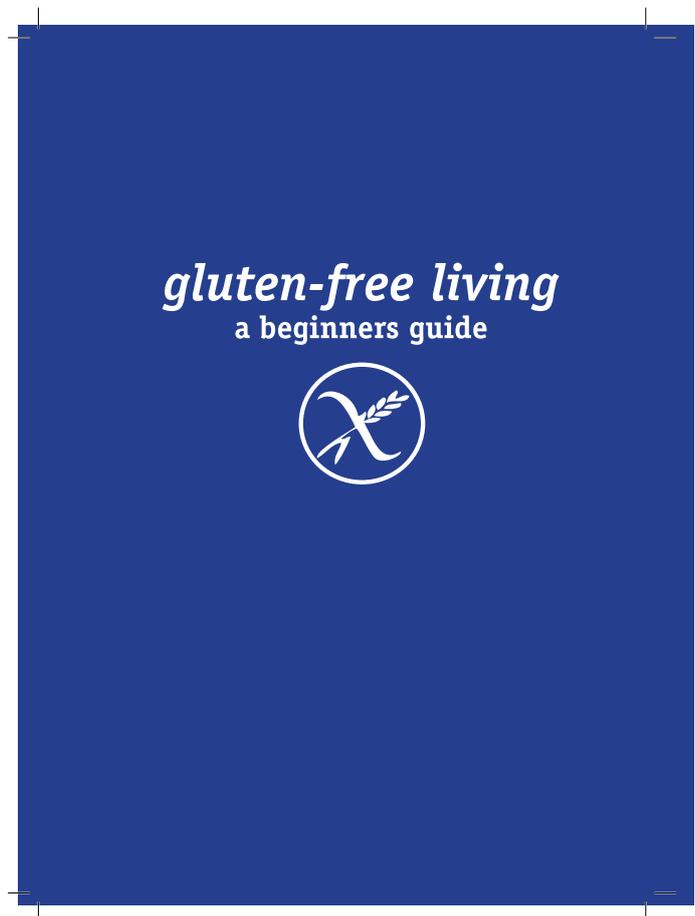
## Appendix H

Images of the handbook

**Figure 38**  
Original colour of handbook.



**Figure 39**  
Revised or alternative colour  
of handbook



## Contents

	WHAT IS COELIAC DISEASE — 1
	WHAT FOOD CAN I EAT? — 9
	SHOPPING — 19
	HOW DO I COOK GLUTEN-FREE? — 27
	FURTHER INFORMATION — 47
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## What is Coeliac Disease?

What is coeliac disease?

What is Coeliac Disease? — 3  
How does gluten affect you? — 4  
Symptoms — 6  
What is gluten? Treatment — 10



**Figure 40**  
Contents and page 1.  
(Not to scale)

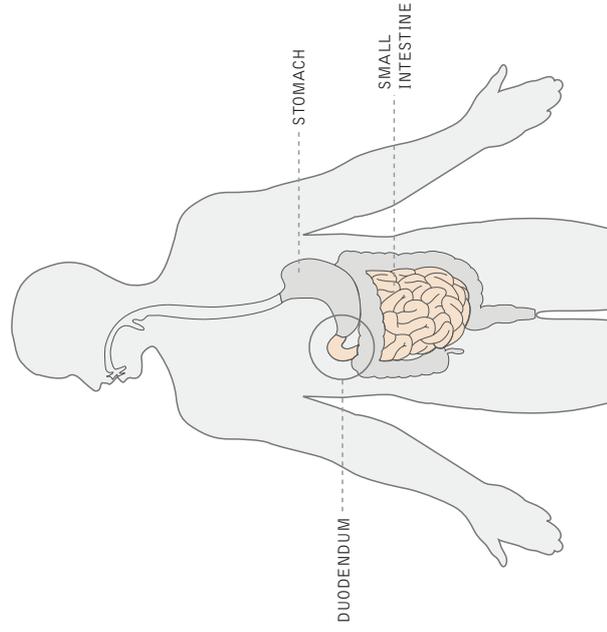
Coeliac Disease is a genetically based lifelong intolerance to dietary gluten. If gluten is eaten, damage to the lining of the small bowel occurs and food is not absorbed properly

2

what is coeliac disease?



### What is Coeliac Disease?



In the Coeliac gluten seems to stimulate the immune system of the body to attack itself. The damage seems to be most severe where the gluten concentration is highest, usually the duodenum first, then the small intestine.

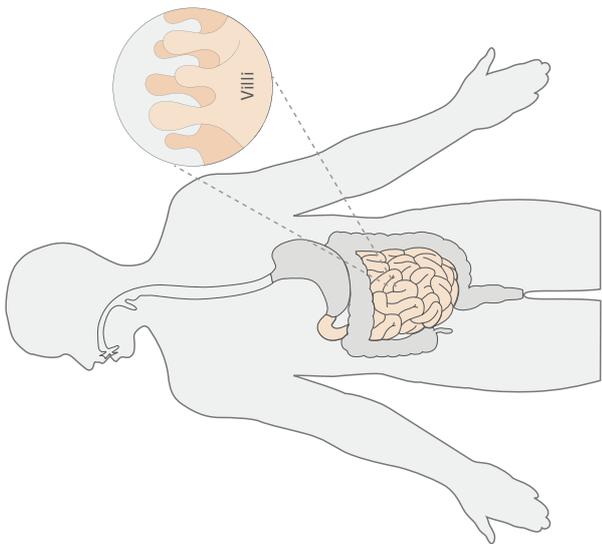
3

what is coeliac disease?



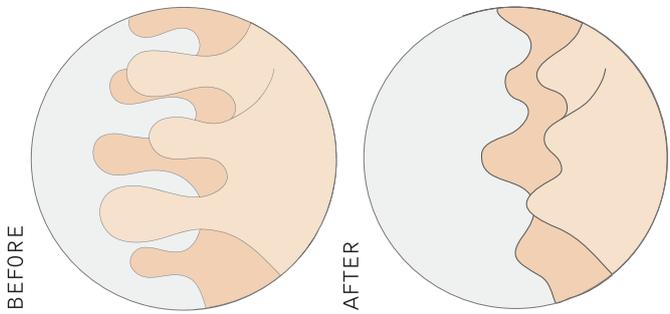
**Figure 41**  
Pages 2 & 3.  
(Not to scale)

### How does gluten affect you?



Even small amounts of gluten in food may affect people with Coeliac Disease. Coeliac Disease can be diagnosed from any age from infant to elderly. Ten per cent of diagnosed Coeliacs have family members who are subsequently found to be gluten intolerant.

### Villi



Damage is caused to the villi which increase the surface area of the intestine enormously. The villi become inflamed then stunted.

**Figure 42**  
Pages 4 & 5.  
(Not to scale)

6

What is coeliac disease?

**Symptoms**

Healthy villi increase the number of cells in the surface area available for the absorption of nutrients from the intestine into the bloodstream. When a person with Coeliac Disease eats gluten the villi are destroyed and flattened. This reduces the ability to absorb nutrients and often results in malabsorption, which leads to nutrient deficiencies and malnutrition.

When the villi are damaged it can be very difficult for the body to absorb enough nutrients from foods. Deficiency of these nutrients can lead to many other associated illnesses or health problems. Some essential vitamins and minerals that the body may become deficient in include: Calcium, Vitamin B12 (needed for building red blood cells and maintaining nerve cells), Folic Acid and Iron.

NB: The villi in the Coeliacs intestine will start to heal back once a gluten-free diet is maintained. In most cases the damage gradually heals and the Coeliac can lead a full life with normal expectancy.

*The page overleaf (fold-out) explains some of the symptoms that can be associated with Coeliac Disease.*

7

What is coeliac disease?

**Figure 43**  
Pages 6 (fold-out) & 7  
(Not to scale)

**Other symptoms?**

Other symptoms may include: Indigestion, irritability, cramps, nausea and vomiting, mouth ulcers, bloating and skin rashes such as Dermatitis Herpiformis.

Some associated disorders of Coeliac Disease include: Thyroid diseases, Type 1 Diabetes Mellitus, Abnormal Liver, Osteoporosis, Epilepsy and Infertility.

**What is gluten?**

Gluten is a protein found in any food made from **wheat, rye, barley, spelt** and **oats**.

Spelt is a wheat free grain, and is low in gluten, but is NOT gluten-free, so should also be avoided.

There are many obvious foods that contain gluten such as bread, cakes, pasta, crumbed and battered foods, as well as many types of pre-prepared and commercial foods where gluten may not be an expected ingredient.

***If in doubt, leave it out.***

**Treatment**

The treatment for Coeliac Disease is to follow a life-long gluten-free diet. By specifically removing the cause of the disease, this treatment allows the abnormalities, including that of the bowel lining to recover and will reduce the risk of developing other associated illnesses.



When the villi are damaged it can be very difficult for the body to absorb enough fats from foods.



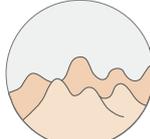
The inability to effectively absorb calcium can lead to brittle bones and **osteoporosis**. It is recommended that Coeliacs get a bone density check.



Malnourishment may lead to **weight loss** or **stunted growth** in children.



Symptoms of **fat malabsorption** include **diarrhoea**, malodorous **flatulence** (foul smelling gas), abdominal **bloating**, and increased amounts of fat in the stool. Some people suffer from **constipation**.



The inability to absorb folic acid and other nutrients may cause problems with **fertility** and may result in miscarriages during pregnancy.



