

Loss Before Life Begins.

The Invisible Babies

and

Their Invisible Deaths.

By Tina Rose

This thesis is submitted to Auckland University of Technology in partial fulfilment of the degree of Master of Communication.

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Full title of thesis:

Loss Before Life Begins. The Invisible Babies and Their Invisible Deaths. How Society in General, The Health Professionals Working In 'The System', and the Media in Particular Further Exacerbate the Trauma of a Woman Experiencing Baby Loss between 12 and 20 Weeks Gestation by Failing to Suitably Acknowledge the Event. And Ways Society, the Health Professionals and 'the System' and Media May be Able to Help Women and Their Families Come to Terms With This Tragedy.

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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.”

Candidate signature

Tina Rose

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My son, Iggy Rose-Yon was literally ‘with me’ in-utero the entire way through the writing of my thesis. His birth and the completion of my thesis coincided in the same week.

As the thesis involved humans, the Auckland University of Technology Ethics Committee approved this thesis on 04032005. AUTEK reference number 5/19.

Abstract

My experience of baby loss was an isolated learning experience and the main objective of my research was to help better resource other women who may find themselves lost in the system caring for women when their babies die. Particularly, I wanted to highlight and possibly remedy the invisibility of women and their babies that die between 12 and 20 weeks gestation.

Loss Before Life Begins was written as four journalistic articles with one of the goals to be that all or some of the articles achieve publication in a mainstream New Zealand magazine. I focussed all the research on the last 20 years, beginning in 1985. Firstly, because it coincides with the establishment of Miscarriage Support Auckland, the first group of its kind in New Zealand. Secondly, because it ensured that the participants' stories would be relevant in the current context of how baby loss is treated by society, the media and the health system.

Each article had a specific purpose and aim. Firstly, *The Language of Loss* investigated the background of our popular understanding of baby loss, including the legal categorisations of baby loss in different gestational periods. It also included research into the language commonly used by health professionals working with women whose babies have died. Quotes from the five women who were participants in the thesis were interwoven in the article. Their stories illustrated the effects of insensitive language on a woman's experience, and the perception of care and treatment received by health professionals. Then I reviewed all mainstream media articles published in New Zealand from 1985. This disclosed the lack of articles about baby loss, and the general dearth of practical information provided when stories did appear.

Secondly, *And Mother Makes Me* was the narrative of the five women's stories interviewed about their babies' deaths between 12 and 20 weeks gestation. I discovered that this timeframe is 'invisible' because women under 20 weeks are not part of the obstetric system, and are cared for by nurses instead of midwives. These mothers are invisible, as are their babies' deaths.

Article three, *The 'System' and the People Working In It* encompasses the sometimes conflicting views of four leading health professionals. Possible explanations for why women whose babies die under 20 weeks are treated differently to women whose babies

are considered stillborn was included. Conflicting views about the importance of the media's role emerged. Small changes in the use of medical language by health professionals were outlined. Finally, possible reasons for society's difficulty with the concept of death, and specifically the difficulties when a woman's baby dies before its life has begun were uncovered.

The fourth and final article, *The Way It Is and The Way It Could Be* summarised the background reading; media analysis from the last 20 years; the themes from the five women's stories; and the array of health professionals' views. Included are a number of specific meaningful ways that health professionals, media outlets and society can better support the invisible women when their babies die. These include updating medical language printed in brochures; including fact boxes in editorials; giving women and their families an opportunity to talk about their losses; and reviewing 'the system' that allows women who lose babies between 12 and 20 weeks to be cared for by nurses instead of midwives.

Introduction

My thesis is a creative journalistically presented piece of work that sets out to research the difficult subject of when a baby dies before its life has begun. It includes clarifying and examining the nature of the trauma, and the effects a baby's death has on the mother whose baby has died.

I chose to write my thesis on baby loss because of my personal experience when my twin girls died in-utero at 18 weeks gestation in April 2004. What I experienced was the shock of giving birth to death at a stage of pregnancy I didn't equate with babies dying. The compounding losses I suffered afterwards were due to the inadequacies in care by many health professionals; society's obvious difficulty with positively acknowledging a loss of this nature; and finally the lack of information available to me in my search for answers in mainstream media. Due to these compounding losses I wanted to know whether this was my own isolated experience, or whether other women whose babies had died also felt the same. What transpired was my thesis entitled 'Loss Before Life Begins. The Invisible Babies and Their Invisible Deaths. How Society in General, The Health Professionals Working In 'The System', and the Media in Particular Further Exacerbate the Trauma of a Woman Experiencing Baby Loss between 12 and 20 Weeks Gestation by Failing to Suitably Acknowledge the Event. And Ways Society, the Health Professionals and 'The System' and Media May be Able to Help Women and Their Families Come to Terms With This Tragedy'.

As one of my original problems was the lack of media coverage regarding baby loss of any nature, I set out to present my thesis as four journalistically written articles. One important goal throughout the thesis development was to aim for part or all of it to be published in a New Zealand mainstream magazine after completion.

I read many internationally published books and recent academic articles, and through this process gained a clear understanding of the common themes women who had lost babies in pregnancy shared. I focussed my specific background reading on New Zealand books, academic articles and mainstream media articles including national and local newspapers and magazines.

What I found throughout both stages of the background reading was a significant amount of literature on miscarriage which is commonly understood as babies dying

prior to 12 weeks gestation, and stillbirth which is commonly understood as babies dying after 20 weeks gestation, when their births and deaths receive legal recognition. What I had experienced, and what is the experience of approximately 2000 to 3000 other New Zealand women a year, was a death in between these two timeframes. This realisation led me to label loss between 12 and 20 weeks gestation as the 'invisible' stage. I labelled it this way for a range of reasons. The group of women I focussed on in this timeframe are invisible because they are not talked about in any meaningful way; they are not treated by normal maternity carers; their babies are often not referred to as actual babies; their babies' births are not registered; and the nurses who have the unwanted task of caring for the mothers, would often rather not. These invisible women should also be considered invisible mothers, as they have already formed an attachment and bond with their babies.

The importance of baby death as a subject to research cannot be understated. Approximately 57,000 women a year give birth to live healthy babies in New Zealand and this equates to roughly 11,000 women losing babies some time in their pregnancies. It is a generally accepted statistic that 80% of these losses occur in the first 12 weeks of a pregnancy, when most women choose to keep their pregnancy state unknown except to close family and friends because they are not in the 'safe' stage. But for most women who do make it past the 12th week, the time has come to share the exciting news. Therefore losing a baby anytime after this is more complex. The complexities exist because it is not a widely understood or acknowledged fact that babies do die after 12 weeks, and the physical and emotional trauma of having to go through the birth process is also not widely realised or understood.

What I discovered throughout the research process both in the secondary research and more specifically through the primary research, was that the issue of baby loss is a multi-layered and systemically complex issue. The five women interviewed whose babies had died in the invisible stage shed light on their unique tragedies and also clarified their shared themes. These themes included the use of insensitive and inappropriate medical terminology to label their babies and their experiences; their difficulty with the medical system which they found themselves in; the lack of information given, both verbally by those charged with caring for them and in the printed literature offered to them; their families, friends and wider society's inability to positively acknowledge their losses, and the lack of adequate support offered in their

time of need; and finally in the lack of practical helpful information available to them after their babies had died in the mainstream media outlets. These themes echoed my own experience and confirmed for me that the problems women face are many and are shared.

It was as important to interview a number of professionals working in the health area, and the four individuals chosen provided a different and valued perspective of their views on loss before life begins.

The final part of the thesis sets out to summarise the findings from all the background reading and both sets of interviews. It also offers clear, tangible, practical improvements that could be made in the health system, throughout mainstream media and within the wider community. This final part was important from my perspective. At the outset of the thesis I stated that one of the primary reasons for the existence of the piece of research, was to hopefully make a difference for the women who may face the unwanted journey of losing a baby, especially those women in the ‘invisible’ stage when their babies have died between 12 and 20 weeks gestation.

Article One

The Language Of Loss

Despite its inevitability and the fact that it is all around us, death of any sort is not an easy subject; not one for the fainthearted, or for any person who is not prepared to confront what is, by its very nature, difficult and uncomfortable. The death of a baby is the most difficult of all, and it somehow seems even worse still if the baby has died before it has had a chance to live. The tragedy is then often exacerbated by most people's ignorance around positively responding towards a grieving mother or family member. Perhaps due to this ignorance, baby loss is a subject that very rarely makes it into the news, let alone everyday conversation. Occasionally a celebrity experiences a miscarriage, and one of the popular women's magazines may run a short piece. More often than not the celebrity is at this stage happily pregnant again, and briefly reflecting on her previous loss. There is a distinct lack of practical advice for women living the loss of their baby in local or national media, and up until recently, scant relevant material in books. The sad fact is that many thousands of women every year in New Zealand are doing their best to work through a very real loss that affects them, their partners, their children and to a lesser extent, their family and friends. And they are having to do it in an information vacuum.

The death of a baby prior to birth is often described as a taboo subject, 'a loss that lives in silence'. A taboo as defined by the *Collins Concise Dictionary*, is a restriction or prohibition resulting from social or other conventions. It is a ritual prohibition, especially of something that is considered unholy or unclean; descriptively outlined as forbidden or disapproved of. Taboo means any topic that has connotations of isolation and misunderstanding. Is baby loss a taboo subject? My belief, and the belief echoed by many others in the literature available on this subject, is that clearly the answer must be yes. The question therefore must be why is baby loss taboo? And does it need to continue to be so? I seek answers to these two questions throughout the following articles.

Taboo subjects are not fixed in time, and meanings are often negotiated by social activity and dialogue. The taboo nature of baby loss is not dissimilar to the way suicide was dealt with, or not dealt with as the case was more likely to have been, a decade and more ago. Ten years ago my 22 year-old cousin committed suicide. At the time this was

a topic rarely discussed publicly, and privately only in whispers. Over the last decade, a change has taken place in New Zealand around society's attitudes to suicide. Through increased media coverage and an acceptance in the wider community that New Zealand has a serious problem in this area, the subject of suicide has been pulled out from under the carpet. The change has been healthy and helpful, not only for those seeking help, but also for those forever burdened with the loss of a loved one through suicide. In writing this thesis about loss before life begins, I hope to begin something of a similar public change around the difficult subject of baby loss.

Although miscarriage is widely understood as being a common occurrence, the term miscarriage does not always appropriately clarify the nature of the baby loss. In 2004, there were 58,070 registered births in New Zealand. By approximating the number of miscarriages, based on the recognised assumption that one in five pregnancies ends in miscarriage (mostly prior to 12 weeks gestation), then somewhere in the vicinity of 11,500 pregnancies a year do not make it to a successful conclusion. Often, the mother does not even know she was pregnant, so many losses go unrecognised. But many more are very much a source of grief. Although a pregnancy ending this early on is relatively common, for many women it is sad, shocking and in reality, far worse than they could ever have anticipated. Journalist Zoe Taylor, author of a recent article that appeared in the *Sydney Sunday Telegraph*, had this to say about women's treatment at the time of suffering a miscarriage. "She sent me away (after miscarrying) with a leaflet full of statistics I had quoted in news stories for years. Suddenly they were real. And, gradually, I realised how real they were for the others who had kept secrets for their own reasons."

If it is the role of a thesis to find a gap in, and add to the body of knowledge, then this thesis hopes to be the beginning of an attempt to fill a vast chasm on the stage of pregnancy loss, commonly referred to as 'late miscarriage' which falls between 12 and 20 weeks into a pregnancy. The confusion around the myriad of medical terms used reflects a deeper confusion of understanding when life begins, what an in-utero life is, how this life has meaning and to whom. The women whose babies die in this gestational timeframe are in a 'no woman's land'. Miscarriage does not adequately explain their experience and stillbirth is a legal term only given to babies who die 20 weeks or over. The women whose babies die between 12 and 20 weeks pregnancy are not talked about; they are not treated by the normal maternity carers; their losses are not referred to as babies; their baby's births are not legally recognised; and the nurses who presently care

for them would rather not. This significant group are invisible, their babies are invisible, and so are their deaths. This invisibility is at the heart of this thesis.

There is no doubt that the subject of baby loss is far more readily acknowledged now than it was even as recently as 20 years ago. But there is still a long way to go, for society and mainstream media publications to make more of an effort to support and provide practical advice to those women who find themselves part of this unenviable club. It is, as Nicola Miller-Clendon; mother, midwife, woman who has lost five babies at various stages of pregnancy, and author of *Life after baby loss*, wrote in 2003, “A club of which nobody wants to be a member. It’s almost a secret society where once you have joined; you will find friends, family and acquaintances that are already members, often unknown to you.”

It is important to understand why this thesis focuses primarily on the loss of a baby between 12 and 20 weeks gestation. The focus on this gestational period of baby loss does not mean that a loss prior to, or after this stage, is any less important. The reason 12 and 20 weeks was chosen is two-fold. Firstly, when I gave birth to identical twin girls who died in-utero at 18 weeks gestation in 2004, the only birth experiences I had been fortunate enough to have, were of two live baby girls in 1996 and 2002. Like many other women who find themselves in this unwanted and often unexpected place, I searched desperately for help and useful information when the twins died. I found little was available. Secondly, this particular stage of gestation is generally understood as the ‘safe’ stage, when a woman can share the happy news of the impending baby, and begin to relax and enjoy her pregnancy. The reason this understanding exists is because something like 80% of pregnancy losses occur in the first 12 weeks, otherwise known as the first trimester. Therefore, if a woman carries her pregnancy past 12 weeks, the likelihood of progressing to full term is far greater. It is uncommon to hear of a woman losing her baby after this time, either because it doesn’t happen often, or because it is not a subject discussed openly when it does happen.

A pregnancy is considered ‘viable’ from about 24 weeks gestation when with neonatal medical advances, many babies born this early can go on to live healthy lives. The 20 week mark is a random gestational stage which draws a line in the sand for legal recognition of a life existing. Miller-Clendon also notes, “There is a group of women whose babies die, and are delivered in the second trimester, prior to the ‘magic’ 20

completed weeks, who feel as if they are in no-man's land." I will refer to this group of women as the invisible mothers and their invisible babies.

Definitions, meanings and terminology abound in the area of loss before life begins. The World Health Organisation (WHO) has its set of definitions; the dictionaries have a set of definitions; Births, Deaths and Marriages provide interpretations of the language used, Fertility Plus also has a set of medical definitions, and then there are all manner of justifications for the terminology used throughout much of the research material available.

There is confusion for women who find themselves trapped in grief and confronted with the vast array of terms, labels and meanings. When interviewing five women who have all had babies die for a range of reasons in the invisible period over the last 20 years, this subject of language, terminology and its appropriateness never took long to bubble to the surface. When one of the interviewees, who wishes to be called Ellen (name has been changed), was told she had experienced a spontaneous abortion, she felt, "There was no way this was an abortion, it was a miscarriage. The word abortion stigmatised what happened to me. That's the taking of a baby's life, and I think that's wrong for people who don't want to be associated as a self-aborter. It made me feel like I had done wrong, and I hadn't, and it made me feel bad inside."

There is no one formal set of terminologies used when it comes to describing the death of an unborn baby, either here in New Zealand, or internationally. The World Health Organisation has a set of definitions, but from country to country there are different interpretations. A commonly held belief is that a miscarriage is when a baby is lost prior to 12 weeks gestation, and that this happens spontaneously. But this is not the understanding of the NZ Ministry of Health that refers to a miscarriage as the *issue* from its mother, before the 21st week of pregnancy, of a dead fetus, weighing less than 400g. The WHO defines a stillbirth as the death of a baby after 22 completed weeks of pregnancy, or when the baby weighs at least 500 grams. The grey area is immediately apparent, because firstly, these definitions are different to each other, and secondly, they both include babies who die after 12 weeks, but prior to 22 weeks.

For the women in New Zealand whose babies either die in-utero or at birth from 20 weeks gestation onward, in other words, deaths that are recognised 'stillbirths' as opposed to miscarriages, the terminology differs again. These babies receive legal

recognition of their existence because a birth certificate is required. Prior to 1996 a stillbirth was not recognised until 28 weeks gestation. Then the law changed, primarily to reflect advancing technological capability to include all babies dying from 20 weeks gestation.

There is no international standard to define when a baby is considered stillborn. In Sweden, babies are considered stillborn at 28 weeks. In the United Kingdom, it's after 24 or more weeks completed gestation. New Zealand, Australia and the United States define stillborn as a baby who has passed the 20-week mark. And in Norway, it is as early as only 16 weeks.

Finally, there is the group of between 2,000 to 3,000 New Zealand women annually, on whom this series of articles will concentrate; whose babies die between 12 -20 weeks gestation. The numbers belonging in this category are only an approximation because under current New Zealand law, no fetal death occurring before the 20 weeks gestation is legally recorded. However, the woman losing a baby in this gestational stage has more than likely had to go through the birthing process.

Baby loss prior to 20 weeks gestation is medically referred to as an abortion; be that abortion spontaneous, medical or therapeutic. The language that is used, and how this language is used to explain or define the situation a family finds themselves in is important. It clearly has the ability to either validate or invalidate the experience. Those cold heartless words may seem on the face of it unimportant, and the best the medical bureaucrats can do, but they affect women in ways those bureaucrats may never have imagined. And these terms are being used at a time when the women are at their most vulnerable.

In this context the word abortion is controversial at best, and insensitive at worst. When one of the five interviewees, Nicole (name has been changed), discovered at a scan that her twin girls had died in-utero at 16 weeks gestation due to twin to twin transfusion syndrome, she couldn't get her head around the literature she was expected to read before giving birth. All the material provided by the hospital referred to her girls as either abortions, or miscarriages. Neither of these terms even vaguely characterised how she felt; they were her baby girls.

Labels create meaning and these meanings can either serve to recognise or equally to invalidate an experience. Whether or not a baby is legally considered to have existed, and therefore to have a birth certificate stating ‘stillborn’, is much more important than it may appear. When Ellen’s fourth baby died in-utero in 1990 at 25 weeks, she thought she could take the baby home and bury it. Instead, she was told that it had to be 28 weeks, and that she had no rights to take that baby home. No rights to take her own baby home!

Treena, another interviewee, has had the tragic experience of losing three babies, and her story articulates the callousness of the language used when she found her losses described in two starkly differing ways. In mid 2003, her first daughter Bella was diagnosed at her 18 week anatomical scan as having serious fetal abnormalities and was therefore, after much consultation and soul-searching, medically induced and born dead at 20 weeks. Bella was called a medical abortion, and at the time of her birth, handprints and footprints were done straight away. A birth certificate was required, giving Treena and her family legal recognition that Bella did actually exist. Then in early 2004, Treena conceived twins which was and still is something she saw as consolation for having lost Bella. The inconceivable happened at 18 weeks gestation. Treena’s waters ruptured prematurely, causing her twins Verity and Cael to be born too early, and before any chance of viability. Born at only 18 weeks gestation, they were deemed to be miscarriages. “It’s like legally they’re not real. I feel ripped off. I’ve got nothing that recognises their lives... To have actually held these two little babies, don’t tell me they weren’t real people. I thought, don’t refer to them as that, they weren’t just peanuts, they were actually little people. I got quite upset. They were so clinical about it... the way they medically refer to them. At the time I felt, don’t be so cold about it.” It was not until Cael was born five days after his sister, that someone thought to take a print of both of their feet and hands.

When Cael was born, Treena found herself in the midst of an argument with a nurse at the hospital. Because she was in a General Admissions ward for the twins, unlike her previous experience with Bella, she had little contact with midwives. The argument was caused because, as far as Treena and her husband could ascertain, Cael was actually alive at birth. “The thing that was the hardest for us, was that he was born alive. He was born, and the nurse asked if I wanted to hold him, and I said of course. He was kicking and moving, and to me, even to this day, it might not be what was actually happening,

but to me he was fine. But he had no lungs to breathe, and there was this horrible woman, this nurse. She said, 'No, he's not alive. It's just the fact that he's still attached to the placenta, which is still attached to you, and it's your heart pumping into the placenta which is making him move'. She cut the cord, and he was still moving. I said, 'Don't tell me it was my heart pumping into him'." So, depending on your interpretation of the WHO definition, was Cael born alive or dead, and who should be the judge and jury of that? In 1975, the WHO defined a live birth as, "the complete expulsion or extraction from its mother, of a product of conception, irrespective of the duration of pregnancy, which, after such separation, breathes, or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut, or the placenta is attached; each product of such birth is considered live born."

The terminology correctly or incorrectly used commonly calls for further explanations to be necessary. Because the language does not appropriately explain a situation, more often than not the grieving mother using the language feels the need to further explain, or justify, what situation she *actually* finds herself in. Something that is already difficult and uncomfortable for everyone concerned, is further exacerbated by the inadequacy and confusion of this language.

Then there is the pseudo-medical terminology that may not be as common knowledge but it is still in use and appears in academic articles, journals and research papers. Perinatal death; perinatal loss; spontaneous miscarriage; involuntary pregnancy loss (IPL); spontaneous loss of pregnancy, before the middle of the second trimester (20 weeks); unexpected pregnancy loss (UPL); death in-utero; therapeutic abortion; late miscarriage; missed miscarriage; late loss; 2nd trimester or mid-trimester loss; intra-uterine death; silent miscarriage; missed abortion.

The terminology that Miscarriage Support Auckland prefers to use is premature stillbirth. An explanation of the term 'premature stillbirth' can be found in the literature provided to women by the organisation directly and on its website. "As a group, we feel the word 'miscarriage' does not adequately, or sensitively, describe what is often the trauma associated with an early pregnancy death. What we experienced was both a birth and a death. A more appropriate name that would better describe and validate our feelings, would be *premature stillbirth*."

While the loss of a baby in New Zealand beyond 20 weeks gestation is acknowledged in a legal framework, even though that framework is clearly cumbersome and inadequate, the invisible women exist in a black hole. They are not allowed to register their baby's birth, and consequently, there is no legal requirement to either bury, or cremate their baby. Because of the invisibility of their babies, a name is an important gesture to validate its conception and short life in-utero. I will refer to that life as 'baby', not 'fetus' nor a 'product of conception'.

When another interviewee Kim, discovered to her horror in April 2003, at her 12 week scan that her baby had died in-utero, she was obviously shocked. On top of this initial shock, when told that the procedure she would have to undergo to remove the baby from within her was called an 'ERPOC'; otherwise known as an 'evacuation of retained products of conception' she was floored. Because of the language used, her baby as far as she was concerned, had been reduced to a product, not even worthy of being termed a miscarriage.

One of the reasons this confused, and sometimes degrading and dehumanising situation has been allowed to persist for so long, is that it's a bit like the War....don't mention it. It's not polite conversation suitable for the dinner table, or even 'girl-talk'. And in the media, where you might expect the issue to crop up every now and then, there is barely a mention in any meaningful fashion.

A comprehensive search of New Zealand based newspapers, magazines and books published over the last 20 years reviewed from the current year (2005) back to 1985, turned up a range of articles with common themes running through them. In the main, the articles had a specific reason for inclusion; book reviews; coinciding with dates like Mothers' Day and Christmas, or as 'sidebars' to current news events. Many of the articles exist because of the campaigning work of SANDS (Stillbirth And Neonatal Death Support), and Miscarriage Support Auckland.

Headlines clearly acknowledge the difficulty of talking about this subject, not only amongst ourselves, but also more widely in the mainstream media. Headlines like 'Support for invisible death', 'A silent grief', 'Shame game: exploiting women's pain',

‘Stillbirth a taboo subject’, ‘A loss that lives in silence’ and ‘Dealing with the unspoken grief of miscarriage’ are commonplace.

An article that appeared in November 1997, in the *Manawatu Evening Standard*, ‘Support for invisible death’, goes some way towards trying to explain this perceived need for secrecy and silence. “Stillbirth is often called the invisible death, because other people don’t see the baby, or form a relationship with it, so there’s nothing for them to focus on.” This quote is from a member of the local SANDS group, and the article goes on to highlight the difficulties that arise due to this invisibility. Discussed is the fact that people ignore the awkward subject of baby death, rather than acknowledging that “something awful has happened in a person’s life.”

