

# Supporting long-term meaningful outcomes in stroke rehabilitation

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## Abstract

*Purpose of review*

Rehabilitation is the mainstay of recovery after stroke, but key recommendations focused on delivering ‘as much therapy as possible’ and stroke survivor outcome measures have remained relatively unchanged for decades. Traditional therapy approaches focus on maximum improvement of physical impairments while a stroke survivor is in hospital to ensure that community discharge can be deemed ‘safe’. This narrow approach sidelines the outcomes that are meaningful to the stroke survivor in the long term and the challenges they may face within their social context. In this article, we highlight the importance of the whole-person approach and review recent research introducing novel considerations to optimise outcomes after stroke.

### *Recent findings*

Psychosocial well-being is a major component of health but is poorly acknowledged and managed for stroke survivors. Evidence supports the use of self-management interventions, peer befriending, and culturally – responsive methods, including deep engagement with Indigenous and cultural knowledge. Cultural safety and involvement of a stroke survivor’s important personal connections are also vital for achieving truly person-centred care and equity in rehabilitation outcomes.

### *Summary*

Outcomes in rehabilitation will be optimised if we shift our mindsets from a sole focus on improving physical impairments to a broader scope of delivering whole-person care.

## **Introduction**

Rehabilitation has been described as the “process of enhancing well-being and attaining – or regaining – a meaningful life in the context of disease, illness, or impairment.”<sup>1</sup> It is a

complex process, with interactions between the person with stroke, clinicians, interventions, and the environment all contributing to outcomes. A key attribute of the rehabilitation process is person-centred, holistic care, framed in the biopsychosocial model of illness - the interaction between biological, psychological, and social factors.<sup>2,3</sup> Yet rehabilitation is only one component in supporting people to live well after stroke. Within this paper, we first provide an overview of current rehabilitation practice and outcomes before drawing on recent evidence to argue for a more expansive, person-centred approach to supporting people to live well after stroke. In highlighting the importance of psychosocial well-being and supported self-management, we propose that we need to expand our notions of what should be addressed in rehabilitation – and indeed, of who is important in supporting recovery and living well after stroke. Our critical commentary is underpinned by our expertise as stroke clinicians and academics who work to support people to live well after stroke in countries with a history of colonisation, such as Aotearoa New Zealand and Canada.

## **Current rehabilitation research and practice**

Current stroke rehabilitation guidelines focus on timing, dose, and delivery of specific therapies which are aimed at improving movement and communication outcomes.<sup>4-6</sup> The Australian New Zealand guidelines strongly recommend commencing out-of-bed activities within 48 hours and delivering “*as much scheduled therapy as possible.*”<sup>4</sup> They provide a weak recommendation for scheduling a minimum of three hours of physical therapy (occupational therapy and physiotherapy) per day and specify that at least two hours of this should be active, task-specific therapy.<sup>4</sup> Although there is limited evidence supporting this dosage and frequency, clinical teams strive to deliver this. Research suggests stroke survivors want more therapy with some reporting boredom and frustration in inpatient rehabilitation, when they have too much down time out of therapy sessions.<sup>7</sup> Although the evidence for ‘as much therapy as

possible' is limited, research with stroke survivors supports that there can be benefit in supporting people to engage in therapeutic, meaningful activities outside of therapy sessions. While the Australian New Zealand guidelines do not provide minimum recommendations for speech language therapy (SLT) treatment, a recent meta-analysis found that the greatest recovery of language is associated with frequent, functionally tailored, mixed expressive-receptive approaches for up to 50 hours total.<sup>8</sup> In addition to SLT treatment, prescribed home practice was identified as an important component of care. Therapy input becomes more challenging once people are discharged from hospital because resourcing of rehabilitation services is focused on delivering care in the acute and subacute phases rather than considering optimal timing based on patient need.<sup>9,10</sup> Longer-term, community-based rehabilitation is often restricted. In Aotearoa New Zealand, community stroke rehabilitation services are offered for a maximum of 6 or 12 weeks.<sup>11</sup> In addition to time-limited services, patients wait for many weeks before community rehabilitation begins, breaking momentum and negatively affecting recovery.<sup>12</sup>