### Symptoms

Fat malabsorption can result in **poor hair and skin health**. Vitamins included in healthy fats include: **Vitamin E:** Needed for healthy blood cells and tissues and **Niacin:** Needed for healthy skin.



The reduced absorption of protein results in low protein levels in the blood. When this occurs fluid can leak out of the blood vessels and into the bodies tissues. This results in **fluid retention**, where fluid leaks into the tissues and causes swelling.



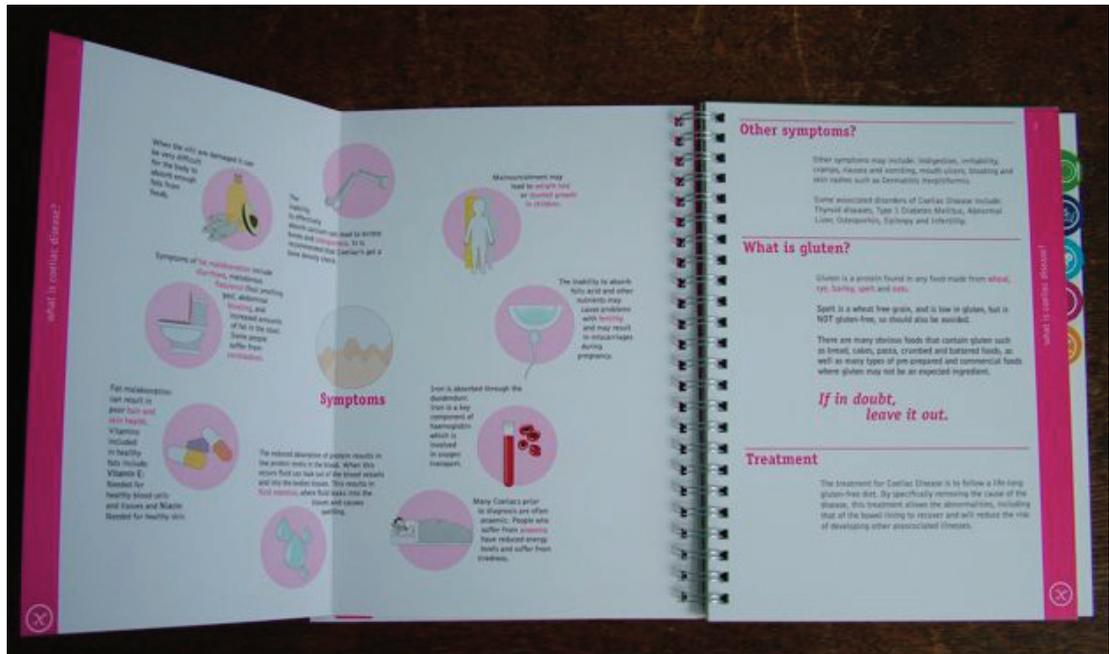
Iron is absorbed through the duodenum. Iron is a key component of haemoglobin which is involved in oxygen transport.



Many Coeliacs prior to diagnosis are often anaemic. People who suffer from **anaemia** have reduced energy levels and suffer from tiredness.



**Figure 44**  
Page 6 - overleaf (fold-out)  
(Not to scale)



**Figure 45**  
Photograph of Page 6 - overleaf (fold-out) and page 7  
(Not to scale)



“If I’ve got to have something, I don’t think Coeliac Disease is a bad thing to have. If you look after your diet you’re fine”

Kevin Marks, Auckland



### The importance of a gluten-free diet.

The treatment for Coeliac Disease is to follow a life-long gluten-free diet. Once gluten has been removed from the diet, symptoms will start to subside and the small intestine will start to heal. The villi, which became stunted on a gluten containing diet can repair, allowing for better absorption of nutrients into the body. This may take around six months depending on the severity of the damage.

Coeliacs may go through periods of lessened sensitivity, as people have differing sensitivities to gluten. However, all Coeliacs will continue to damage their small intestine when they consume gluten.

Continued damage may cause an increase in the severity of symptoms and potential risk of developing further complications or related illnesses. There is an increased risk of cancer and lymphoma of the small intestine in untreated Coeliac Disease.



*The following pages outline foods that are gluten-free, and foods you cannot eat.*

**Figure 47**  
Pages 10 & 11  
(Not to scale)



## Which foods are gluten-free?

Food type	Gluten-free	May contain gluten
<b>Alcohol</b>	— Wine — Champagne — Port — Sherry — Liqueurs — Spirits — Cider	— Beer
<b>Beverages</b>	— Tea/coffee — Herbal teas — Milk — Soft drinks — Juice — Cordial	— Barley drinks (lemon & barley cordial) — Malt drinks (Milo, Horlicks & some drinking chocolates)
<b>Dairy &amp; Eggs</b>	— Milk — Cream — Cheese — Natural yoghurt — Eggs	— Malted milks — Some flavoured milks — Some icecream flavours — Ice cream cones
<b>Grains, Flours &amp; Cereals</b>	— Corn — Maize cornflour — Polenta — Rice — Buckwheat — Amaranth — Soy flour — Millet — Potato starch — Quinoa — Arrowroot — Chickpea flour — Tapioca — Pea flour	— Wheat — Rye — Barley — Oats — Semolina — Bulgur — Kumat — Spelt — Dinkel (or German wheat) — Wheatgerm — Wheatmeal — Gluten flour —



Food type	Gluten-free	May contain gluten
<b>Fats &amp; Oils</b>	— Butter — Margarine — Vegetable oils	— Wheatgerm oil
<b>Fruit &amp; Vegetables, Nuts &amp; Seeds</b>	— All fresh fruit & vegetables — Fresh herbs — Plain nuts & seeds	— Seasoned vegetables (e.g. wedges) — Breaded vegetables — Vegetables in some sauces
<b>Meat, Fish &amp; Poultry</b>	— All fresh meat and fish	— Sausages — Stuffed meat — Battered fish — Some processed meats — Imitation seafood
<b>Soups</b>	— Soups made from fresh ingredients without thickeners, or thickened with gluten-free flour	— Any made with pearl barley — Any made with noodles or pasta — Any thickened with non-gluten-free flour
<b>Spreads &amp; Condiments</b>	— Jam & Marmalade — Honey — Peanut butter — Maple syrup — Golden syrup — Mollasses — Sugar — Tomato puree — White vinegar — Red wine vinegar — Balsamic vinegar — Tamaril soy sauce — Some mustards — Chocolate	— Vegemite, Marmite & Promite — Meat & fish paste — Malt vinegar — Some mustard powders — Some commercial sauces — Worcester sauce — Some flavoured chocolate — Some confectionary

**Figure 48**  
Pages 12 & 13  
(Not to scale)

14

what food can I eat?

### Things that may catch you out!

Food	Type	Information
Meat	Sausages	Breadcrumbs used to bulk
	Bacon & ham	What the meat is cured with
	Luncheon Sausage	Breadcrumbs used to bulk
Spreads & Condiments	Vegetite & Marmite	Malt
	Mayonnaise	Malt vinegar
	Malt vinegar	Malt
	Ground spices	Flour can be used to prevent clumping
	White Pepper & mustard powder	Flour used to bulk
	Ground almonds	May be bulked with breadcrumbs
Grains, Flours & Cereals	Soup powders	Wheat thickener
	Gravy mixes	Wheat thickener
	Sauce mixes	Wheat thickener
	Some cereals	Malt flavouring
	Flavoured chips	Wheat flavouring
	Pasta	Wheat flour
Beverages	Noodles	Wheat flour
	Couscous	Durum wheat
	Pasty	Wheat flour
	Bread & breadcrumbs	Wheat flour
	Milo/Horlicks	Malt flavouring
	Beer	Malt/Barley
Misc	Frozen chips	Floured for whiteness/crisp
	Play dough	Flour (especially for children)
	Medicines	Flour thickeners
	Cosmetics	Flour thickeners
	Bulk-Bin stores	Cross-contamination
	Yeast	Edmonds Surebake is not GF
Pre-grated packets of cheese	Flour used to bulk	

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what food can I eat?

**Figure 49**  
Pages 14 & 15  
(Not to scale)



## A gluten-free pantry.

After diagnosis you may be faced with the realisation that a lot of the food in your pantry is not gluten-free. Gluten-free food is often more expensive, however do not be faced with the dread of having to spend a huge amount of money in replacing all items that you cook with immediately.

You can replace items in your cupboards slowly — picking up one or two gluten-free items in each weeks shopping. You may find you already have some items that are gluten-free, such as rice. What is important is you replace the 'essential' items that you would usually cook with that are not gluten-free in order to start your gluten-free diet straight away.

*The following page outlines essential items you need to replace in your pantry.*



## Essential items for your pantry.

Food type	Brand
— Cornflour	▲ Fielders
— Baking Powder	▲ Edmonds
— Icing Sugar	▲ Chelsea
— Rice Flour	▲ Heatheries or Bin Inn
— Yeast	▲ Edmonds Active Yeast (not Sure Bake)
— Gluten-Free flour	▲ Simple, Heatheries, Bakers
— Cocoa Bombs - Lowan	▲ Cocoa Bombs - Lowan
— Cereal	▲ Koala Crisp - Envirokids
	▲ Porridge - Simple
	▲ Muesli - Simple, Hubbards
— Crackers	▲ Rice crackers - Fantastic & Sakata
	▲ Corn thins - Real Foods
	▲ Rice Crispbread - Orgran
	▲ Rice Wafers - Heatheries
— Rice Cookies	▲ Amotts
— Snack bars	▲ Orgran, Gluten-free Goodies Co., Eat Right, Freedom Foods
— Bread	▲ Venerdi, Bakedworks
— Breadcrumbs	▲ Bakedworks, Orgran
— White vinegar	▲ DYC
— Cider vinegar	▲ DYC
— Stock powder	▲ Massel
— Tamarini (Wheat-free soy sauce)	▲ Ceres Organic
— Hot chocolate	▲ Cadbury

*Note: The items mentioned above may be available in other brands. This list is intended only as a guide. Always make sure you check ingredients on the packaging for eating.*

**Figure 50**  
Pages 16 & 17  
(Not to scale)



# Shopping.

- Where to shop — 21
- Food additives — 22
- Vegetable gums, Manufactured Food List — 23
- Reading labels — 24
- Label examples — 25



**Figure 51**  
 Pages 18 & 19  
 (Not to scale)



“It’s not easy to live this way, and it’s reasonably expensive — but the health benefits are worth it!”

