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SUPPORTING WELL-BEING AFTER STROKE

A FRAMEWORK FOR CARE THAT SUPPORTS WELL-BEING

Contents

Introduction

> “How do you live with strokes, physically, mentally, spiritually? How do you do that? What tools are there to help us manage those aspects of stroke? What can you give us?”
>
> (Māori stroke survivor)

This quality framework is designed to support healthcare professionals and services to provide care that supports well-being after stroke. It is the result of a four year research project exploring well-being after stroke in Aotearoa New Zealand. It has been a privilege to learn from people with stroke, whānau and healthcare professionals as they reflected on their experiences.

I am particularly grateful to Rukingi Haupapa (Ngāti Whakaue, Te Arawa) for his guidance, advice and support throughout this research.

It is clear that well-being is a critical area commonly impacted by stroke, and it needs to be explicitly and proactively addressed within stroke services. Yet we have heard many instances of this not happening - often with significant ramifications for the person with stroke and their whānau. We have also heard that healthcare professionals want to be able to provide more support for well-being but often do not feel that this is seen as a priority within their services. They described wanting practical strategies to help them to feel more confident and competent in prioritising and supporting well-being.

Our research participants have generously shared their suggestions for how things can be different. The intent of this framework is to make these ways of working more visible so that healthcare professionals can reflect on what is currently happening and what needs to change. We also provide tangible suggestions for how well-being could be better supported by stroke systems, services, and healthcare professionals in the future.

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Background to the framework

Background to the framework

Well-being is important for living well and flourishing after stroke. However, a focus on well-being is not routinely integrated into stroke care, resulting in it being a leading area of unmet need following stroke (Stroke Association, 2015).

This framework was developed as part of the study "Psychosocial well-being after stroke: A study of care practices and processes in Aotearoa New Zealand". This study explored:

- How people experience well-being after stroke in Aotearoa New Zealand.
- How stroke care practices can influence well-being.
- How services and care might change to more consistently support well-being.

While stroke survivors and whānau in this research described some pivotal events in care that influenced their well-being, it became clear that well-being was influenced by a myriad of 'small moments and small actions' woven throughout their experience of stroke services. This framework aims to make these 'small moments and small actions' visible, and to illustrate how services could "do things different" as we were prompted by stroke survivor, Poihaere Morris (Ngāti Awa).

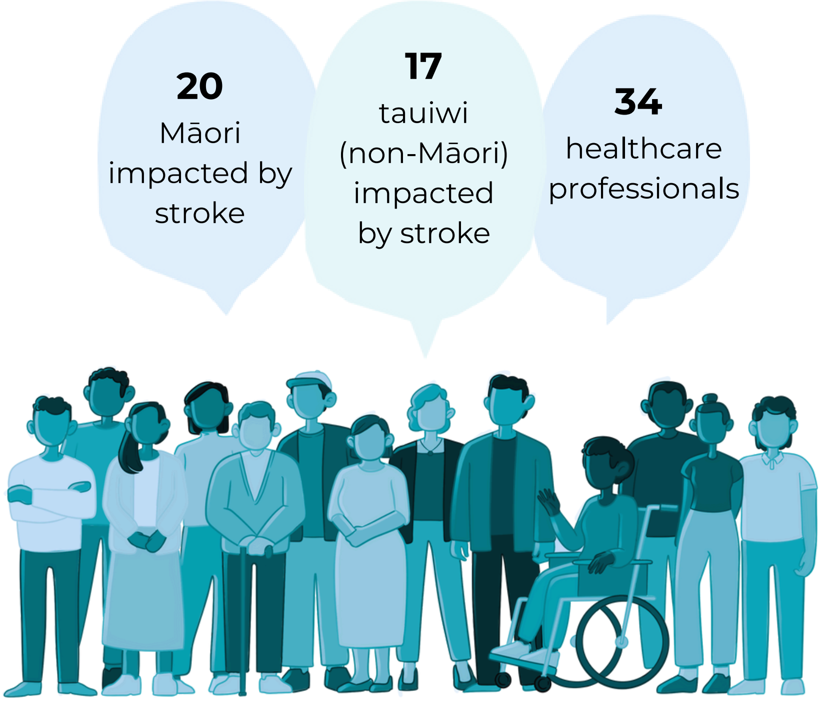
The framework aims to foster a proactive approach to supporting well-being after stroke, offering examples of actions that may be considered by policy makers, educators, service leaders, and individual healthcare professionals to prioritise well-being in stroke care.

Background to the framework

Thirty-seven stroke survivors and whānau from across the North Island of Aotearoa New Zealand contributed to this research. They generously shared their experiences of well-being, the impacts of stroke on well-being, and how their time in stroke services influenced their well-being both during care and beyond.

We explored key areas that were important for long-term well-being after stroke. We then traced back to people's experiences in stroke services and specifically looked at how people perceived that services facilitated or inhibited the areas important for well-being. This resulted in the development of eight domains of quality care that support well-being after stroke. These are centred in the experiences of stroke survivors and whānau.

In addition, we interviewed 34 health professionals and stroke service leaders. We draw on these interviews to provide illustrative examples of care that supports well-being throughout the framework. We also draw on these perspectives, along with literature, to describe factors that support health professionals to prioritise well-being in their practice.



Components of this framework

This framework provides an overview of the eight areas of care. Examples of actions that people with stroke, whānau, healthcare professionals, and the literature have suggested might be helpful are shared.

More detailed explanations of each of the eight areas can be accessed at https://cpcr.aut.ac.nz/findings/resources/wellbeing-after-stroke. We present each of the eight areas in standalone booklets. These contain a definition and description of each. Differences between care that supports well-being, and care that can be problematic are illustrated through descriptors, quotes and vignettes. Each of these is accompanied by prompt questions to support stroke teams and individual healthcare professionals to reflect on, and strengthen, current practice, and the suggested actions for improving care are repeated.

We have also developed a reflective process for stroke services and healthcare professions to consider how well-being is currently addressed in their service and areas for future development. Material for supporting this process can be accessed on our website; people are also welcome to contact us for support in the reflective process.

Who this framework is designed for

The quality framework is intended to assist stroke services and healthcare professionals working in stroke care to consistently support the well-being of people and whānau impacted by stroke. It is clear from our interviews with healthcare professionals that they can only provide comprehensive support for well-being when they have the skills, confidence, knowledge, and organisational support to prioritise well-being, when they themselves are experiencing a sense of well-being, and when they see well-being as a core component of their role as healthcare professionals.