Stroke rehabilitation services prioritise impairment and functional outcomes<sup>4,5</sup> driven by the intent to optimise recovery of impairments during the neuroplastic window.<sup>13-19</sup> The service-centric goal of 'safe' and efficient discharge from inpatient rehabilitation is also a key driver, leading to an orientation on activity limitations and related measures.<sup>20-23</sup> These outcomes are also important to people and families affected by stroke,<sup>24</sup> yet stroke affects a person in other ways, including, for example, social participation, and quality of life<sup>25-29</sup> as shown in Figure 1. We argue that existing guidelines and practice reflect a biomedically-oriented approach where the focus is on treating the impairment, with rehabilitation teams driving the rehabilitation process, raising questions about whether current rehabilitation practice has moved away from treating the 'whole person'.<sup>30</sup>

While the dominance of the biomedical model has been questioned,<sup>30,31</sup> and health professional education, professional competencies and rehabilitation guidelines increasingly call for broader models of care,<sup>32</sup> a focus on impairment and activity limitations in stroke rehabilitation persists. However, solely measuring impairment as an indicator for progress or ‘recovery’ is problematic. In recent years, a plethora of prediction tools have been developed with algorithms to improve prognostication following stroke.<sup>33–37</sup> Supporters of prediction tools contend that these tools have the potential to support personalised rehabilitation plans.<sup>35</sup> However, prediction tools also tend to be limited to predicting outcome at an impairment-based level and are focused on discrete outcomes (such as upper limb function). As such, how they are used, interpreted, and communicated needs careful consideration. There is risk in taking away one’s sense of possibility for the future, given the role that psychosocial resources, such as hope,<sup>38</sup> play in retaining engagement in the process of recovery and adaptation following stroke.<sup>10,25,39</sup> It is also possible that over-emphasis on these predictions, or interpreting the findings out of context, has the potential for deleterious effects on access to rehabilitation, which, by its nature, might be crucial in supporting to navigate life in the context of persistent impairments.

### **Refocusing on long term health and well-being for people following stroke**

For rehabilitation to have maximum benefit, clinicians and services need to utilise a whole person approach.<sup>40</sup> This requires a focus beyond impairments and function, to also support the person to look to what matters in life in the *long-term* beyond the specific episode of care and empowering the person to take charge of their own rehabilitation.<sup>30</sup> As such, this should prompt a rethink of what outcomes matter, and what outcomes need to be explicitly addressed in stroke services. Rehabilitation has become focused on what can be delivered within the time available, leading to clinician-centric goals and episodic care. The dominant

focus of communication in stroke care continues to be concentrated on short-term recovery and on the criteria that must be met before a person is discharged,<sup>21</sup> and can see clinicians abdicate responsibility for broader outcomes that they assume will be addressed by someone else in the continuum of care.<sup>23,41</sup> In essence, this focus on more immediate short-term outcomes means that rehabilitation services fail to invest in therapeutic activities which may also be critical for long-term health and well-being of people and families following stroke.<sup>42</sup>

One example of this is psychosocial well-being. This is increasingly recognised as an important outcome in stroke rehabilitation. Health professionals working in stroke care acknowledge the importance of psychosocial well-being, but report that physical well-being is often prioritised, in part due to organisational goals such as patient flow, productivity and efficiency.<sup>41</sup> People with stroke state that well-being is a hallmark of a good outcome after stroke, yet it remains poorly addressed by stroke services.<sup>41,43</sup> A recent review highlighted that post-stroke anxiety and depression each affect approximately 30% of people after stroke,<sup>44</sup> with these rates nearly doubled in people with aphasia.<sup>45</sup> Depression rates are consistent across the year post-stroke, while anxiety rates are higher in the 6-12 months post-stroke,<sup>44</sup> a time after many stroke-specific services have finished.<sup>11</sup> Psychological impacts, which include mood, coping, and self-efficacy, have been associated with poorer outcomes such as participation<sup>46</sup> and disability.<sup>47</sup> As such, addressing the psychological impacts of stroke is critical for supporting people to live well after stroke. Recent guidelines in Aotearoa New Zealand and Australia, Canada, and the United Kingdom all specify the need for proactive screening for all people with stroke, and assessment and intervention of mood disorders where indicated.<sup>6,42,48</sup>

However, psychosocial well-being extends beyond *psychological* well-being. Indeed, a wider concept of well-being is important for people's quality of life long-term.<sup>49</sup> This includes domains such as sense of identity, connections with cultural identity, autonomy, hope for the future, spirituality, and sense of purpose.<sup>49,50</sup> Understandings of well-being are culturally located and are commonly relational; as such, it is important to consider how well-being is understood for people and communities.<sup>49,51</sup> While the predominant approach to addressing psychosocial burden has focused on treating psychological disorders, taking a wider perspective to psychosocial well-being may reveal new ways to support well-being. It is not just the absence of negative psychological factors, but the presence of positive psychosocial factors that contribute to long-term well-being.<sup>52</sup> Thus, attending to how rehabilitation can explicitly support meaningful life outcomes, beyond our traditional focus on recovery of impairments and engagement in daily activities,<sup>21</sup> is critical in supporting *all* the outcomes that matter to people with stroke.