Jenny Hill, Stratford



## Where to shop.

Depending on locations, some places have a wider range of gluten-free products than others. You may have to shop around to get everything that you need. Below are a few places you can shop at to get various gluten-free items.

Place to shop	Information
▶ Supermarkets	— Some chains are more ‘gluten-free friendly’ than others, so you will need to shop around initially to see what supermarkets in your region offer. If your local store doesn’t have items you would like, consider asking them to add those items to their stock list
▶ Health Food Stores	— These shops can often be more expensive, but may offer gluten-free products not found in supermarkets
▶ Asian Food Stores	— These are well worth exploring. Many of these stores have a good selection of rice-based products (e.g. rice noodles) that are gluten-free.
▶ Bin Inn	— Bin Inn offers a cheap selection of bulk gluten-free flours and many other gluten-free products
▶ Hospital pharmacies & local pharmacies	— You are entitled to get some of your food on a health subsidy <b>See: <i>Further Information section for more information on this entitlement.</i></b>

**Figure 52**

Pages 20 & 21  
(Not to scale)



**Figure 53**  
Pages 22 & 23  
(Not to scale)

## Food additives.

When shopping for food many newly diagnosed Coeliac's become confused about food additives, and whether or not they are gluten-free. This section explains what food additives are gluten-free and how to identify gluten on food labels.

In New Zealand the eight most common allergens must be shown on the food label — this includes cereals that contain gluten and their products (wheat, rye, barley, oats and spelt). The ingredients are listed on the package in descending order of in-going weight. The list also includes additives, preservatives, flavours and colours. These can be identified by their function and name or code number, for example: Thickener (Pectin) or Thickener (440).

The vast majority of food additives with allocated numbers are chemical compounds which don't contain gluten.

Modified starches or thickeners are probably the group which cause coeliacs most concern. The modified starches (1400-1450) can theoretically be derived from a range of cereal products, for example wheat, maize, tapioca and potato starch.

Information from NZ food manufacturers is that modified starches used in this country with numbers from 1401-1450 are maize, tapioca or potato based, with the raw material obtained predominantly from NZ, the United States of America and Asia. 1400 is produced from a wheat based source in Australia<sup>1</sup>.

1401-1450: Maize, Tapioca and Potato starch derived  
1400: Wheat based

<sup>1</sup> Information adapted from: Steeper, A. Manufactured Food Database (2004).



## Vegetable gums.

Another additive that can be confusing for shoppers is 'vegetable gums'. Vegetable gums are used to stabilize or thicken the product. Almost all vegetable gums are from natural origin and are gluten-free. Below is a list of some common gluten-free vegetable gums used in New Zealand manufactured foods.

Number	Additive	Derived from
410	— Locust bean gum or Carob bean gum	— Seeds of carob tree
412	— Guar gum	— Guar beans
413	— Gum tragacanth	— Sap of Astragalus shrub
414	— Gum arabic	— Sap of Acacia trees
415	— Xanthan gum	— Produced by bacterial fermentation

## Manufactured food list.

To guide the process of selecting gluten-free products, The Ministry of Health maintains a database of Manufactured foods. Alongside reading labels, the database helps you identify which foods are gluten-free in your supermarket. Each year the Coeliac Society NZ prints an updated 'Manufactured Food List' which outlines gluten-free foods included in the database. This is sent out to members annually, however manufacturers sometimes change their ingredients throughout the year, so it is advisable to check ingredient lists as well.

The *Manufactured Food Database* is also available online: [www.mfd.co.nz](http://www.mfd.co.nz)





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how do i cook gluten-free?



## How do I cook gluten-free?



how do i cook gluten-free?

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**Figure 55**  
Pages 26 & 27  
(Not to scale)

“He’s been gluten-free for eight weeks now and he’s come out of his shell. He’s got so much more energy — he’s bouncing off the walls!”

Gina, Browns Bay – talking about her 3 year old son



## Cooking gluten-free.

There are many naturally gluten-free foods available, such as fresh meat, fresh vegetables, rice, rice noodles and pulses. Many of your favourite recipes can be adapted so they are gluten-free just by making some small adjustments to ingredients. It is unlikely that you will even notice a taste difference.

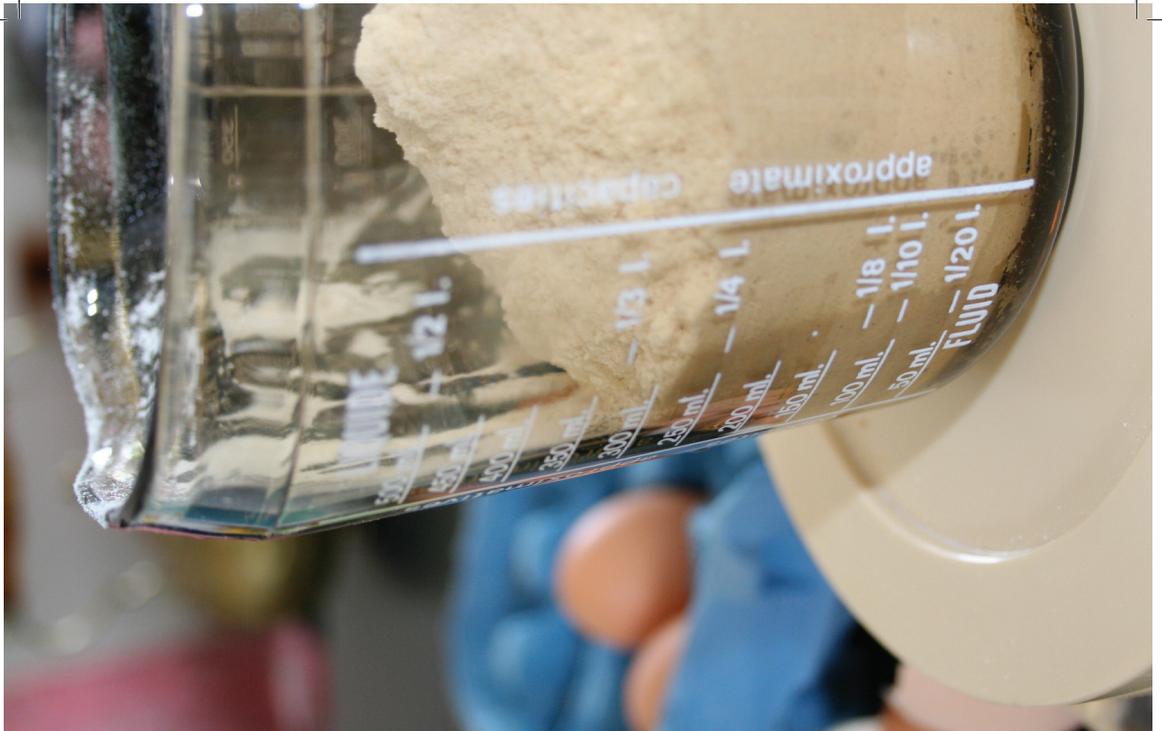
Plenty of gluten-free cereals and grains are available at your supermarket or at bulk food outlets such as BIN INN. You can also purchase baking and bread mixes.

Gluten-free flours do not work the same as regular flour, and may take some experimentation with different quantities and mixes. After you familiarise yourself with gluten-free flours, you will find you can still cook with as much success and ease as your normal meals.

*The next pages outline some suggestions and simple substitutions you can make to your recipes using gluten-free alternatives*



**Figure 56**  
Pages 28 & 29  
(Not to scale)



**Figure 57**  
Pages 30 & 31  
(Not to scale)



## Gluten-free flour.

Gluten enhances elasticity, stabilises, improves rising and holds moisture in bread. For this reason gluten-free flour cannot be simply substituted for wheat or rye flours — you will not get the same result.

When using gluten-free flour as a substitute, it is important to use a binder (to act as a replacement for the gluten). More raising agent may be needed when working with gluten-free flours. If using pre-mixed flours, not all brands work the same, and may therefore produce different results.

## Combining flours.

It is recommended to combine two or three different gluten-free flours together when substituting for wheat flour (it is important to mix these flours together well). Mixing flours will provide better texture and flavour than one alone.

The following table provides suggestions on how to mix gluten-free flours.

Flour 1: Crumbly or grainy	Flour 2: Binder	Binder	Texture & flavour
Corn	Buckwheat	Egg	Ground almonds
Rice	Arrowroot	Pectin	Ground linseed
Millet	Tapioca	Guar gum	Ground sesame seed
Amaranth	Potato starch	Xanthan gum	
	Potato flour	Sago	
	Pea or pulse flour		

Combine 1 or 2 units of Flour 1 with 1 unit of Flour 2.  
Mix these flours with 1 or 2 different binders and for optional texture and flavour add 1 or 2 types of seeds.