This framework is for everyone who works in areas related to stroke care. This includes those who train healthcare professionals, professional regulators, funders and policy makers, service and organisational leaders, and healthcare professionals in all roles and disciplines.

Supporting well-being is everyone's business, not just the responsibility of an individual healthcare professional.

The quality framework is a living document. It will be further developed and refined over time with the feedback and input of people with stroke and whānau, healthcare professionals, stroke services and health system leaders.

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Well-being after stroke in Aotearoa

What is well-being?

‘Well-being’ is hard to define. The experience of well-being is different for each person, and can change over time. While well-being is unique to each person and whānau, there are key aspects that appear important. These include:

STRONG CONNECTIONS

Having strong connections with family, old friends and new friends who also had strokes, and a sense of reciprocity, helps provide a sense of belonging and well-being.

SITTING WITH THE UPS AND DOWNS

An ability to find a sense of balance, despite the ups and downs of life after stroke, underpins well-being.

FEELING LIKE ‘I’M ME’

Having a strong sense of self grounds people. This is helped through feelings of independence, choice and autonomy, and engagement in meaningful roles.

HOPE FOR THE FUTURE

Having a vision of a possible future, and a sense of moving toward this desirable future, gives people hope and purpose.

Whānau Māori expressions of well-being

ORANGA WAIRUA

In addition to the aspects outlined above, many whānau Māori described additional layers of of well-being. Some suggested the term ‘oranga wairua’ reflected appropriate kupu for talking about well-being.

WHANAUNGATANGA AND NGĀ HONO

A deep sense of connection, belonging and reciprocity, not only within whānau and community, but with places of meaning and with the spiritual world, supports well-being.

WAIRUA AND MANA

Having one’s mana acknowledged and upheld influences the sense of wairua and overall experience of well-being.

KO AHAU

Knowing oneself, and feeling connected to one’s identity as Māori, helped to ground people, foster resilience, and connect them with strengths that support well-being.

RANGATIRATANGA

When whānau had a sense of autonomy and control over their stroke recovery journey, this enhanced their personal and collective well-being.

The context of stroke care

> Nurses are doing [care] so fast. They're also trying to support their patient as much as they can and they just, all they can remember is the task that they've done or haven't done, and how that makes them feel like they haven't provided the best care for the patient. (Clinical nurse specialist)

Our research highlights that the ways in which healthcare professionals work is shaped by the practice context. This page reflects just some of the ways practice was influenced by different levels of the health system, as evident in the experiences shared by the participants in the research.

For healthcare professionals to provide robust, sustainable and high-quality support for well-being, they must be supported by systems, professions, and services that make it possible for them to work in these ways.

Health system
Western system, institutional racism, biomedical focus, hospital-centric

Stroke system (national and international)
National specifications, biomedical orientation, focus on acute care and physical function, evidence base and guidelines, increasing demand

Profession
Professional culture and identity, accreditation, tertiary curriculum, professional development, scope of practice

Stroke service
Culture and leadership, key performance indicators, documentation, service timelines, contracts, discharge criteria

Organisation
Culture and leadership, funding models, contractual requirements, mandate, staffing mix, staff resourcing and requirements

Healthcare professionals
Personal values, clinical skills and experiences, caseload, autonomy, confidence, professional identity, view of their role in well-being

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Domains of care that support well-being

Domains of care

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Care attends to people’s holistic well-being, in the present and for the future

Care supports people through uncertainty

People's uncertainty is acknowledged. People have the information they want and need, giving them a sense of control and hope about their future.

> When you've first had a stroke, you don't know what's happening, you don't know where you're going. It's a big unknown. (Person with stroke, Pākehā)

People and whānau experience great uncertainty and disruption following stroke. They need healthcare professionals to acknowledge and support them through this time. When this aspect of care is working well, healthcare professionals explicitly acknowledge the uncertainty people are feeling. They clearly and empathetically explain the stroke, its causes, and the care process, including what to expect next. They ensure ample opportunities for discussion with people with stroke and their support networks, allowing for questions. Instead of providing generic information, healthcare professionals focus on what is meaningful to the person and their whānau. They discuss the specific information and topics the person wants to explore, such as culturally relevant perspectives of stroke or future possibilities. Before leaving hospital people understand what to expect from post-discharge services, including contact timelines and details. Mechanisms are in place to help people understand and access available supports throughout their recovery. This approach to care supports people with stroke and whānau to feel a sense of stability and reassurance, to have greater control over their care and to look to the future.

Recommended actions

- Healthcare professionals introduce themselves and explain their role.
- Healthcare professionals acknowledge the huge disruption and uncertainty that stroke causes.
- Healthcare professionals explain what happened during the stroke and what might have caused it, in a way that makes sense to the person.
- People understand what is happening and why (e.g. the purpose of assessments and tests, and what the next step will be).
- People know what to expect each day, for example through timetables, staff continuity, and clear and regular information about their care plan.
- Ensure all the key people are included in conversations.
- Provide information that responds to the questions, priorities and life context of the person with stroke.
- People know what to expect from services once they get home, including when to expect contact and what this will involve.
- People have a contact point within the health service after discharge, and a phone or in-person check after formal services have finished.

Care supports people through uncertainty

“She [nurse] pretty much broke it down to me about what I had, showed me pictures, and explained to me how a stroke works… It doesn’t make any sense until someone explains it thoroughly and properly, it’s like ‘wow ok.’…It was only at that time I thought ‘oh ok…I know what’s happening’.”
Pacific person with stroke

“[Community therapists meet patients on the ward before their discharge home] and we sometimes will get them in to do the home visits with the patients.”
Allied health, Pākehā

"They [OT and PT] were fantastic, they were really good. A lot of the time our sessions went longer than they were meant to because we were just yakking about what had happened and what I could look at achieving at those sorts of things, and how the progress was going and things to look out for…"
Person with stroke, Pākehā

Care supports people through uncertainty

SYSTEM LEVEL ACTIONS

- Review funding and service delivery models to allow for access to services over time as the needs of people and whānau impacted by stroke change.
- Improve integration of health information systems to facilitate communication and referrals within and between services.
- Integrate training on challenging conversations into healthcare professional education (tertiary education and continuing professional development) including subjects such as: acknowledging and validating uncertainty, discussing recovery trajectories, and prognosis.