Although the subject of loss before life beginning is not hard news, it is something that is very much a part of the fabric of human life. When baby loss did appear in the print media over the last 20 years, newspapers had the lion’s share, with the *New Zealand Women’s Weekly* magazine following close behind. Patently obvious is the fact that this is a subject primarily for women, and more specifically for women who choose to read women’s magazines. However few articles focus on the invisible stage of baby loss, in general they are about either stillbirth or miscarriage. Only a few books and a small number of medical based magazines and journal articles, are written specifically with this gestational stage as the focus.

The *Otago Daily Times (ODT)* dedicated nearly a whole page to baby loss in May of 2005, to coincide with Mothers’ Day. Details of a service to remember babies is highlighted. “We were simply acknowledging the need for a place to go to remember those babies who have died. Many have no graves; many were given no chance to be farewelled.” The second article on the page was about the Dunedin Baby Bereavement Group publishing a booklet this year (2005) specifically aimed at “aspects including miscarriages, ectopic pregnancies and therapeutic terminations, through to personal experiences.” Headlined ‘Booklet to be widely circulated’, the article illustrates the point that there is still a lack of information readily available for women.

The Aucklander (City Edition) in April 2005, ran an article ‘Coping with Loss’, by Auckland Miscarriage Support Group President, Vonney Allan. Again, lack of

information is the key point. “Parents are aching for information about the loss which comes with miscarriage.”

The larger dailies, like the *New Zealand Herald*, rarely publicise baby loss, except when it has sensationally made it into the headlines. At the beginning of 2005, two pre-term babies were found dead within three weeks of each other in Hastings. The mothers’ whereabouts were unknown, and the two babies (named Aaron and Moses), were given burials “by a group of strangers.” Both discoveries were newsworthy and consequently one newspaper dug a little deeper into the issue of baby death. *The Dominion Post* included a news feature in early January 2005 in direct response to the abandoned babies stories appearing in the nationwide headlines, which went further and attempted to unpack the ideas and understandings society has about the experience of baby loss. ‘Mum on trail of baby deaths’ interviewed Dr Jane Zuccollo, the only practising perinatal pathologist in New Zealand who is based in Wellington. Dr Zuccollo touches on loss from the parents’ point of view. “Very often I have taken the baby from the family. Of course I look at it as a child. You treat the child as you would want your own to be treated.” Although the headline is about baby abandonment, it actually focuses more on her job. “The majority of the cases are obstetric deaths – still births, fetal abnormalities and miscarriages. A few are new-born deaths or sudden deaths in children... It is the loss of an expected life, sometimes completely unexpected. Most people want to know why it happened, is it going to happen again and what will we do the next time.”

Many of the articles that appear in the major dailies and the high circulation mainstream magazines, are of a purely scientific or medical nature. An example of this was in the *Listener* in late November 2004. The front page lead story, ‘Secrets from the womb’ focussed on research carried out by Professor Gluckman of the Liggins Institute, (a world class research centre which is part of the University of Auckland), in collaboration with a professor from the United Kingdom. Their research was about the importance of a pregnant woman’s diet for the growing baby, and the ongoing inter-generational effects of this prenatal existence. It essentially talks about science, and although the book described in the article is written with the “level of the popular reader in mind”, this is a purely medical exercise. The fact that the publication of the book made the front page of the *Listener* magazine, suggests that the authors and publisher aimed for a greater audience than just the medical fraternity.

Possibly the only articles that appear throughout most of the mainstream media outlets which look at the emotional aspect of losing a baby, are those in the *New Zealand Woman's Weekly* magazine. The reality is of course that not all women - and fewer men, except those who find themselves waiting for their takeaways with nothing better to read – are this magazine's target market. In early November 2004, Suzy Cato of 'Suzy's World' children's television show fame was on the front cover 'After loss & heartbreak Suzy Cato shares her baby joy.' In it she discloses feelings of sadness, and her personal struggle to come to terms with two early miscarriages. She and her husband chose not to "share their personal struggle with all but a few very close friends and family members." The 12-week 'safe stage' is discussed along with her relief in her current pregnancy, of reaching the end of her first trimester and feeling "able to exhale." The fundamental problem with this and many other similar articles, is the lack of concrete advice or information for women who may be going through this experience. It is the good news stories that are published. Suzy was 24 weeks pregnant, and therefore past the most dangerous stage.

The Woman's Weekly 'Real life, real people, real stories' section is the place reserved for stories of baby death. 'My baby shared my womb with a time bomb' in August 2004, and, 'My son's twin is his guardian angel', appeared two weeks prior to that. At least these stories get to see the light of day, but again in a women's only magazine, and from a purely narrative perspective. And again no practical information is provided for the women who may be in this situation.

In early October 2004 the *Dominion Post* ran an article, 'Learning to cope with the death of a baby'. Obviously spurred on by the local SANDS group in Wellington, the article highlights the plight of women dealing with the deaths of their babies. A member of SANDS Wellington whose baby had died in-utero at 28 weeks gestation six years earlier, had this to say. "You don't expect a baby to die. Nothing can compare to it." It covered the importance of raising awareness of pregnancy loss and infant death, including acknowledging International Baby Loss Awareness Week, October 9-18.

As recently as August 2004, the need for a proper memorial site, at a cemetery in Pahiatua, was highlighted in the *Evening Standard*. The reason for this need came about because of the possible laying of a concrete burial strip, directly above an area where

babies had previously been buried in unmarked graves dating back to 1911. A local funeral director took his concerns directly to the media. A spokesperson for the local SANDS group interviewed for the article, said no-one from the council had approached them. “We could perhaps excuse it (disturbing a sensitive area), 20 years ago, when we thought it didn’t matter anymore, but now we know, it does matter.”

Three days prior to this article appearing, the same publication ran an article, ‘No consultation morally wrong’, in which the funeral director, Mr Burt, is extensively quoted. Burt himself had a little brother buried in the Pahiatua cemetery, and his father had been the funeral director before him. The council’s excuse for recycling the grounds where stillborn babies lay with no headstones was, “We have all the cemetery records going back to the 1880’s, and there is nothing to say any children were buried in that main area, or where the new concrete berm has been laid.” Burt’s response to this council spokesperson, “This wasn’t surprising, as there used to be no requirement for local councils to record the burial of such babies.” It was only in the 1980’s that this particular council passed a bylaw allowing headstones for babies buried in the past to be erected.

The issue of burial sites came up time and time again in media articles. Many smaller cemeteries have only recently become aware of the need to offer families a suitable place to remember their children. *The Press* in May 2004, disclosed that the Christchurch City Council was asking families to remove items from their babies’ graves. Whereas in Napier, at the same time yet in complete contrast to this move, the council was erecting a monument to lost babies, including miscarriages.

Still in 2004, ‘Loving the departed’ in the *Christchurch Press* goes some way towards uncovering the tough issues of baby loss. The ex-chairwoman of the local SANDS group is interviewed, and she discusses how many members who lost babies 30 or more years ago are still grieving, because their grief at the time was not acknowledged; to the point that it was not acceptable to even see your baby back then. But with reference to today she says, “We still have a long way to go. Parents have a double whammy – not only with the unexpected pain and loss, but also trying to cope in a society that expects quick fix solutions: they should just ‘let them go’ and get on with it.”

The Dunedin Baby Bereavement Group managed to get more publicity in May 2004 in the *Otago Daily Times*, when the group commemorated ten years of being. The article highlights the number of projects in which the group is involved, including talking to midwives at the Otago Polytechnic School of Nursing; raising funds for information and awareness material to be distributed amongst medical centres, Plunket rooms and funeral directors; and searching for infant death notices, and sending cards to bereaved parents to inform them of the group's existence. Publicity for organisations such as this are essential because if the need arises, women need to be aware that there is help available for them, should they choose to access it. This type of useful information is not always given to women at the time of their loss through hospitals or by their general practitioners.

Publicity makes a difference for support groups and health professionals working with bereaved families. The amount of voluntary work going on behind the scenes up and down the country becomes apparent, when the few but important articles appear in local and national newspapers. The *Whangarei Leader* contributes to this publicity with its May 2005 article, 'Baskets ease pain, bring dignity to a sad event'. When a member of a Northland health worker's whanau suffered a stillbirth, she realised how inadequate the baby's presentation to the family was. This motivated her to come up with the idea of a basket, which allowed the family to take their baby away with dignity. She is now working on the idea of a 'kete maumahara', a kit for memories. There are people who realise the need to make a difference, and this is an example of an individual who understands and acted on her understanding in a practical way.

What is also apparent are the number of articles appearing in mainstream media in more recent years, in comparison to the number even ten years ago. Obviously there is an acknowledgement that losing a baby is a traumatic and unexpected event, and that supportive people are needed to make the experience less painful. When Nicola Miller-Clendon published her book in 2003, *Life after baby loss*, a couple of publications picked up the story. Not surprisingly *Little Treasures* magazine ran a piece in the 'Real Life' section, 'When a baby dies'. The subject of lack of information appears in the first paragraph as the primary reason for the book's existence. Not new to publishing, having already written in her capacity as a midwife, *The User's Guide to the New Zealand Pregnancy* in 2001, and *The User's Guide to the New Zealand Baby* in 2000, Miller-Clendon knew first hand the lack of available information for women losing a baby, at

whatever stage of pregnancy. The review is thorough, covering all aspects of the book. It is a shame it didn't appear in many mainstream media outlets. Again, *Little Treasures* is targeted at women, particularly the first time mother. *The Dominion Post* did pick up on the launch of the book with 'A loss that lives in silence.' It managed to get some decent editorial space, and included quotes from the women in the book, as well as the inclusion of some salient facts. "It is conservatively estimated, that one in five conceptions end in pregnancy loss. In New Zealand, that means that for the 57, 500 births in 2000, it is possible more than 14,000 pregnancies were lost."

Next magazine, targeted exclusively towards women, only had three articles relating to baby loss over the 20 year period. 'After William' written in the first person in June 2003, appeared in the magazine's 'Private Lives' section. The mother of William, who died weeks from his due date, eloquently describes the incongruity of loss before life beginning. "What we weren't ready for – and I don't believe anyone ever could be – was the enormous sense of loss, and pain, that threatened to engulf us when William's birth was inextricably wrapped up in his death." She also mentions the cementing of that incongruity when the condolence flowers began to arrive. "I couldn't look at them: I couldn't face the flowers – they were too bright and cheerful."

One of the more comprehensive articles to appear in the *New Zealand Women's Weekly*, was in May 2003, 'A little knowledge could save your unborn baby's life – it did mine.' The woman telling her story of five miscarriages before 12 weeks and a stillbirth at 20 weeks, shares the reality of having Lupus, an autoimmune disease which only affected her in pregnancy. Two blood tests and taking low-dose aspirin in the early stages of pregnancy to rectify the problem was all it took, but that was discovered seven years down the track. "Overseas they test for lupus routinely, but here not a lot of people seem to know about it. It seems a bit hit and miss – unless your doctor is on to it, it can go undetected. If more people knew about it, they could prevent so many babies being lost."

One of the more informative articles to appear in the *New Zealand Herald* was in November 2002, 'Dealing with the unspoken grief of miscarriage.' Three prominent spokeswomen regarding miscarriage were interviewed including Sandra Van Eden Long, co-founder of Miscarriage Support Auckland; Dr Hilary Liddell, founder of the then Recurrent Miscarriage Clinic at National Women's Hospital; and Lois Tonkin,

Christchurch grief counsellor and author of the book *Still Life*, published in 1998. *Still Life* is essentially a retrospective of women's stillbirth stories in New Zealand, dating back 20 years. Tonkin noted, "While attitudes have changed – people now often take their dead baby home, take photos and hold funeral services – many women who have experienced a stillbirth or miscarriage, in particular, believe their loss and grief is not always acknowledged."

New Zealand is not the only country to have difficulty dealing with this issue. A feature in the *North Shore Times* about a woman's losses appearing in April 2000, 'Pregnancy defies medical advice' was about a woman who is now based in New Zealand, but who previously lived in Australia. She had a daughter, then suffered five losses. Then against the odds, she conceived again and gave birth to a healthy baby at 35 weeks gestation. "There was no miscarriage support network in Sydney to help her cope emotionally with the loss of her babies." The woman herself goes on to talk about wanting and needing information, but that it just wasn't there to be had. Now a volunteer for Miscarriage Support Auckland, she only discovered the organisation's existence a year after her second daughter was born. "The group estimates around 2000 families in the greater Auckland area are affected by miscarriage each year." After five losses including a stillbirth, why did this woman not find out about the existence of Miscarriage Support until well after her second daughter was born?

The media outlets that publicise support groups and support initiatives, contribute to the public recognition families and the support groups crave, and deserve. In January 2002, the *Nelson Mail* reported that the local hospital had been donated a bassinet, to be kept in the new bereavement room once the hospital's redevelopment was completed. These tangible donations may seem small, but to a family who only get to be with their baby for the briefest of time, something like this can make a world of difference to their loss, and to their ability to cope with the ensuing grief. Baby loss happens often enough that even in places like Palmerston North, the local SANDS branch had 700 members back in December 2001. These people are the ones making the difference for those unfortunate enough to travel this path after them.

The article that appeared in *Next* magazine in December 2000 was unique because of the more intellectual approach taken to the subject matter, and the inclusion of a fact box. This in itself makes the article more valid than the run of the mill sad stories that

appear in many of the other women's magazines, and in a number of the newspaper articles. Women are seeking information to help them through the death of their baby, as well as the opportunity to hear another woman's experience. A fact box makes an article more valid and helps women who are seeking information. With the headline 'A silent grief', photographer Emma Bass discussed her latest photographic project that was 'breaking taboos'. "Shrouding miscarriage in silence, only makes it harder to cope with." Many of the recurring themes are mentioned. Well-meaning misplaced comments; a sense of failure; feeling guilty; and lack of information. "Emma searched for books and found 'loads about pregnancy, loads about abortion, but hardly anything about miscarriage. I felt very alone. Miscarriage is a huge silent grief, it really is'."

More profound are her comments about the long-held tradition of women keeping silent about their pregnancies until they have reached the 12 week stage. "The polite custom of keeping a pregnancy quiet in its first three months, effectively ensures that only a woman's closest confidantes will know she's lost a baby, and she's generally expected to shrug it off, and get on with life." The article also included comment from one of the co-founders of the Miscarriage Support Group, Sandra Van Eden Long.

The media can provide a platform where taken for granted responses can be openly challenged and better ways of responding to grief be communicated. One of the more lengthy articles to appear in any newspaper or magazine, was in the *Manawatu Evening Standard* in November 1997. The health reporter for the paper interviewed a group of parents whose babies had died. It alludes to the fact that 25 years ago there was far less acknowledgement of the effects of baby loss, and that fortunately times have changed. However, stories of couples that lost babies in the early 90s are also included, and their stories are full of the same pain; medical professionals not acknowledging their loss, and friends and family finding it all too uncomfortable to deal with. This particular article specifically included stories from the invisible couples about the deaths of their invisible babies.

The media can also highlight how politics impacts directly on the grief experience for women whose babies die. In August 1996, *The Press* reported that a protest had been held outside the Southern Regional Health Authority offices in Christchurch, because of impending cuts to the Christchurch Women's Hospital social work department. The lack of appreciation that counselling for women losing babies is important was clearly apparent. "The obstetric part of the social work service was for women whose babies

had died of stillbirth and neonatal death. The cuts meant that the 50 to 60 women in the system would no longer have a social worker.”

Articles in publication are an opportunity for women to read a personal account of a tragedy not uncommon, but rarely discussed candidly and graphically. *Next* magazine published the article ‘Loved and Lost’ in the ‘First Person’ section in December 1995, about a woman who had suffered a miscarriage at 15 weeks. She describes the sensitivity displayed by a young doctor, who called her loss a baby. But in absolute contrast, the insensitivity of a nurse. “Only one comment jarred: ‘Just be thankful you’ve got four other healthy children!’” She also eloquently lets the reader in on her state of mind. “At times, I wondered quite seriously if I was going mad. The loss had disorientated me in a quite fundamental way, so that I felt unhinged, cast adrift, lacking in basic confidence.” This, coming from a well educated woman with other children. And there are hospital boards nationwide that have considered reducing counselling services to women suffering a loss, for the short term goal of saving money!

There is no doubt that the publicity generated by articles appearing in local media make a difference. A letter appeared in *The Evening Post* in March 1995 from the organiser of a memorial garden for stillborn babies at Taita Cemetery. It states that the story published the previous month about the cemetery “evoked a very wide response.” Letters and phone calls were received, with people from the south island preparing to travel north to be involved with the dedication.

The Dominion ran a brave article back in December 1993, before any formal SANDS groups had established nationally, with verbatim quotes from many women attending the local SANDS meeting. It included comment about men and women’s different grieving processes, and the importance of family and friends talking about the baby, without changing the subject.

Again and again the women quoted in articles talk about the difficulty of dealing with people’s well-meaning platitudes. It is human nature to try and make things seem better than they are, and to compare one tragedy to what could be considered a worse one. But in the case of baby loss, this is just no good. Women who already have children are constantly reminded to be thankful for those children, which doesn’t help. No words can make a woman and her family feel better, but as the woman who was quoted in a

September 1993 *Women's Weekly* article said, "The best thing others can do, is to acknowledge a parent's loss. They should say they're sorry, give cuddles and hugs, ask questions and listen – and do not compare the loss with any other."

Journalists can help make processes around baby loss transparent and show how differences in services affect women's experiences. There is a lack of communication and standardisation of literature from one hospital to the next. The journalist writing the *New Zealand Women's Weekly* article in March 1992 identified specific examples of this, including the lack of sympathetically written information for bereaved parents. *Empty Arms* is a booklet parents are given at the time of their baby's death at National Women's Hospital in Auckland. It was written by a woman who, in March 1991, suffered the death of her baby in-utero at 27 weeks gestation. The booklet came about from a letter of complaint she sent to the hospital, regarding the inadequacy of the treatment she received while giving birth to her stillborn baby. When the magazine ran the article a year later, headlined 'Hospital nightmare', about the author's experience and subsequent publication of the booklet, it clearly identifies the hospital's lack of respectful procedures at the time. The grieving woman's mother had sent a booklet written by a nurse on the West Coast to her daughter at the time of her loss. The journalist noted that similar booklets are available at Wellington and Christchurch Women's Hospitals. Her research uncovered that other hospitals throughout the country had procedures in place to help parents in their grief. This lack of material available at the time, in the biggest maternity hospital in the country, serving the largest population base, seems remarkable and incomprehensible.

Celebrity stories about baby loss can open the floodgates for other women to talk about and share their experiences. In 1991, the *New Zealand Women's Weekly* featured a piece about "the leading lady of breakfast radio in Wellington." She personally thanked the 200 women who responded to her story about losing her unborn baby. Her miscarriage occurred at 16 weeks gestation, and after initially "shutting their grief outside the studio door" she opted to stop perpetuating the invisibility of miscarriage, and 'came out' about her loss. "Professional women with city careers, housewives from country areas, grandmothers who had never spoken about their experience of miscarriage before...I've got long letters, poems, photographs, books."

Media can also aid research about the experience of baby loss. The now defunct feminist magazine *Broadsheet* had the most comprehensive articles to appear anywhere in the last 20 years. Although not a mainstream publication, it did achieve maximum publicity for an important project that is still making a difference today. In April 1985, and June/July 1987, two articles appeared, both headlined ‘Coping with Miscarriage’. The first article was written specifically to publicise the impending publication of Kitch Cuthbert and Sandra Van Eden Long’s book, *Coping with Miscarriage*. Included in the article was a miscarriage questionnaire for readers to fill out, and return to Cuthbert and Van Eden Long. Eight hundred completed questionnaires were received from the request that appeared in several publications including *Broadsheet*, *New Zealand Women’s Weekly* and *Parents’ Centre Bulletin*. The overwhelming response to the questionnaire left the pair in no doubt that this matter was important. The second article two years later, again with the same two women, reviewed the results of the survey, and the subsequent publication of their ground breaking New Zealand book. Not only did Cuthbert and Van Eden Long fulfil their promise of giving women more information than they had when they both suffered their miscarriages, but they also set up the Miscarriage Support Group in Auckland – a first in New Zealand.

Highlighting the way in which bureaucratic systems can affect a woman’s grief experience is another role media can and should participate in. The *Parents’ Centre Bulletin* in June 1989, featured ‘Losing baby Thomas’. The article was written by the co-president of the Timaru Parents’ Centre at the time about her double tragedy of going into premature labour twice. She gave birth to Thomas, who was dead at 24 weeks gestation. Then close to a year later, she gave birth to a daughter, who also did not survive at 20 weeks gestation. When the article’s author reflected on these events, she had this to say. “Even though he wasn’t in-utero long enough to warrant a birth or death certificate, our baby was named and people saw him and held him... Thomas will always be a special member of our family.” If she had given birth to either of her babies from 1996 when the law changed from 28 weeks to 20 weeks for a legal stillbirth, they would have received the legal recognition she highlights they didn’t ‘warrant’.

The media has not supported a large response to baby loss over the last 20 years. If it wasn’t for the work of SANDS groups and Miscarriage Support Auckland, many of these articles would not have appeared. Through the combined efforts of these two

active support groups, stories of baby loss and some practical help for grieving families has been sporadically publicised.

Baby loss is a difficult subject with particular reader appeal. But not discussing something doesn't make it go away, it just keeps it hidden. If the media's role is to cast light on issues and provoke debate, then their contributions on this issue over the last 20 years represent a disturbingly low output. What is clear from the articles that did appear however, is that women do want to talk about their personal tragedies, partly for their own healing process, but also to help other women who may also be entering that dark place of loss before life begins.

Article Two

And Mother Makes Me; Five Women's Stories of Loss Before Life Beginning

The rationale behind interviewing five women, from five different walks of life, who are different ages, but who all share the common theme of losing a baby in the invisible stage between 12 and 20 weeks gestation, was to ensure that their stories represented a uniqueness of the individual circumstance, yet uncovered similarities.

The last 20 years has seen some major developments in technology in the area of pregnancy, including far better scanning technology; more tests available to determine fetal health; an increased role of the midwife in the process of pregnancy, birth and post-natal care; and finally, a greater awareness and acknowledgement of the trauma and tragedy of loss before life begins.

Each of the stories of Kristen, Kim, Treena, Nicole (name changed), and Ellen (name changed), represent a time and place in New Zealand over the last 20 years of experiencing the loss of a baby between 12 and 20 weeks gestation. As is the case with every healthy baby born, every baby not born alive, also has a unique story. I set out to interview five women who had suffered a loss in the invisible stage, but what I found was that four of the five women had actually suffered more than one loss, and not all in this gestational timeframe. They were given the opportunity to tell their story in their words, and to be able to include or exclude their other losses. These are their stories...

Kristen is a young woman who although not born in New Zealand, has lived here for more than ten years and considers this country her home. She is well educated and currently busy continuing her education at tertiary level. She is no wilting flower, standing tall, and having a sharp wit about her. More often than not, she is the one who friends come to because of her strength and ability to empathise with whatever situation they may have found themselves in.

Kristen's story begins when her waters broke at 2 o'clock in the morning in late February 2005. Even for a woman expecting a healthy baby around the due date, when the membranes break it is often an unexpected and terrifying event. For Kristen, who was only 16 weeks pregnant at the time, it was disastrous. At this early stage, there was absolutely no likelihood of a happy outcome. Currently 24 weeks is the earliest stage a baby is viable outside of its mother's womb. The scan revealed that her baby was still alive but there was little fluid left around him. Kristen and her partner waited for her body to miscarry naturally, but this didn't happen. After another day of excruciating waiting and a significant amount of physical pain, Kristen began the process of having her baby medically induced into the world, to say hello, and goodbye. This process did not go smoothly either and Kristen did eventually labour naturally, with many complications: blood transfusions, and general chaos ensuing. Her wee boy Tane died during labour, and was born on 26th February, 2005.