**Figure 58**  
Pages 32 & 33  
(Not to scale)



### Adaptations — helpful hints.

- ▲ Instead of using regular flour to thicken gravies and sauces use cornflour
- ▲ Simply substituting your stock can make your meal gluten-free
- ▲ Use Tamarri instead of regular wheat-based soy sauce
- ▲ Rice paper wrappers can be used as 'wraps' instead of tortillas
- ▲ Rice noodles are a quick and easy gluten-free food
- ▲ Freeze old gluten-free bread, or bake a loaf to use later as breadcrumbs
- ▲ Some people react to guar gum, so xanthan gum may be better. Use this to replace the elastic qualities of gluten
- ▲ Fish can be tossed in rice flour or crumbed with gluten-free bread crumbs
- ▲ Use white vinegar instead of malt vinegar
- ▲ You can buy gluten-free pasta, or try making your own for lasagne sheets

*Remember: All fresh fruit, vegetable, meat and fish are gluten-free!*

### Basic meal ideas.

- Breakfast — 34
- Lunch — 36
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- Dinner. Eating out. Takeaways — 38



## Breakfast.

Being on a gluten-free diet doesn't mean you have to skip breakfast! Supermarkets now stock a range of gluten-free cereals, or you can make your own using ingredients such as millet, puffed rice, quinoa and dried fruit and nuts. Eggs are a good gluten-free source of protein. Also remember fresh fruit and yoghurt is also gluten-free.

- ▲ Gluten-free bread (for toast)
- ▲ Eggs
- ▲ Buckwheat pancakes
- ▲ Natural yoghurt
- ▲ Fresh fruit
- ▲ Gluten-free cereal
- Simple: muesli & rice porridge
- Hubbards: 'Thank Goodness'
- Lowan: Cocoa Bombs
- Environkids: Koala Crisp
- Natures Path: Mesa Sunrise



**Figure 59**  
Pages 34 & 35  
(Not to scale)

## Lunch.

Gluten-free lunches can be the most challenging meal for Coeliacs. Gluten-free bread (for sandwiches) does not travel easily, and can be very crumbly. If on the run, you can't just drop into a bakery and grab a filled-roll or a pie.

It often pays to be prepared for lunches. Get used to freezing down small one-person servings of leftovers!

*Below are some suggestions and ideas for gluten-free lunches.*

- ▶ Corn chips with cheese and humous
- ▶ Yoghurt
- ▶ Left over meat dishes (e.g. mince, roast chicken)
- ▶ Fruit
- ▶ Vegetables and salads
- ▶ Eggs — omelettes, scrambled, poached, boiled
- ▶ Rice crackers or crispbreads — topped with ham, cheese, tomatoes etc
- ▶ Frittatas
- ▶ Stuffed potatoes or kumera
- ▶ Risotto's and other rice dishes
- ▶ Sushi (remember to use Tamari soy sauce!)
- ▶ Soup (no pearl barley)
- ▶ Gluten-free muffins
- ▶ Toasted sandwiches with gluten-free bread
- ▶ Smoked or tinned salmon with rice
- ▶ Gluten-free pizza (home-made, or from 'Hell pizza')



## Children's lunch-boxes.

Children's lunches require some planning, as a quick, simple sandwich is not an option, unless made with gluten-free bread. As gluten-free bread can get quite crumbly, it may be better to fill children's lunchboxes with a variety of gluten-free snacks.

*Below are some suggestions and ideas for children's gluten-free lunches.*

- ▶ Snack-sized corn chips or rice crackers
- ▶ Rice cakes with a topping (e.g. peanut butter)
- ▶ Yoghurt
- ▶ Snack-sized raisins, nuts or popcorn
- ▶ Fruit
- ▶ Raw vegetables (e.g. carrot sticks)
- ▶ Boiled egg
- ▶ Cheese slices
- ▶ Home made gluten-free muffins or cakes
- ▶ Gluten-free nut bars
- ▶ Salami sticks

*Make sure your child is discouraged to swap lunches. Gluten-free food will not harm a child who is not Coeliac, but the opposite is true for a child with Coeliac Disease.*

**Figure 60**  
Pages 36 & 37  
(Not to scale)



## Dinner.

Meal-time can be healthy and wholesome. Avoid pre-mixes, convenience and processed foods, and opt for fresh meat, fish and vegetables. Also try to maintain a balance between amounts of protein, fibre, fats and carbohydrates.

Meals such as curries, nachos, risottos can all be made with gluten-free ingredients. You can purchase gluten-free pasta from supermarkets, or try to make your own for lasagne. Meat and vegetables, rice and pulses are gluten-free.

*Info: The Coeliac Society NZ has a range of gluten-free cookbooks for loan or purchase*

## Eating out.

More people are becoming aware of Coeliac Disease, and people within the food industry are starting to respond to this need. In most cases gluten-free alternatives are available.

If you can, ring the restaurant in advance and speak to the chef. At the restaurant, don't hesitate to ask questions — it is your right.

## Take-aways.

Not all take-away food is off limits, but exert the same care as you would do eating in a restaurant — and ask questions! Fish and Chips should be avoided. The fish is usually battered in wheat flour or breadcrumbs, and is prepared in the same fryer as the chips, which will cause cross-contamination.

**Italian** restaurants will usually offer gluten-free options despite their reputation for pizza and pasta. Try a risotto, salad or polenta.

**Indian** restaurants are often safe to eat at, as long as they cook with fresh ingredients. Indian cooking usually uses



chick-pea flour, which is gluten-free. But always double check. Poppadoms are gluten-free.

**Chinese** restaurants can be tricky because of the use of soy sauce. Make sure you ask for soy sauce to be left out of the meal, or you could opt to bring your own Tamari for them to use.

**Thai** restaurants also use soy sauce in their cooking. Make sure you check that soy sauce is not an ingredient in your meal. There are however, plenty of gluten-free options available at a Thai restaurant, providing they use fresh ingredients in their cooking.

**Burger Fuel & Hell Pizza.** Both burgers and pizza are usually not gluten free, however Burger Fuel and Hell pizza are an exception. Both outlets offer gluten-free alternatives, with buns and pizza bases made by Venerdi. Just make sure the fillings are also gluten-free!

**Figure 61**  
Pages 38 & 39  
(Not to scale)



## Basic recipes

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### Bread.

Gluten-free bread can have various results. You may need to experiment using different flours and seeds, and try altering your breads one ingredient at a time to see how it affects your bread.

Make sure you do not use Edmonds 'Surebake' yeast, as this is not gluten-free. However, Edmonds 'Active Yeast' is.

*Below and overleaf are some basic recipe suggestions to get you started cooking gluten-free*

### Bread recipe 1 (oven).

- ▶ 300 ml warm water
- ▶ 1 ½ level tsp xanthan gum
- ▶ 2 large eggs
- ▶ 2 tbsp vegetable oil
- ▶ 1 tsp cider vinegar
- ▶ 2 tsp salt
- ▶ 30g dried milk powder
- ▶ 1 tbsp sugar
- ▶ 200g potato flour
- ▶ 50g white rice flour
- ▶ 4 ½ g dry yeast

Into a measuring jug mix the oil and xanthan gum well for a few seconds, then add the water and stir vigorously for 2 minutes to form a 'loopy texture'. Put the eggs, vinegar, salt, milk powder and sugar into a mixing bowl and add the xanthan gum/water mixture. Mix well with a wooden spoon for about 5 minutes. Then add the flour and mix for another 2 minutes. Finally add the dry yeast and mix again briefly.

Stand mix in a warm place for 1–2 hours until it rises, then pour into a greased loaf tin and bake in a pre-heated oven at 220C (430F) for about 30 minutes, or until cooked through. Leave to cool.

*Note: you can try using a breadmix instead of the flours suggested, but recipe results may vary.*

**Figure 62**  
 Pages 40 & 41  
 (Not to scale)



## Bread recipe 2 (breadmaker & oven).

- ▲ 3 tbsp sago
- ▲ 1 ½ cups thick natural yoghurt
- ▲ 4 ½ cups BakeIt's breadmix
- ▲ 1 tsp guar gum or xanthan gum
- ▲ 1 tsp salt
- ▲ 1 tsp sugar
- ▲ 1 tbsp HiMaize (available from the Coeliac Society)
- ▲ 1 ½ tsp Active Yeast
- ▲ 2 tbsp linseed (opt)
- ▲ ½ cup of sunflower or pumpkin seeds (opt)
- ▲ 2 ½ cup warm water

Soak the sago in the yoghurt and leave while you prepare the other ingredients. Dissolve the sugar and yeast in half of the warm water. Let stand.

Mix dry ingredients in a large bowl, then make a well in the centre and add the yoghurt & sago mixture. Then add the yeast, sugar & water mixture and remaining water.

Either bake in a breadmaker: Basic cycle, Medium crust, or bake in Oven: Use two greased loaf tins and bake at 160C for 35-40 minutes. Leave to cool.



## Chocolate chip muffins.

- ▲ 1 ¾ cups gluten-free baking mix or flour
- ▲ 1 tsp baking soda
- ▲ 1 cup caster sugar
- ▲ ¼ cup cocoa
- ▲ ¼ to ½ cup chocolate chips
- ▲ 100 ml oil
- ▲ 1 egg
- ▲ 1 cup natural yoghurt
- ▲ ½ cup milk
- ▲ ½ tsp vanilla essence

Mix dry ingredients together in a large bowl. Into the dry ingredients mix the egg, yoghurt, milk and vanilla together until smooth (do not over mix).