SERVICE LEVEL ACTIONS

- Introduce designated roles to ensure people with stroke and whānau have a central point of contact.
- Explore what a 'navigator' role might look like in your service context, and what resources and other factors would be required for implementation.
- Promote in-reach of downstream services to foster continuity of care.
- Provide a means of follow-up or contact for people after leaving services.
- Provide consistent staffing and timetables where possible.
- Explore opportunities for information sharing amongst stroke survivors and whānau.
- Ensure discharge summaries clearly outline what services or supports have been referred to, what the person or whānau can expect regarding follow up, and any recommended supports for the next service to explore with person and whānau.
- Develop stroke 'packs' containing culturally appropriate and accessible information that is shared in a variety of ways (eg: video, audio, written, pictorial), to be used as a tool to facilitate conversations about things that cause uncertainty. These may include stroke and its causes, impacts of stroke (emotional, social, spiritual), grief and losss, what to expect, and support options.

Care supports people through uncertainty

HEALTHCARE PROFESSIONAL ACTIONS

- Open each session or engagement by checking in, asking how the person is, prioritising time to listen and acknowledge what they say.
- Orientate and welcome the person with stroke and whānau to the service.
- Negotiate changes in care with the person with stroke and their whānau.
- View time sharing (and repeating) information as a valuable use of time in supporting that person's well-being.
- Document what has been shared so other healthcare professionals know and can follow up.
- Actively explore services available in the community and communicate regularly with them regarding referral processes.
- Connect people and families into the next service they will enter through a handover process, physically introducing the next healthcare professional who will work with them where possible. Allow time for whanaungatanga and answering questions.

Care fosters a sense of belonging and connection

People are comfortable in the physical environment of care, feeling welcome in therapeutic spaces that are designed for them. They are connected with others with stroke, building relationships with others like them, navigating similar experiences.

> The time in hospital, you actually kind of built up a whānau there. (Person with stroke, Māori)

A sense of belonging and connection appears invaluable for people with stroke. It involves a sense of physical belonging - where people are comfortable in the spaces of stroke care - and a sense of relational belonging - where people are connected with others like them, navigating similar experiences. When this aspect of care is working well services provide welcoming, comfortable and age-appropriate environments for people with stroke. Timely transfers to stroke specific care, and minimising the frequency with which people are moved between services can support a sense of belonging. Services offer people with stroke and whānau facilitated connections with others, for example through peer support or community groups, or simply through introductions on the ward. Connecting with other people with stroke can help people navigate life after stroke, support them to recognise their strengths, and help them maintain hope for the future. It can also provide an opportunity to support others, a critical component of well-being. Whānau Māori are offered connections with other whānau Māori. Services create space for people with stroke and whānau to draw on supports outside of formal services that provide a wider sense of connection and belonging that can last long-term.

Recommended actions

- Services provide a welcoming, age-appropriate environment for people with stroke.
- Staff welcome people and their whānau into comfortable and inviting therapeutic spaces.
- People see themselves reflected in the environment around them.
- Te ao Māori is reflected in the physical service environment and in care practices and processes.
- Healthcare professionals minimise the frequency with which people are moved between services.
- People are offered facilitated connections with others impacted by stroke, for example through peer support or community groups, or simply through introductions on the ward.
- Whānau Māori are offered a connection with other whānau.

Care fosters a sense of belonging and connection

"The community team ended up getting another one of their clients, because he was a young guy like my husband, similar stories, and they had their gym sessions together. And that was good for him because he needs to see people and it's always good for him to chat to someone that kind of understands, they've lived similar things, frustrations and that."
Family member, Pākehā

My mates from hospital. They're like whānau to me... Cause you know, we've been there...it made me feel like it's not just me...I'm one of the many."
Person with stroke, Māori

"It's lots of fun when we're together because we acknowledge each other's confusion sometimes, but we don't have to justify it. You know, we just sit there and crack up and laugh and it's fun and I think that's the healing part for me personally, so I don't have to justify and explain myself. That's the part that's really really healing."
Person with stroke, Māori

Care fosters a sense of belonging and connection

SYSTEM LEVEL ACTIONS

- Work with Māori to determine how whānau can feel a sense of connection and belonging when accessing healthcare.
- Review funding models to minimise inequities in service provision: (a) between people in different age groups, noting that there are significant differences in funding and care options depending on age which can result in a people feeling they are in services not designed for them, or be unable to access services, and (b) between people impacted by accidents vs health conditions.
- Increase availability of age appropriate, dignified supported living options for people of all age groups.

SERVICE LEVEL ACTIONS

- Consider how the name of the service conveys who is welcome in the service and who the service is designed for.
- Co-locate people of similar ages when in inpatient environments or group settings.
- When in services that are not specific to stroke, explore options for co-locating people with stroke.
- Ensure information about stroke and support services is visible and readily available.
- Provide access to interpreters.
- Help people know how the ward and/or service work so they can feel a sense of familiarity.
- Consider how the physical environment might provide opportunities for people with stroke and whānau to connect together, outside of clinical spaces such as therapy gyms or shared bedrooms.
- Explore opportunities to provide services in supportive environments, such as Marae, community spaces, or inviting, relaxed clinical spaces where appropriate.
- Offer or build relationships with Kaupapa Māori therapy programmes and services.
- Develop peer support programs for people and whānau impacted by stroke.
- Offer people with stroke resources that share the progress and journeys of other stroke survivors, for example through written or audio stories.
- Build connections with community organisations that may offer opportunities for connection with others with similar experiences beyond formal stroke services.
- Foster a sense of cohesion and belonging within the team.

Care fosters a sense of belonging and connection

HEALTHCARE PROFESSIONAL ACTIONS

- As healthcare professionals, consider how you welcome people into 'your' space of stroke services. Consider how you show manaakitanga, care that upholds the mana of everyone and extends the gift of hospitality.
- Introduce yourself and your colleagues to people and whānau so they feel welcome and know who different people are.
- If working in an inpatient setting, encourage people to bring personally meaningful items in to help them feel comfortable in the space.
- Offer introductions between people and whānau impacted by stroke in the service.
- In assessment and rehabilitation, draw on information and resources that reflect a diverse range of cultures and languages, appropriate for the people you work with.
- Get to know community service providers, organisations or groups in your area that might benefit people with stroke and whānau. Have their details available to pass on to people and whānau.
- Provide therapy in personally meaningful contexts where possible.