Twenty-one years old is relatively young in New Zealand to start a family these days, but for Kristen and her partner, although a shock, and without doubt a complete change of lifestyle, the news was greeted with joy and nervous anticipation. It could also be said that it was greeted with a measure of trepidation. Kristen's mum had suffered the loss of twins late in pregnancy many years earlier, and had also lost a baby girl on another occasion. Neither Kristen or her brother's birth had been easy pregnancies either. So clearly there was a family history of difficulties, prior to Kristen conceiving Tane.

Kristen got the run-around when she first discovered she was pregnant. Consequently, she had not managed to settle with a midwife when Tane came into the world, 24 weeks too soon. Her main carer at this point was still her general practitioner. Kristen had voiced her fears about this baby's chance of survival given her mother's prior history, and had also talked at length about 'not feeling quite right'. Of course, being so young the assumption that all will be well was made by her GP. Kristen clearly remembers the words, "You're 21, you're healthy, and you're in your prime. Nothing bad will happen." Unfortunately for Kristen, the worst that could happen, did. She wonders whether she could have done anything differently; rest; take it easy; not work so much.

Kristen is clear that what happened to her was a miscarriage. Her waters broke, and her baby was too little to survive. The terminology is not an issue. But something she does

recall is the loss of her baby being purely medical, with very little value placed on the emotional toll. The scan she had after her waters broke clearly demonstrates this point. Tragically, this early on in the pregnancy there was no doubt that her baby, although still alive inside her, was not going to survive. At the scan when Tane was discovered to be without amniotic fluid a doctor said, "I'm happy with the scan results." Kristen remembers thinking, "Well, I'm pleased someone in this room is happy." There are times when sensitivity is a priority, and for Kristen, this was one of those times.

Some of the people who made a positive difference for Kristen were the nurses, many of Pacific Island descent. She found them caring towards her. What's more, they also treated her 16 week gestational baby as just that, a baby. She opted not to hold Tane, but he was respected by all the people who came into contact with him. A treasured possession - and there are precious few of those when one has had a baby who does not live - is the booklet given to Kristen with Tane's name, date of birth, weight, length, hand and footprints, and a photo. Tane was buried with his granddad at a cemetery in Auckland, at a funeral with both families in attendance. A minister led the service, and Tane had a dignified goodbye. No post mortem was carried out on Tane's body, because Kristen's partner is of Maori descent and it is not custom to disturb the body unnecessarily.

An unfortunate by-product of losing a baby before life begins is guilt. Kristen questions whether there was more she could have done to save Tane. "I think I should have rested more - that's what I get for why it happened; I didn't actually look after myself as a pregnant person."

For Kristen, at the age of 21, she was the only one of her peers to be pregnant, let alone to have lost a baby. Her disappointment was palpable regarding her friends' inadequacy, and obvious difficulty in being able to collectively support her, at the exact time when she needed them most. Being a strong young woman and normally the one to support others, having the ability to ask for this help proved challenging. "I felt at the time, like my friends disappeared. I don't think they knew what to do." Perhaps oddly enough, one friend who had gone through an abortion was supportive of Kristen, and in some strange way understood where she was at. "Because she had the grief and the guilt, and all that kind of stuff to go with it." Some friends made the incorrect assumption that Kristen would want to be left alone. She was told second-hand that a close friend had

even said, “Don’t say sorry, just act as if everything’s fine and normal.” Kristen acknowledges that when you’re upset, you just want to hide and not see anyone, “but you just say it.” This is not the time for the grieving person who needs help to have to ask for it, especially from the very people who should be there for them.

Kristen’s strength has come from within, and from her mother knowing what she is going through, and from her partner. The funeral for Tane was nearly two weeks after his birth, because she was so unwell physically. She reflected on the Maori people’s ability to grieve. “They have such a good way of grieving, and at the funeral they all cry. The whole family just cry, like nothing on earth. And then, as we left, they put the sand over the coffin. And after, you go wash your hands, because it’s finished. I think that’s healthy. And it’s so much better than Europeans do.”

Poignant reminders of a pregnancy that ended tragically prompted Kristen to contemplate throwing her 2005 diary away. Every week of her pregnancy is marked off, right up to her due date of 10th August. Her mum’s advice was to keep it, and not throw it away. That it’s okay to be reminded of her baby, painful as that may be.

When asked if she could change anything around what happened, this young woman’s comment was loud and clear. “I think, because I was young, and I was pregnant, it was a shock to everyone. And then there was a baby, and it was more of a shock to everyone. It was just easier for everyone to pretend it didn’t happen. I would like to change all that, everyone just shies away from it. It’s like, it’s not spoken of.”

Under entirely different circumstances, 29 year-old Kim discovered to her horror at her first and much anticipated 12 week scan, that her baby had died in-utero some time earlier. Having spent most of her 20’s concentrating on forging a career, and with this mission successful, she turned her attention to starting a family. She approached motherhood in much the same way as carving out a career, with a determination and thirst for as much knowledge as possible. With an analytical, scientific bent, Kim’s understanding of her rocky road to becoming a mother is admirable. When she found out her baby had died in-utero, although in shock she immediately began the process of trying to digest the news. “We got in the car, and proceeded to drive home as well as we could, pulling over every now and then to register what was happening.” Because they were going overseas in a couple of weeks, Kim wanted to find out what was supposed

to happen next. There was no call from her midwife, and the local hospital told her not to bother coming in, because they were too busy. Kim was left without any professional help or advice, all the while knowing her baby was dead inside her.

The next morning Kim decided that enough was enough, so she asked her GP to refer her privately, as she had medical insurance. The answer was no, so she persevered with the public system. “I got examined by various doctors, in rooms they hadn’t set up. They had to put a blanket over the windows, because it wasn’t private. It was really badly handled.” After more waiting, she was informed that ‘the procedure’ would not go ahead that day. So, after a well justified tantrum, she had 15 minutes to get to a specified private hospital, for the dilation and curettage (D & C) to take place.

“The minute I walked in the door, it was so totally different; people were caring from the start. The (public) hospital was like (being) a sausage on a barbecue. I know they have hundreds of people to deal with, but there was a lack of information, a lack of care. They made you feel like it was something unimportant. They look purely from a medical point of view, not what’s going on in your head. They not once asked me if I’d like to talk to someone about it, or anything like that.”

Kim’s ‘procedure’, to clear her body of the remains of her baby, is called an ERPOC – an evacuation of retained products of conception. When she rang her medical insurer for prior approval for the D&C, Kim called her loss a miscarriage, not an ERPOC. For her, the baby she had wanted and loved, even for such a short time, was more than a mere product of conception. “The thing is, from the minute you know you’re pregnant, you start making plans as to how your life’s going to change, what’s going to happen. Hey, in December, I’m going to have a baby, so what are we going to do for Christmas, for example. Then, suddenly, your whole world falls apart. You’ve got all these plans in place, and none of it is relevant anymore.”

Kim also talked at length about the reactions of family members, and friends, to her loss. “I think you make a quick assumption that people are going to be there to support you, and they are going to see it as a loss. But I very quickly learnt that they don’t see it as a loss. They don’t see it as a baby, they see a bunch of cells, get over it.” Kim turned to the internet, and found herself at everybody.co.nz, the website supported by Miscarriage Support Auckland. She got no information from the hospital at the time of

her loss, other than the literature explaining what a D&C is, and about care following an ERPOC. For her the website has been invaluable, to the degree that a group of women who have met via this website have since formed a group with a specific place where they go to chat online.

Kim feels disappointment in the way she was treated by the health system, and the lack of follow-up care. Fortunately, she has a good GP who took the time to phone her to see how she was, a couple of weeks after her loss. But concerning the role of her midwife, she was far from impressed. "I guess it probably is not my midwife in particular, but the way they have been taught to do things. They don't follow-up. They're there to care for you and your baby, and it doesn't extend to caring for you if you've had a miscarriage, because the baby's not there. It's almost like they're not interested anymore. That really disappointed me, more than anything." An observation she made in the context of this conversation, is that the body recovers relatively quickly. "But no-one seems to care about the other end, how you're thinking."

Unfortunately, Kim lost a second baby in December 2004. This time she was far more aware of the situation, and in her mind one positive aspect was that she actually miscarried naturally this time. "Luckily, I suppose it was lucky, I miscarried the day before I was booked in for the D&C. I would rather it happened naturally than have to go through the whole hospital thing again, which I really didn't want to do."

She was disappointed once again with the majority of her friends. "There's no support from people in general. All your friends – 'that was six weeks ago, it's old news'. They expect you to have got over it by now." She believes people just don't know what to say, "instead of saying anything, they said nothing." One of the people who has made a difference is a woman she is in contact with through her professional life, whose baby died at eight months old. "Her and I both sat there and bawled our eyes out, sharing our experiences. I mean, they were so different, but again, she'd found the same thing. People just couldn't go there, and couldn't understand. She had no-one to talk to either. There were a lot of parallels about what people said, and what she had been thinking. It's frustrating, people aren't aware of the impact it has."

Kim clearly wishes she had been given the opportunity to speak with someone who had an understanding of her experience, to ensure that what she was feeling was 'normal'.

She constantly questioned why she was feeling the way she was. “It’s not disbelief it’s just, you feel you almost have to justify why you’re feeling down about it. Why you are still getting those feelings. You wonder if you’re being silly because you have all these people saying it wasn’t a baby, it was a bunch of cells.”

Treena, a woman in her mid thirties, has a story that would test anybody’s strength of character. Her intelligent, clear blue eyes match her mental agility. Like a number of other women interviewed, she has a thirst for knowledge. This thirst extends to holding down a full-time job, and furthering her education by studying part-time. She has also spent a significant amount of time trying to understand what happened to her, and her babies.

In February 2004, at 18 weeks gestation, a couple of days after her much anticipated anatomical scan, Treena’s waters broke in the middle of the night. This signalled the beginning of the birth of her twins, Verity, and five days later, Cael. For Treena and the rest of her family, this was the beginning of not one tragedy, nor even two, but three tragedies. In July 2003, Treena was pregnant and had discovered at her anatomical scan at 19 weeks that Bella, the baby girl growing inside her, had serious and irreversible abnormalities.

With Bella’s poor prognosis, the inevitable choice they were being forced to face was soul-destroying. They had opted not to have a 12 week scan because they just wanted a baby, and whether it might have a chance of Down’s syndrome was unimportant to them. So, when they went for their first scan at 19 weeks, the last thing they could ever have anticipated was being told that their baby had very serious complications. The likelihood was that Bella would possibly not survive the pregnancy, let alone have any quality of life should she survive through to birth. After much consultation with the hospital professionals and a review by the medical council of her case, Bella was medically induced at 20 weeks gestation. Treena’s reflection on this awful time in her life is concise. “We feel we made the best decision for her, because if she had managed to live to full-term, then she was going to have no sort of life at all.”

Three months later after Bella’s tragic birth and death, Treena and her partner married and she conceived once again. This time they did opt to have an earlier scan and in early December 2003, discovered at the 12 week scan to their amazement they were to have

twins. “I was crying, and for me that was my redemption, my salvation from losing Bella – I was getting two babies in return. And I still look at it like that today. That was my consolation prize I guess, for having lost one baby. I was now going to have two babies.”

The worst possible scenario eventuated though when one Sunday night, in early February 2004, Treena’s waters broke prematurely. She had only had the 18 week scan two days earlier, and all was well with her babies. Her waters broke 22 weeks too soon, and after a mad dash to the local hospital, Verity was born shortly after. Remarkably, when a scan was done, Cael the little boy was still very much alive inside Treena. She spent five exceptionally long days in a ward, playing the waiting game. “I thought, we’ve lost one, we’ll be able to keep the other one.” There was discussion at this point of her being able to return home. But again, the worst happened and her waters broke for the second time. As far as Treena and her husband are concerned, Cael was born alive. The nurse disagreed and showed no emotion or empathy for the situation they were in, instead choosing to argue with them. After Cael was born, as is often the case with severely premature labour, passing the baby, or in this case the babies’ placentas was not happening and medical intervention was required.

Treena had previously had a D&C after giving birth to Bella the year before, but this time was entirely different. Controlling the bleeding proved extremely challenging for the medical team working on Treena, and performing an emergency hysterectomy was discussed. Fortunately, her midwife managed to stop this happening. Treena had custody with her husband of adolescent twins, of which he is the biological father from a previous relationship. In her file, the hospital staff misread this, thinking she already had children. Because of this they assumed it wouldn’t be the end of the world, if she did need to undergo a hysterectomy. The midwife in this case made the world of difference. Treena recalls her checking her chart and protesting to the medical team that they should not perform the hysterectomy, because their records were wrong. She fought the cause for two people who were in shock and physically, let alone mentally, incapable of fighting this battle on their own.

Adding insult to injury, after Treena had given birth to Verity at 19 weeks, and Cael at 19 weeks five days, they were both deprived of birth certificates. “So for a matter of days, they weren’t real people.” Under current New Zealand law, a baby born prior to

20 weeks gestation is not required to have a birth certificate, or for a burial or cremation to take place. In contrast, Bella had been born at 20 weeks five days, at least providing some legal recognition of her existence.

From Treena's perspective, "You know legally, they're not real. Legally, they're a miscarriage." She clearly remembers Bella being referred to as a medical abortion, and the twins as miscarriages. It felt cold, medical and clinical. This was definitely the case with the doctors, gynaecologists and surgeons, but the nurses and social workers were different. When Treena finally returned from surgery after her ordeal with Cael, she remembers, "there was a really nice older nurse. She had actually taken both of them away and put them in little gowns, and in a nice little bassinet together. She put little bonnets on them and took footprints of them." This was five days after Verity was born, but at least someone had thought to make the effort. For Treena, this was very important and appreciated in a way that words could not express.

Although times have changed, some things have not. When Treena arrived at the hospital, after her waters had broken with the twins, she was admitted into a general ward. "The thing that got me was there was a woman two down with her baby because she had mastitis (a breast infection). So there was a crying baby two doors down. I was not wanting to be lying there listening to that. Obviously they didn't do it intentionally, but..."

Being a general admissions ward, the staff were also unprepared for this situation as well. "I remember when I had Verity, I was lying in bed holding her one day, and this young girl, about 17, came in to get my lunch tray. She looked over and said 'what's that?' I said, it's my baby, and she asked if it was real. Just being in a general admission urgent type ward, you probably don't expect to see dead babies. I felt sorry for her, because she was probably freaked out completely."

Treena recalls the effects the medical and legal terminology had on her. "I thought an abortion was before 12 weeks. Anything else over and above that, I wasn't even aware. I hate the term abortion. I don't mind when you're talking about something you don't want, but not something that you so desperately want, and they refer to it as that. To me that's two totally different things. And then I think there's a miscarriage. And then I

think there's a stillbirth, which I think should be from 18 weeks onwards. That's how I see it, but abortion was the only medical term I knew before."

As far as the provision of information goes, Treena's two situations were obviously entirely different. In one hospital it was a medical emergency, and she was dealt with immediately and physically, first and foremost as is right. In the other hospital where she was induced to have Bella, she was required to fill out a lot of paperwork. It was not until she went in for the actual induction two days later, that she was provided with much of the information she should have received earlier. What is loud and clear is that in both situations, it depended on the individuals Treena came into contact with, as to how the process went. At one hospital the doctors related to her in a purely medical way, and the nurses seemed inexperienced and out of their depth. In the other hospital, the literature was inappropriate but the midwife was exceptional. "We ended up sending the midwife flowers to say thank you because she made the whole process so much easier."

One of the saving graces for Treena has been the support from her friends. She lives in a specific type of environment where people are in close contact with each other, and this has made the grieving process bearable. "You can tell who's comfortable and who's not comfortable, and you can see it in their faces. They don't quite know how to ask how you are, or how you're going, or what happened or whatever. I get to the point where I'm trying to be nice for them." She did seek counselling and it helped her realise she wasn't going mad, and that the feelings she was having were normal. She also did a huge amount of reading, both books and on the internet. This helped her understand what she was feeling, and as importantly, to understand the types of reactions she would face from others having difficulty with her tragedies.

However being around pregnant women is challenging and still hurts. There are children she knows who are now 18 months old, and she can't help wondering what her children would have been like at the same age. Similarly, she often feels emotional and tears come easily. "I could be watching television and Bambi dies. The next thing, I'm crying because I've lost my babies. Then it's over and I move on to the next day. It'll be fine for weeks and weeks, then something else will happen."

All three of Treena's babies were cremated and sit in a container on the mantelpiece together. "Because of our jobs and stuff, we're not going to live in this city forever. There's no way I could have buried them at a cemetery, and then move away." Bella, Verity and Cael have a place in the family, and are very much a part of the fabric of life in Treena's household.

Nicole (name has been changed) is immaculately presented, extremely eloquent, and clearly comfortable in her spotless domestic environment. With a successful corporate history behind her, she appears equally happy in her current role of mother to her young child. Reliving the loss of her identical twin girls brings back painful memories she tends not to revisit often. Nicole learnt that her babies had died in-utero in December 2002, the day after flying back to live in New Zealand permanently, and when she went for her 16 week ultrasound scan. Although she had experienced a small amount of bleeding prior to getting on the plane for the journey home, she had no idea anything was seriously wrong. Her first and most persistent reaction to the worst news ever was absolute disbelief. These babies were meant to be, and that was that. She had two more scans to verify that the twins were definitely dead, and then began the traumatic reality of beginning the process of giving birth to death. The first actual step of beginning this ordeal was taking the drugs that take three days to do their job. At this time she was also given an array of reading matter to support this process.

Nicole cannot to this day, come to terms with the pamphlets that were supplied to her. "All the literature that they give you, the pamphlets, everything on what's going to happen, is written on abortions, termination. I'm like, 'hold on, I'm not having an abortion, I'm not having a termination, I am having these babies that I desperately want'. I'm thinking, 'how can they give you literature like this to go home and read that's got abortion and termination all through it?' I just couldn't get that. How insensitive is that?"

"We turn up on the morning of delivery, because now we've had to go through three days of knowing you have got dead things, (because that's how I was relating to them at that stage). These were my beautiful little babies, my girls, and now they're these dead things." To make matters worse, on their arrival there was no bed, so Nicole and her partner spent three hours in a small room, also being forced to play the waiting game. "You know you're going in there to give birth to these babies, and you would think you

were therefore their priority, because there's all the emotional whatever. But this was obviously not the case." They finally started Nicole's induction, but no-one had explained to her what might happen. This was her first pregnancy and consequently her first experience of labour, and she felt that there was a complete lack of information provided.

For Nicole, giving birth to her babies was a slow and painful process. She had arrived at the hospital in the morning, and it wasn't until just before midnight that her waters finally broke and she delivered the first of her twins. Very quickly after that, her second baby was born. Nicole's biggest fear had been that she would not have a midwife with her, when her babies were born. The whole way through her ordeal she was reassured that this would not happen. But when her waters did finally break, no midwife was in sight. She was not mentally ready or prepared in any way for "the giving birth bit." She was terrified of what the babies would look like and paralysed by this fear, when the babies were born, she didn't move or look at either of them. The babies were moved to somewhere else by the midwife who turned up afterwards. Nicole was taken to surgery for a D&C to be carried out. The mental anguish she suffered at this time, was amplified by the lack of a midwife being in attendance when the babies were born. This fear of looking at her babies did not go away.

Nicole initially had every intention of seeing her babies when she returned from the procedure, and everybody she and her husband came into contact with urged her to do so. Then the chaplain came to see her and she began explaining what they looked like. "What I wanted to be left with was the picture I had of them in my mind. Not of something that was going to freak me out. At that stage you're in shock, horror and confusion, and although everyone told us we should see them, we talked amongst ourselves and decided not to. They had been taken out and put in a little basket and they took photos, and the chaplain went to bless them."

It had been the week from hell. Leaving a big job overseas to return to New Zealand with the impending birth of her twins ahead. Then discovering the babies had died, giving birth, followed by an operation. "I mean, my world just ended."

Looking back, Nicole can talk about what happened with the benefit of time to lessen the immediate feelings of shock and disbelief. Her pregnancy was planned, and the

babies were conceived using a procedure called IUI (intrauterine insemination). She had always wanted twin girls from when she was a young girl, and now she had got tantalisingly close to realising her dream. She wanted to know whether her twins were the girls she had dreamed of for so long.

When she had her babies in the gynaecological ward with only nurses on hand, no-one could tell her whether her twins were boys or girls. The uncertainty went on for weeks and weeks. She questions now how it can be possible to tell the sex of a baby in-utero as early as 13 weeks gestation via a scan, but that it was not possible to tell, “in real life.” Nicole found it impossible to get on with her life or even to get on with the process of grieving, until she knew conclusively what sex her babies were. “I didn’t do anything until I knew, and had some explanation of what happened. I just couldn’t.” After a campaign of harassment, she was finally told late in January that the twins were in fact the girls she had so badly wished for, and dreamed about. It was not until the end of the same month that she discovered the cause of her twins’ death – twin to twin transfusion syndrome.

Then the anger kicked in. How was it possible to have had four scans and to not know of this dire situation? The reality was that Nicole had been overseas, in a country where the medical technology was not as advanced as New Zealand. Although it was clear in the photos from the scans that the twins were different sizes, none of the medical people she had dealt with seemed able to explain this anomaly.

Twin to twin transfusion syndrome occurs in up to 15% of all identical twin pregnancies, because the babies share one placenta. The earlier the syndrome occurs, the worse the outcome generally is. New Zealand does not yet have the equipment to perform fetal laser surgery to attempt to correct the problem, which lays with the placenta, not the babies. Ironically, the surgery is available at Brisbane’s Mater Hospital, only a two hour flight away, and has been performed successfully on babies in-utero as early as 15 weeks gestation. The mortality rate for babies afflicted with this placental syndrome is close to 100% if there is no intervention.

Nicole will forever struggle with the loss of her beloved girls, and refuses to give them any label. “I could not swallow that I had ‘a miscarriage’ at 16 weeks.” But miscarriage was the word used by all the health professionals she came into contact with at the time

of her loss. She remembers disputing this and being ignored, or listened to, but without a change in language occurring. The only person who allowed her to say her 'babies' had died, was the chaplain. As far as she is concerned, the nurses on the ward were ill-equipped to deal with grief, or even to empathise in any way with the trauma she was going through. To Nicole, her babies died and because of this, they had to be removed medically. They were not miscarried and she does not, and never has used this term to explain her tragedy.

The terminology in the pamphlets provided to her at the time still irks. "I think they are getting women all the time who are having to come in and give birth. So just the fact that the basics haven't been done, of making sure that what's written in a pamphlet (and it doesn't have to be a fancy pamphlet with pictures, just a piece of typed paper explaining what is going on), in terminology that isn't offensive, like abortions or terminations."

This inappropriate, insensitive terminology, at the most difficult of times, is bizarrely coupled with a distinct lack of general information given. Nicole only came across the Twinloss Support group while doing her own research online, well over a year after she had the twins. She questions why nobody thought to put her in touch with this organisation when she gave birth to her girls, or why no list of helpful organisations was provided. "I must have been searching or whatever, and up it came. I sent an email and I found that contact valuable. You leave hospital and nobody wants to know. Give it a month and they say, 'build a bridge; get over it, shit happens.' For me of course, this was my life dream. So to have this connection, and to be able to read other people's stories, I find it invaluable. Because it's something I'll never get over."

Since losing her beloved girls, Nicole has given birth to one healthy baby girl; miscarried at six weeks gestation, and is currently pregnant again. She has made as much peace as she is ever likely to, concerning the loss of her twins.

Now in her early fifties, Ellen (name has been changed), can talk about her multiple losses with some degree of objectivity. Many years have passed, and with two healthy teenage children, a successful career, an intact marriage and the benefit of wisdom, she shares her story for the first time.

At just 17 years of age, Ellen was sent to England to deal with her much frowned upon pregnancy, that ended in disaster. She gave birth in a room on her own, to a full-term severely deformed baby in mid 1972. She never got to see her baby, or to say goodbye.

Seven years later, and still in England, Ellen was pregnant again, but this time under much happier circumstances. Tragically while at work one day at 30 weeks pregnant, she slipped over and went into labour prematurely. That baby also died and once again, Ellen didn't get to see her baby, or even find out what sex it was.