Divide the mixture evenly between 12 medium-sized muffin tins that have been well coated with a non-stick spray. Sprinkle extra chocolate chips on if desired.

Bake at 200C for 10-12 minutes or until the centres spring back lightly when pressed.

Leave to stand in pans for about 3 minutes before removing and cooling on a wire rack.

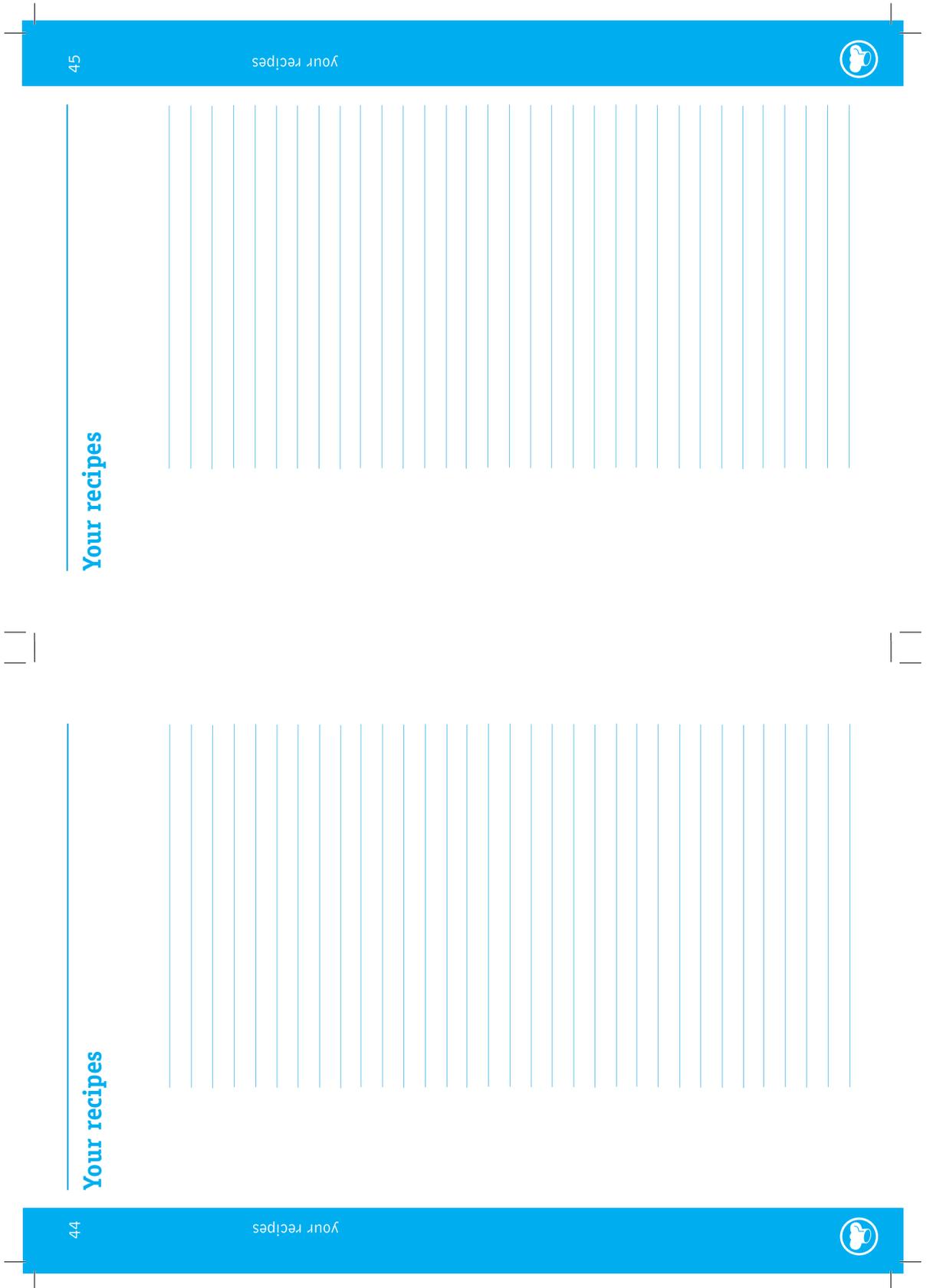
## Gluten-free roux.

The roux can be used to thicken sauces or gravies.

- ▲ 110g butter
- ▲ 50g rice flour
- ▲ 50g cornflour

Melt the butter in a saucepan and add the cornflour and rice flour. Combine the mixture using a wooden spoon and cook for 2 minutes on a low heat stirring occasionally.

**Figure 63**  
Pages 42 & 43  
(Not to scale)



**Figure 64**  
Pages 44 & 45  
(Not to scale)

**Your recipes**

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Your recipes



**Further information.**



further information

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**Figure 65**  
Pages 46 & 47  
(Not to scale)



**Figure 66**  
Pages 48 & 49  
(Not to scale)



**Figure 67**  
Pages 50 & 51  
(Not to scale)

## Dermatitis Herpiformis (DH).

Some Coeliac's also suffer from an uncommon skin condition called Dermatitis Herpiformis (DH). DH sufferers develop rash-like little blisters on certain parts of the body, mainly on the knees, elbows and buttocks. The association of this skin condition with bowel changes was not known until twenty years ago.

The rash of DH is intensely itchy even in the presence of a mild rash. The rash may be hive-like, resemble chronic pink and scaling dermatitis or show grouped blisters. DH is a chronic disease. It is more common in males and is generally a disease of adult life (twenty to fifty-five). DH is strongly associated with gluten sensitive enteropathy.

The patients who present to dermatologists very often have asymptomatic bowel disease, i.e. they do not very often have diarrhoea or bloating. The skin rash and particularly the itch is improved by a strict gluten free diet although it may take six months to achieve moderate improvement and two years to achieve good control. Because most patients with DH do not have significant bowel symptoms maintaining a strict gluten free diet may be difficult for some patients to chose to adhere to. However, this is the mainstay treatment for DH and it must be remembered that it may take many months on a gluten free diet before the benefits of the diet are noted.

Alongside a strict gluten free diet, medication can be used to alleviate symptoms. The most common medication used for DH is Dapsone. Dapsone needs careful supervision, and may produce side effects<sup>1</sup>.

<sup>1</sup> Adapted from a paper written by Dr. Elizabeth Gow, Dermatologist, NSW.



## Lactose Intolerance.

There is a link between Coeliac Disease and lactose intolerance. When the gut is inflamed, as in newly diagnosed or untreated Coeliac Disease, there is a deficiency of the lactases (the enzymes that digest and absorb lactose – the sugar in milk). This is because the lactases are housed in the villi, which are flattened and reduced in Coeliac Disease.

Symptoms similar to Coeliac Disease may occur in associated lactose intolerance including bloating, cramps and diarrhoea. To minimise these symptoms the individual must limit the amount of dairy products containing lactose that he or she consumes. Many people find that once they have been following a gluten free diet and the gut is less inflamed, they are able to tolerate milk products again<sup>2</sup>.

<sup>2</sup> Information from: Allen, Darina: Healthy Gluten-free Eating, (2004).



## Travel.

When travelling it is advisable to get into the habit of taking some gluten free food with you. There are many gluten free snack bars available now on the market, so it's a good idea to always keep a few in your car or handbag as you never know when you may be caught out.

If you are travelling to another country try to take some 'safe food' with you like rice cakes, bread or wrapped snack bars. You may need to declare your food at customs, however this is more of a routine than a problem and in most cases you get through customs quicker. It is advisable to have with you a letter confirming your dietary needs from a doctor or specialist.

When planning your travel you can write in advance to the secretary of the Coeliac Society of the country you are visiting. They will be able to give you information on what is available for Coeliac's and where to find it.

*See: <http://www.celiactravel.com> for travel cards written in several languages, which explain what Coeliac Disease is and what foods you can't eat. You may find these useful to use in countries in which you don't speak the language.*



## Air travel.

Most airlines are happy to accommodate special dietary requirements on national and international flights, and this need not be a problem providing a few simple rules are followed:

1. **Always book your gluten free meal with your flight reservation, whether it be through a travel agent or direct booking**
2. **Confirm this again when picking up your ticket or checking in for your flight**
3. **Confirm your meal requirements again if you change your itinerary as it may not automatically follow your booking**

Meals on flights departing from NZ are made up in Auckland, however all meals are made to the same gluten free standard throughout the world regardless of the departure point. If you are sceptical about any of the contents of the meal, do check with a flight attendant it is gluten free. Sometimes you may be given a roll with your meal which may not be gluten free. Check before consuming.

Please note Air New Zealand no longer provide gluten free food on their short-haul journeys (e.g. Trans-Tasman). Make sure you take some gluten free snacks with you to eat on the plane.

**Figure 68**  
Pages 52 & 53  
(Not to scale)

## Pharmaceuticals.

On a gluten free diet great care must be taken with medicines, both prescription and non-prescription. The inert ingredients that are used to bind tablets may also have gluten as well as direct ingredients. Some products to be wary of include: cough medicines, cold & flu tablets and some vitamins.

It is the pharmacist, not your doctor that you should rely on to ensure the medicine dispensed is gluten free. You may need to communicate with the pharmacist to make sure they check if the medicine is gluten free. They can check this in several ways:

1. Reading the label (some companies clearly state 'gluten free')
2. The Pharmaceutical Society of New Zealand publishes a 'Dispensing Guide' that lists companies that state that some of their products contain gluten
3. If the pharmacy is a 'Life Pharmacy' they can access a list of gluten free medications from 'Med Plus Info Line'
4. They could ring the company and ask that a drug information query be put through to the manufacturer



**Figure 69**  
Pages 54 & 55  
(Not to scale)



## Subsidies & benefits.

Every Coeliac diagnosed by biopsy is entitled to a subsidised prescription for gluten-free foods. In order to receive this subsidy you firstly have to obtain a health benefit number from your doctor or specialist. Once obtained, this health benefit number is issued for life.