Care prioritises relationships and connecting ‘as people’

People feel known and understood as individuals. They feel they know their healthcare professionals, and feel a sense of safety and trust with them.

> The rehab assistant was different than everybody else… She treated everybody like people, she got to know people. She was charismatic and she had a great sense of humour, she knew everybody’s names. She wasn’t just there to do her job. She really went above and beyond. She just had the X factor, and she really cared. (Family member, Pākehā)

Relationships with healthcare professionals can significantly impact a person’s experience of care. When this aspect of care is working well healthcare professionals are empathetic and engaged, taking time to understand people and whānau by asking about their lives, interests, and what matters to them. Healthcare professionals use various communication methods including touch, tone, body language, and humour to convey empathy and connection. Conversations with healthcare professionals cover a wide range of topics, allowing them to gain a deeper understanding of the person and their whānau beyond the impacts of the stroke. Healthcare professionals also share of themselves, creating a personal connection rather than just a clinical one. Healthcare professionals create an environment where people feel comfortable reaching out anytime (including after discharge), by indicating they have time to answer questions, and providing people with a contact as they leave services. Positive interactions with healthcare professionals have a cumulative, uplifting effect on people with stroke, helping to build their self-belief.

Recommended actions

- Healthcare professionals get to know people by asking about their lives, interests and what matters to them.
- Healthcare professionals feel able to prioritise time building and sustaining relationships.
- Healthcare professionals share of themselves to help build a therapeutic connection.
- Healthcare professions are engaged and interested in the person, their life and their recovery.
- Conversations with healthcare professionals cover a range of topics, allowing them to gain a deeper understanding of the person and their whānau beyond the impacts of the stroke.
- Healthcare professionals provide flexible care in response to the person’s particular strengths and needs.
- People feel comfortable reaching out to healthcare professionals anytime, and are given a point of contact to make this easier.

Care prioritises relationships and connecting 'as people'

> "The therapist and I had quite a bit in common. She was a twin too. We'd talk about our sisters, and it was good like that because she was very positive, and she never put me down. Yeah so, I would say she had a big impact in my recovery of that depression."
> *Person with stroke, Pākehā*

> "The physio's strength became my strength."
> *Person with stroke, Pākehā*

> "There was just something about their relationship that I think helped him a lot. Like the specialist would acknowledge his capabilities and how it's a bit harder now, talked about his studies, yeah...she talked to him often quite personably, like personal conversation."
> *Family member, Māori*

Care prioritises relationships and connecting ‘as people’

SYSTEM LEVEL ACTIONS

- Integrate relationship-based care approaches throughout healthcare professional education at a tertiary level and as on-going professional development.
- Include relational competencies as core professional competencies.

SERVICE LEVEL ACTIONS

- Ensure service performance indicators are flexible, allowing healthcare professionals to prioritise relationship building and responding to the needs of people with stroke and whānau.
- Explore how your service could recognise and encourage ‘caring conversations’ that healthcare professionals have with people and whānau - for example through caseload allocation, factoring psychosocial needs into staffing models, messaging and role modelling by senior staff.
- Consider ‘easy’ ways to help build connections. This might be staff photos and names on the wall of the ward, an information sheet about the staff which includes their name, a photo and 1-2 sentences about the person.
- Consider how the relational work of healthcare professionals is captured in documentation. Are there opportunities to encourage this?
- Support staff to develop their relational skills through professional development opportunities, mentoring and supervision.
- Provide staff with training opportunities in supported communication to ensure positive engagement with people with communication impairment.
- Provide people with a contact as they leave the service should they have any questions in the future.

Care prioritises relationships and connecting ‘as people’

HEALTHCARE PROFESSIONAL ACTIONS

- Prioritise time for whanaungatanga with people with stroke and their whanau and friends.
- Share something of yourself to create reciprocal relationships with people and whānau impacted by stroke.
- Reflect on how you interact with people. How do you show that you are interested in the person and invested in their recovery?
- Use a range of communication techniques when engaging with people to help them feel comfortable. These may include empathetic touch, tone, body language and humour.
- Recognise that relationship-building is helped by small actions like saying hello and making eye contact, sitting down when you’re talking to someone, threading a little bit of ‘small talk’ through interactions, and acknowledgeing common interests or other points of commonality.
- Maintain an ‘open-door policy’ where possible to signal that people and whānau are welcome to reach out to you.
- Seek out training or mentoring in supported communication techniques to help you feel confident engaging with people with communication impairment.

Care attends to the emotional impacts of stroke

People feel heard and supported as they navigate the emotional impacts of stroke.

> The nurse picked up on how my husband was feeling and was always available for a chat. (Family member, Pākehā)

The emotional impacts of stroke are common. Many people described deep distress during their time in care. People need healthcare professionals to attune to their emotional experience. When this aspect of care is working well, healthcare professionals recognise that stroke commonly has significant emotional impacts and are attentive to the emotional responses of people affected by stroke and their whānau and friends. Healthcare professionals intentionally provide opportunities for people to express their feelings if they wish to do so. This is helped when healthcare professionals show genuine interest and availability through unhurried, empathetic interactions. They talk to people about the emotional impacts of stroke and the fact they are common, but also validate the person's experience without minimising it. People and whānau impacted by stroke receive psychologically informed care. This includes access to culturally safe counselling or psychological support if they choose. People are encouraged to access cultural supports from outside stroke services if they feel this would be beneficial. This approach to care helps people to feel heard and supported as they navigate the emotional impacts of stroke.

Recommended actions

- The emotional impacts of stroke are proactively talked about so people don’t feel they are the only ones feeling this way.
- Healthcare professionals ask how people are feeling, and what they feel would be most helpful for their emotional well-being.
- Healthcare professionals explicitly take time to listen to people and validate, but not minimise, their experience.
- Healthcare professionals are unhurried, and empathetic in the way they engage.
- People and whānau are offered access to social work and psychology support.
- Emotional care is culturally safe, including the offer of culturally grounded counselling and supports.
- Healthcare professionals support people to access the emotional support they need, including from outside of formal stroke services when needed.
- Healthcare professionals have the knowledge and skills to support people through difficult emotions, and the confidence and willingness to have emotionally challenging conversations.
- Healthcare professionals recognise that emotional well-being is not distinct from physical well-being.
- Healthcare professionals understand that emotional well-being is more than the absence of anxiety and depression.
- Healthcare professionals recognise that for many whānau Māori, emotional well-being incorporates attention to wairua (spiritual well-being) and hinengaro (mental well-being).