Back in New Zealand in 1985, her suffering continued. Her third pregnancy was ectopic which is extremely dangerous, because the baby is growing in the fallopian tube. With no option other than emergency surgery, the pregnancy was ended.

Happily, in 1989 Ellen gave birth to a beautiful healthy baby boy at 37 weeks gestation. But she wanted a big family and was not prepared to stop there.

So in 1990 Ellen was pregnant for the fifth time. She started bleeding at 25 weeks and went to the hospital. She was told the baby had died and that she needed a D&C. Not sure of why this had to happen, she just remembers being asked if she wanted more children, which she emphatically answered yes to. And so under a general anaesthetic, the procedure was carried out. She awoke on the ground floor of the hospital with absolutely no privacy to see her husband. "We were like battery operated hens. Everybody could see what you were doing and it was quite embarrassing. I felt very embarrassed although I had done no wrong. I just wanted to put the covers over my head, and forget about what had happened. I never saw the baby, never knew what sex, and I don't know whether it came out in one piece, or in bits." By 1990, scanning technology was widely used in New Zealand, and Ellen had already seen her baby many times, at eight, 12 and 20 weeks gestation. At each point everything had been fine.

Under the doctor's advice to go home 'and start making babies again,' within two months Ellen was pregnant for the sixth time. Her pregnancy ended when she started bleeding heavily at 16 weeks while at work. This time, when she took herself to hospital in a hysterical state, she was offered a psychiatrist. "I didn't want to be put to sleep until I saw my husband. I had just told everyone I was pregnant, and then I was bleeding.

There I was again at that hospital, and it was a battery hen set-up for three or four hours.”

Pregnancy number seven in 1991 ended in disaster at home. “I was 12 weeks and I’d just had a first scan and it was there, and perfect. Whatever it was its heart was beating very nicely.” Again she had to go into hospital for a D&C. Two months later, she was pregnant for the eighth time. She was only six weeks gestation and was once again at home when the loss occurred. So she returned to the same dreaded hospital for another ‘procedure’.

Finally at this point, she was referred by her doctor to the then recently established Recurrent Miscarriage Clinic. Her doctor, with remarkable understatement, said she was a good candidate for their services, and asked her if she’d like to try. “I said I’d try anything, sleep on nails, if I could get a baby.” The reason Ellen kept losing her babies was relatively simple, following all that pain and heartache. Her body produced antibodies that attacked the baby, and the antidote to this was just a quarter of a Disprin a day. In 1992, she gave birth to a beautiful healthy baby girl at 37 weeks gestation.

Ellen believes she wound up in the particular hospital she was in for each of her losses because, “I was not classed as having a baby. I think we were sent there because it was like one place is for giving birth, and one place is for getting rid of it. I have a funny feeling that’s where they did all the abortions, and I didn’t really like being classed with people who wanted to get rid of their babies. I was trying desperately to hold onto them.”

She clearly remembers the type of literature that was available at that hospital. It was all in relation to counselling for rape, and material regarding underage pregnancy. “That’s what made me think it was a place to go and have abortions.” There was nothing about counselling of any description, losing babies, or grief. “It probably wasn’t intended to be, but I picked up on those sorts of things in my emotional state and I hated the place. I really did.”

Ellen has distinct memories of the word abortion being used with all her losses. She was told that if a baby died before 40 weeks gestation it was an abortion, not a voluntary one, but a spontaneous one. “The word abortion though has been stigmatised with the

taking of a baby's life. I think that's really wrong to use for people who don't want to be associated with being a self-aborter." She also remembers feeling "violated" each time she was given a D&C. The reason for this feeling is because no-one discussed with her what they were doing, or why.

She also doesn't feel that she was treated any differently at any stage, or that the situation improved over the years. "I don't think they were obviously mean to you, it was just the way you were, a piece of meat on the slab. That's exactly how they treated you up there, as just another piece of meat coming up on the slab. That's how I felt anyway. It was very cold and uncaring." This feeling continued when asked about whether any of the health professionals had treated her more than purely medically. "The piece of meat didn't have feelings, or any thoughts of their own. An unconscious thing, on a slab."

Ellen never got any test results, nor had any reasons given to her as to why her babies kept dying in-utero. It wasn't until she was finally sent to the Recurrent Miscarriage Clinic that some questions were asked, and some answers were found. Her grief was contained within and only on one occasion over all those years did Ellen share her story with a friend over a bottle of wine. "Apart from that, I didn't discuss it with many people. Because it was very raw and I was trying to work full-time, and trying to maintain my sanity. By discussing it I would have actually opened up a whole can of worms, which I really didn't want to open. So I just kept quiet."

As far as grieving for her babies is concerned, Ellen doesn't feel she ever had the opportunity to do this. "I grieve still, I still feel for them. I still think sometimes, 'oh my, they would have been this stage.'" If she could change anything she would put a bomb under the hospital concerned, pointing all her anger at a building. But more poignantly she would have liked a chance to see some of her babies, to say goodbye. "They don't belong, they're soulless. Because they haven't been sanctified, they haven't been blessed, they haven't done anything. They are little souls that aren't there. I would have liked someone to give them their last goodbye."

For Kristen, Kim, Treena, Nicole and Ellen, their babies will never be forgotten. All these women in their own unique ways, have learned to live with their grief. It was not a

question of ‘getting over it’ but of ‘getting through it’, and being able to come out the other side with their sanity intact and their memories validated.

These five stories of five completely different women, spanning the last 20 years in New Zealand illustrate that change was necessary and in some areas is still necessary in the ways that we as a culture respond personally and systematically to loss before life begins. The loss of these women’s babies is a tragedy. It is not always possible to change the outcome of a pregnancy, but the manner in which the loss is dealt with by society, and by health professionals can be altered. Babies dying before life begins will occur as long as humanity exists. Therefore, the question of how we as a society can help the women who find themselves in this tragic situation in the future, is an important one.

One of the primary and most powerful methods of change available to everyone who comes into contact with a woman losing a baby, is having the ability to talk with them. The lack of communication pervasive in all these stories was one of the most common themes, and undoubtedly one of the most profound tragedies they all articulated, on top of the loss of their babies. When someone dies, the people that love that someone need to be able to talk about them should they want to. The availability of counsellors, chaplains and social workers within the health sector has gone a long way to rectifying this problem, but there is still much room for improvement. Perhaps it is time for the health professionals working at the coalface of baby loss, along with the politicians legislating, to re-assess the appropriateness of some of the terminology currently in use, and to continually look to improving the written communication given to women at the time of a loss.

Sadly, there are more women every day in New Zealand who join the unwanted club of those who have suffered loss before life begins. Therefore, there is an opportunity to debate the issues raised here; to look to promoting change for future sufferers, and to constantly assess the appropriateness of the manner in which loss is dealt with, by society in general, and more specifically, those working in the medical profession.

Article Three

The 'System' and The People Working In It

When a woman's pregnancy ends before 12 weeks, her miscarriage is a sad, unfortunate and tragically all too common event. Eighty percent of baby losses occur before the 12 week mark and because of this well-known fact, most women delay telling family and friends of their pregnancy. But after 12 weeks most feel confident enough to share their exciting news with the people that matter, and often even with the people that don't matter so much because they are now 'safe'.

Losing a baby between 12 and 20 weeks is not nearly as common, but for the approximately 2000 to 3000 women a year in New Zealand that this happens to, it can be catastrophic. It is a different loss to that of the early miscarriage, not least due to the fact that it is often physically harrowing because women must deliver their baby as opposed to having it surgically removed. Equally it is a different loss to a stillbirth from 20 weeks onward, because it is not legally recognised. The invisible women and their invisible babies exist in a black hole, not fitting into either category comfortably.

Scenario: A woman walks into either a hospital or a private establishment to have a scan and discovers that her baby has died in-utero. Or maybe her baby is alive, but due to severe fetal abnormalities is possibly not going to live in-utero much longer, or has absolutely no chance of a normal life when born. It may be that her waters have broken unexpectedly and so labour has begun much too early for her baby to be viable.

The scenarios are endless, but for the woman whom this happens to between 12 and 20 weeks into her pregnancy, the beginning of a profound sense of loss has just begun. She is no longer pregnant and happy, instead her womb has gone from a life giving place to a graveyard.

She is now forced to connect with the medical system unexpectedly and unprepared. How she copes with that situation and how well the system meets her needs is primarily what this article is about. She will more than likely be completely unprepared mentally, emotionally or physically for the system she is now a part of. How this woman is treated is now out of her control, she is no longer treated as a maternity matter, her 'episode' is now a gynaecological issue.

After the 20 week mark a baby is considered to have been stillborn. Prior to 1996 the legal gestational stage for a baby being considered stillborn was 28 weeks, but the reality was that many babies being born before 28 weeks were surviving. The earlier stage of 20 weeks was settled on because one third of women are unsure of when they got pregnant, and a scan might be plus or minus two weeks of correct gestational stage. Professor Peter Stone, Head of the Obstetrics and Gynaecology Department with the Faculty of Medicine and Health Sciences at the University of Auckland, was part of that decision to change the stillbirth stage. “It wasn’t saying that there is something magical at 20 weeks. It’s a quality measure for how good maternity services are and it also is a health issue. We thought if we go for 20 weeks, we’ll deal with people whose dates may be wrong, and we might also future-proof the system in case paediatricians get really smart and babies can do well this early.”

Although there is a general understanding in the health professions around the relevant chronological dates, a distinction exists in how this understanding is lived out in health practice. Every hospital around the country has a different approach to dealing with the invisible mothers and their invisible babies. There is no co-ordinated protocol nationwide, or even within a particular region. This situation contrasts significantly with the situation for a woman who loses her baby after 20 weeks. The baby is considered to have been stillborn and there is a well-established and often seamless system in place, and the care she receives is from trained midwives.

By definition gynaecology is the branch of medicine concerned with diseases and conditions specific to women, whereas obstetrics is concerned with pregnancy and childbirth. Herein lays the problem because although the woman was clearly pregnant, if her baby has died before 20 weeks gestation she is treated as a gynaecological patient rather than an obstetric one. This is a curiosity not only to the women I interviewed for this thesis, but also to the health professionals who must work within the system. Not one of the professionals interviewed for this article either agreed with or understood this practice. Women at their most vulnerable are being treated in the wrong place by the wrong health professionals, for no other reason than what appears to be an ‘administrative’ convenience. The question is, whether the location where women under 20 weeks are currently being treated, and the fact that they are cared for by nurses instead of midwives is appropriate? The current model affects doctors, midwives and nurses. None of these professionals I spoke to was happy, and all would like a system

that would be better for the women concerned. There's no doubt they are all individually doing their best to make the system work better, and they do appear to be making small changes to it, which is making things easier for some women.

Any woman who is pregnant for between three and five months is not considered a maternity patient. She finds herself in the gynaecological ward of a hospital, if it is big enough to have one, or on a general ward if not. The practice of placing women in a gynaecology ward is clearly done for administrative purposes and it is not women-centred at all. Professor Stone blames the inflexibility of government funding for women whose babies die or are medically induced before 20 weeks being deemed to be part of gynaecology, not obstetrics. "What we have always argued from both personal and medical points of view, is that it's all part of obstetrics. It's all part of a woman's reproductive history. From a woman's point of view and from a pregnancy point of view, nothing magical happens at midnight in the 20th week of pregnancy, but that's the way they (the government) look at it."

The Charge Nurse of a major hospital who has asked not to be identified but for the purposes of this article will be referred to as Charge Nurse Jane, doesn't believe the current situation is acceptable either. She manages a ward that includes the 'unwanted' gynaecological services. It is primarily a surgical ward, which includes urology, gynaecology and general surgery. Dealing with women whose babies have died is not the nurses' "core business". When the hospital concerned inherited gynaecology, the staff felt that the gynaecology service was forced upon them because "it doesn't sit in obstetrics, it sits in gynaecology."

When something goes wrong in a pregnancy, including the extreme situation of a baby dying prior to 20 weeks gestation, it is not deemed a 'maternity episode' but a 'gynaecological episode'. Ms Jackie Gunn, Head of Midwifery at AUT (Auckland University of Technology) School of Midwifery also has no idea why this is the case, or what logical reason there could be to justify it. "It's been like that for as long as I can remember. I think that's a hugely complicating factor in women's lives. It might be an organisationally neat way to do it, but it actually isn't very helpful for a seamless experience with continuity of caregivers."

The grieving mother suddenly finds her whole support system whipped out from under her. The midwife who may have been her primary carer, suddenly no longer has a role because she works in maternity, not gynaecology. The woman has crossed the invisible line from primary care into secondary care. Primary care services are delivered in the community to women experiencing a 'normal' pregnancy. Secondary care is delivered in the hospital environment when intervention is necessary due to 'complications'.

So the woman begins her journey of loss moving from a maternity system she understands, to one that is completely foreign to her. She will be supported by nurses not midwives, and her lead maternity carer up until that point will no longer be part of the process. How she is cared for and by whom will be entirely dependent on the hospital she is in.

Unfortunately for women losing their babies in smaller centres around the country, the services provided are even less adequate. Professor Stone points to a provincial hospital by way of example. "In the smaller hospitals they are managed in a variety of places. In Rotorua the women having a medically managed miscarriage are actually managed in the delivery unit, which seems to me to be quite insensitive. In other parts of the country these women are managed on surgical wards, and the reasons for that are because these are small hospitals with limited staffing. In a small hospital with say only two or three wards, if you are in Rotorua, Whakatane, New Plymouth or places like Nelson, if you are running at a weekend and you close your gyny wards and just run one acute ward, then you are going to be nursed by people who have limited experience medically. But they probably have very little or any experience in terms of social aspects."

There is very little suggestion that this situation is going to improve. Because of this demarcation between gynaecology and obstetric services, hospitals are being designed with these services separated. An example of this is that National Women's Hospital no longer has its own facility, but is merely a part of the gigantic Auckland City Hospital. Professor Stone is not happy about this. "It's a great sadness to observe what's happened in New Zealand. Apart from Christchurch, we've witnessed the demise of women's services and women's hospitals. And it's been a sadness to me that the midwives and nurses, for whatever reason, are part of that. I think the women's movement in New Zealand is impotent at the moment. It has no effective power, and it

was unable to have any input into the shape of the services in Auckland and Wellington.”

Professor Stone takes this unacceptable situation one step further, maintaining that this model leads midwives to believe that looking after the invisible women whose babies have died before 20 weeks is out of their scope of practice. Ms Gunn doesn't think the model in its current form works either, but for entirely different reasons. As far as she is concerned, the problem lies with the system, not the midwives. “Personally I think that if you are looking after women in their childbearing year, you look after women in their childbearing year, and you care for them right the way through. I actually don't believe the gynaecological services are for women who are losing their babies. I've never thought that, I've always thought that's stupid. I think that women who experience early pregnancy loss should still be managed and looked after by the maternity service, because they're part of the maternity experience. It seems queer that it's in another service altogether really.” The problem here though is that because the maternity service currently does not reliably cater for women whose babies die before 20 weeks gestation, midwives are ill-equipped to provide this type of care at the moment. So the nurses in the gynaecological or surgical wards aren't specifically trained or employed to be caring for the once pregnant women under often tragic circumstances, and the midwives don't have either the mandate or the experience to take on the role.

Charge Nurse Jane deals with this conundrum on a daily basis and believes it's far from ideal, for anyone. “They should go to midwifery care, that's what I think they need. They don't need to be on an acute surgical ward with noise and crying babies around the place. It's just not the right place for them.” Judith Cameron is the full-time Pregnancy Loss Counsellor at National Women's Hospital (which is now one level of Auckland City Hospital) and has been in this position since 1994. Before that she worked as a social worker in the Neonatal Intensive Care Unit, (NICU) at National Women's. The 'gyny' ward is, in Ms Cameron's words, “Just so busy, it is a frantic service. Often the nurses simply don't have the time for the woman.” Because hospitals are busy places and babies dying is a daily event, National Women's has just in the last year employed another counsellor part-time. Between the two counsellors, they now do what the nurses working on the gynaecological ward don't have time to do.

The bottom line for Ms Gunn is that if National Women's can provide an excellent and highly workable service for women whose babies are considered stillborn, why is it not possible to build a similar service for the invisible women whose babies die before this time, and that this service also be delivered by maternity caregivers. Her belief is that women while they are pregnant should be considered part of maternity at least from 12 weeks onwards, and consequently treated in midwifery services "whatever the pregnancy episode." She sees no difference between early or late pregnancy loss, because the loss is catastrophic whenever it happens.

When a woman discovers she is pregnant, one of her first tasks is to find a lead maternity carer (LMC). Unless there is a previous history of complications in which case an obstetrician's services may be used, the majority of women choose a midwife. Midwives are the people who specialise in the care of pregnant women before, at the time of, and after the baby has been born. Part of a woman's decision in choosing her midwife is made because of the perceived continuity of care aspect of a midwife's service. Under ideal circumstances this means that the woman will primarily have one carer for the duration of her pregnancy. The assumption that midwives can provide continuity of care is called into question when the death of a baby before 20 weeks interrupts the previously understood context of midwifery care.

No woman goes into a pregnancy that has progressed beyond the 12 week mark expecting her baby to die, or for it to have serious complications in the second trimester. There is no explanation in case of complications of how the system will work, and what this might mean for the woman in the middle of it. Professor Stone questions the concept of midwives being able to effectively provide 'continuity of care' because his belief is that the model itself is flawed. "It can't provide continuity, because people can't physically be there 24 hours a day, seven days a week. They can try, but there are issues around it. Then if they get a complication where they are either out of their depth or out of their scope of practice, or they haven't got time, then they're gone."

The current fractured experience is not only problematic for the woman at the receiving end of what is without doubt a confusing system, but it is not good for the midwives either. In Ms Gunn's opinion, it is the reason people clearly delineate their territory of responsibility. The woman finds herself thrust into another service "that looks at the world in a different way. The way services are currently structured means that midwives

actually don't have the experience to look after women who lose babies prior to 20 weeks gestation."

It is obviously impossible for any health professional to provide absolute continuity of care, so a compromise that is women-centred must be found. But Professor Stone sees a far more collegial model working more effectively for everybody, and it is one that would include the midwife who has up until the complication happening, been the pregnant woman's point of contact. "I've always felt we should have a collegiate model and that's why it should be the expert (the midwife) in normal labour and delivery. But she or he should be able to work in some sort of system where when there's help required, there's help there."

Another inexplicable oversight in the present system is that women whose babies die in-utero or whose babies are delivered because of fetal abnormalities are not offered counselling, as a right. This is the exact opposite situation to the women who chooses to have a 'social termination', commonly referred to as an abortion. For the woman whose pregnancy was otherwise ongoing, the larger hospitals do offer a counselling service, but this is not the case in the smaller regions. Professor Stone believes that counselling being offered to all women, irrespective of when their loss occurred is paramount. "It is very important every woman or couple is at least entitled to an opportunity to meet a counsellor, and they may or may not choose to continue that relationship. There may be couples who decide they can manage. But there may be couples who for them, there are a whole heap of issues that unless somebody who is qualified raises them, they are not raised. They sort of fester, or the questions are never answered. There is no national protocol...ironically there is a national guideline for abortion services, but not for so-called normal reproduction."

So, for the thousands of invisible mothers whose invisible babies die in New Zealand every year, they find themselves in a situation where counselling might not be routinely offered. If this is the case, they must then assume the role of navigator through their own and their family's grief, often without either the resources or prior experience. It can be a lonely path, not only in the hospital setting but also afterwards, when friends and family are confronted with the death of a baby and the obvious end of a once viable pregnancy.

Ms Cameron would like to see more counselling positions such as hers in place at other hospitals around the country. When she took on the role, a role largely created due to the lobbying of Miscarriage Support Auckland, she took it on because of her previous experience working with women and their families in NICU. She was surprised at how strongly the women from NICU were reliving their previous experiences of an earlier baby loss, and how this consequently compounded the very real fear of this baby dying as well. “That reinforced for me that miscarriage is big, and when the position came up I leapt for it. Once I started talking with women I realised they were so lonely. Within the hospital to a certain extent, but in the wider community there was no acknowledgement of the significance of a pregnancy loss, be it five weeks or 19 weeks.”

The Miscarriage Support Group, partly responsible for Ms Cameron’s position being established, first began in 1985 because of the determination of its two founders, Sandra Van Eden Long and Kitch Cuthbert who had experienced miscarriages themselves. Disenchanted with the treatment they received and the dearth of information available, they felt compelled to help others treading the same unexpected path. They wrote a book, *Coping with Miscarriage* in 1987 based on the results of 800 questionnaires included in a variety of women’s magazines. The findings of the survey echoed their own experiences and this spurred not only the book, but the establishment of the first miscarriage support group in New Zealand. Ms Cameron credits the group for being instrumental in lobbying for National Women’s Hospital to employ a full-time pregnancy loss counsellor. Initially the counselling service was offered to any woman in the Auckland region, but because of sheer volume, this couldn’t be maintained. What ‘restricted service accommodations’ means is that women who reside in Auckland City and come to National Women’s Hospital have counselling offered to them by right, but women out of this specific region cannot access the services. They must rely on a counselling service being available at the hospital where they had their baby, and this is not always the case.

For any woman whose baby has died the experience is traumatic enough, but for the invisible women, the trauma is often compounded because of the negative impact of the unavailability of staff for support. The workload is an issue for health professionals, which has an even greater impact on the amount of time available for the woman whose baby has just died. The tragic paradox is that it is how sensitively a woman and her

family are treated by the professionals they encounter that is what is remembered most clearly; and for the longest time. Ms Cameron thinks many of the health professionals who deal with a woman and her family at the time of their loss have no real understanding of the impact their time constrained behaviour may have on the woman's well-being. "The only thing women remember, families remember, when they leave the hospital is the quality of the emotional care they received. Women are in hospital to attend to their physical needs, but the other needs are just as important. If this is not acknowledged, bad mental health is the result."

Charge Nurse Jane agrees that the workload reduces the standard of care. "They have all their other patients to look after, plus a woman who's in a really traumatic situation, and a risky situation. They've got to try and support that person and their partner or whoever, plus their other patients. It's too much work for them on some occasions."

For the woman who's lost her baby, she sometimes needs time for her emotional needs to be met, more than her physical needs. Time is necessary to comprehend the loss that has occurred and to ask questions about what has taken place. She needs time to say goodbye to her baby in the way she sees fit. If a woman is denied the precious commodity of time, then she may find herself less well-equipped to cope with her loss.

Shortage of time also directly impacts on training for health professionals. Nurses are busy people and because the staff responsible for delivering gynaecology services on a surgical ward do not consider this area a part of their 'core business', their training is not focussed in this area. Although Charge Nurse Jane felt that some in-unit training would be beneficial, the reality for her is who would do it, and when would they get the time for it. She relies solely on the Women's Health Team which is the first point of contact for the women whose babies have died, and this contact continues throughout the process. They act as a complete support service for the women and their families, therefore the nurse's job on the ward is primarily to take care of the physical process. The nurses simply don't have the time or the training to deal with anything other than the woman's immediate physical needs.

Professor Stone Stone believes the training given is perfectly appropriate, but there is just not enough of it. "There's a balance between having Pregnancy Loss Counsellors who are experts in the field, and then people like us. The risk is that you will pick up the

phone and ring the counsellor and they sort it for you. The problem with that is if people have no empathy for what all these groups do from a woman's point of view, she (the woman) gets pushed around." The point here is that all the professionals involved in a woman's care need to have an understanding of the other professionals' jobs. One professional will often be asked for their opinion of something that is not strictly part of their job. "Being able to answer those questions is really important. I don't think the trainees get enough of that, they learn on the job." He sees the issue as more a lack of knowledge than a lack of time.

Ms Cameron disagrees, strongly advocating that more training is high on the top of her wish list. "I would want a hell of a lot more training in medical schools, nursing and midwifery schools. A lot more training around the impact of pregnancy loss, be it once again five weeks or 39 weeks." She thinks more training is needed to alleviate the problem of health professionals learning on the job and consequently dealing insensitively with a woman, often without having an understanding of what mistakes they might have made. She only gets to spend one hour with hospital registrars during their training. A registrar is more senior than a junior doctor, but less senior than a consultant. She feels that one hour for specialist gynaecological registrars is woefully insufficient.