## **New approaches to rehabilitation**

New ways of providing rehabilitation have emerged in the literature in recent years. The following approaches are supported by a growing evidence base, which demonstrates their effectiveness in supporting people's engagement in meaningful activities after stroke. Examples and evidence supporting these approaches are summarised in Table 1.

**Supported Self-Management.** Historically, self-management in stroke referred to the tasks that are undertaken by a stroke survivor to live with stroke,<sup>53</sup> but more recent work has highlighted it extends beyond this, including managing medical and emotional needs and maintaining valued life roles.<sup>54</sup> Supported self-management recognises the role that health

professionals and the broader healthcare system play in supporting people to self-manage.<sup>55</sup> It is centred around a trusting, supportive relationship between clinician and stroke survivor, “characterised by mutual respect for each other’s knowledge, experience, and capabilities”.<sup>56</sup> Successful supported self-management programmes have been modelled on psychological theories, such as social cognition theory, self-efficacy, and self-determination theory. The Bridges Self-management programme is long-standing and has been used internationally with people with stroke and other health conditions.<sup>57</sup> It seeks to build self-efficacy through clinicians’ ways of working and engaging with patients – finding out what is important to people and using these to develop long-term aspirational goals and small steps that work toward these goals that are addressed in and out of rehabilitation. It aims to build confidence, develop patient reflection skills to help them see how their efforts contribute to progress, identifying and using real-world resources in the community to support recovery, and enhancing self-discovery through trying new things, problem-solving, and finding new ways of working.<sup>58</sup> A recent review article highlighted the growing evidence for Bridges in improving self-efficacy.<sup>58</sup>

More recently, Taking Charge After Stroke (Take Charge) was developed, framed by values important within Te Ao Māori\* to address the inequity of experiences and stroke outcomes for Māori and Pacific people in Aotearoa New Zealand.<sup>59</sup> Take Charge is a person-centred, talking therapy delivered by a trained facilitator, supported by a workbook that encourages exploration of identity, hopes, and fears, to establish a sense of purpose, autonomy, mastery, and connectedness with others. Two randomised controlled trials with Indigenous and non-Indigenous New Zealand stroke survivors (n = 580) showed that Take Charge consistently

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\*The Māori worldview

improved quality of life and social participation, and reduced dependence up to 12 months after stroke.<sup>59,60</sup>

What is common across different approaches to supported self-management is the central role of therapeutic relationships and supportive conversations. They support people with stroke to identify priorities and solutions beyond the stroke, engaging with things of personal meaning and value.<sup>61</sup> These practices can be in tension with short-term, discharge-oriented services, yet may offer significant benefits in supporting people's long-term well-being after stroke.

**Peer befriending.** Traditional approaches to rehabilitation are based on the clinician as the source of support and as key in enabling recovery. The value of stroke survivor-led innovations is often under-recognised. Peer befriending has been shown in feasibility studies to be an acceptable and effective mode of support for people with aphasia, something valued by both the peer support recipient and provider.<sup>62,63</sup> Stroke survivors involved in peer befriending have described that it builds interpersonal connections through a shared process of mutual encouragement, creates friendships, and addresses unmet needs.<sup>63</sup> Actively optimising social support may be preventative against clinical mood disorders<sup>64</sup> and can be important in supporting community integration.<sup>65</sup>

**New technology as modes of delivery.** Technology offers new ways of conceptualising *how* rehabilitation is provided. Telerehabilitation was quickly operationalised during the COVID-19 pandemic and has a role in improving access to rehabilitation for people with stroke in geographically isolated areas. Pre-pandemic, a systematic review found telerehabilitation to be non-inferior to in-person care, but studies were of low-moderate quality.<sup>66</sup> There is growing call that telerehabilitation should be considered as part of an integrated model of

care as an alternative resource to in-person approaches, that can be drawn upon depending on the person, their context, and what is right for them at that time.<sup>67-69</sup> It may not be appropriate for all stroke survivors, and further research to ensure that it does not create or exacerbate inequities is necessary, particularly for people who may not have digital access, or who have cognitive or communication difficulties. Similarly, virtual reality-based rehabilitation has been piloted in stroke rehabilitation, and evidence for efficacy compared with usual care is still exploratory.<sup>70,71</sup> Theoretically, its immersive nature may improve patient engagement, and simulation of real life may enhance functional and participatory skills practice. However, the use of virtual reality-based rehabilitation is limited by cost, cost-effectiveness, translatability, privacy, and other concerns.<sup>72</sup> Some stroke survivors show interest in engaging with digital health technologies as part of recovery, while others do not.<sup>73</sup> This requires clinicians to develop their knowledge and skills in the appropriate and engaging use of technology; it also requires structural supports and resourcing if rehabilitation is to meet patient expectations.