Care attends to the emotional impacts of stroke

“The nurse just spent a lot of the night with me. I really was disturbed, couldn’t sleep and I was restless, and she just was there, and then she’d say, ‘look you’re not comfortable, how about you sit on the side of the bed for a while?’…And she wasn’t in a hurry. It was as if ‘well no one else needs me, I’m here to help you’, you know?”
Person with stroke, Pākehā

“The nurse picked up on how the person was feeling and were always available for a chat.”
Family member, Pākehā

"It’s good talking to the psychologist, I find… If I talk about stuff and get it off my mind that normally eases my mind – I don’t think about it all the time."
Man with stroke, Pākehā

Care attends to the emotional impacts of stroke

SYSTEM LEVEL ACTIONS

- Challenge how the mind and body are separated in stroke care processes, including building care pathways between mental health and physical health services.
- Build healthcare professional skills and competence in addressing emotional impacts of illness through including these in healthcare professional education, professional development and accreditation standards.
- Utilise existing clinical networks to provide psychological training and mentoring support across services.
- Consider how specialist roles can be created to work across services and districts to provide support for healthcare professionals.
- Build skills and competence in working with the emotional impacts of stroke in professionals outside stroke services. This includes developing providers' skills in working with people with cognitive and communication disorders and ensuring services for those with limited English and from different cultural needs and perspectives.
- Factor emotional and psychological needs and complexity into staffing and workload models.

Care attends to the emotional impacts of stroke

SERVICE LEVEL ACTIONS

- Develop resources about common emotional impacts of stroke so people don't feel alone in their experience.
- Build healthcare professional skills and confidence in attending to emotional impacts of stroke through access to professional development opportunities.
- Offer a range of supports for the emotional well-being of staff such as professional supervision, debrief or mentoring opportunities, and access to the Employee Assistance Programme.
- Explicitly integrate emotional well-being into clinical care pathways and documentation requirements. This may include aphasia-friendly well-being screens.
- Allow protected time for social workers to provide grief counselling and emotional support within their role.
- Review the stepped care model of psychological care. Identify the current strengths and gaps in your service.
- Ensure that as a team healthcare professionals are having conversations with people and whānau about how they are feeling, and that these go below the level of "How are you feeling?" to "Why is it that you're feeling that way?"
- Share information about the person's emotions in documentation and team meetings.
- Consider who, within the team, is able to provide emotional support for the person.
- Recognise that people who have pre-existing mental health challenges are more at risk of post-stroke psychological issues. Proactively monitor and support.
- Identify cultural services in your locality that may be able to provide culturally informed emotional support for people.
- Have private spaces available within your service where people and whānau feel able to raise well-being issues.

Care attends to the emotional impacts of stroke

HEALTHCARE PROFESSIONAL ACTIONS

- Recognise the value of supporting people's emotional needs. This can be as simple as asking how they are feeling and acknowledging their response. Sometimes this requires a longer time.
- Build time to 'check in' with your patient into your interactions.
- Reflect on the psychological safety a person may feel in their interactions with you. If not with you, are there some healthcare professionals who the person has a stronger relationship with?
- When people are sharing how they are feeling, acknowledge and validate this (e.g. "I hear you're feeling really upset. That must be really hard".) While it can be helpful to normalise this and let people know it is common, it is important that you also validate what that individual person is feeling and sharing.
- Ask about the things that support people's well-being in life beyond stroke. What are the things that usually help them feel grounded, that might give them a sense of peace, or that bring them joy? Work to explicitly ensure that there is space for those things and those people and places within their recovery journey.
- Introduce yourself to cultural support teams in your organisation and learn about their work.
- Consider what training and support you need to support people's emotional well-being. Build this into your professional development plans.

Domain Five

Care centres people’s preferences and enables them to have choice and control

People’s knowledge and perspectives are sought and respected. They have control and autonomy throughout their recovery.

> The staff were all engaged, they would ask, and they would listen to the answer I gave. (Person with stroke, Pākehā)

People and whānau are the experts in their lives and must be seen as a partner in their care. They hold important knowledge about what will be best for them. When this aspect of care is working well, healthcare professionals actively seek their perspectives. People are asked about what matters to them and what they want to see happen in their care. Healthcare professionals integrate this together with their stroke-specific knowledge in care planning. Care feels like a process of shared problem-solving about what will work best for the person and their whānau, with healthcare professionals acknowledging the effort and problem-solving that people put into their recovery. As people’s abilities change, their desire for greater control over day-to-day activities may also change. Healthcare professionals respond to this, for example by ensuring people can practice tasks, undertake personal care or go outside as and when they choose. Throughout care, healthcare professionals share different options and help people choose what will work best for them. Services are flexible and available at times that suit the person and their whānau. Healthcare professionals and services honour the fundamental right of whānau Māori to determine their healthcare journey and their stroke recovery. This approach to care supports people with stroke and whānau to have a greater sense of control and autonomy throughout their recovery.

Recommended actions

- People are asked their perspectives about what they would like to happen in their care.
- Healthcare professionals listen to and respect their perspectives.
- Healthcare professionals acknowledge the effort and problem-solving that people put into their recovery.
- Healthcare professionals share options with them, and to collaborate with the person and their whānau about what will work best for them.
- Healthcare professionals help people to feel comfortable asking questions and discussing their care needs and preferences.
- Healthcare professionals explore with whānau Māori how care can align with areas of meaning for them.
- Healthcare professionals act on what they have discussed - people can see that the team are true to their word.
- When a person's wishes cannot be upheld, alternative options are discussed together.
- Staff encourage people to challenge themselves.
- Healthcare professionals are responsive to people's changing abilities and desire for autonomy.

