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Care attends to people's holistic well-being, both 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.

Introduction

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

"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 are 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.

Supporting holistic well-being

An example of a positive approach to supporting holistic well-being in services

Rawiri was an active man. He spent lots of time on the awa. He had been involved in waka ama for years, and now was regularly on the awa with his mokopuna.

After his stroke, Rawiri spent several weeks in hospital. Throughout his stay, the charge nurse on the ward regularly popped in to see Rawiri and his whānau and check on how they were coping. A few days after his admission, the charge nurse sat down with Rawiri and his whānau and asked about them - their wider whānau, their interests, and the work they were each involved in. She also chatted about where she was from, her family and what she liked to do in her free time.

During this conversation, the charge nurse asked Rawiri and his whānau what they would find helpful and supportive during his recovery – both while he was in hospital and when he got home. Rawiri's daughter explained how important the awa was to her father.

"We knew we had to get him to the awa, that was what was going to help him."

Rawiri agreed that it would be a place of healing for him during his recovery.

"The awa makes me feel connected, it nourishes me."

The charge nurse, Rawiri, his whānau planned together to support him to visit the awa the following day. The charge nurse made sure he was assisted to get ready early in the morning, and ensured a healthcare assistant could accompany Rawiri and his whānau to help them during the outing. Rawiri was able to visit his awa and watch the waka ama training that had been part of his daily routine for years. This experience helped to bring Rawiri a sense of peace, and he looked forward to continuing to visit his awa throughout his rehabilitation and into the future.



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.

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“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 awahi him more today. And what can we do to awahi 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

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“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

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“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

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Supporting holistic well-being

What people described when they perceived that holistic well-being was not being addressed:

- Care focuses on what is 'broken' - the impairments from the stroke.
- People might be asked what is important to them, but these are not meaningfully integrated into care in ways that the person with stroke could recognise.
- Goal-setting discussions are the main opportunity to talk about what matters - but these are done in a "tick box" way and nothing is noted about what matters for well-being.
- Goals, and care, focus on discharge and being able to do short-term tasks. While these are important to people, the people with stroke in our study said it meant they were not supported to look to a more holistic life and holistic sense of well-being, after services ended.
- There is little consideration of what roles people hold and what supports their well-being in the community.
- There is an implicit message given that once people achieve physical independence, *then* well-being automatically follows - rather than being something that needs attention in its own right and is not necessarily tied to physical independence.
- People don't feel able to express what is important to them and their well-being.

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“No services put any weighting on his ability to reconnect on the marae or in any other space apart from getting your physical capability back, get your hand working, get yourself back into employment... things that were important to him were not factored into any of their rehabilitation programmes. It's very very linear, just get your body working again, your heart's an issue so we're gonna do this to fix your heart...none of the wider picture.”

Whānau member, Māori

“I feel that the aim of community rehabilitation is to get functionality back...feels like in our case, and I could be completely wrong, 'can you walk well enough?' Tick... 'What can you do around the house with your arm? How can you make your own cup of tea and your toast? Okay that's fine.' Tick.”

Family member, Pākehā

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Supporting holistic well-being

An example of where there were missed opportunities to support well-being in stroke services

Following his stroke, Jack recalls being asked what his goals were during his rehabilitation. He found this difficult to answer, in part because it was very early in his hospital stay. He was still trying to make sense of what had happened, and he didn't know what might be possible. Further, the discussion seemed to be thrust upon him suddenly.

“Only superficially they'd come around with a form and say, 'what are your goals?' I am like, 'what do you mean what are your goals? I want to get out of here.'”

Jack racked his brain for something to say and decided on going fishing for want of anything else. In this way, the process felt like a 'tick the box' exercise.

This goal was revisited after a few weeks. However, again it felt somewhat superficial. By this stage Jack knew what was really meaningful for him – spending time with his daughter, returning to work, and walking his dog. However, he did not share these with staff.

“What are your goals wasn't something I really needed to write down or talk about, it was just me.”

Jack feels the process may have been better as an ongoing conversation, with staff learning about his life and explicitly acknowledging that his goals would likely change over time as he progressed and learned what might be possible.

Jack worked hard in his therapy sessions, wanting to give his best to his recovery. Whilst acknowledging the pressure that staff were under, he struggled with the focus on basic functionality to enable discharge.

“I think they, well, because they have so many, there's only so much they can do and so much you can do each day. So an example is walking, its like 'just walk' – it doesn't matter how – just walk so you can go home really.”

His wife Christie similarly found this difficult in the community setting. The couple felt that Jack was not encouraged and challenged to be the best he could be, or to reengage with activities that were meaningful for him.

“Correct me if I'm wrong but I feel that the aim of community rehabilitation is to get functionality back...feels like in our case and I could be completely wrong, 'can you walk well enough?' Tick... 'What can you do around the house with your arm? How can you make your own cup of tea and your toast? Okay that's fine.' Tick.”

Reflecting on practice

These questions offer a focus for healthcare professionals and stroke teams to reflect on and discuss to clarify and strengthen practices that support holistic well-being.

- How is well-being understood in your service? Are any holistic, culturally-informed models of health and well-being used?
- How is long-term well-being currently addressed in your service - in assessment, rehabilitation, information sharing, conversations? Is it directly addressed?
- How can assessment processes and other aspects of care support healthcare professionals to explore what is meaningful for a person's well-being?
- Do you know what supports a person's holistic well-being? How might you find that out?
- What are the mechanisms for integrating what you find out about a person's well-being into their everyday care?
- Is there sufficient flexibility in service processes to allow healthcare professionals to integrate meaningful activities into a person's care? If not, where are the opportunities to change things to make this possible?
- How is information about a person's long-term well-being shared with other team members? How is this information shared with other services across transitions?
- How does your service engage and work with organisations and groups in the community that might be able to support long-term well-being?
- How do service outcome measures, processes and key performance indicators address long-term well-being? Do these orient staff more toward short-term or physical well-being? Are the opportunities to modify these to support an orientation to holistic aspects of care that support long-term well-being?
- Do any concerns come to mind when you see that this framework suggests people should prioritise therapeutic relationships?

Actions to enhance care

These are examples of actions suggested by people with lived experience of stroke and healthcare professionals in the research.

Systems level actions

- Create national stroke service quality indicators that support services to consider 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.

Actions to enhance care

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.



This quality framework has been developed from a four year study of well-being after stroke led by Associate Professor Felicity Bright. Research was completed by Felicity Bright, Claire Ibell-Roberts, and Bobbie-Jo Wilson.

This booklet summarises one of eight domains of high quality care to support well-being and is designed to help stroke services and healthcare professionals reflect on current practice and identify areas for future development.

Full details and further supporting material, can be found at cpcr.aut.ac.nz.

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