**Family-centred approaches to care.** Rehabilitation services commonly focus on the individual who has experienced the stroke. However, by not expanding our view from the stroke survivor to their wider circles of support, rehabilitation providers are likely to miss important opportunities to support stroke survivors to live well.<sup>74</sup> Many people with stroke receive significant support from family members and their role as supporters and people with expert knowledge of the person with stroke are important to integrate into rehabilitation, including in areas such as goal-setting and discharge planning. However, family-centred care goes beyond this. The well-being of family members is often impacted by stroke and changes to the family and carer role.<sup>49,75</sup> This suggests that stroke services need to view family as people who have been impacted by stroke who have their own unique needs. There is a

growing body of evidence on interventions to support family members; interventions that combine information provision, problem-solving, and psychoeducation appear to support carer resilience.<sup>76</sup>

**Attending to the social determinants of health and well-being.** It is important to consider *who* has the conditions to flourish and live well after stroke. Recent work outside stroke has called attention to the impacts of social determinants of health, including socioeconomic deprivation and racism, on physical and psychosocial well-being.<sup>77</sup> Post-stroke recovery may be impeded on these grounds. Socioeconomic and social determinants of health are risk factors for mental health conditions post-stroke<sup>44,64</sup> and a recent review of transitions in stroke care called for attention to social determinants of health in stroke care delivery.<sup>78</sup> To optimise outcomes after stroke requires us to look beyond individual stroke impacts and consider the wider contexts that surround and shape stroke survivors' lives. There has been work to unpack how social determinants may be addressed in stroke prevention.<sup>79</sup> While there is increasing awareness of the role of social determinants on rehabilitation access, experience, and outcomes, there is little guidance on how clinicians may address these.<sup>80,81</sup> If we are to achieve equity in experience and outcome, this may be an area where future research is required.

### **Culturally safe and appropriate rehabilitation practice and research**

Culturally safe and appropriate rehabilitation is a particular concern in colonised or majority world countries as traditional rehabilitation services are based on Western European principles of health, designed by and for people of European descent. As a result, in Western countries, Black, Indigenous, Hispanic, Asian, and underserved populations may experience

rehabilitation services that do not meet their cultural needs, that can be racist, and that can perpetuate existing inequities.<sup>82-85</sup> In this context, a lack of culturally safe service provision has been conceptualised as an intermediary determinant of health.<sup>86</sup> Post-stroke outcomes are consistently found to be worse for Indigenous peoples and other marginalised groups.<sup>87-90</sup> Research with Māori and Aboriginal communities (Indigenous peoples of Aotearoa New Zealand and Australia respectively) highlights that services in stroke and other cardiovascular conditions commonly disconnect people from the very things that support their well-being and recovery, including connection to land, to family and wider community networks, and to cultural resources and knowledge.<sup>84,91-93</sup> To better serve the needs of *all* stroke survivors and their family or whānau (Māori term for those within wider networks who the person with stroke considers important), a review of how rehabilitation services are delivered, by whom, and in what environments, is required.

There has been increasing focus on provision of culturally safe services, that is, practitioners, services and systems that critique taken-for-granted power structures, providing services that patients and communities define and experience as safe.<sup>94</sup> This contrasts with earlier models of cultural competence which focus on knowing about and “*being competent*” in other people’s cultures.<sup>94</sup> Cultural safety includes shifts in power from the health professionals as ‘experts’ to one where the strengths, expertise and experience of the person with stroke and their whānau are legitimised, valued and acted on.<sup>95</sup> However, this alone is insufficient. Fundamental change to structures and questioning what is privileged within stroke services is also needed. For instance, in Aotearoa, Māori researchers have called for the development of assessments and interventions, by Māori communities for Māori with stroke, based on Māori knowledge.<sup>82,96,97</sup> Māori impacted by stroke have called for whānau and communities impacted by stroke to hold *tinō rangatiratanga* (self-determination), generating community-

led and community-based solutions, and to receive the resources that enable them to do this.<sup>82</sup> Rethinking who provides services, how these are structured and how these are funded is required if we are to truly optimise outcomes and achieve equity.