Care centres people’s preferences and enables them to have choice and control

“If you asked for something, you noticed she actually did it...Like a lot of people listen to you and go away and say they’ll do something and nothing ever happens...”
Person with stroke, Pākehā

“The physio at home really helped me by asking ‘what is most important for you each day?’”
Person with stroke, Pākehā

What I really liked about the community team, it’s all about...like coming home and doing stuff and you know, it’s like, ‘okay what is it that we can help you figure out how to do?’"
Person with stroke, Pākehā

Care centres people’s preferences and enables them to have choice and control

SYSTEM LEVEL ACTIONS

- Review funding and service delivery models to allow for more flexible provision of services. For example, is there scope for some services to be offered at different times that better meet stroke survivor and whānau preferences?
- Challenge the notion of healthcare professional as ‘expert’ within healthcare professional education, and place greater emphasis on person centred care.
- Embed the perspectives of people with lived experience into system planning and tertiary education programmes.
- Prioritise funding models that support people’s autonomy and ability to have choice and control, and access to activities and supports that are meaningful.

SERVICE LEVEL ACTIONS

- Offer people greater choice in when and how they access stroke services.
- Ensure flexibility of service performance indicators, such as timeframes for completion of formal assessments, to allow healthcare professionals to explore people’s priorities and their needs.
- Develop healthcare professionals’ skills in communicating empathetically when the preferences of a person or whānau cannot be met. This should include exploring alternative options with them.
- Review goal setting and interdisciplinary team meeting processes to ensure they reflect the perspectives and aspirations of the person and whānau.
- Structure family meetings to ensure the perspectives of the person with stroke and their whānau are prioritised. Create an environment where people and whānau can share their thoughts and ask questions in these meetings.
- Co-design service initiatives with current and/or former patients and whānau to ensure their perspectives inform future service delivery.

Care centres people's preferences and enables them to have choice and control

HEALTHCARE PROFESSIONAL ACTIONS

- Ask what matters to people with stroke and whānau, and what they want to see happen in their care. Integrate this throughout care, and revisit the conversation over time.
- Share different care and support options with people and whānau, and have a conversation about what they think would work best for them.
- Ask whānau Māori how care can align with areas of meaning for them. For some this may involve integration of te reo Māori, access to cultural support, or the freedom to draw on support from outside the health system (for example, connecting with a particular place, with wider whānau, or traditional healing practices).
- Always act on the things you have talked about with the person with stroke and their whānau.
- Share what you learn about the perspectives of people and whānau, and what matters to them, with the team. This could be through documentation, within team meetings, or during informal conversations with colleagues.
- When it is not possible to uphold the wishes of a person or whānau, have a conversation to try to find an alternative.
- Reflect on the ways you currently seek a person's perspectives, for example, through goal-setting. Do these help you to understand what is most important for the person and their whānau? Do they prioritise clinical needs?
- Foster opportunities for people to practice independence. For example, are there opportunities to walk independently to the dining room, or to go outside? This may require 'supported risk-taking' in care.
- Learn about options that give people and whānau greater control over care into the future, for example individualised funding or paid family carer support.

Care honours Māori knowledges and practices

Māori knowledges and practices are recognised, valued, and supported within stroke services.

> You know what you were before stroke. You still belong to your own iwi, your own reo, your own tikanga, your everything. (*Person with stroke, Māori*)

Māori perspectives of well-being interweave holistic elements that reflect the 'whole' person and extend beyond the physical. Māori impacted by stroke spoke of wairua and reciprocal connections that supported their well-being which were unique and varied. These included a sense of connection and belonging within whānau and community, cultural identity, whakapapa (geneology), engagement with te ao Māori (the Māori world) and te taiao (the natural world). Interwoven connections supported a strong sense of self and autonomy which could anchor people as they navigated life after stroke. Whānau need culturally responsive care where services recognise elements of well-being important to them, including engaging in cultural practices or te ao Māori. When this aspect of care is working well, whanaungatanga is prioritised and Māori worldviews, knowledges and practices (tikanga) are upheld, including within information and resources. When whānau Māori have space and autonomy to be 'themselves' and determine their health and well-being journey(s), their mana is upheld and they feel listened to, understood and respected. Service providers understand that key supports for Māori may come from outside of formal services, including connections with other whānau.

Recommended actions

- Healthcare professionals prioritise space and time for whanaungatanga.
- Service processes prioritise time for whanaungatanga.
- People are able to connect with what is meaningful for them, which for some may include whānau and community, cultural identity, whakapapa (genealogy), te ao Māori (the Māori world) and te taiao (the natural world).
- Healthcare professionals ask people about what is important to them and what they want to happen in their care, and support their choices.
- Information and resources reflect Māori experiences and worldviews.
- Healthcare professionals and stroke services uphold Māori worldviews, knowledges, language, and practices (tikanga).
- People are offered connections with other Māori within care.
- Healthcare professionals and services recognise their own cultural perspectives and how these might influence care
- Healthcare professionals support people to access other sources of support in care if they choose to, including from outside of formal services where desired (for example through rongoā, whānau and community).
- People can access services at the right time for themselves and their whānau.

Care honours Māori knowledges and practices

“We start and finish with karakia, whanaungatanga, then we tell them about who we are and what we’ve experienced as a stroke survivor. Then we’ll get them to share their experiences…And before the end are their goal setting and that’s when I’ll be talking to them about tinana, hinengaro and wairua and I say ‘now, you need to have goals for all of them’ because the support has to be balanced.”
Kaupapa Māori community organisation

“She was a kapa haka teacher. So, I said ‘why can’t we use the kapa haka part of her activity?’ So, the therapists started using that and she started to respond. That was more productive for this nanny than trying to do a board game or look at different words. We’ve done that with various cultural parts – weaving, another person was into arts. So, it was tapping into that activity that they’ve been doing for many, many years.”
Allied health, Māori

“We’re always telling our stories and the more that I do, I found that the less I will cry and be emotional and then I can see the real facts from what’s going on in my heart and the Kaupapa Māori group allows us to do that because we continue to always talk about our stories.”
Wahine Māori with stroke

Care honours Māori knowledges and practices

SYSTEM LEVEL ACTIONS

- Uphold Te Tiriti o Waitangi and honour the fundamental right of Māori to self-determination at all levels of the health system.
- Ensure healthcare professional education respects and supports tikanga being upheld.
- Create meaningful pathways for Māori into healthcare professions.
- Ensure safe education and work environments where Māori can be Māori.
- Ensure healthcare professional competency frameworks, discipline specific assessment frameworks and clinical guidelines are culturally located in Aotearoa New Zealand (Eustace et al., 2023).
- Ensure stroke services are designed with and by Māori.