Because of Ms Cameron's 11 years of counselling women who have suffered a loss, she sees them as the unwilling teachers who are actually the true experts. Her belief is that it is these 'experts' who could best make a difference with the health professionals. Although she acknowledges the difficulty women face talking about their losses, she suggested that this could be by way of an invitation for these women to talk to those going into positions of responsibility. Giving more time for training would therefore increase the inexperienced health professionals' knowledge, and their appreciation of their own impact on women and their families.

Learning on the job which is how most of the training is done, means that mistakes are made and women are the guinea pigs. Ms Cameron's job now entails far more training of staff than she could ever have anticipated. Her realisation of the need to educate general staff around the issues of baby death has been one of the most significant developments of her job. Although by her own admission she doesn't particularly enjoy training, she became aware that there was a need that had to be filled, and that in her

position she would have to be the one to do it. Professor Stone thinks the training is acceptable and given the average age of most medical students, questions the impact more discussion on the subject of baby loss would have. Charge Nurse Jane doesn't see this area as a nurse's 'core business' anyway, and leaves all but the physical process to the Women's Health Team. And finally Ms Gunn feels that the three year Diploma of Midwifery is definitely fulfilling the teaching requirements necessary to prepare new midwives for the not uncommon reality of baby loss.

The impact of fully trained midwives on the system is yet to be felt though. Specialised midwifery training in New Zealand only began in Auckland and Otago in 1992, and since 1996 in the rest of the country. The AUT School of Midwifery is the largest school of its kind in New Zealand and the programme is three years full-time. Since 1992 AUT has graduated approximately 300 midwives.

The AUT Midwifery diploma programme deals with the issue of baby death in each of the three years, building firstly on the students' prior knowledge, then on their growing knowledge as midwives in training. Tackled in the first year is the work of Doctor Elisabeth Kübler-Ross, psychiatrist and author of the book *On Death and Dying*. Originally published in 1969, Kubler-Ross' theory is studied because of her groundbreaking findings regarding 'the grieving process' and her work is now commonly accepted as true. In the second year, more in the context of babies dying, is an introduction to death and dying and early pregnancy loss in terms of the physical process. Finally in year three, when the students have a lot more experience, they do a paper called 'Complicated Childbirth'. As part of this, members of SANDS (Stillbirth and Neonatal Death Support) are invited to talk with the students. They also study communication papers including the concept of empathy, and the importance of communicating effectively with others who might be different from themselves. The expectation is also that they have spent time working with midwives who will have had some degree of experience in their practice with pregnancy loss.

Midwives who have been practising for 10 years or more have come through the old system where they were previously trained as general nurses. The average age of midwives practising in New Zealand currently is 50 years old, so some midwives a woman may come into contact with whilst she is pregnant will quite possibly have limited specific midwifery training. Ms Gunn believes that 20 years ago when she

became a midwife, “midwives became midwives because they were looking for other qualifications, or because they wanted to work with babies.” This clearly differs from the midwives of today, who are primarily choosing this profession to work with women, and they are being trained to look after them holistically, not just physically.

But for the invisible mothers and their invisible babies, it is still neither here nor there because it doesn’t change the fact that nurses instead of midwives take care of them in their precarious and delicate situation. Until the model changes, a simple panacea would be to deal with the vexed area of terminology and the appalling negative affects it has. The use of insensitive or seemingly inappropriate language is how many of the health professionals still trip up. Whether a woman’s loss is referred to as a *baby* or a *fetus*, if she is having a *miscarriage* or a *spontaneous abortion*, or if she is undergoing a *medically induced termination* or an *abortion*, the implications of the language used to communicate with her and to describe her experience cannot be underestimated.

Ms Gunn believes that the term miscarriage works perfectly adequately for a woman whose baby dies under 12 weeks. “Miscarriage you tend to associate with loss that happens before they look like a baby.” She points to the well established and well founded belief of being unsure a pregnancy will be successful prior to the 12 week time. “They’re praying and hoping, but they’re semi-prepared to lose the pregnancy, because it happens such a lot. The impact is no less, but I think women are prepared in their own minds. You’re never prepared in your heart. And because your mothers and grandmothers tell us to wait ‘just in case’...they never say what of, they just say ‘in case’. So in our culture, the pregnancy actually isn’t secure until after 12 weeks. Probably, miscarriage is a comfortable word to use and something people can say when they talk to other women and to other family members. They can say it without having to say ‘my baby died’. It might be a term that’s quite useful. But I don’t think it’s useful over 12 weeks.”

Miscarriage as a label might work when a baby has died before 12 weeks gestation, but it doesn’t have any linguistic currency beyond this time. Again from Ms Gunn’s perspective as a midwife, she believes that “the term miscarriage diminishes the experience of losing babies that are grown and look like babies. I would like the term stillbirth to be able to be used, because it’s a term able to be understood. Not to have a word used that diminishes it somehow. I think miscarriage might well diminish it.

People don't want to have to go into the gory details just to explain what happened. But if there was a word to explain what happened, that would be a better proposition."

The bottom line is that either way, in the end, "your baby's died and that's really what happened. And our great aversion to dying in our culture, especially if it's babies or little children, is difficult to deal with. We call it something else, and that is prevalent in our culture."

Professor Stone felt that many improvements had been made in the area of appropriate language, as did Ms Cameron. But neither of them had recognised until it was pointed out to them, that the same brochures are given to women who choose to have a social termination as are given to women who have to have a termination of an otherwise ongoing pregnancy. This overlap of information may seem small and possibly trivial, but to the woman who wanted her baby and is grieving for that baby, reading that she is having a termination is painful and insensitive. It is perceived this way because she doesn't see what her experience is as a choice, which is the opposite of our cultural understanding about the 'choice' implicit with an abortion.

Change comes about slowly. The process of changing terminology was helped by midwives being available to explain to young registrars why it is important to think about the impact of the terminology they use. As midwives no longer play a part in looking after women under 20 weeks, this education no longer takes place either. Even so, Ms Cameron thinks that this is an area where she has managed to make inroads. "On the admissions board in the diagnosis column, a miscarriage used to be called a missed abortion. After talking to the young doctors who are now registrars, it's not called a missed abortion any longer. Although strictly speaking that is the terminology, it's now referred to as a threatened miscarriage or an IUD (intra-uterine death)."

With midwives not having any involvement at the invisible stage of baby loss, there are less opportunities for them to contribute to the educative process about what the appropriate terminology is, and to make sure it is being used. Professor Stone's understanding of this is that "it tends to go in tight circles. Because the midwives feel protective of the woman, they restrict other people being involved, which I think is appropriate. But if you actually involve junior people and show them what you're doing, you will actually change behaviour."

Often the first place a woman will learn of her baby dying or having severe abnormalities is when she has a scan. The Australasian Society of Ultrasound Medicine which is the professional body overseeing this group of health professionals, has guidelines for the use of the word abortion. So a woman who has a fetal abnormality that could be ongoing will probably hear the words *termination of pregnancy* instead of the word *abortion*. A woman who is having a spontaneous pregnancy loss and consequently a miscarriage would not hear the old medical term *spontaneous abortion*, but would instead hear the more sensitive term (in this case) *miscarriage*. Medical students are also taught that the word abortion means an ‘induced procedure’. The change in acceptable terminology being used when women are having scans and get given bad news, is an indication that there is increased recognition that language and its appropriateness is important.

When interviewing health professionals for the purposes of this article, it became clear that the role of the media is an area of dispute. Ms Cameron does not think there is enough publicity either acknowledging baby loss as an issue, or that the loss of a baby at whatever gestation is both significant and has an impact on those involved. Professor Stone questions whether the media should have any role in raising awareness of baby loss at all. For him what is most important is maintaining balance. “Things do go wrong. We don’t really value reproduction, whether it be using contraception, protecting ourselves from sexually transmitted diseases, smoking during pregnancy, drinking or whatever. But on the other hand, I am pleased to say that most babies are normal, and you don’t want to do anything more than we’ve already done to spoil the enjoyment for people who are having a healthy pregnancy. So the challenge for groups working around miscarriage and stillbirth is to build the awareness up in a way that people can deal with.” He would rather see these groups focus their attention on the health professionals involved, than worry about what publicity there might or might not be in the newspapers, magazines or on television.

At the heart of the pain of loss before life is the unanswered question of when is a baby considered a baby? Although Ms Gunn works in the area of midwifery education, she worked independently as a midwife as recently as three years ago. She believes a baby is a baby is a baby at whatever gestation. “I don’t think the legal thing matters. In my opinion, the legal thing determines viability and it doesn’t matter two hoots when the

woman had the baby. The baby is either legally viable or not. What matters is that a woman gets an experience that helps her maximise her ability to cope with the event, and that's the important thing." All the health professionals interviewed for this article agree that it is 'the system' that has determined when a baby is considered a baby. Unfortunately the system in its current state is less than adequate for the woman who neither wanted to be in the position she has found herself in, or has any control over how that system cares for her. She is at the mercy of the people working in it and sometimes it is good, and sometimes it is not. No system is perfect, but under the circumstances something better and more women-centred could and should be implemented.

Women who lose babies under 20 weeks gestation should still be treated obstetrically, and therefore their care should be from midwives, not nurses. This goes hand in hand with treating them from a maternity perspective instead of the current gynaecological perspective. The current situation translates to inappropriate 'treatment' that could and should be remedied. Whilst it is clear that the health professionals who are charged with caring for these shocked and grieving mums are doing their best and making small changes where possible, the system itself is fundamentally flawed. All the small changes in the world are not going to fix the bigger systemic problems that are apparent. The overall issue stems from a 'tidy' administrative procedure that impacts significantly on how validly the death of a baby under 20 weeks is considered. Ultimately the fact that the invisible women are made to fit into a gynaecological service designed for ill health and not babies or pregnancy, is the proverbial 'hot potato' of the current maternity model in New Zealand.

It must be remembered that each woman experiencing the loss of her baby in pregnancy has gone from being pregnant to not being pregnant; from being cared for as a pregnant woman by a midwife, to being cared for by nurses, sometimes reluctantly, because her baby died under the arbitrary 20 week watershed. Clearly, she has moved from a happy, exciting place to one of great sadness and tragedy. Adjusting to this takes time, support and understanding; firstly from the health professionals in the hospital and then from family, friends and wider society.

Society's reaction to baby death is often far from supportive. Ms Cameron has the last word which I believe clearly and coherently illustrates the changes in attitude that

should and must take place within our society. “I think we need to start by desanitising death. I think it needs to start with death, and knowing that a person is a person no matter how small. Knowing that the death of a dream is devastating, and even though sometimes there isn’t a concrete little body, it’s gutting for both men and women. I guess if I had a magic wand I would give men and women the ability to talk about what happened. I would give them permission to talk and society at large permission to talk. And I’d give them a good pair of ears to listen to what people are saying.”

Article Four

The Way It Is and The Way It Could Be

The Way It Is

The invisible women and the deaths of their invisible babies is without doubt a difficult subject. For society to acknowledge that babies die before birth appears to be more difficult in many ways than the already uncomfortable concept of death in general. The level of just how uncomfortable the subject of baby death is, becomes apparent in the language used to label loss before life beginning; the medical system's inadequacy in the current practice of placing women whose babies die under 20 weeks gestation in gynaecological care instead of being treated as a once pregnant woman in a suitable obstetric environment; the scarcity of publicity in the media, and the way in which the subject is dealt with when it does get editorial space; and finally in society's inadequacy about how to positively respond in ways that will better support women and their families when a baby dies before birth.

The loss of a baby between 12 and 20 weeks is not better or worse than before or after this gestational timeframe, it is just different, and the differences need to be acknowledged and understood. The group of approximately 2000 to 3000 women a year in New Zealand who find themselves losing babies in this timeframe are invisible because they are not talked about in any meaningful way; they are not treated by normal maternity carers; their babies are often not referred to as actual babies; their babies' births are not registered; and the nurses who have the unwanted task of caring for the mothers, would often rather not. These invisible women could also be considered invisible mothers as they have already formed an attachment and bond to their babies.

Adding to the invisibility is the fact that presently no statistical information is kept or collated nationwide or even within each hospital of the number of losses under 20 weeks gestation. Instead they are referred to as miscarriages or intra-uterine deaths (IUDs) that are not recorded. Although tidy from an administrative perspective, the simplicity of pigeon-holing all women under 20 weeks as the same, renders their individual experiences and the loss of their babies as inconsequential. It ceases to enable

any meaningful or even rudimentary analysis of women's experiences of loss in this timeframe. These truly are the invisible babies and their invisible deaths.

There is a well-founded, long standing unwritten rule in our society that 12 weeks is the accepted period to wait before sharing news of a pregnancy with anyone other than those closest to the pregnant woman. The chance of having a miscarriage is relatively common as up to 80% of unsuccessful pregnancies fail before 12 weeks has been reached. Because of the regularity in which early loss happens, the impact on the women and their families diminishes in importance to those people not directly affected by loss at this stage.

The impact of the loss of a baby between 12 and 20 weeks gestation is diminished even more, as there is little awareness in society that thousands of women a year in New Zealand will have a baby die, or a baby that needs to be medically induced due to fetal abnormalities in this timeframe. This stage of loss is too late to be comfortably labelled as a miscarriage, yet it is not late enough in a pregnancy to be considered a stillbirth. Babies dying at this stage are also called miscarriages, and this label contributes to the invisibility of the baby's existence. Many of these invisible babies are medically induced, which equates to being given birth to, and often the baby's gender is known. The invisible babies are not merely *tissue* or a *product of conception*, they are fully formed, albeit small human beings that were loved and wanted. Many families choose to have post mortems carried out to ascertain (when possible) what caused their baby's death, and to try to alleviate concerns for future pregnancies. Every story of a baby who dies before life begins is as unique as every live birth, even when that story may be hidden from all but their immediate family.

Because technology is constantly improving and death is more preventable than ever before, the expectation that every pregnancy will be successful after 12 weeks is commonplace. The culture that prevails is one that celebrates life and often fails to acknowledge the ever prevalent end product of that experience, which is death. There is a silence shrouding death that further serves to alienate and isolate women and their families who suffer this tragedy.

In contrast to the invisibility of pre-20 week babies, the babies who die from 20 weeks onward are legally considered stillborn. By law their birth must be registered and the

family must either bury or cremate the baby. Because babies born prior to this time are not legally recognised, the invisibility of their existence is confirmed. Consideration of legal recognition is important and relevant, because no system is in place to support the women who fall into this earlier category. They too must make decisions about what will happen to their baby's body, but without any structure in place to help them in this task with no clear boundaries. The decisions become based on their own cognition of whether they considered their baby a baby or not. The path may be made easier if they affiliate with a religion or cultural identity, which may in some way dictate what they should do. But most importantly their decisions may also come down to their emotional and mental capability to deal with the gravity of their task, at such a vulnerable and confusing time, and the personal support they have available to them.

There is no reliable system in place for the invisible babies and their invisible mothers. This lack of standard procedure impacts on the amount of information given to women at the time of their loss in the hospital, or afterwards in the media or in books. The lack of recognition of their loss permeates throughout the tragedy from when the news is first delivered to the parents, through to after their baby has been born when they are left to deal with their loss, often independent of any professional help. Without reliable information and left to their own devices, many women suffer guilt as an integral part of baby loss. Questions and confusion abound as to what they might have been able to do to stop their baby dying, or what they might have done differently had they had any inkling that their pregnancy was going to end so catastrophically.

Unfortunately the inadequacy of the system in place for the invisible women extends to the area of counselling. The larger hospitals in the larger cities do provide counselling, although priority is given to women 20 weeks and over whose babies have died. When looking at the smaller hospitals, the system is ad-hoc and unreliable. Often women are left to counsel themselves through their loss or to privately consult a counsellor, without any financial help from the government.

But baby loss in any gestational timeframe is more readily acknowledged now than it was 20 years ago when the now well established group Miscarriage Support Auckland was first set up. The two women who founded the group, Kitch Cuthbert and Sandra Van Eden Long did so because of their own less than satisfactory experiences when suffering miscarriages. Their original aim was to write a book to provide important

information to women who might find themselves as unsupported and under-resourced as they did. The gravity of this need was realised when they distributed a questionnaire through a number of women's magazines and had an overwhelming response from women nationwide. Although publicity, awareness and empathy is better now than it was two decades ago, there is still room for much improvement.

A telling technological change has taken place in more recent years, with the internet now being used as a pseudo support service. One of the most widely used websites for New Zealand women, but also with many global users is <http://www.everybody.co.nz>. The miscarriage section of this website is specifically for women who are seeking contact with other women who have been through an experience similar to their own, and who are still working through the grieving process. Miscarriage Support Auckland no longer offer face to face support groups, but instead refers women who make contact with them to this website. They also monitor the website traffic and provide feedback to women where necessary.

There has been some improvement in the media coverage of baby loss in recent times. However, when mainstream media outlets do run stories, they are primarily narrative rather than information based. Many of these articles are bland and not useful for women dealing with the horror of a baby's death. Women want to read other women's stories, but they also want solid information to help them along their path of grieving for the life that might have been, and to come to terms with their loss in a healthy manner. Many of the articles that do exist are due to the campaigning work of SANDS (Stillbirth And Neonatal Death Support) and Miscarriage Support Auckland. It is clear from the fact that so many of the articles appear in women-targeted magazines with a specific readership, that the subject of baby loss is perceived to be the domain of women only, making it an issue with a bias toward one gender. This perceived bias is significant because it has implications for society's responses to baby death, for the women and the men directly affected by it.

Not only does the written word have an impact on the perceived importance of the loss of a baby, but the medical language used takes on huge significance when a baby dies. The vocabulary is confusing to women who view the language used by health professionals, whether it is medically correct or not, as inappropriate and insensitive. Language deemed inappropriate by the women at the receiving end of it, used at the

most sensitive of times, can further invalidate the existence of their baby. This confusing vocabulary often also causes further justification or explanation of what *actually* happened to the baby to be necessary. For example, the label *miscarriage* does not adequately explain the situation for a woman who has given birth to her baby that died in-utero, and therefore needed to be medically induced. It may in fact be medically correct, but it does not sufficiently reflect what actually happened. Society equates birth with life and thus of ongoing motherhood, whereas in this instance a birth has taken place, but the mother has in fact given birth to death with no ongoing opportunity to ‘mother’ the child that was up until recently, growing inside her.

Part of the inappropriateness of language relates to the literature given to the invisible women while at hospital. This group of women whose pregnancies have ended catastrophically and for tragic reasons, wanted their pregnancies to be ongoing and do not see their losses as a *terminations* or *abortions*. They do not feel that the term *miscarriage* is any more appropriate either, especially if they went through the ordeal of the birthing process. The literature given is the same as is given to women who have chosen to have a ‘social termination’, which is the absolute opposite of the invisible women’s tragic situations. In this case, one size does not fit all.

Words have a significant impact on the ability of a woman to deal with the death of her baby in a healthy manner. Women remember behaviour and more specifically the type of communication used by health professionals, not the necessary physical treatment given. When a woman’s pregnancy is thought to be ongoing and progressing successfully, she will have bonded with her baby and does not appreciate or understand her baby being referred to as a *fetus*, *termination* or *spontaneous abortion*.

Fortunately terminology used in scanning has improved due to guidelines in place from the Australasian Society of Ultrasound Medicine. No longer is *abortion* accepted linguistic currency, instead a woman will hear *termination of pregnancy*. Changes such as this example go some way towards acknowledging that something important and sad has happened, and that the language can positively influence a woman’s ability to get through this tragedy with her mental health intact.

The use of business vocabulary further undermines the tragic reality that a dream has been shattered. The term ‘core business’ used by some health professionals holding

management positions is a clear illustration of how the death of a baby has become 'administrative' in language as well as in practice. The death of a baby is a real life event and no benefit can be gained from placing it in a commercial context.

The system in its current form is fundamentally flawed, and all the small changes individual health professionals attempt to make are not going to change or fix the bigger problem. The problem is an administrative practice that recognises loss and the grief associated with losing babies as having more validity when a baby dies from 20 weeks gestation onwards.

The concept of 'continuity of care' is a misnomer and this fact should be made clear to every woman when she chooses her lead maternity carer (LMC). It is physically impossible for any health professional to be available 24 hours a day, seven days a week, even in an uncomplicated pregnancy. When there are serious complications and there is none more so than a baby dying, care is transferred from community based primary care of a midwife to hospital based secondary care. It is at this point that any continuity of care that may have been established, ceases to exist in any form.

The medical care provided to the invisible women whose babies die under 20 weeks gestation is not either patient or women centred, but hospital or 'system' centred. The physical location of the care is in the gynaecological unit, not the maternity unit. Because the loss is viewed as a gynaecological episode instead of a pregnancy episode, the care is for the physical 'ailment', with little consideration for the emotional impact the woman may be experiencing. This situation is even worse in the smaller hospitals around the country where the women are cared for on a general surgery ward. The size of the hospital may mean there is no dedicated gynaecological ward, so women are placed in the general admission ward that includes gynaecology as part of its services. These wards are too busy to provide appropriate care for a woman suffering the loss of her baby. The 'service' of dealing with women whose babies have died or need to be medically induced is an unwanted addition on a busy surgical ward. Dealing with women whose babies have either died in-utero or are being induced because of fetal abnormalities are not viewed as the ward's 'core business'.

Because of this there is a distinct lack of specific training to enable health professionals to behave more appropriately or sensitively. The lack of training in addition to the

pressures on the health professionals' time, equates to too much learning on the job and women being the guinea pigs for this learning. Time is one of the most precious commodities that can be offered to a woman when her baby has died. She is often in shock, confused about who is caring for her, without her lead maternity carer as support and in a system that is not adequately equipped to deal with her. Hospital staff need to remember that when a baby dies, there are no second chances. Time spent with the baby should the mother and her family want this is imperative, and as important is the location of where that time is given.

The invisible woman's lead maternity carer, more often than not a midwife, has no role in this process currently and all care is handed over to those working within 'the system'. Nurses are not trained and have not chosen specifically to work with women in their reproductive stage of life. Their ongoing professional development is not in the area of midwifery or in dealing with women whose babies have died. They are required to learn on the job and do the best they can, which unfortunately is not good enough because they are often ill-equipped or too time constrained to deal with this particular sensitive situation in the most appropriate manner.

The average age of practicing midwives is 50 years old so what this means is that many midwives a woman may come into contact with are not trained the way midwives in the last ten years have been trained, through the specialised midwifery schools. The midwives who have been practicing for a long time have come through the previous system of training as nurses first, and then they may have moved into midwifery for a variety of reasons. In this case they may not have any specific midwifery training. In contrast, the institutes delivering the midwifery courses incorporate a holistic approach to looking after women and their babies, which includes training for the uncomfortable reality of baby loss, death and grief.

Re-registration of midwives who initially trained as nurses only began in 2005, so they are only beginning to receive specialist midwifery training now. As the midwives with a specific midwifery qualification from a recognised institute enter the workforce, women's treatment should improve. But this is not a quick process and more needs to be done to help women in the meantime.

Giving birth to death is a part of life. Society's inability to positively acknowledge that a loss has taken place serves to further exacerbate the problem of denying that something tragic and important for a woman and her family has happened.

Baby loss is not just the domain of women; it affects fathers, siblings and grandparents, and to a lesser extent other extended family and friends. The ending of an otherwise ongoing pregnancy is traumatic for all those involved. Partners are expected to remain stoic and to support the women, with very little external support for their own grieving process. Siblings are often the forgotten ones, especially when other people enquire as to the wellbeing of the family. These other children are ill-equipped to deal with the loss on their own. Grandparents are grieving both for their own children, and for the grandchild that might have been.

Some kind of tangible farewell to honour the invisible baby is healthy and is an important part of recognising that a life did exist, even though that life ended before the legally recognised 20 weeks. The choice of taking a baby home, or having either a burial or cremation at an established cemetery is becoming more common amongst many cultures, not only in the Maori culture. Women and their families are claiming the right to recognise their babies in an ongoing way, even though that recognition is not legally required.