A typical prescription for one person should look like this:

- 3 x months supply of gluten-free flour — \$15 prescription fee
- 3x months supply of gluten-free pasta — \$15 prescription fee

Take your prescription to a chemist/pharmacy or to your local hospital pharmacy. If you collect all your prescriptions at once you will only need to pay a charge of \$15 per product line, plus the subsidy charge (this can differ with each pharmacy).

You only pay the prescription charge once; repeats cost subsidy charge only.



## Child disability allowance.

A child disability allowance is available for children with Coeliac Disease under the age of 16 to assist with the cost of gluten-free food. The following information is from the Work and Income website.

Child Disability Allowance is a non-taxable allowance that is available to the principal caregiver of a dependent child who has a serious disability. It is paid because of the extra care that may be needed by a child who has a physical, sensory, psychiatric or intellectual disability. The client may also be able to receive a Disability Allowance to meet any additional costs the child has because of their disability.

There is no income and asset test for Child Disability Allowance. Child Disability Allowance is a non-taxable allowance which is usually paid to the principal caregiver of the child. These guidelines apply to applications:

- ▶ That are included in the definition of a benefit *or*
  - ▶ Where it is unknown whether the application will be for a benefit
- The application process for benefit can be considered to be complete when:
- ▶ A written application form is completed and received by Work and Income *and*
  - ▶ Any supporting evidence reasonably required for that benefit is received by Work and Income *and*
  - ▶ Any assigned pre-benefit activities have been completed, if applicable

The application form and any supporting evidence required must be received within 20 working days after the client's date of first contact or the application for benefit lapses.

See: <http://www.workandincome.govt.nz/get-assistance/extra-help/disability-child-allowance.html> for further information or ring: 0800 559 009

Figure 70  
Pages 56 & 57  
(Not to scale)



## Useful websites.

Coeliac Society (NZ)  
[www.coeliac.co.nz](http://www.coeliac.co.nz)

New Zealand Manufactured Food  
[www.nmfd.co.nz](http://www.nmfd.co.nz)

Southern Cross Health Information  
[www.southerncross.co.nz](http://www.southerncross.co.nz)

Auckland Allergy Clinic  
[www.allergyclinic.co.nz](http://www.allergyclinic.co.nz)

Gluten Free Goodies Company  
[www.glutenfreegoodies.co.nz](http://www.glutenfreegoodies.co.nz)

Everybody — Information for New Zealanders  
[www.everybody.co.nz](http://www.everybody.co.nz)

Family Doctor  
[www.familydoctor.co.nz](http://www.familydoctor.co.nz)

Heatheries  
[www.heatheries.co.nz](http://www.heatheries.co.nz)

Coeliac Society (UK)  
[www.coeliac.co.uk](http://www.coeliac.co.uk)

Doctor Gluten — Doctor Rodney Ford  
[www.doctorgluten.com](http://www.doctorgluten.com)

Coeliac Society of Australia  
[www.coeliac.org.au](http://www.coeliac.org.au)

Australia and New Zealand Coeliac Research Fund  
[www.coeliacresearch.com](http://www.coeliacresearch.com)



## Useful books to buy.

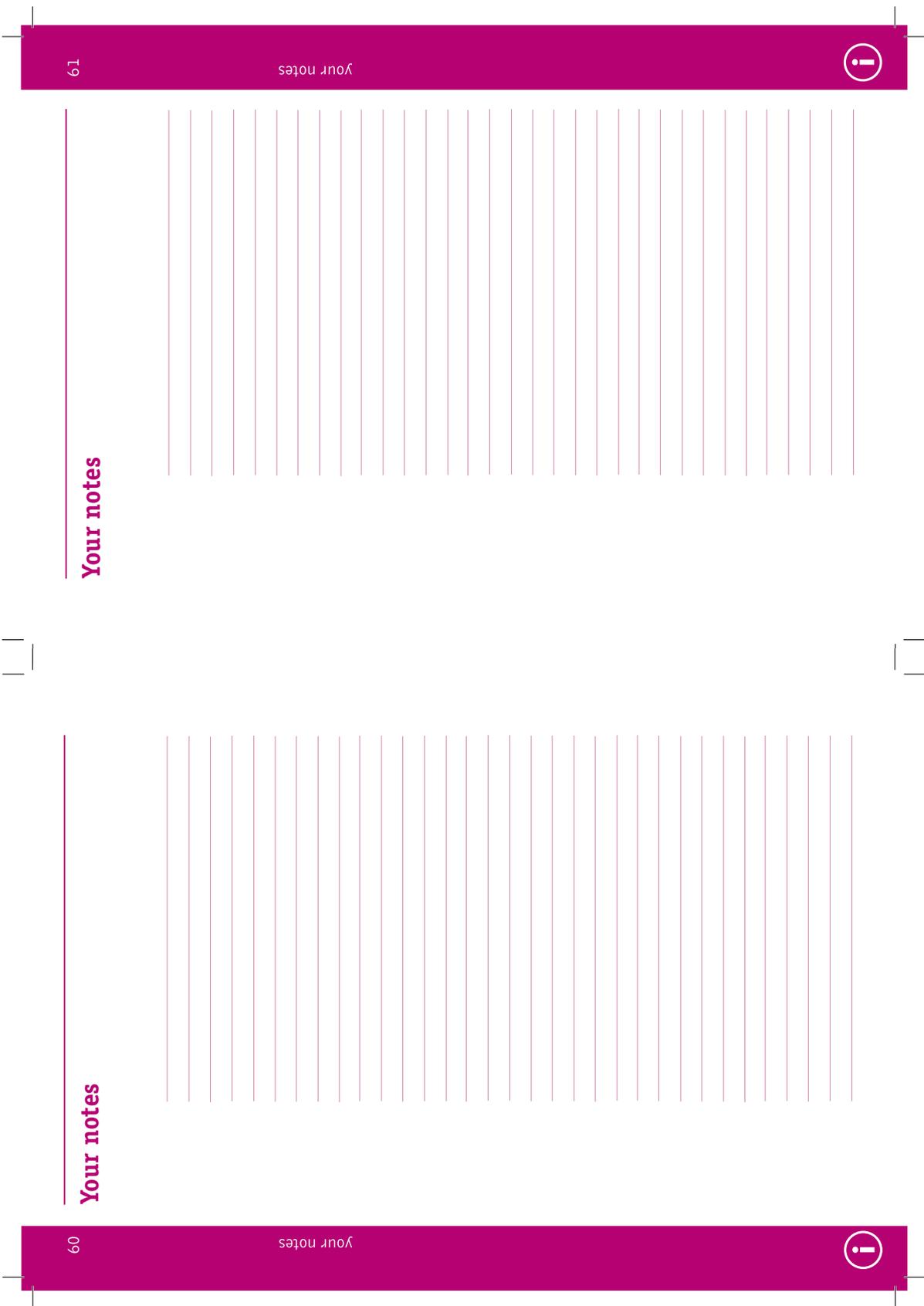
Wheat Free, Worry Free  
 Danna Korn  
 ISBN: 1-56170-991-3

Healthy Gluten-free Eating  
 Darina Allen & Rosemary Kearney  
 (supported by the Coeliac Society UK)  
 ISBN: 1-85626-542-0