Stroke rehabilitation research also needs to value culturally safe and appropriate practices. At a high level this includes critically reflecting on *who* is leading knowledge production, *how* knowledge is produced, and *what* forms of knowledge are legitimised and made to matter in stroke guidelines. Ideally, we need stroke rehabilitation research which centres the expertise and knowledge systems of researchers from the cultural groups likely to take part, benefit from, or be impacted by the research. Co-design approaches are increasingly used in stroke research. While these may often privilege majority perspectives, examples of partnership approaches are increasing.<sup>98</sup> One example is the Yarning Up After Stroke study in Australia. This uses the Take Charge<sup>59,60</sup> philosophy as a platform to build relationships with the Aboriginal and Torres Strait Islander communities in Gomeri/Kamilaroi/Gamilaroi Country, North-Eastern New South Wales.<sup>99</sup> The project team has significant Aboriginal membership, including people with lived experience of stroke, and emerging and experienced Aboriginal researchers, health workers, and Elders. Through this work they have co-designed a strengths-based, culturally informed conversation tool to support stroke recovery which will be piloted in a feasibility trial. We agree with Indigenous researchers that there is a need for more research led by and with those in Indigenous and marginalised communities. Indigenous-led research which centres the needs and aspirations of people in these communities and that values cultural ways of knowing which differ to dominant western knowledge paradigms will be necessary to more systematically address the inequities experienced by these groups currently.<sup>100</sup>

## Conclusions

To best support long term outcomes after stroke requires a radical shift in how we conceptualise and provide rehabilitation. Although the biopsychosocial model is recommended, the biomedical model of care is what we practically deliver. Not only does it disempower the stroke survivor by sidelining psychological needs, but it fails to account for the stroke survivor being situated within a wider context of family, community, and social environment. That we have remained within the biomedical model for so long may reflect the types of knowledge that have been historically prioritised. Other forms of knowledge, such as qualitative evidence, lived experience from stroke survivors, and Indigenous and culturally diverse ways of knowing, are legitimate forms of evidence that need to be incorporated into how we plan, fund, and provide care. In this review, we have outlined some specific priorities that need to be addressed to enable a paradigm shift in rehabilitation.

First, we must prioritise outcomes that are meaningful to people with stroke. We need to increase the visibility of those outcomes, to centre them in stroke and rehabilitation research and practice, and account for them in guidelines and policy. Second, we must advocate for including new approaches to rehabilitation: incorporating supported self-management, family-centred care, telerehabilitation, and providing access to and resource for interventions and approaches that extend beyond formal stroke services, such as peer befriending and Take Charge. Third, it is essential that rehabilitation of the stroke survivor acknowledges and responds to people's cultural context, level of health literacy, and the social determinants of health that impact them, to ensure that rehabilitation is culturally safe, meaningful, and effective. This may mean that rehabilitation is provided with and by communities, outside usual services and structures. Finally, to truly honour person-centred care and improve rehabilitation outcomes, the voices of stroke survivors need to be heard, understood, and

acted upon. We lay down a challenge for those who hold positions of power in funding and resourcing stroke services, and in determining what constitutes best practice evidence and practice guidelines to rethink what and who is prioritised in rehabilitation.

## **Disclosures**

VF was the lead author of the Take Charge intervention results paper. The authors declare that they have no competing or financial interests.

Table 1 – Novel approaches to improve stroke rehabilitation outcomes

Approach	Description	Evidence	References
Take Charge	Community-based, person-centred, talk therapy	Improved stroke survivor QOL <sup>†</sup> , social participation, dependence (mRS <sup>‡</sup> ) at 12 months after stroke	59–61,101,102
Bridges Programme	Provider-training driven programme, supportive coaching, appeals to intrinsic motivation of healthcare staff	Improved staff satisfaction, change in clinician mindset, increased integration of self-management strategies into care	57,103
Peer befriending	Supportive friendships with other PWLE <sup>§</sup> (s)	Peers providing insight, reclaiming self-sufficiency, understanding shared experiences of stroke	62,63
Culturally responsive methodologies	Deep engagement with Indigenous knowledge, world views, and PWLEs	Hui Process and Yarning Up After Stroke	98,99
Beyond the person with stroke	Carer / Family / Community – centred care	Information provision, problem-solving, psycho-education, addressing socio-economic determinants of health	76,78
Use of technology to deliver rehabilitation	Telerehabilitation Virtual reality	Promising and likely to have a role to play. Efficacy data still limited.	66,70,71