SERVICE LEVEL ACTIONS

- Maintain an explicit focus on the service's responsibilities under Te Tiriti o Waitangi.
- Build genuine relationship with Mana Whenua.
- Consider how Māori have been involved in the design and delivery of your service. Does anything need to change to make this more possible?
- Undertake regular critical review of the cultural safety of the service.
- Connect with local Hauora Māori services, dedicate time to building relationship and explore ways of working together.
- Explore opportunities for Kaupapa Māori therapy programmes, and what would be required to implement these. The first step may involve building relationships with partners.
- Integrate regular cultural safety training, supervision and professional development as a requirement of employment.
- Provide welcoming physical spaces for whānau to gather close to the person with stroke, and to engage in therapeutic activities together.
- Have interpreters readily available, incluing in te reo Māori.
- Seek resources that are designed by and for Māori.
- Provide services that work for whānau by ensuring flexibility in service processes.
- Recognise traditional ways of healing as legitimate and important for people and whānau to access should they choose.

Care honours Māori knowledges and practices

HEALTHCARE PROFESSIONAL ACTIONS

- Reflect on your own cultural perspectives and worldview. How might these influence the care you provide?
- Recognise the importance of whanaungatanga. Prioritise time to get to know people and whānau, and share something of yourself.
- Don’t assume what people and whānau want or need – ask each person and whānau how they want to work together in the care journey and what they would find supportive of their well-being. Revisit this conversation throughout care to ensure you understand whānau perspectives and can best support them in the ways that they choose.
- Integrate the Hui Process into care practices (Lacey et al., 2011).
- Seek out cultural support teams in your organisation and introduce yourself. Get to know them and what they do, and how they wish to work with stroke services.
- Read and listen to Māori discussing their experiences of healthcare and stroke services.
- Use culturally appropriate assessment, therapy and care resources.
- Offer people with stroke and whānau connections to other whānau impacted by stroke.

Care responds to the strengths and needs of whānau and friends

People remain connected within their support networks. People in these networks are equipped to provide long-term support.

> When we engage with whānau, don’t make assumptions. Look, listen, see. Then try and figure out what strengths are there within this whānau… Let’s focus on what is shining. (Peron with stroke, Māori)

Whānau and friends play a crucial role in the recovery of a person with stroke, and are a source of well-being, offering practical, emotional and cultural support. They also bring deep knowledge of the person with stroke. Whānau need to be recognised as an integral part of the team, while also having their experience and needs understood and supported. When this aspect of care is working well, whānau are warmly welcomed by healthcare professionals who introduce themselves, maintain regular contact, and keep an 'open door' policy. Healthcare professionals learn who the key whānau members or friends are, and recognise and respect their knowledge and perspectives. Healthcare professionals enquire about what is important to whānau or friends, what supports they need, and how they would like to be involved in the care process (to the extent agreed by the person with stroke). Services are equipped to meet both the immediate and future needs of whānau. There are comfortable spaces provided for whānau to gather and spend time together. This approach to care helps people remain connected within their support networks - a key feature of well-being.

Recommended actions

- Healthcare professionals introduce themselves and make whānau and friends feel welcome in the service.
- Healthcare professionals ask who the key whānau members and friends are, and don't make assumptions.
- In agreement with the person with stroke, whānau and friends are asked how they want to be involved in the person's care, and what supports they need themselves to feel supported in both their immediate needs, and as they look to the future.
- Healthcare professionals support whānau and friends to understand what the person with stroke is experiencing.
- Healthcare professionals include whānau and friends in information sharing and decision-making, as agreed is appropriate.
- Healthcare professionals welcome whānau and friends in therapy and ward activities, as agreed with the person with stroke.
- Healthcare professionals are attuned to whānau and what they might be experiencing, and work to listen to and address their concerns.
- Whānau feel welcome, prepared for, and listened to, in family meetings. These are a genuine two-way conversation.
- There are spaces for whānau to be together in inpatient settings.
- A navigator is available to walk alongside whānau for as long as needed – as a point of contact, an advocate, a source of information and a guide to accessing services at each stage of care.

Care supports the strengths and needs of whānau and friends

“Once dad was out of the immediate danger zone, we felt he needed to be back in his own environment...he didn’t know where he was, it was really foreign. So, for us to get him home, so long as it was safe, we thought was best for him...He had a wonderful specialist...he was amazing and he agreed with that plan and we took him home.”
Whānau member, Māori

"I would always be able to ask questions and bring things up and they were always very forthcoming. And one day, I can’t remember what it was, something had really upset me and the OT picked up on that straight away and asked me what was wrong and talked me through...I felt like I could ask her anything.”
Family member, Pākehā

"I always work with whānau – okay, what is it that you want to look at, what are the main things you want to bring across, what are your thoughts about where you want to be and what your goals are? What do you think would need to happen for you to feel comfortable that your whānau’s being looked after for you to feel comfortable to remain here as a patient and continue getting rehab?"
Allied health, Māori

Care responds to the strengths and needs of whānau and friends

SYSTEM LEVEL ACTIONS

- Resource services to support whānau and friends, both in their immediate needs and as they look to the future.
- Simplify access to individualised funding and paid family carer schemes to give people and whānau more control over their care needs.
- Consider how stroke systems might reframe stroke from primarily being an acute medical event to a long-term condition that impacts an individual and the collective around them.

SERVICE LEVEL ACTIONS

- Offer space for whānau members to stay on the ward where possible and appropriate.
- Offer a navigator to walk alongside whānau for as long as needed, as a point of contact, an advocate, a source of information and a guide to accessing services at each stage of care.
- Develop information resources that respond to common queries and concerns of whānau.
- Ensure there are discussions about caring responsibilities. This should include discussing the expectations, their support and training needs, and carer relief and well-being.
- Set up family meetings for success by ensuring the person with stroke and their whānau know what to expect, can contribute to how the meeting will run, what topics will be discussed, and who will attend. Critically consider the power dynamics in play. This might mean fewer healthcare professionals are present, or meetings are held in neutral spaces. The person with stroke and whānau should have ample time to ask questions and raise their own points for discussion. Family meeting documentation requirements that prioritise person and whānau goals, perspectives and preferences may support this process.
- Ensure clinical assessments, documentation and discharge summaries explicitly incorporate the strengths, perspectives and needs of whānau and friends (where appropriate).
- Provide information about whānau support services during the episode of care and in the discharge summary.