The Way It Could Be

Many of the challenges of improving the care for the invisible women and their invisible babies are systemic and may take some time to implement. Fortunately there are other improvements that can be made more readily and should therefore be a priority. Terminology and the way language is used in both the verbal and written contexts is one of these priorities.

The invisible woman deserves to have her baby referred to as a premature stillbirth, which is the preferred term of Miscarriage Support Auckland. The label of miscarriage does not adequately explain the death of a baby after 12 weeks gestation. This inadequate language can lead to negative feelings being harboured toward the health professionals, and confusion for the woman about whether her baby dying was a real event.

Many women keep memento boxes as a reminder of their babies' short existence, and in it may well be the literature given to them when they were in hospital. Very few tangible memories can be gathered when a baby dies at this stage, so it is important that all literature given is suitably appropriate and sensitive. Making small but significant editing changes to these pamphlets and brochures is simple to do, inexpensive to implement and can be done in a relatively short space of time.

Using the term *product of conception* may be acceptable amongst health professionals as a label for a baby in the early stages of growth in-utero, but to the mother who has already begun bonding with the life that she thought was growing inside her, the baby is a baby whether viable or not. The health professionals should be sensitive to this and when communicating with the family, refer to the baby as a baby.

The way the media represent death, including death before life begins is important and worthy of review, because it is in the media outlets that a subject often considered silent or taboo should have a place to be aired. The media have a responsibility to publicise issues that are difficult and could be seen to make readers feel uncomfortable. This responsibility also extends to providing appropriate, balanced, intelligent articles that educate and inform their audience.

There is no doubt that baby loss is far more readily acknowledged now than it was even as recently as 20 years ago. But, there is still a long way to go for mainstream media publications to make more of an effort to support and provide practical advice to those women who find themselves part of the unwanted club of loss before life beginning. An easily implemented and highly effective tool for media outlets to use, is to include fact boxes with narrative pieces, thus providing interesting stories and helpful information. People's stories contribute to providing vital information that needs to be disseminated in a balanced way. This type of editorial contributes to further developing healthy support networks that may be otherwise unavailable.

The 'system' clearly needs reviewing. None of the health professionals I spoke with are happy with the way women are made to fit the system, or how the system in its current form impacts on their jobs. For the women who find themselves in this unknown and confusing environment, they are even less equipped at such an emotionally vulnerable

time to cope with the care they receive. They should not have to deal with this added unnecessary stress at this most vulnerable of times.

Statistical information should be kept and collated nationwide and within each hospital about the number of losses that occur under 20 weeks gestation. The collation of this data would illustrate and identify exactly how many women are losing babies under 20 weeks, and these statistics could provide a framework to institute a national protocol of care.

Whether the lead maternity carer (LMC) is a midwife, a general practitioner or a specialist obstetrician, the LMC must clearly explain how the system changes in the event of complications to all women early on in their pregnancies. Simple, easy to understand literature in the woman's first language to support what has been articulated to her verbally should also be provided, to enable her to refer back to later and to avoid confusion if such a situation does eventuate.

Pregnant women should not be cared for by nurses but by maternity trained staff. The current situation translates to inappropriate 'treatment' that could and should be remedied. Either a counsellor or a trained midwife should be available to women to provide explanations of the process they will undergo, and to answer any questions they may have. The more information provided throughout the process, the better the outcome is for the women. Unanswered questions and confusion are well known contributing factors to depression after the loss, or at the time of a subsequent pregnancy.

Moving services from gynaecology with care provided by nurses, to maternity with midwives providing specialist care would better reflect that women have lost a baby, not just suffered a 'gynaecological episode'. As well as this systemic change, some level of consistency of service delivery, whether in large or small hospital nationwide, should be implemented. If the system were to change to allow midwives to remain a part of the team, additional training would need to be provided if the midwives had not already gained a specific midwifery qualification from a technical institute.

In the meantime, whether the hospital deals with the invisible women on a surgical ward or a dedicated gynaecological ward, adequate facilities must be provided for the

emotional as well as physical process they must endure. The experience of one of the thesis participants being placed in a room with a hurriedly placed blanket over the window to maintain some semblance of privacy is not good enough.

There are many practical and relatively easily implemented ways to make a difference for women losing babies under 20 weeks.

Implement Ms Cameron's (National Women's Hospital Pregnancy Loss Counsellor) request that the true 'experts' share their stories, by giving article two of this thesis 'And Mother Makes Me' to every training midwife, nurse and registrar working in this area of health. These stories may help to illustrate how the health professional's behaviour can affect a woman's experience for better or worse. The stories may also have more of an impact because they are real and narrative based. Stories touch people in a way that theory and statistics cannot.

Provide more specific training for would-be nurses, midwives and doctors dealing with women whose babies have died or must be delivered due to fetal abnormalities. Initiate this more substantial and specific training by increasing the communication between women who have lost babies and are strong enough to speak about their experiences with the tertiary institutes providing the educational qualifications. Then support this initial training provided by the educational establishments, with structured on-going professional development after graduates have moved into an actual job dealing with actual women.

Initiate and implement a national protocol for all hospitals to offer women counselling by right, just as women who opt for a 'social abortion' are required to have. At the very least offer a minimum of two 'mental health' checkups with the women's general practitioners to ensure no-one 'falls through the bureaucratic cracks'. Every woman whose baby has died, irrelevant of the gestation, should be extended the courtesy of being able to access some professional help free of charge to support her ongoing mental health.

Provide the booklet *Empty Arms* to all women suffering a loss at Auckland City's National Women's Hospital, not only the women whose babies have died 20 weeks or

over. Ensure that all hospitals have either this specific booklet for all women who have lost babies, or ensure that similar material is provided nationwide.

Provide literature at the time of the medical intervention regarding what is actually going to happen, not only what the drug is or what a D&C is. Include information about how long the labour might take; what the baby might look like including its approximate size and weight; how many centimetres most women must dilate to for the specific gestational stage the woman has reached. Fear comes from not knowing and in this instance, ignorance is not bliss!

Whatever the time constraints may be for the health professional, remain sensitive to the woman's trauma and think before speaking. Providing time ensures an environment that respects and validates the need and right to have whatever time may be necessary for the woman who is not only dealing with the physical aspect of her baby dying, but as importantly, the mental and emotional impacts.

Ensure every woman leaves hospital with some kind of memento of her baby, whether this is information about the baby including weight, length, footprint/handprint or photo. A memento could also be an identification bracelet or 'birth certificate' which would at least provide some tangible recognition that a baby has died and been born.

As soon as is feasible, include a paper in the re-registration process for midwives who initially trained as nurses about the complexity and sensitivity of loss before life begins.

The term 'society' implies a homogeneous group which is obviously not the case. Many cultures, including New Zealand's own indigenous Maori culture deal with death differently, including the death of a life before it has had a chance to begin in a positive, healthy and healing manner. Unfortunately, the prevailing western culture is not so positive in this area, and baby death is often not dealt with well. Platitudes are defined as trite or unoriginal remarks, and the number and type of platitudes offered to a grieving mother and her family are endless. There are many simple, easily implemented ways to support women who have had a baby die.

Don't compare the loss with any other loss as this just serves to further minimise the experience for the woman and her family.

Friends and family need to speak up and not remain silent in the face of a loss. Don't wait for the grieving family to ask for help, as this is yet another task on top of the task of putting one foot in front of the other.

Society in general needs to start talking more openly about death. Ignoring a subject that is difficult does not make it go away. Acknowledge somebody's loss as a loss, and don't pretend that nothing has happened.

The pain of a death does not go away quickly and does not adhere to a specific timeline. Do not expect quick fix solutions and give women and their families' time to come to terms with their loss in the manner they feel is appropriate without judging them.

Demystify death and even if the loss is invisible, acknowledge that something tragic has happened. Give grieving women and their families permission to talk about their baby. Listen to what they are saying without trying to change the subject or minimising the loss.

The health professionals responsible for caring for women suffering the tragedy of a baby that has died, society as a whole and media outlets, all have a responsibility to act in a way that will help women through their situation in the healthiest way possible. Nothing about this subject is easy. The solutions to many of the bigger systemic problems may not be easy to implement, but for the sake of the invisible women and their invisible babies who have died, change must happen.

Exegesis

The purpose of this exegesis is to elucidate and clarify the relationship between the central concept, key contexts, focus and methodology of the creative work, thereby setting the thesis in its relevant critical context. The exegesis includes documentation of both developmental work and the final thesis.

The central concept of my thesis was to uncover the complexities of ‘Loss Before Life Begins’. The journalism pieces are presented as four articles that can be read individually or as a complete series, and considers how babies that are born dead between 12 and 20 weeks gestation are in some ways invisible medically, socially and statistically, as is the woman who was pregnant with them. The study explores how the health professionals, society in general and the media can contribute to further exacerbating the trauma of a woman experiencing baby loss in this gestational timeframe, by failing to suitably acknowledge the event. The thesis includes practical recommendations for the health professionals, media outlets and society generally. It is hoped that the health professionals will be able to provide better care for the women when their babies die; that the media will be more able to provide relevant information on this issue; and that society will learn how it could better support women and their families as they recover from this tragedy.

The thesis is written as four journalistic articles in partial fulfilment of the Master of Arts Communication majoring in print journalism at Auckland University of Technology. After discussions with the primary supervisor it was decided to write the four articles from a journalistic perspective for a number of reasons. Because of the alarming lack of practical, accessible information available to women who have lost a baby in the invisible period, it was important to me that the creative work be placed in the journalistic context. This was to enable it to be submitted for publication in a mainstream media outlet after completion and examination, to add to the body of information women could tap into. A significant amount of information on the topic of baby loss is available internationally in academic journals focussing primarily on early miscarriage (which is commonly understood as being prior to 12 weeks gestation), or stillbirth (classified as being from 20 weeks gestation onwards). The aim of this thesis is different because it focuses primarily on the ‘invisible stage’ of baby loss between 12 and 20 weeks gestation; and in the New Zealand context; and is written for the ‘average’ reader of a mainstream magazine.

The reason I set out to focus on the subject of baby loss was primarily due to my own experience in April 2004, when I had twin daughters die in-utero at 18 weeks gestation. This personal journey led me to discover that the amount and type of information available to women suffering a loss in this gestational stage was scant and inadequate. I had already developed a keen interest in the way media outlets choose to publicise a difficult topic throughout my M.A. journey. This interest led to my desire to research in more depth the type of information about baby loss available to women in mainstream media publications.

The uncomfortable silence pervading the death of a baby before that baby's life has begun was illustrated to me first hand, and I wanted to know why the subject appeared to be shrouded in secrecy and taboo. Finally, I had experienced the inadequacies of the current medical system and its response to women whose babies have died under 20 weeks gestation. I set out to find answers as to why this treatment was ad-hoc at best, and systemically failing at worst. Part of the inadequate treatment experienced and a theme echoed throughout all the background reading undertaken, was the use of inappropriate and insensitive language pervasive in the area of baby loss.

There were a number of key contexts that set the relevant parameters for the thesis. It was vital that boundaries be placed around the period of time the thesis covered, and that it would have a specific focus to enable it to be accessible to the reader of a mainstream magazine. This focus was aided by attending a Postgraduate Writing Course delivered by AUT that culminated in a literature review of three publications relating to the thesis topic. Three books were reviewed and this review has been included as appendix one of the thesis. *Miscarriage: Women sharing from the heart* written by Marie Allen and Shelley Marks in 1993 and *Help, comfort & hope after losing your baby in pregnancy or the first year* by Hannah Lothrop in 1997, were both published overseas. The third book was Nicola Miller-Clendon's book *Losing a baby* published in 2003, in New Zealand. The themes represent women's experiences, whatever part of the world they live in. Themes included women's confusion surrounding the medical language used by health professionals; grief experiences of the women interviewed; the isolation women feel following the loss of their baby; and the lack of understanding from family, friends and wider society of the nature of the grief experienced. The other common thread running through all of these books was that every author had lost a baby themselves, giving them a unique and essential

understanding of the experience. Although the books were all written at different times, by different women and in different countries, they all included some interviews with other women and their families. All three books had a combination of narrative story telling and academic factual information.

Although the review focussed on the three books mentioned, many other books were also read to provide the depth of knowledge necessary. *When a baby dies: The experience of late miscarriage, stillbirth and neonatal death* by Nancy Kohner and Alix Henley first published in 1991 and most recently in 2000 in the United Kingdom, also helped clarify the prevalent themes. “The significance of a baby’s death has not been recognised in the past and bereaved parents have often struggled alone with a grief which others have neither understood nor acknowledged” (p. 1). The writing of this literature review enabled me to clarify my understanding of the topic, and to narrow my focus for the actual thesis to concentrate on women in New Zealand who have experienced baby loss between 12 and 20 weeks gestation. Miller-Clendon (2003) acknowledges in the introduction of her book, how pregnancy loss is divided into two categories. She makes the clear distinction of a baby who dies before 20 weeks and also includes the language associated with this ‘early’ loss.

Right up to 20 weeks it (pregnancy loss) is generally referred to as a miscarriage. You may also hear it referred to as a spontaneous abortion, which is the medical term for miscarriage as opposed to an induced abortion or termination of pregnancy. Since the term ‘abortion’ has many connotations, medical professionals are being encouraged to use the term ‘miscarriage’ (p. 9).

The national focus adopted enabled me to establish a clear timeframe for the entire thesis covering the last 20 years. In 1985, Kitch Cuthbert and Sandra Van Eden Long established the Miscarriage Support Auckland group. Originally their aim was to publish a book, but what they discovered after receiving 800 completed miscarriage questionnaires back from a variety of women’s magazines the questionnaire had been published in, was that the need for a support group was just as great. So, they established a group first, before focusing on the book. “We are a small non-profit, NGO (non-governmental organisation) incorporated society that started in 1985 with two women looking for answers” (MSA). Two years later, in 1987, their book *Coping with miscarriage* was published in New Zealand. Cuthbert and Van Eden-Long sought to provide previously non-existent information to women finding themselves lacking any practical or adequate support after suffering a miscarriage, as they had experienced

themselves. The reason the support group's establishment was so relevant, along with the subsequent publication of the book, was that both of these tangible events marked a clear and definite acknowledgement that baby loss was an issue worthy of more than a cursory nod. Baby loss affects a significant proportion of New Zealand's population.

The 20 year timeframe also worked as a chronological focus, because although technology in the field of fetal development has improved in this time, it has not substantially changed. Women in New Zealand had access to scanning equipment to monitor their babies' health in 1985 as they do now; it has merely improved in quality. This enabled the thesis to include women's stories from the last two decades, and to include all media coverage in that same timeframe giving the thesis a number of key contexts.

My final decision to focus my research solely on the New Zealand experience was developed through background reading undertaken for the thesis. Once the background reading had been completed, the secondary supervisor requested a pre-suppositions essay be written, to ascertain my own assumptions regarding what I expected to discover in the writing of the thesis, and this has been included as appendix five. This essay focussed on the assumptions I held related to the main themes raised in both the international and New Zealand based background reading. Also included were my assumptions of what the five women who would be interviewed for their personal stories might uncover. Many of these assumptions were confirmed in Ms Cameron's article that appeared in the *Social Work Review* in September 1997. Cameron was employed in 1994 as the first full-time social work counsellor at the then National Women's Hospital in Auckland, and still holds this position today.

"The experience of miscarriage can be a profound one. Isolation, despair, guilt, and feelings of inadequacy are inherent to the crisis. These responses are compounded by societal attitudes which in the main, do little to permit women and their families to mourn the loss of their child. The occurrence of miscarriage is common, therefore it cannot be significant. This article is dedicated to the hundreds of women who have taught me otherwise (Cameron, 1997, p. 33).

To ensure a complete and balanced understanding of the topic had been attained from as many perspectives as possible, I also undertook a literature review of all medical and academic articles from the last 20 years published in New Zealand about the subject of baby loss. This article is included as appendix six in the thesis. Many of the same themes that were raised in the books published in New Zealand and from overseas, also

appear in the articles aimed specifically at health professionals. Cariad Milmine, an independent midwife, wrote an article in 1999 that appeared in the *New Zealand College of Midwives Journal* where she noted,

Miscarriage is the commonest complication of pregnancy...because of its common occurrence the resulting psychological trauma has largely been ignored. When family size was larger, the loss of a pregnancy was deemed less important by society, but as family size has declined, the loss of a desired child by spontaneous miscarriage has acquired much more significance (p. 19).

Another theme that appeared recurrently across all publications, academic and mainstream, was the lack of information for the woman whose baby has died. Of particular interest was the article that appeared in *Nursing Praxis New Zealand* in 1999. “Unfortunately, most of the available information appears to be based on what health professionals consider women need to know rather than what women themselves feel they need” (Benn, Budge & White, 1999, p. 5).

From the women’s perspective, the treatment by health professionals toward them when their babies had died was of primary concern. Registered Nurse Chris Stanbridge published an article in *New Zealand Practice Nurse* in 1993, about the impact the health professional’s behaviour can have on a women’s experience.

Parents in their grief may assume that health professionals are used to the situation. They may give disproportionate weight to what is said, and the way it is said to them. Choose your terminology with care – miscarriage rather than abortion, baby rather than fetus or products...Ask the parents the baby’s name. Then you should always refer to the baby by name. It is important to the mother that her baby, at whatever gestation, is still a person (p. 69).

The primary aim of the thesis was to always remain women-centred as they are the people who experience the loss of their baby physically, emotionally and mentally. All the research was conducted with this focus as the priority, and this was especially the case with the professional interviews of the four people working in their specific health fields. The recurring themes to emerge from the health professionals’ interviews were lack of time to adequately care for the women in their vulnerable states, and the lack of specific training for some of the health professionals.

Background reading included some academic articles from overseas to clearly ascertain common universal themes, but the heart of the thesis research into mainstream media articles was exclusively New Zealand based. The women’s stories clearly came from the prevailing western culture in New Zealand, but as New Zealand’s population base

has grown and broadened culturally, this dimension was also revealed. The health professionals were all chosen to reflect the New Zealand context of the thesis and represented a range of health professionals from various occupations in the system, such as a doctors, midwives and counsellors.

A fundamental part of the methodology chosen for the thesis was its journalistic approach to writing the articles. For an interesting story to be told throughout the thesis that would appeal to a mainstream magazine reader, points were illustrated by using excerpts from the interviews conducted with the five women chosen as research participants. Their reflections were used in articles one and three, as well as article two which was written from a narrative perspective describing the participants' experiences.

The research began by searching for books written specifically from a New Zealand perspective on the subject of baby loss, and the most recent and relevant book found was Nicola Miller-Clendon's book published in 2003, *Life after baby loss*. The book included specific reference to the loss of a baby in what I came to refer to as the 'invisible stage', which is babies born prior to 20 weeks gestation.

"There is a group of women whose babies die and are delivered in the second trimester prior to the 'magic' 20 completed weeks who feel as if they are in no-man's land. Many of these women are starting to use the term 'intrauterine fetal death', or simply 'early fetal death', which they may have heard or seen on their hospital notes, rather than miscarriage. Fetal death is an acceptable term for any baby that dies before it is born (p. 10).

From the distinction drawn by Miller-Clendon between pre and post 20 week gestation, I drew a further distinction between pre 12 as opposed to between 12 and 20 weeks gestation periods. I created this particular focus to show that cultural pre-existing knowledges inform the way women respond to health and social realities. Commonly women in New Zealand society have an understanding that the 12th week of a pregnancy marks the end of the 'danger' period. After that stage, they can safely tell their family and friends their news, and confidently celebrate the growing life within. Narrative examples from my reading highlighted the shock and trauma of having this belief shattered. There are often remarkable physiological differences in ending the pregnancy between the two gestational periods. What I discovered and already knew from my own experience, was that after 12 weeks 'miscarriage' does not adequately describe the 'procedure' that is medically required to remove the baby from within its mother. Most commonly, women give birth to their dead babies after 12 weeks, and this

process requires an induced labour. The experience of baby loss after 12 weeks more closely resembles the experience of women having stillbirths after 20 weeks, than it does women having a miscarriage prior to 12 weeks.

To further illustrate the scarcity of information available to women whose babies have died in the invisible stage, I undertook to review all mainstream media outlets' articles over the 20 year period, beginning in 1985. This media review formed the second part of article one.

All the mainstream media articles were found either by using the tool IndexNZ or by going to the media outlet's website and searching through the archive facility. The articles were sorted into chronological order from the most recent back to and including all the articles that appeared in 1985. Each piece was reviewed systematically to discover the themes, specific reason for the article's existence, and any other extenuating information. Not every article was included, as the focus was to review any articles written specifically about or including the invisible women and their invisible babies. As the number of articles that covered the invisible stage were minimal, the review included focussing on articles that confirmed one or more of the established themes. Some articles also revealed historical information previously undiscovered about situations relating to baby loss. An issue not known before the media review, was the lack of respect shown to families that had babies buried in stillborn sections of some cemeteries. The *Manawatu Evening Standard* ran an article by Janine Rankin in August 2004, that highlighted this concerning situation. Pahiatua funeral director Chester Burt chose to take his concerns directly to the media regarding a planned burial strip that was to be laid directly over many stillborn babies' graves. The paper sought comment from Mrs Keane, the Manawatu co-ordinator of the local SANDS group (Stillbirth And Neonatal Death Support). "We could perhaps excuse it 20 years ago when we thought it didn't matter anymore, but now we know, it does matter."(p.2). On a positive note, the media coverage prompted the local council to erect a memorial to honour the babies. This was only one example of a nationwide change taking place at cemeteries, where specific areas were being established for the burial of stillborn and miscarried babies. These changes illustrated the importance some councils were giving to this relatively new practice.

Once all the secondary research had been carried out, the research moved into the first part of the primary research phase; the interviews with women who had all experienced the loss of a baby in the last 20 years in New Zealand, and who still reside in New Zealand. The reason these interviews were all conducted after the completion of the readings, was to ensure that a clear understanding had been reached about the subject matter, and to conduct the best interviews possible to support the point of the thesis. The interviews with all five women confirmed the recurring themes discovered in the literature review, but also provided new perspectives that had not become apparent in the secondary research.

After securing ethical approval for my thesis from the Auckland University of Technology Ethics Committee (included as appendices two, three and four), I set out to find five women who were willing to be interviewed and taped to share their stories of the deaths of their babies. All five women who agreed to be interviewed for the second article did so willingly, and with full knowledge as to what their interview would be contributing to. Some participants came through word of mouth, others were personal contacts, one was from the everybody.co.nz website and another came from a letter sent out in co-operation with the Twin Loss Support group. Many other women requested to take part, but as a qualitative piece of research, the point of these interviews was to represent a cross-section of women who had suffered their loss or losses in New Zealand in the last 20 years rather than undertaking a quantitative study. The aim of the study was to uncover and shed light on a number of private losses, not to draw any substantive generalisations from the women's stories. This perspective is adequately represented by the media view of the last 20 years covering loss before life begins. The interviewing had to stop somewhere, and the five women chosen each brought a unique dimension to the article explained further on in this exegesis.

Limiting the research to the last 20 years enabled my choice of participants to only include women who had experienced baby loss in the invisible period since 1985. Prior to 1985 and the coincidental establishment in that year of Miscarriage Support Auckland, the prevailing belief was that baby loss was not a tragedy and that women should 'get over it'. Much has been published in mainstream media and academic journals nationally and internationally about the lack of empathy and support women received when their babies died. An article that appeared in the *New Zealand Herald* in 2002 quoted Sandra Van Eden Long, one of the founders of Miscarriage Support

Auckland about this very point. “At the time (of my miscarriage) there were no support groups (she set up Miscarriage Support Auckland in 1985) and like most women then, she was told by the doctors, “Never mind dear, go home and try again”(p.2).

Each of the participants were chosen for a specific reason. Kristen’s baby Tane was born at a large urban hospital at 16 weeks gestation early this year in 2005 due to her waters breaking in the middle of the night. She was only 21 years old at the time which is relatively young to have a baby in New Zealand. Although her pregnancy was unplanned, it was an exciting event and Kristen and her partner were looking forward to parenthood. Kristen was not born in New Zealand but has lived here with her family for over a decade, and her partner is Maori.