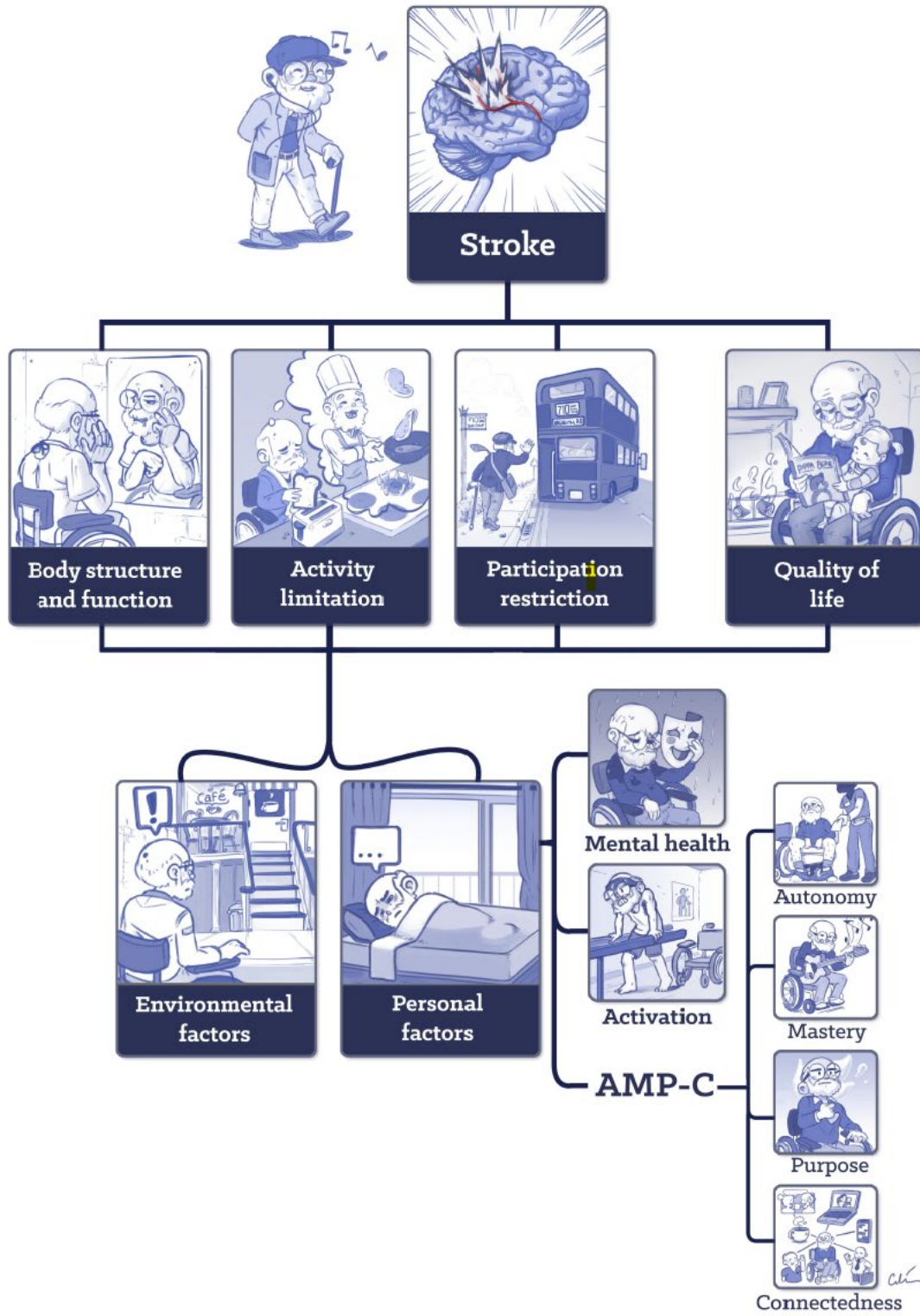
<sup>†</sup>QOL – quality of life

<sup>‡</sup> mRS – modified Rankin scale

<sup>§</sup> PWLE – person with lived experience

Figure 1. Stroke viewed within the World Health Organization International Classification of Functioning, Disability, and Health framework (*Original artwork by Dr Ciléin Kearns, Antibiotics. Reproduced with permission.*)

# The International Classification of Functioning, Disability, and Health (ICF)





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