Care responds to the strengths and needs of whānau and friends

HEALTHCARE PROFESSIONAL ACTIONS

- Introduce yourself to whānau and friends and welcome them into care.
- Get to know the person with stroke and their whānau, and find out about their lives outside of care. Recognise that whānau often know the person with stroke best, and have important perspectives to offer. However, also recognise that each whānau is unique. Don't make assumptions about the roles and dynamics of a whānau. Rather, get to know them, and where possible, ask the person with stroke how they want whānau to be involved in their care.
- Discuss with whānau or other close supports how they may be involved in care, and what information or support they may need themselves.
- Ensure whānau and friends have a key contact within the service who engages with them regularly.
- Where appropriate, invite and engage with whānau and friends in therapy or care activities.
- Share information with whānau regularly, and include them in decision-making (to the extent agreed by the person with stroke).
- Help whānau members to understand what the person with stroke is experiencing and the stroke recovery journey, and how they as whānau can provide support.
- Check in on the well-being of whānau members throughout care, and connect them with support where possible. This might include offering a facilitated connection with other whānau for peer support, involving social work in their care, or exploring options for community-based supports (e.g. primary care providers, iwi providers).

Care attends to people's holistic well-being, in the present and for the future

People are connected to, and engaged with the people, places, and areas of meaning and importance that sustain their well-being beyond stroke services.

> It takes conversation, it takes recognition of who you are, where you're from and all those things are incorporated into the way you think and do things. (Person with stroke, Māori)

Well-being is fostered when people can connect with areas of meaning and importance to them. People with stroke need to be seen in the wider context of their lives and supported to (re)connect with the things that sustain their well-being beyond the timeframes of services. When this aspect of care is working well, healthcare professionals recognise that long-term well-being has many aspects. It is supported by relationships. It is grounded in a sense of identity, where people feel connected to who they are, and to areas of meaning in life. Healthcare professionals know what helps each individual's long-term well-being and integrate these areas into a person's care plan early - not waiting until the person has physically recovered. Healthcare professionals actively support people to engage in activities, roles, relationships, cultural practices and social contexts that support their well-being, and that will continue to support their well-being long after services have finished.

Recommended actions

- Healthcare professionals find out what helps a person’s well-being, including what has supported their well-being in the past.
- Staff actively support people to engage in activities, roles, relationships and social contexts that support their well-being
- People are encouraged, and supported, to draw on supports for holistic well-being that are meaningful to them, including supports from outside formal services such as cultural and spiritual supports.
- Care is holistic, focusing on what supports people to be and stay well in themselves.
- Care brings in the wider aspects of people’s lives that are important for their well-being, for example social connection and community integration, rather than focusing only on the physical impacts of stroke.
- Well-being is evident within care plans.
- Goal-setting processes reflect areas that matter for people’s well-being. Healthcare professionals are able to connect the activities to the areas that matter for well-being. People are supported to connect the progress they’re making with the things that matter to them for their long-term well-being.

Care attends to people's holistic well-being, in the present and for the future

"It's just tolerance for stuff like 'this man's not coping today. Look that's absolutely fine, and that's really normal, let's awhi him more today. And what can we do to awhi him? What does that look like?' Like a patient who's had a dense stroke. Her cat came in yesterday. For her that's critical. That's all that she wants, you know?"
Nurse manager, Pākehā

"The manager lady she came and talked to me once and because she knew I was a teacher, the Catholic school was on the corner so she offered if I would come and be a teacher aide."
Person with stroke, Māori

"I encourage therapy to think outside the box. It's not always just medical and psychological, it's about whānau, skin on skin, reconnecting ...It's about feeling connected, feeling loved, feeling accepted, even though my body's like this".
Allied health, Māori

Care attends to people's holistic well-being, in the present and for the future

SYSTEM LEVEL ACTIONS

- Create national stroke service quality indicators that relate to the long-term well-being of people with stroke and their whānau.
- Interrogate the use of deficit-orientated framing in healthcare professional education.
- Fund community-based services that provide support beyond the first three months after stroke.

SERVICE LEVEL ACTIONS

- Explore goal setting processes that start with the person - their personality and priorities - rather than clinical or service priorities and intentions.
- Integrate aspects of long-term well-being into care (e.g. actively working on community integration, supporting friends to learn more about staying connected with people with cognitive and/or communication needs).
- Integrate well-being related questions and space for comments into clinical assessment tools and discharge summaries.
- Draw on culturally-informed models of health and well-being in service processes. This could include structuring ward rounds, family meetings, and clinical documentation around such frameworks.
- Identify who provides vocational rehabilitation in your locality and make early referrals.
- Establish relationships with local cultural, spiritual and community groups and service providers.
- Identify how service processes can detract from, or support a focus on long-term well-being. Consider how these could be modified to support staff to address long-term needs.

Care attends to people's holistic well-being, in the present and for the future

HEALTHCARE PROFESSIONAL ACTIONS

- Get to know people by asking about what is going on in their lives outside of care. Who and what is important to the person? These are ongoing conversations that you may like to return to often.
- Ask people what has supported their well-being in the past and draw on this in care.
- Help people connect with people, places and other sources of meaning that support their well-being, for example by helping people go out of the ward or seeing their pets. This might involve doing things differently to usual practice.
- Reflect on the goal-setting process you use. How are the things that foster people's long-term well-being supported by the goal-setting process?
- Integrate a focus on community integration, support people to build the confidence, skills and strategies to engage in meaningful community activities and interactions.
- Consider how social connections and relationships are supported, and in particular, how these might be addressed in rehabilitation. This might include working with friends, family and others, not just the person with stroke.
- Encourage people to access supports outside of healthcare if they wish, for example cultural or spiritual support.
- When addressing short-term needs, issues and function, help the person see how this connects to their longer term hopes, dreams and well-being.
- Encourage people to have personally meaningful items with them (e.g. photos of significant people and places).
- Get to know local community-based services and organisations and find out about the work they do.
- Learn about different cultural models of well-being and consider how these may inform your practice.

04

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05

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