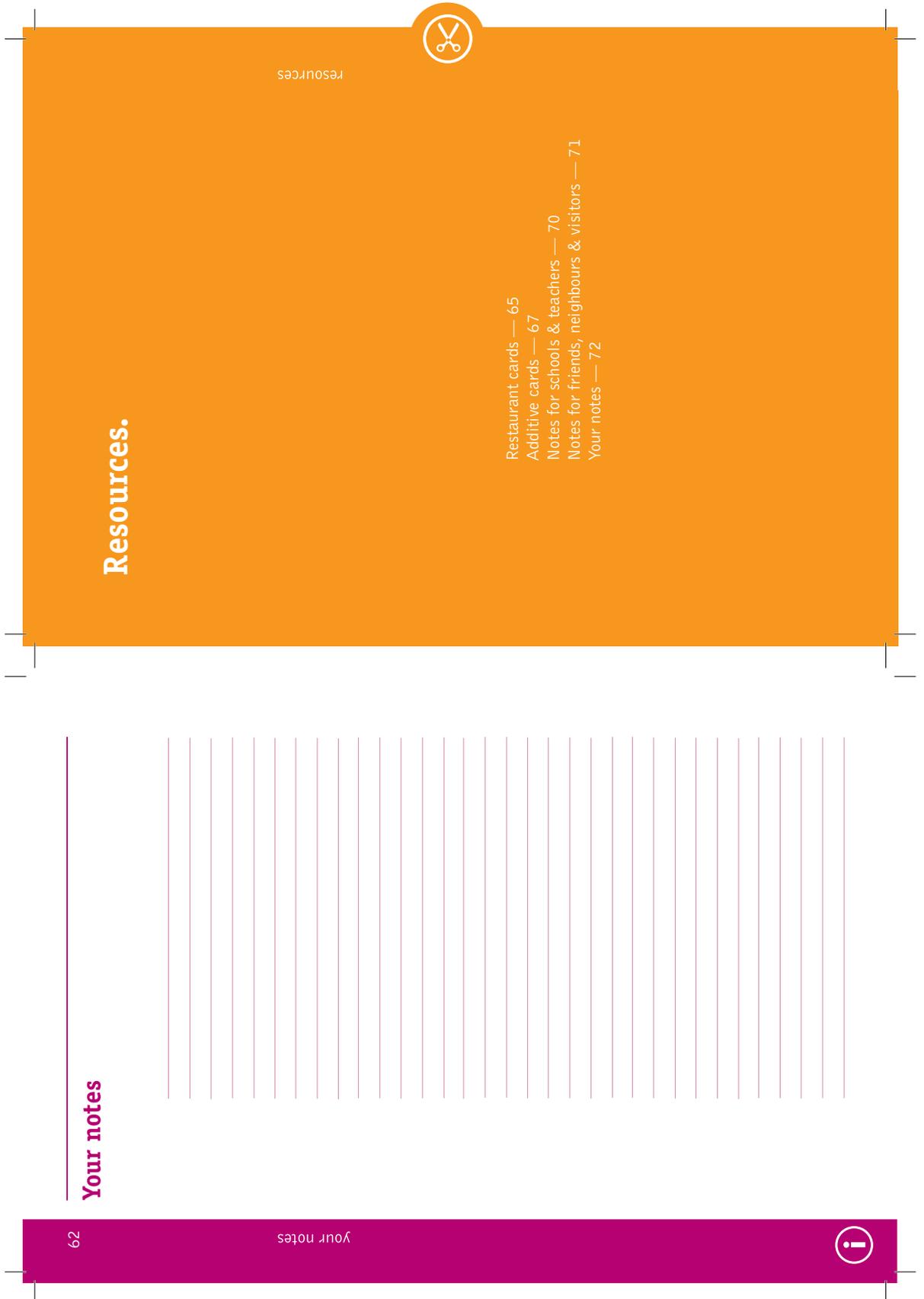
Irresistibles for the Irritable  
 Sue Sheppard  
 ISBN: 0-9751957-0-0

Are you gluten sensitive?  
 Dr Rodney Ford  
 ISBN: 0-476-00917-0

**Figure 71**  
 Pages 58 & 59  
 (Not to scale)



**Figure 72**  
Pages 60 & 61  
(Not to scale)



**Figure 73**  
Pages 62 & 63  
(Not to scale)



“It doesn’t even cross my mind to be embarrassed asking a waiter, because it’s absolutely critical. They should know what’s in the food”

Iain Munroe, Auckland

## Restaurant cards

Cut out & keep ✂



Coeliac restaurant card



Coeliac restaurant card



Coeliac restaurant card



**Figure 74**  
Pages 64 & 65  
(Not to scale)

## Restaurant cards

✂ Cut out & keep

I have an illness called Coeliac Disease and have to follow a strict gluten-free diet.  
***I may therefore become very ill if I eat foods containing flours or grains of wheat, rye, barley and oats.***  
 I can eat food containing rice, maize, potatoes, all kinds of vegetables and fruit, eggs, cheese, milk, meat and fish  
***– as long as they are not cooked with wheat flour, batter, breadcrumbs or a sauce containing these grains.***  
 If you are at all uncertain about what the food contains, please tell me.

**Thank you for your help.**

I have an illness called Coeliac Disease and have to follow a strict gluten-free diet.  
***I may therefore become very ill if I eat foods containing flours or grains of wheat, rye, barley and oats.***  
 I can eat food containing rice, maize, potatoes, all kinds of vegetables and fruit, eggs, cheese, milk, meat and fish  
***– as long as they are not cooked with wheat flour, batter, breadcrumbs or a sauce containing these grains.***  
 If you are at all uncertain about what the food contains, please tell me.

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I have an illness called Coeliac Disease and have to follow a strict gluten-free diet.  
***I may therefore become very ill if I eat foods containing flours or grains of wheat, rye, barley and oats.***  
 I can eat food containing rice, maize, potatoes, all kinds of vegetables and fruit, eggs, cheese, milk, meat and fish  
***– as long as they are not cooked with wheat flour, batter, breadcrumbs or a sauce containing these grains.***  
 If you are at all uncertain about what the food contains, please tell me.

**Thank you for your help.**



## Additive cards

✂ Cut out & keep



**Additive card**



**Additive card**



**Additive card**

**Figure 75**  
 Pages 66 & 67  
 (Not to scale)



## Additive cards



Cut out & keep

1401–1450: Maize, Tapioca and Potato starch derived  
1400: Wheat based

- 410 — Locust bean gum or Carob bean gum
- 412 — Guar gum
- 413 — Gum tragacanth
- 414 — Gum arabic
- 415 — Xanthan gum

1401–1450: Maize, Tapioca and Potato starch derived  
1400: Wheat based

- 410 — Locust bean gum or Carob bean gum
- 412 — Guar gum
- 413 — Gum tragacanth
- 414 — Gum arabic
- 415 — Xanthan gum

1401–1450: Maize, Tapioca and Potato starch derived  
1400: Wheat based

- 410 — Locust bean gum or Carob bean gum
- 412 — Guar gum
- 413 — Gum tragacanth
- 414 — Gum arabic
- 415 — Xanthan gum



## Notes for schools & teachers.

Photocopy this page



Coeliac Disease is a life long condition in which the small intestine is damaged by coming into contact with gluten. The damage decreases the absorption area of the intestine resulting in poor nutrition due to lack of minerals, vitamins, carbohydrates and fats essential for good health.

**Gluten is found in wheat, rye, barley, oats and any product made with these cereals.**

The symptoms of Coeliac Disease include poor growth, irritability, chronic fatigue, anaemia, diarrhoea, bloating and stomach cramps. There is no cure for Coeliac Disease, but it can be effectively controlled and treated by adhering to a strict gluten-free diet. Provided the gluten-free diet is maintained the Coeliac child is normal and should be treated as such; there is no need for restriction to sporting or other activities.

Should food containing gluten be eaten don't panic, symptoms are rarely sudden or dramatic. They can occur within 24 hours or sometimes not manifest for up to three weeks and can last one to ten days before subsiding. However, even if no symptoms seem apparent internal damage would have been caused.

People are born with the predisposition to develop Coeliac Disease, but the time of onset can vary. **It is not infectious and cannot be caught by other people.** As long as a Coeliac child adheres to a gluten-free diet, growth and development will be normal. Most school-aged children will be aware of the restrictions to their diet and should be trusted about which foods they eat.

As a teacher of a Coeliac child you can help by being familiar with the condition and the problems it can cause. In the case of young children extra care around play dough and some wheat-based pastes should be taken and hands should be washed immediately after play. **Lunch swapping should be avoided.** Gluten-free bread will not harm a child of a normal diet, but the opposite is the case for a child with Coeliac Disease. Let parents know in advance of any special event where food or sweets may be distributed, then if need and alternative can be arranged. Allow gluten-free substitutions for ingredients in cooking classes.

Should you observe any unusual behaviour, fatigue, lack of concentration or learning problems please contact the parents. **Your support and understanding is important to the Coeliac child and their family.**

**Figure 76**  
Pages 68 & 69  
(Not to scale)



## Notes for friends, neighbours & visitors.

Photocopy this page 

Dear:

..... has Coeliac Disease, and because of this they must not eat foods containing gluten as they damage the lining of their bowel. This damage may not be immediate or obvious, but happens every time something containing gluten is eaten.

The main foods to avoid are bread, cakes, biscuits, pasta and wheat cereals. **Gluten is also found in rye, oats, barley.** Any products containing these cereals should be excluded. A lot of pre-packaged food contains gluten, but most labelling is pretty reliable and says if the product contains gluten or wheat (or perhaps thickener; starch etc). If in doubt, leave it out.

Fresh meat (not manufactured), fish, eggs, dairy products, rice, corn, fruit and vegetables are all gluten-free.

Please be assured that Coeliac Disease is not infectious and cannot be caught. Aside from having to adhere to a gluten-free diet Coeliac children are normal and no other medication or treatment is required to control their symptoms.

Thanking you for your consideration and co-operation on this matter.