Kim discovered at her 12 week scan at a semi-rural hospital that her baby had died in-utero some weeks earlier. Her pregnancy was planned and both she and her partner were both excited about their baby’s arrival. Kim had a successful career at the time of her pregnancy but had decided that the time was right to start a family. Being scientific and curious by nature, Kim determined to gain as much knowledge and acquire as much information as quickly as possible about what the procedure and process would be to end her unsuccessful pregnancy.

Treena was in her mid-30’s when she conceived twins on her honeymoon. Her waters broke prematurely at 18 weeks gestation, and her daughter Verity was born dead at the hospital, and five days later her son Cael was born, but was too small to be viable. This double tragedy was actually a triple tragedy, because the previous year Treena had also lost a baby in pregnancy. At her 18 week scan she was informed that her daughter Bella was suffering serious complications. The decision was made to medically induce Treena at 20 weeks gestation, and Bella was born dead.

Nicole, who chose not to use her real name, discovered that her twins had died in-utero at 16 weeks gestation the day after returning to New Zealand with her husband from living abroad. The twins had been artificially conceived and were keenly wanted by the couple. The tragic news was discovered while having a scan, and Nicole’s babies were medically induced later that week.

Ellen who also chose not to use her real name, has suffered multiple losses in New Zealand and also overseas. Now in her early 50's, she took the opportunity to share her story for the first time. In 1972 whilst overseas, Ellen gave birth to a deformed stillborn baby whom she never got to see. Many years later she suffered an accident at 30 weeks pregnant and her baby died inside her. On her return to New Zealand in 1985, she suffered an ectopic pregnancy and this was followed in 1989 by the birth of a healthy son at 35 weeks gestation. In 1990 she was pregnant for the fifth time, and at 25 weeks gestation her baby died. Later that same year she was pregnant again, and at 16 weeks gestation her baby died in-utero. Pregnancy number seven ended at 12 weeks in 1991, then later that year she lost pregnancy number eight at six weeks gestation. Finally in 1992, Ellen gave birth to a healthy girl at 37 weeks gestation.

Being prepared to candidly talk about a private and tragic event in one's life takes courage. Each of these women generously gave their time and emotional energy the interviews demanded of them. Their stories are important and through article two found a place to be aired frankly, honestly and each of them was retold in the spirit in which they were shared.

The second part of the primary research which involved interviewing health professionals, formed article three of the thesis. These interviews took place after the writing up of article one and article two for a specific reason. It was important to not only have a clear understanding of the existing themes prevalent when discussing the death of a baby, but also to have had an opportunity to hear the stories of women directly affected by the medical system. I had undertaken a medical literature review previously (appendix six) and so had isolated themes and questions I had for the health professionals.

After interviewing the five participants, it became clear that the medical system had a separate categorising system for treating women which was based on the 20 week gestational age of the baby. The differences in health provision were coded as gynaecological for pre-20 week deaths, and obstetric for post-20 week deaths. After making this discovery, it was apparent that I needed to talk to staff working in the general or gynaecological system, as well as obstetric specialists.

The four professionals interviewed for article three were chosen for a variety of reasons, but all are based in Auckland as it is the largest city in the country. Geographic consideration of their workplace was considered to ensure that some of the health professionals interviewed came from different hospitals within the region, and that they all had a different job to do to ensure balance in their perspectives.

Ms Cameron Cameron has worked full-time at National Women's Hospital in Auckland as their Pregnancy Loss Counsellor since 1994. Before that she worked as a social worker in the Neonatal Intensive Care Unit (NICU), also at National Women's. Ms Cameron was chosen because she has responsibility at the biggest maternity hospital in New Zealand to support women and their families who have suffered the loss of a baby. This gave her a unique and valuable perspective from a professional point of view of both the women's experiences, and the limitations of the medical system.

Professor Professor Stone has been Head of the Obstetrics and Gynaecology Department with the Faculty of Medicine and Health Sciences at the University of Auckland since 2001, and Professor of Maternal Medicine since 1998. He began his career in Wellington in 1987 as the Head of Department at the School of Medicine there, which is part of the University of Otago. Professor Stone has extensive experience and knowledge regarding baby loss and its impact on the women concerned. His clinical interests include maternal fetal medicine, obstetric ultrasound and prenatal screening and diagnosis. His research interests include recurrent miscarriage along with placental implantation, fetal welfare, and assessment and doppler ultrasound. Professor Stone is an academic, but also continues to consult for National Women's Hospital with women who are in 'high risk' situations. He has extensive experience in this area and holds a unique position of responsibility.

The Charge Nurse of a major urban hospital was also interviewed, but preferred to remain anonymous for the purposes of the thesis. She has been in her current position for more than five years, and was part of the team for 20 years prior to taking on the job of Charge Nurse. As the invisible women under 20 weeks gestation are treated in the hospital system on gynaecological wards by nurses, it was important to interview a nurse in a position of responsibility within this specific type of ward.

Jackie Gunn is Head of Midwifery within the School of Midwifery at AUT (Auckland University of Technology). She has held this position for nearly three years and prior to this time was Programme Leader for the Midwifery programme at the same institute. She is also a practising midwife, although she hasn't practised independently for the last three years. In consultation with the primary and secondary supervisor of this thesis, it was decided to interview a midwife whose job it is to look after a pregnant woman. Ms Gunn was chosen because she also understands the training environment for people who are choosing to make a career in the specialised field of midwifery. This gives her the unique position of having practised herself as an independent midwife, interacting regularly with many independent and hospital-based midwives, and working in the important field of midwifery education at the largest training institute of its kind in New Zealand.

The purpose of the fourth and final article was to make conclusions and offer practical recommendations and improvements where possible. All three earlier articles were re-read, as were the appendices included in the thesis, to formulate both parts of article four. This process ensured that my original aim of being able to provide recommendations for practical improvements to be implemented, could be achieved. Tangible recommendations were reached, and a summary of the shortcomings in the current practice were included.

In conclusion, throughout the research process applied to the creation of my thesis, I have uncovered the multi-layered and systemically complex workings of an otherwise 'invisible' process. My own experience of baby loss was a huge isolated learning experience, and I hope that my research helps to better resource other women who may one day find themselves lost in the system that cares for women whose babies die. Particularly, I hope that this research highlights and remedies the invisibility of women whose babies die between 12 and 20 weeks gestation. The research reveals that there is much the health system, the media and the community can do to help make this tragic experience less painful.

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APPENDIX 1

Keys Literature Review

October 2004

Assessment

This assignment is a short review (1000-1500 words) of three items of academic literature on a topic of your choice. The purpose of this assignment is to give you an opportunity to apply some techniques you will study in class.

Assessment Criteria

- Literature review submitted by due date
- Structural organisation of review, eg thematic arrangement
- Effective introduction
- Acknowledgement of philosophical basis of selected literature
- Critical analysis of the selected literature
- Academic style, eg, effective paragraphing, appropriate vocabulary
- Flow in the writing, eg, use of transitional passages and discourse markers
- Proofreading to minimise errors in grammar, spelling and punctuation
- Authors are quoted or paraphrased; referencing is consistent and thorough

Student Name

Tina Rose

Student ID Number

9039049

Department

School of Communication Studies

Lecturer Name

David Parker

Word count

1692

Perinatal mortality; intra-uterine foetal death; spontaneous abortion or early foetal death is when a foetus dies in-utero no later than 20 weeks gestation. This is medically termed either a miscarriage or a spontaneous abortion. This type of miscarriage is when the woman's body miscarries the foetus without any initial medical intervention (Miller-Clendon, 2003). An 'induced abortion' is when the death of a foetus is discovered through the lack of a heartbeat. When this occurs the woman must give birth to the baby in order to end the pregnancy. There is no legal requirement prior to 20 weeks gestation for a birth or death certificate, and the family can choose to leave the baby at the hospital for 'disposal', or to find an alternative place of rest for her. In contrast, a baby who dies from 20 weeks gestation onwards is considered a stillbirth, and legal requirements must be adhered to.

Although miscarriage is not uncommon, it is rarely discussed and complexly misunderstood by many people who come into contact with a woman grieving for her embryo, foetus or baby. In the year 2000, there were 57,500 births in New Zealand. Conservative estimates suggest that one in every five pregnancies end in miscarriage. Of those miscarriages, 20% of these losses occur after 12 weeks gestation, equating in that year to at least 2,800 pregnancies (Miller-Clendon, 2003). Unfortunately this estimate is just that, because miscarriage in New Zealand is not a notifiable event.

The books reviewed in this paper are focussed on women in their role as mothers. Within this group there are a small number of women who have experienced a pregnancy and then the subsequent loss of their baby before 20 weeks gestation. The hermeneutical approach has been used in all three books reviewed; the authors have interpreted the participant's stories. This theoretical paradigm suggests that the relationship between the researcher and the participant is interlocked. "In order to interpret a participant's story credibly, as the researcher you must understand and make explicit your position in relation to the phenomenon under scrutiny" (Grant and Giddings, 2002, pg 17). This review is not seeking to find an argument, but to explore some of the many common themes running through the narratives and supporting literature. The mother's voice articulates in ordinary terms the unique and tragic aftermath of losing a baby in pregnancy. I will use the word 'baby', but in many cases women lose more than one baby, so the term therefore includes multiple pregnancy loss.

Included in this review is an exploration of a number of themes found in all three books. The common themes explored include the medical language associated with miscarriage; the grief experiences of the women interviewed and the coinciding isolation women often feel. I explore the nature of extraordinary grief, which is the very essence of perinatal mortality. These themes include the unpredictable and often misunderstood nature of grief for the women concerned.

It is important to include the unique perspective of the writer in this review, as I am also a woman who has recently experienced intra-uterine death with the birth of my identical twin daughters in April 2004, at 18 weeks gestation. As is apparent in all three books included in this review, the personal journey of the authors through the miscarriage or stillbirth experience mirrors in many ways the experiences of the women interviewed. This is why the theoretical paradigm is so relevant.

The three books under review are all presented in some type of chronological order, with a combination of narrative and author comment. The grief expressed stems from the loss of potential life, dreams of a child's future and the shock of a happy event turning into a tragedy. Lamb as cited in Lothrop (1997) asserts that it is universally understood that the bond between mother and baby begins before the existence of a 'life' can be detected. "The Chinese say that a baby is a year old at birth" (Lothrop, 1997, pg 4). The grief experience is clearly illustrated through the women's stories and illustrates the depth of this grief at the time of miscarriage (Miller-Clendon, 2003; Shelley and Marks, 1993; and Lothrop, 1997). For the mother experiencing the loss of her baby firsthand, the grief is real, tangible and not in her control. A sentiment echoed in all three books is that "the point at which your loss occurred has no bearing on how the loss will affect you" (Miller-Clendon, 2003, pg 10).

Although clearly by the statistical evidence shown the number of miscarriages is significant, the lack of understanding is in itself a contributor to the grief. This lack of understanding is from the woman herself; her partner; family; friends and the medical team she comes into contact with. Placing a time limit on the grieving process is a common contributor. "Families, friends and acquaintances are usually the ones who put a time limit on your grief" (Miller-Clendon, 2003, pg 53).

In her 15 years spent working in this difficult area of supporting women and their families through the birth and grief process, Lamb as cited in Lothrop (1997) has an extraordinary insight into the nature of this loss. "Grief for perinatally bereaved parents can be aggravated by the fact that society belittles this loss, that it is often shrouded by taboo, that the baby is unknown to others and is not perceived as real, that there are no memories to share with others and that parents feel isolated" (pg 156). The grief and the isolation are linked and at the same time unexpected, because more often than not, the miscarriage itself is unexpected.

Pregnancy is supposed to be a happy time when new life is coming into being and life is being affirmed. For the woman who is pregnant, and then shortly after, not pregnant, the experience is often debilitating. Both Allen and Marks were themselves intelligent, educated women when they experienced their miscarriages. What occurred surprised and saddened them, enough to write a book on the subject for women coming after them. "We had both always been under the impression that miscarriage was no more than a brief disappointment, and people treated ours accordingly...But we were devastated" (pg 3).

There is inevitability that women will feel isolated at the time of their miscarriage, as it is an individual physical experience. What contributes to the grief and isolation and is explored thoroughly throughout all three books both by the authors' comments and the narratives, is society's silence and seeming lack of willingness to face what is 'difficult'. Pregnancy and the assumption of birth leading to new life leave little room for when things go wrong. "For some people recognising the experience of miscarriage as the loss of a baby, challenges their acceptance of abortion. Our own attitudes can lead to a lack of appreciation of the significance of the pregnancy loss to the woman" (Miller-Clendon, 2003, pg 180).

Allen and Marks (1993) echo this sentiment of universal themes surrounding grief and the ensuing isolation. "While each woman we interviewed expressed a unique degree and style of grief, specific themes and problems were echoed again and again among them" (pg 12). The misconceptions, societal myths and clearly the basic lack of understanding of grief, serve to further isolate the woman from those around her. Often, as Allen and Marks outline in the chapter dedicated to exploring many of these common myths, people are conforming to what is acceptable behaviour in their communities. If a woman displays one or any number of these behaviours because of her grief, society

responds accordingly and so, therefore, does the woman. If what she is feeling is not 'acceptable' then it is logical that she will feel and therefore actually will be isolated. Allen and Marks (ibid) include the story of Hannah, who suffered a miscarriage at four months pregnant, "I felt very isolated. I felt there was something wrong with me...I have been touched by tragedy. I will never be the same. It lessens with time, but it is always there. It has left a hole" (pg 174).

The isolation women experience with the death of a baby has many facets. It is the isolation of the actual experience that ultimately only other women who have shared their experience really understand. It is also in the unique nature of the relationship that is so apparent where birth and death have fused. Miller-Clendon's (2003) book about pregnancy loss as I have discussed earlier, is written from her unique perspective of being not only a woman who has experienced miscarriage, but she also has four children and is a midwife. Published recently, it is a New Zealand perspective of her experience along with 39 other women from New Zealand who have suffered a miscarriage (or multiple miscarriages) at various stages of pregnancy. "Bereaved parents often find it difficult to know where to turn. Maternity services no longer seem appropriate, and friends and family can sometimes unknowingly do more harm than good" (pg 4).

Often the source of this isolation is society's lack of acknowledgement of the loss. Lothrop (1997) explains that both parents feel compelled to share their story in order to gain acknowledgement and to validate their baby's existence for them. This is exceptionally difficult for people to do with the loss of a baby in-utero because they do not know the baby – it is an intangible loss for those around the grieving family. Lothrop (ibid) shares a woman's story of clutching the paid invoice from the cemetery where her baby was buried, as proof that a miscarriage had actually happened.

Although all three books have been written in different countries and at different times, they share many of the same themes. The commonality that all the authors have themselves experienced miscarriage, and all include interviews with other women, is one of the most important themes. Each story is unique, but the same issues are echoed time and time again. Grief and the isolation that follows are inextricably linked as has been shown here. One does not necessarily confirm the presence of the other, but in the case of extraordinary death as is the nature of babies dying before beginning life, it seems almost inevitable.

APPENDIX 2



MEMORANDUM

Academic Services

To: Brad Mercer
From: **Madeline Banda**
Date: 3 March 2005
Subject: **05/19 Loss before life begins: New Zealand women's experiences of death in-utero over the last twenty years.**

Dear Brad

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 14 February 2005. Your ethics application is now approved for a period of three years until 4 March 2008.

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 at http://www.aut.ac.nz/research_showcase/pdf/appendix_g.doc, including a request for extension of the approval if the project will not be completed by the above expiry date;
- A brief report on the status of the project using form EA3 which is available online at http://www.aut.ac.nz/research_showcase/pdf/appendix_h.doc. This report is to be submitted either when the approval expires on 4 March 2008 or on completion of the project, whichever comes sooner;

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 or by telephone on 917 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

A handwritten signature in black ink, appearing to read 'M. Banda', with a stylized flourish at the end.

Madeline Banda

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: Tina Rose tina.rose@manukau.ac.nz

Participant Information Sheet

Date Information Sheet Produced: 27 January 2005

Project Title Loss Before Life Begins – How Society in General and the Media in Particular Further Exacerbate the Trauma of a Woman Experiencing Death in Utero by Failing to Suitably Acknowledge the Event. And Ways Society May be Able to Help Women and Their Families Come to Terms With This Tragedy.

Invitation

You are invited to take part in this study on New Zealand women's experiences of death in-utero over the last 20 years.

This study forms the thesis component of my Master of Arts degree majoring in print journalism in the School of Communication Studies at Auckland University of Technology.

What is the purpose of the study?

The purpose of this study is to explore what is commonly called 'late miscarriage' in New Zealand over the last 20 years. The study will be written in a journalistic style in the form of four articles including background information; five case studies with women living in New Zealand at the time of their death in-utero and who continue to live in New Zealand; an exploration into the themes raised in the case studies and conclusions and possible recommendations for dealing with this issue in the future. It will also include an exegesis, the academic piece explaining and justifying the theoretical approach and methodology used underpinning the four articles. One of the primary purposes of the study is to aim for the articles to be published in a mainstream New Zealand publication after completion of the thesis. The reason for this aim is that death in-utero is not commonly discussed in mainstream media and I believe this contributes to the apparent lack of understanding for women experiencing late miscarriage in New Zealand.

How are people chosen to be asked to be part of the study?

The people chosen to be part of the study have been recommended by word of mouth and by utilising the network of Miscarriage Support Auckland Inc that was established in 1985. As a participant you must be an adult of at least 20 years of age; have experienced death in-utero between 12-20 weeks gestation yourself in New Zealand and still be living permanently in New Zealand.

What happens in the study?

As one of the five women chosen to be part of the study you will receive an outline of the interview questions presented as themes prior to the face to face interview, to firstly decide whether you want to be part of the study and to then begin thinking about the answers to the various themes in their own time prior to the interview taking place. The interview will be carried out face to face in a neutral and safe environment at a time and on a date that suits both you and the researcher. As the researcher I will have a list of questions to ask you and I

estimate that the initial interview will take approximately one hour. If clarification is needed or other questions arise, with your consent I will either telephone or email for a follow-up conversation.

What are the discomforts and risks?

Death in-utero is a difficult subject to discuss and therefore being asked to remember in detail the events surrounding your particular experience may cause psychological discomfort.

How will these discomforts and risks be alleviated?

The risks are limited to facing this difficult subject again in detail and will be dealt with by the offer of three free counselling sessions for you should you feel this necessary after the interview at a suitable time for you from an approved AUT counsellor.

What are the benefits?

There are no direct benefits to you personally. For some, the re-telling of your experience may be a further step in the healing process of the loss you have suffered and the information shared will contribute to a thesis meant primarily to help those women who may experience death in-utero some time in the future.

How will my privacy be protected?

As a participant all your identifying material (including names and place of residence) will remain confidential in the publishing of the thesis, the publishing of the article in mainstream media and conference papers published subsequent to the thesis as the content is relevant, not the identifying material. You will be asked to provide a pseudonym, a name which will be used when writing up your story. Your privacy can also be protected by you choosing a time and place for the interview which suits you. No material that could personally identify you will be used in any reports on this study. The person who transcribes the audiotapes into a written form will be required to sign a declaration of confidentiality. As a part of the process of analysing what you have told me, I may discuss with colleagues a portion of what you have told me. I will not reveal your identity to my colleagues, who are also bound by confidentiality.

All the information that you give me will be kept in a secure place. For example, while I am doing the study, your tapes will be kept in a locked place, as will the computer discs being used. Following the study, my supervisor is required to keep all the information in a secure place at the Auckland University of Technology for 10 years, and it will then be destroyed. If you withdraw from the study, your information will be destroyed immediately.

You need to be aware that even if you use another name, I cannot guarantee anonymity. Because some of your personal story will be quoted in the thesis, it is possible that someone who knows you will recognise your story.

How do I join the study?

Once you have read the participant information sheet and the consent to participate in research form and signed the documents, you will receive approval to join the study and a date, time and location for the interview will be mutually agreed upon by both yourself and myself, the researcher.

What are the costs of participating in the project? (including time)

The initial interview will take approximately 60 minutes and may be followed up for further information or clarification by telephone or email.

Opportunity to consider invitation

As the participant being invited to consider joining the study you have two weeks (14 days) from receiving the information regarding the study to agreeing to be part of the study. Participation is completely voluntary and you as the participant can at any time up until completion of the data collection (approximately one month after the interview) decide not to take part in the study for any reason you feel is valid. No adverse consequences of any kind will be experienced if you change your mind. Any further information that may be required by you will be provided upon request.

Opportunity to receive feedback on results of research

If you wish to receive a copy of the thesis that will act as a report of the outcomes you are welcome to at no cost to yourself.

Participant Concerns

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor.

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTECH, Madeline Banda, madeline.banda@aut.ac.nz, 917 9999 ext 8044.

Researcher Contact Details: Tina Rose, bobandtina@xtra.co.nz, 968 8000 ext 8343 or 021 567 337.

Project Supervisor Contact Details: Brad Mercer, AUT, mcmerc@xtra.co.nz, 917 9999 ext 7904.

Approved by the Auckland University of Technology Ethics Committee on
04032005 **AUTECH Reference number** 05/19

Appendix 4

Consent to Participation in Research

Title of Project: **Loss before life begins – New Zealand women's experiences of death in-utero between 12-20 weeks gestation in the last 20 years.**

Project Supervisor: **Brad Mercer**

Researcher: **Tina Rose**

- I have read and understood the information provided about this research project (Information Sheet dated 27th January, 2005.)
- I have had an opportunity to ask questions and to have them answered.
- I understand that the interview will be audiotaped and transcribed.
- I understand that the transcript of my interview will be made available to me for approval.
- I understand that I may withdraw myself or any information that I have provided for this project at any time up until completion of the data collection (approximately one month after the interview), without being disadvantaged in any way.
- If I withdraw, I understand that all relevant tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research: tick one: Yes ☐ No ☐

Participant signature:

Participant name:

Participant Contact Details (if appropriate):

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

Date:

Approved by the Auckland University of Technology Ethics Committee on 04032005 AUTEK Reference number 05/19

Note: The Participant should retain a copy of this form.

Appendix 5

Loss Before Life Begins – Presuppositions Essay

An angel, in the Book of Life, wrote down my babies' births.

Then quietly whispered as he closed the book, "Too beautiful for Earth."

When a woman experiences an intra-uterine death the extent of the grief, loss and feeling of lack of control over her circumstances depends on her attachment to the baby that was growing inside her. No research carried out in this area suggests that there is any real difference in the feelings of loss between a woman who has suffered an early miscarriage (including an ectopic pregnancy), late miscarriage or stillbirth. For early miscarriage sufferers there is bleeding and often no intact baby in which to grieve for, the loss is literally unseen. Also, most women don't tell people about the pregnancy until after 12 weeks – the mythical 'safe' time in which to share the happy news with family, friends and work colleagues. So the likelihood is that very few people were aware of the pregnancy at all. A death in-utero between 12 and 20 weeks prior to recognised stillbirth often involves giving birth to the baby (or babies) and therefore it is a more tangible experience with an intact baby to dispose of. Prior to 20 weeks gestation, no birth or death certificate is required or legal burial or cremation necessary, affecting the validation of the baby's existence.

The actual experience is unique to women as is a successful pregnancy with a live baby. Physically the loss is often painful and time is needed for recovery, as is the case in a live birth. Because miscarriage is so common (especially early miscarriage prior to 12 weeks gestation), many people working in this area are immune to the effects this loss may have on the woman concerned, and treat it as just another medical situation. The difference here is that it is not just another medical situation – it is often a physical, emotional and spiritually confronting event in the life of the mother to be.

The confusing and sometimes callous nature of the terminology used when losing a baby in-utero can add to the overall pain of the experience. Being told you are having a spontaneous abortion when the pregnancy was planned and wanted; having a health professional discuss the loss as a miscarriage or abortion (spontaneous or therapeutic);

or calling the baby a fetus can cause anger toward the person who is merely the messenger and who may not be aware of this linguistic confusion. It can place the shocked woman in a situation of having to explain what actually happened and feeling the need to provide a justification for why she feels confused, hurt and/or offended.

For many women who may not have planned the pregnancy and possibly experienced a period of ambivalence toward the pregnancy and consequently the baby, when the death occurs the feelings of guilt can be extreme. “Was it my fault this happened because I didn’t love the baby immediately?” For other women a previous pregnancy may have been terminated and the guilt lies with that experience, but manifests itself in the current loss. This guilt can cause an increased risk of depression or lack of ability to deal with the current grief effectively.

Understanding that every loss is unique and therefore every reaction to the loss that has occurred is also unique, will be borne out in my research findings. Conversely, although there is an element of uniqueness there is also an element of similarity. Many studies, articles and books both written from a New Zealand perspective and from overseas highlight these themes. Included are isolation; guilt; emptiness; failure to bear a live child; depression; loss of control; anger with people’s lack of empathy (both health professionals and friends and/or family); anxiety (especially relating to live children and any subsequent pregnancies).

It is entirely possible that some of the women interviewed for the case studies part of the thesis may have experienced more than one loss. Although my research is focussed on late miscarriage between 12 and 20 weeks, I expect that these women may take the opportunity to discuss all their losses in the context of their life stories.

Because I am looking at the period from 1985 through to the present day, all the women interviewed will have experienced their loss or losses in that time. Although technology has advanced (for example scanning technology has improved), it has not changed significantly. Thus what a woman might talk about from 20 years ago, is still relevant today. Some changes have taken place that affects the context of the women’s stories. In 1996 the definition of stillbirth changed from 28 weeks gestation onwards to 20 weeks gestation onwards. The reason for this development was that due to medical advances, many babies now live who are born from around 23 weeks gestation. This change is

significant because of the legal implications, and also because the health professionals would have gone through a period of readjustment to alter their course of action with women at this time giving birth to a dead baby eight weeks earlier than previously recognised as stillbirth.

The other major change that has occurred in this 20-year period is the role of the midwife in the birthing process. In 1990, midwives gained autonomy through the 1990 Nurses Amendment Act. This act enabled midwives to practice independently of doctors and claim funding from the Maternity Benefit. In 1993 this autonomy was further cemented when the Maternity Benefit Tribunal upheld the equal value of primary care provided by a general practitioner (GP) and a midwife, thus ensuring midwives could claim equal funding. This legal recognition has meant that since 1990 women have had the option to choose a midwife as her LMC (Lead Maternity Carer) instead of being under the care of an obstetric GP or an obstetrician. A shared care option was also made available.

Societal attitudes to death differ amongst different cultures, but in New Zealand the dominant culture in the areas of health and media is western. What this means is that death and especially the fusion of birth and death are not discussed openly in many situations. Health professionals in the main still treat the situation as purely medical, often not realising the extent to which people's lives are affected. I expect some of the participants to remember clearly the health professionals who made a positive impact and just as legitimately, a negative impact on the woman's overall feelings surrounding her loss. A woman's memory of the events leading up to, at the time of, and after the loss are clear and often are not forgotten, ever. Many health professionals either forget this, or are unaware of the impact they may have on these memories for the woman concerned. Situations where the woman, her family and/or the baby have not been treated with the appropriate respect are not uncommon, even today.

As far as mainstream media is concerned, the death of a baby in-utero is not something that is commonly reported in newspapers or magazines. The majority of articles from the last 20 years appear in the *New Zealand Women's Weekly* and are centred around either the publishing of a book or the experience of a celebrity losing a baby. For the woman who does not read this magazine and other women's magazines, she may never have read anything anywhere about death in-utero, contributing to her lack of

knowledge about the situation she has found herself in. The lack of media coverage further exacerbates the denial that this pain and loss does occur, and often.

Because scarce media coverage further cements the societal attitude that the subject of baby loss is not open for discussion, women turn to those they trust. Depending on these people's own experiences, values and cultural norms, the woman who has lost the baby may be no closer to receiving good advice, helpful support or just an empathetic ear to listen to her story. Many women talk about their mother's lack of empathy for the loss because 'in their day you just got on with it and tried again'. What this attitude does is limit the opportunity for real, helpful grieving to take place in a safe, loving and supportive environment. This problem may be further perpetuated with the male partner of the woman if there is one. Men and women grieve differently, and in this case it is the woman who has both the physical and the emotional pain to deal with. It is not uncommon for women to discuss the lack of real support from their partners, and for relationships to become strained, and in some cases to disintegrate entirely. The original loss of the baby is further compounded by the loss of trust for the people the woman always thought she could rely on.

In western society death has become so medical and placed behind closed doors, friends may not be helpful for the grieving woman either. Much of this will depend on these people's own experiences of death, not necessarily or exclusively related to the death of a baby. Even the most basic formal way to grieve may not be supported, which is the funeral or memorial service. It has become more common for a woman to want to formalise the death of her baby and have some type of service. Whether this formal goodbye is just for the immediate family, or friends as well, will differ from person to person. People living in western society tend to leave the griever alone to 'get on with it' which is often not what the griever needs, but it may be too difficult or uncomfortable for them to ask for support. Conversely, in Maori culture the tangi provides the perfect vehicle for mourners to gather and support the family and contribute effectively to the grieving process, further validating the woman's loss. In the case of the tangi, support does not need to be asked for, it is given as a natural part of the process of loss.

Not all the women will share all the themes outlined here, but I believe some of the themes will appear as a thread throughout all the case studies. It may be the language

the women use to describe their experiences that are similar; it may be the difficulty with the language used by health professionals; it may be the reactions of family and friends to the loss; it may be the partner's reactions. As I stated at the outset, each woman's experience is unique, but many themes are shared.

APPENDIX 6

Health Publications Literature Review – 20 Years Of Publication

It is only natural that the health professionals who come into contact with women suffering the loss of their baby will have an entirely different perspective of the situation they are faced with. For the woman who has suffered the loss of her baby, whether it is by natural miscarriage or through a necessary medical intervention, that loss is not just physical. It also carries with it an emotional impact. This clearly is not the case for the health professional whose primary job is to deal with the physical situation, and then to move on to the next patient.

This convergence of needs is often acknowledged in the literature available in New Zealand and overseas. The subject of baby loss can be found in a number of academic journals. This article's aim is to review the articles appearing in relevant journals over the last 20 years in New Zealand.

In late 2004 the *New Zealand Medical Journal* published *Obstetric perspectives: quality within choice* specifically discussing the issues facing obstetric medicine in New Zealand today. The overriding theme of this piece, written by Dr Rosemary Reid, from Obstetrics and Gynaecology at Christchurch Women's Hospital, was about the lack of standardisation of information available to health professionals. This lack of information impacts on the quality of care a pregnant woman receives in New Zealand, and makes it difficult for the health professionals to do their job to the best of their ability. "In conclusion, women within New Zealand should be able to have a high standard of healthcare within pregnancy, particularly with the availability of an excellent GP service, and the funded one-to-one care during maternity, with lead maternity carers (LMCs) from midwifery and medical backgrounds linking together. A comprehensive national perinatal database has long been called for to provide the data to inform health practitioners and the public on maternal and perinatal outcomes." It appears that the lack of this database's establishment comes down to a lack of funding but "we will only achieve the best outcomes for women and their babies by accessing the strengths of all potential relevant healthcare workers involved in the provision of maternity care."

This theme is not new and appears earlier in a *New Ethicals Journal* article *Quality Assurances for Maternity Services: Perinatal Audit* back in late 2001. Dr Neil Pattison, a registered Maternal Fetal Medicine Specialist, part-time academic with the University of Auckland and private practitioner wrote this hard-hitting article. The ongoing dissatisfaction with the databases available to health professionals relates to the crudeness of the data collection. The information is available; it is the integration of the information that is the problem. By comparison, Australia has the Australian Maternity Database which provides one central place for postnatal data collection, and because of this “substantial analysis of the data is reported on an annual basis.” Australia has a population more than four times that of New Zealand’s, and is geographically far larger, yet it still manages to comprehensively record national information. The bottom line is that professional standards are being compromised through this lack of reportage. “Indirect benefits of clinical audit arise from the fact that the process provides benchmarks for caregivers and encourages self-or college collegial audit. Most practitioners are unaware of their outcomes...but if we do not audit our practice, we limit our ability to learn from our own experience.” Pattison summarises that New Zealand “is significantly handicapped in its ability to analyse or improve healthcare for mothers and babies.”

How this lack of cohesion affects the treatment of a woman and her family, at the time of losing her baby, is an important point. In January 2001 the *New Zealand College of Midwives Journal* also focussed on this lack of standardised information gathering. The article, ‘Midwifery autonomy in New Zealand: How has it influenced the birth outcomes of New Zealand women?’, is primarily about medical intervention in childbirth, but it is in relation to the available information about this. “Access to maternity service and outcome related data has been very limited as a result (of several major restructurings). This has made it difficult to measure the success or otherwise of the changes brought about by midwife autonomy. Health providers have continuously called for the establishment of a standardised national perinatal database to bring some conformity to data entry and analysis.”

The recurring theme of lack of information permeates through nearly every article reviewed. In 1999 an article appeared in *The Practicing Midwife*. ‘Situations vacant – midwives wanted ‘down-under’ is written by an English woman who immigrated to New Zealand with her family for a lifestyle change. She was employed as a midwife

and she wrote about the difficulties facing midwives from abroad, wanting to practice in New Zealand. With the shortage of midwives and active recruitment for them by the New Zealand government, there appeared to be a number of problems these women were facing after their arrival, all centred around a lack of information. “It would appear that at the heart of the problems overseas midwives face, is a lack of information about the maternity services and midwifery profession.” The article is positive on the whole about the practice of midwifery in New Zealand, but it clearly shows areas where misinformation is being given. The author attempts to outline areas for improvement in communication.

Still in 1999, and still with the recurring theme of information, or lack thereof, ‘Women planning and experiencing pregnancy and childbirth: Information needs and sources’ appeared in *Nursing Praxis in New Zealand*. This article was in response to a questionnaire completed by 50 women about their choice of who they approached for information regarding pregnancy issues. Meriting a place in the introduction, “Unfortunately, most of the available information appears to be based on what the health professionals consider women need to know rather than what women themselves feel they need.” The authors, three academics from Massey University working specifically in the fields of midwifery and psychology believe from their findings that this lack of information being made available to the pregnant woman is because of an “underestimation of women’s information needs.” The conclusions reached were that information be made available to the women, specifically relating to their individual place on the pre-pregnancy, pregnancy, post-partum spectrum. The other main theme is that the health professional needs to constantly remember the perspective the woman may be coming from. “What seems obvious to the health professional may not necessarily be so for the pregnant woman. It seems that most pregnant women are relying on their midwives for medical information, as well as advice regarding their pregnancy and child care practices. It is important that health professionals, who are in a position to provide medical as well as practical advice, ensure that the information they give is pertinent to the woman at the time of asking and addresses the issues about which the woman herself expresses interest or concern.”

Clearly none of the articles reviewed thus far directly relate to baby loss, but the lack of information both about pregnant women and for pregnant women directly impacts women who have had babies die as well. The articles also provide context to explain

environment the health professionals are working in. The fact remains that all women who have lost a baby have been pregnant and therefore exist on the pre-pregnancy, pregnancy and post-partum spectrum as much as women who give birth to a live baby.

A few articles are written within the context of baby loss. In April 1999, the *New Zealand College of Midwives Journal* focussed on 'The psychological sequelae of abortion (spontaneous and induced) and subsequent pregnancies'. The article is written by an independent midwife who begins with her own musings about the questions she asks new patients in relation to their previous losses, and what these questions might mean for the woman answering them. She then moves into the well-known statistics of miscarriage, and the fact that "because of its common occurrence, the resulting psychological trauma has largely been ignored." She notes that this trauma may be due to the size of families these days, compared with yesteryear, when "the loss of a pregnancy was deemed less important by society." An interesting acknowledgement is that although a spontaneous abortion and an induced abortion are very different, "there are many similarities with the psychological symptoms experienced after the event." Namely those of grief, depression, guilt, impact upon identity, societal attitudes, defense mechanisms, anxiety and subsequent pregnancy and finally the midwife's response to abortion.

The article also includes acknowledgement from an international perspective that the grief associated with miscarriage "was as intense as after stillbirth", and the reality that this grief is directly related to the woman's attachment to that baby. Whether subsequent depression occurs after suffering a loss appears to be linked to the woman's mental well-being after the baby's death. The author raised the complex issue of guilt. This feeling of guilt is often exacerbated for women if the pregnancy was unplanned, and therefore there may have initially been feelings of ambivalence towards the baby. Also included were many women's feelings of believing they were being punished for a previous termination, or having a difficult pregnancy after a termination had taken place. The impact on a woman's identity was discussed including how many women have feelings of being less feminine, inadequate and that they therefore suffer from a lowered self-image. The recurring themes about the attitudes of society in general are stated. "Literature and women agree that society does not generally accept spontaneous abortion as a significant loss." Included is a reference to the fact that in the last 20 years more understanding and sympathy of the impact of this type of loss occurring does

exist. But that still, only a few hospitals offer counselling. Much has been written in international journals regarding anxiety and subsequent pregnancy and the subject is touched on here. “The legacy of miscarriage haunts the next pregnancy, with the possibility of it all going wrong again.” Something rarely mentioned elsewhere is that for women who have experienced a loss, they too have crossed a threshold in their life, just as women who have a live baby cross a threshold into motherhood. “It is a threshold where the crossing is hidden, but it may likewise make a profound difference to the way a woman lives her life in the future.” And finally, the midwife’s response to abortion raises some pertinent points for those practicing in this field. “Midwives need empathetic understanding when caring for women who have experienced any pregnancy loss, whether it be spontaneous or induced, early or late...for these women life goes on, and with them goes the memories, acknowledged or repressed, of the child who never came to be.”

Late in 1998 *Kai Tiaki – Nursing New Zealand* highlighted miscarriage in a comprehensive article. It often takes a person who is a health practitioner themselves to have had a negative experience for a change to take place. In this instance, a nurse suffered three miscarriages within two years, and due to the care she received felt motivated to publicise her story. “Some of the nursing care I received following my miscarriages was positive and helpful in resolving my grief and helping me plan for the future. Other care was distressing and contributed to the devastation I felt.” She asks the question of why a health professional may feel that they can do nothing to help, when a death or loss is inevitable. “The loss of the unborn child is not where professional help ends, but rather where the more human side of caring begins.”

Again, the fact that baby loss is common is acknowledged, but the author questions whether this contributes to the often callous treatment of the patient who is suffering the loss. “Some couples who experience miscarriage tell of the negative comments from health professionals, and the lack of information and support. A woman feels isolated as she comes to terms with being a pregnant woman looking forward to the birth of her baby, to a pregnant woman facing the loss of her baby.” The bottom line is that no matter how common a miscarriage might be for the health professional, “it is not an everyday occurrence for the families experiencing it. It is tragic and stressful and every person deals with it in a different way.”

In April 1998, *New Zealand Doctor* published 'The grief of miscarriage deserves closer scrutiny'. The significance of miscarriage and the impact of the loss, not only for the mother, but the other members of the family, is highlighted by the author who is a registered psychologist. Society's apparent lack of support is raised, but this time in the context that a greater awareness of the number of babies dying and the effects this tragedy has on the women would help with appropriate support being available to those needing it. The article includes a breathtaking statistic that "research indicates that 48 to 51 per cent of women in western countries develop a depressive disorder following a miscarriage...there is often no routine medical follow-up for women."

Finally the recurring themes of guilt, personal identity issues and a loss of sense of self are raised. This is one of the few articles that constantly acknowledges how much baby loss impacts on the entire family. "When a miscarriage occurs, a major readjustment to the couple's vision of their future occurs." The importance of including children in the resolution of grief was outlined and the impact of the trauma was shown. "The negative impact on the relationship and family can remain for years to come. For example, a male client talked to me about the ending of his marriage. He reflected that the beginnings of the breakdown in the relationship dated back to the loss of the couple's baby daughter through miscarriage five years prior."

'Miscarriage: the dilemmas of unacknowledged loss' authored by Ms Judith Cameron Cameron, Pregnancy Loss Counsellor at National Women's Hospital in Auckland, appeared in the September 1997 edition of the *Social Work Review*. Society's attitudes are raised immediately. "Isolation, despair, guilt and feelings of inadequacy are inherent to the crisis. These responses are compounded by societal attitudes which, in the main, do little to permit women and their families to mourn the loss of their child. The occurrence of miscarriage is common, therefore it cannot be significant."

It was only eleven years ago, in April 1994, that funding was made available for one full-time social work counsellor at the then National Women's Hospital in Auckland. Ms Cameron was employed to fill this position, and her first job was to establish a protocol for dealing with women suffering a loss. The aim was for every women to be offered counselling, preferably face to face. Ms Cameron acknowledges that although on the whole, most health professionals are sensitive and responsive to women's needs in this time of crisis, "health care professionals working in an acute admitting area,

where each day four or five women suffering some form of pregnancy loss are admitted, may be guilty of dismissing the event as a minor one, with little need to recognise or accept the depth of the women's emotional response." The impact of this insensitive treatment can be profound, and this she also acknowledged. "When the emotional needs of women and their partners are not met by health professionals, nor their own family and peers, the experience of miscarriage is negated and the grieving process is inhibited."

This article is the first place that any reference to the inadequacy of the language of loss appears. "The terminology, while technically correct, is seen as inappropriate by women who would feel accepted if more emotive language could be employed. For these women miscarriage is the death of their baby, not a *fetal demise*. The term *spontaneous abortion* may create anger and confusion, and women will often request this term to be struck from their records. Wherever appropriate, evocative language is used. The word *fetus* is replaced by 'baby', *miscarriage* by 'death of your baby'". These may seem small, and perhaps inconsequential alterations to the outsider looking in. But to the woman dealing with her feelings, these changes can make a profound difference to the feelings associated with the loss of her baby, at whatever gestation under 20 weeks.

The feelings of the many women Ms Cameron has counselled over the years since her employment began are articulated in this important article. She clearly outlines the contributing factors to many women's perceptions that they have been abandoned, both by the system and by society. This perceived abandonment is deemed to be because the 'event' is common and therefore it cannot or should not have a significant impact on an individual. This, she believes, is also about "society's discomfort with the issue of death." In direct contrast to this attitude, and on a positive note, the Maori response to death is outlined. "An increasing number of young Maori parents are requesting the return of their fetus and pregnancy tissue. Accompanied by their Whanau, they will take it back to the family burial grounds. Thus, the unborn child is acknowledged in the same way as any family member... The unborn child is accorded the significance it deserves." The obvious success and helpful nature of the way Maori families deal with death has been further offered to all families. "A brief explanation of the value of farewell rights is introduced at this stage, with the couple being offered the return of remaining pregnancy tissue if surgical intervention is necessary. To bury the tissue is surely the

most symbolic means of fare-welling the baby, the lost hopes and dreams for the future.”

As for the role of counselling contributing to a woman’s acceptance of her loss, and consequently her ability to move forward in a healthy manner, Ms Cameron believes this opportunity is vital, should a woman choose it.

For the brave women who choose to tread the path of pregnancy again, Ms Cameron believes most of them feel a loss of innocence following a miscarriage, and that this will continue into at least the first trimester of their subsequent pregnancy. She stresses the need for health professionals to be empathetic when dealing with women if this anxiety is apparent.

An issue alive and well in the international research, is men’s and women’s differences toward grief. Cameron states that at least half the couples that choose to come to her for counselling do so because of communication difficulties. “It cannot be assumed that men do not grieve intensely from the loss of their unborn child...Gender socialisation discourages men from articulating their emotions. Men report that, while family and friends will enquire about their partner’s well-being, there is little acknowledgement that they too may be suffering.”

The final message is that as long as there are health professionals who continue to deny that there is an impact associated with miscarriage, they “devalue the consumers they are employed to serve. It is well documented that grieving and stressed people simply do not have the emotional resources to complain. It needs to be remembered that women and their partners retain memories of the emotional care given at the time of their crisis, rather than the technical and medical care.”

In December 1993, *New Zealand Practice Nurse* published, ‘An unnatural order – death during pregnancy and early life’. Stanbridge, the author, herself a registered nurse, speaks with sincerity and compassion about this painful subject. The photos of dead babies are sobering, but bring with them the reality of the loss. It is a ‘how to behave appropriately’ for all nurses who come in to contact with a woman who is either threatening to miscarry, has miscarried, or needs an induced birth. Stanbridge’s honesty and clarity about how a nurse should behave are refreshing, “Expressing your feelings

does not imply lack of professional conduct.” Her awareness of the parents’ perspective is clear. “Parents in this situation may assume that health professionals are used to this situation. They may give disproportionate weight to what is said, and the way it is said to them. Choose your terminology with care – miscarriage rather than *abortion*, baby rather than *foetus* or *products*.”

At the time this article was written, a stillbirth was not considered as such until 28 weeks gestation. Even so, Stanbridge suggests the nurse, “Ask the parents for the baby’s name. Then you should always refer to the baby by name. It is important to the mother that her baby, at whatever gestation, is still a person.” She includes the importance of collecting ‘tangibles’ for the family, even with miscarriage. These might include photos; a lock of hair; hand or foot prints; a Plunket book with the baby’s measurements and name cards. The article finishes with the delicate subject of subsequent pregnancy and how the treatment surrounding the loss, specifically for the mother concerned, can have a significant impact on the next pregnancy. Included is a sidebar with recommended books.

Christian magazine *New Zealandia* published ‘Stillbirth: The hidden grief’, in April 1991. The article is worthy of inclusion despite its clear religious bias because it questions whether a church community offers support to those suffering the loss of a baby. The fact of the matter is that many people when faced with death and grief will examine their faith, whatever that faith may be. Mentioned is the positive way that the Maori culture acknowledges baby loss, and that more and more, people who are not Maori are emulating this type of practice. Unfortunately, for many people who face this peculiar and unique type of death, many faiths do not have a clear guideline as to how the church (in this case) should behave. Father McCabe, a Parish priest and former hospital chaplain, disclosed his observations. “The apparent lack of suitable response ties in with the legacy of the “silence” which so traditionally surrounded the death of a child by miscarriage or stillbirth.” This article is in-depth in both content and length. Included is a historical perspective of women and the church in relation to baby death; interviews with women who have experienced loss of this nature; academic research is cited, as well as quotes from spokespeople from a variety of support groups. Finally and significantly, it goes on to discuss the lack of acknowledgement in the wider community when baby loss occurs.

The last three articles reviewed all appeared in the *New Zealand Medical Journal* between March 1989 and May 1988. Of most significance was the 1988 article by a group of medical professionals practicing in Dunedin. ‘Use of classification of primary obstetric factors in perinatally related mortality surveillance’. At this time, the perinatal period was legally from 28 weeks gestation onward. Interestingly, the authors chose to focus on the period from 20 weeks onward, because “with modern neonatal intensive care making it not uncommon for babies born before 28 weeks gestation to survive.” This type of classification was the case at the Queen Mary Hospital in Dunedin from September 1982, well before the law caught up with technology. Included is a table of definitions and a table of classification of death. In this latter table, ‘spontaneous prematurity’ is the term used for women suffering a loss relating to immaturity. Also noted is the fact that had the study only included women whose babies died from 28 weeks gestation onward, “Only a third of those in the spontaneous prematurity group...would be considered perinatal deaths.”

The WHO (World Health Organisation) recommendations for 22 weeks gestation onward being considered a stillbirth is also discussed. Of relevance is also the acknowledgement that, “Multiple pregnancy was found to be associated with a third of all spontaneous prematurity deaths at the Queen Mary Hospital, all before 28 weeks gestation, and this highlights the need for more intensive early monitoring of twin pregnancies...in countries where its prevention has been a priority, encouraging results have been achieved, and should be an area for development in this country.”

All the articles reviewed appeared in academic journals targeted at specific groups of health professionals. Many of the themes and issues raised are the same as the issues raised by the support groups that drive the publicity apparent across mainstream media outlets.