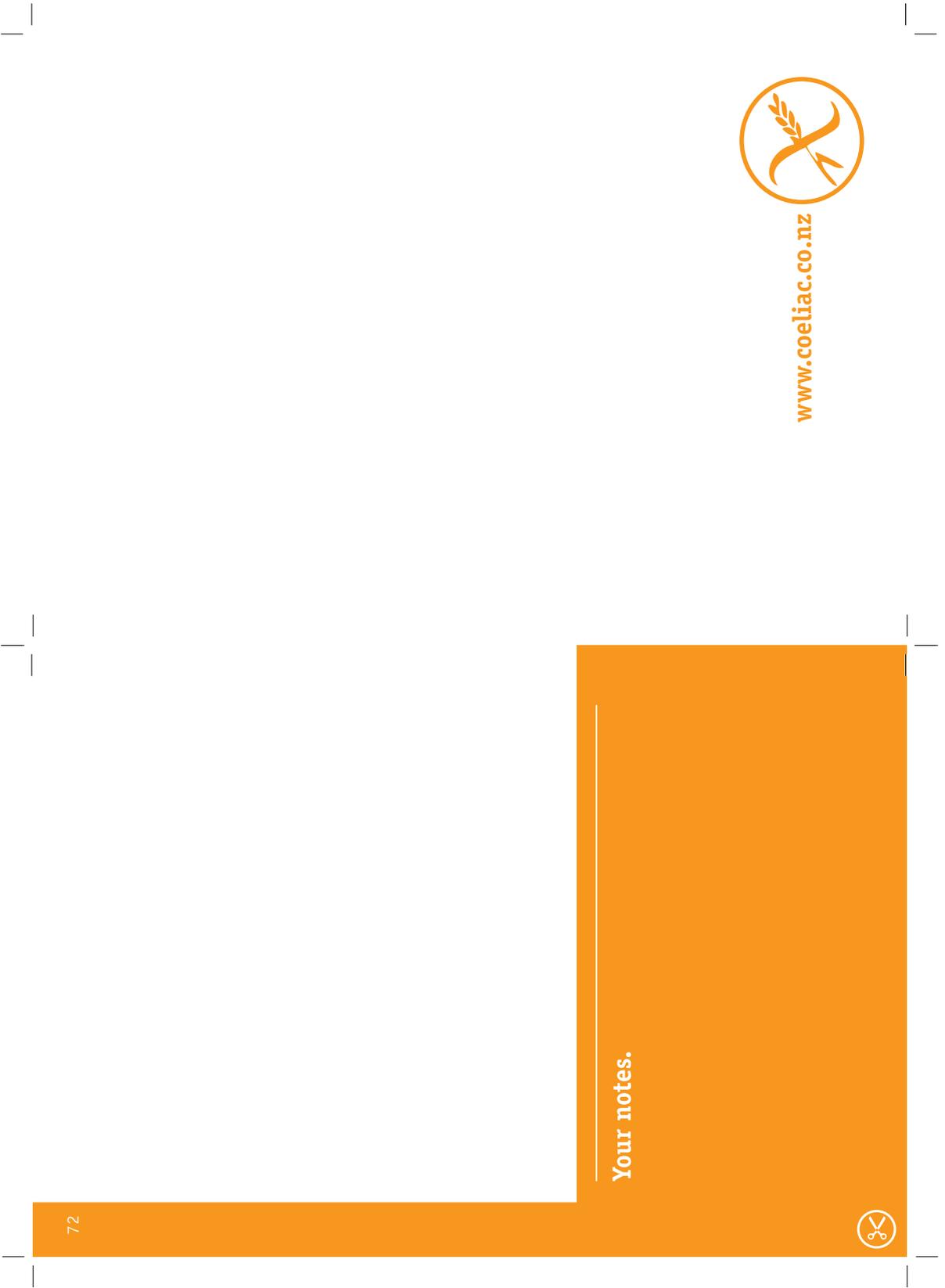
Yours Sincerely,

.....

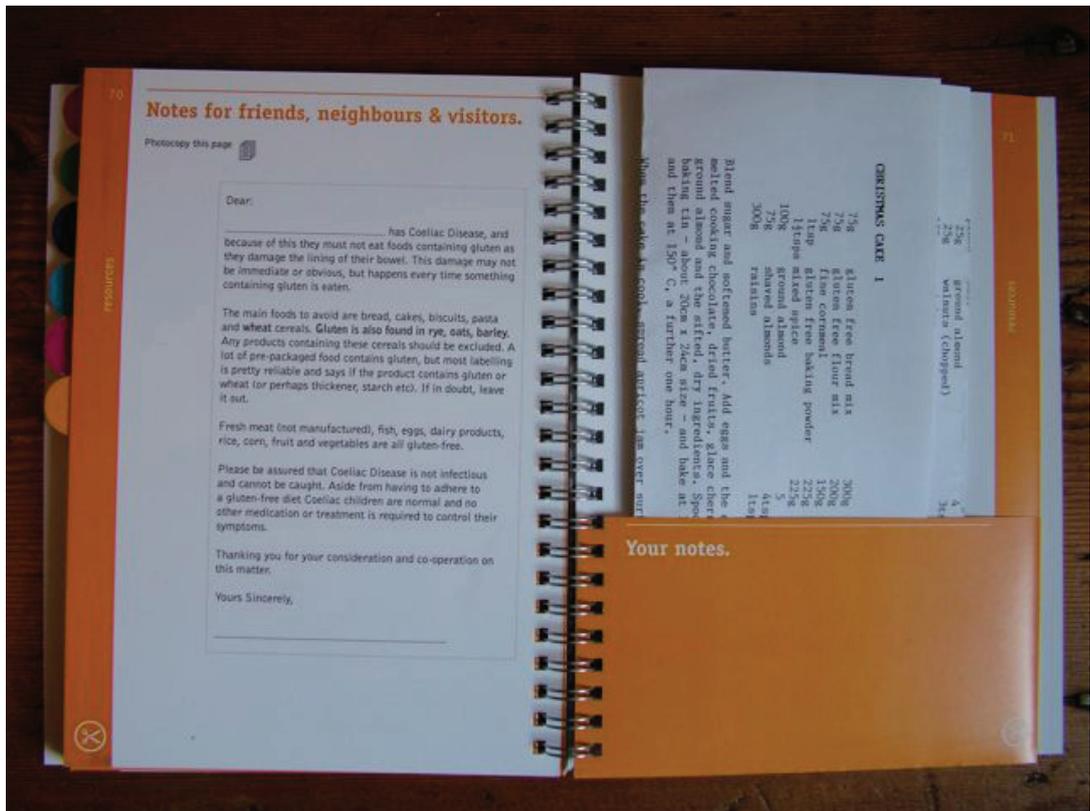


Your notes.

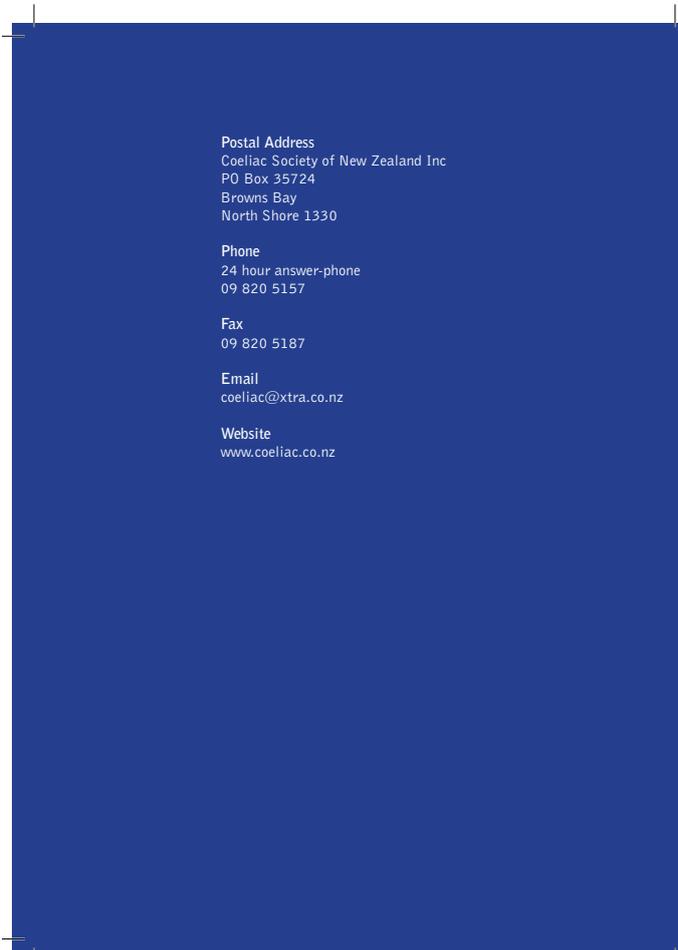
**Figure 77**  
Pages 70 & 71  
(Not to scale)



**Figure 78**  
Pages 72 & back cover -  
inside  
(Not to scale)



**Figure 79**  
Photograph showing notes pages in hand book  
(Not to scale)



**Figure 80**  
Back cover of handbook -  
revised colour  
(Not to scale)

## List of Figures in Appendices

### Appendix F

Figure 35

Original Coeliac Society handbook folder being used to store Coeliac Society 'Link' magazines. (Film still)

Figure 36

Member's handbook that has been modified to meet their own and others needs. Showing image of a book made for newly diagnosed Coeliac's in their local area. (Film still)

Figure 37

Drawing given to patient after endoscopy to explain procedure. (Film still)

### Appendix H

Figure 38

Original colour of handbook

Figure 39

Revised or alternative colour of handbook

Figure 40

Contents and page 1. (Not to scale)

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Pages 2 & 3. (Not to scale)

Figure 42

Pages 4 & 5. (Not to scale)

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Pages 6 (fold-out) & 7. (Not to scale)

Figure 44

Page 6 - overleaf (fold-out). (Not to scale)

Figure 45  
Photograph of Page 6 - over-leaf (fold-out) and  
page 7. (Not to scale)

Figure 46  
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Figure 47  
Pages 10 & 11. (Not to scale)

Figure 48  
Pages 12 & 13. (Not to scale)

Figure 49  
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Figure 51  
Pages 18 & 19. (Not to scale)

Figure 52  
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Figure 65  
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Figure 66  
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Figure 68  
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Figure 70  
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Figure 71  
Pages 58 & 59. (Not to scale)

Figure 72  
Pages 60 & 61. (Not to scale)

Figure 73  
Pages 62 & 63. (Not to scale)

Figure 74  
Pages 64 & 65. (Not to scale)

Figure 75  
Pages 66 & 67. (Not to scale)

Figure 76  
Pages 68 & 69. (Not to scale)

Figure 77  
Pages 70 & 71. (Not to scale)

Figure 78  
Pages 72 & back cover - inside. (Not to scale)

Figure 79  
Photograph showing notes pages in hand book. (Not to scale)

Figure 80  
Back cover of handbook - revised colour. (Not to scale)