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



PEOPLE'S KNOWLEDGE AND PERSPECTIVES ARE SOUGHT AND RESPECTED. PEOPLE HAVE CONTROL AND AUTONOMY THROUGHOUT THEIR RECOVERY.

Introduction

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.

Centring people's preferences

An example of a positive approach to centring people's perspectives and offering choice and control

Jeff and his wife Hannah had busy lives juggling work, parenting and outdoor based hobbies when Jeff had a stroke. Navigating the shock and disruption of the stroke has been a challenging journey. However, during Jeff's inpatient rehabilitation stay and community rehabilitation input, the couple encountered staff who wrapped services around them and listened to their perspectives and needs.

Naturally an early riser, while an inpatient Jeff found it challenging to lay awake in the mornings unable to move. The couple recall a nurse who discussed with Jeff how the team could better support him.

"She'd say, 'Okay so if we got you the electric wheelchair or if we showered you earlier in the morning - we've got this staff member that starts at this time - would that make you happier?' And Jeff would go, 'actually yes, that would make a huge difference'. So, she was very good at recognising the simple...You know, just something little but yeah..."

The couple felt listened to through the way the nurse prioritised time for a conversation with them, gave them options and listened to what they wanted. Moreover, she was always true to her word.

"If you actually 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..."

Jeff and Hannah attended a family meeting as part of Jeff's community rehabilitation after his stroke. The couple appreciated the collegial environment and explicit focus on how the team could best support the family.

"We had a meeting this morning and it's like the focus is what do they need to carry on to make my life easier? That's a big thing."

Hannah noticed a big difference between the family meetings in hospital which were quite directive, and those in the community which felt much more like a shared conversation about what was best for Jeff and their family.

"The one in hospital, I don't know, I don't know if it's structured the best way it could be... And then you've got these ones, it's like oh okay, they're more of a, it's just a good catch up where it's probably driven more from us. Whereas in the hospital it's like 'okay well this is how it is, da, da, da'."

Throughout care the couple felt respected for the knowledge and strengths they held. They felt treated as individuals, not simply patients who needed care.

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.

Centring people's preferences

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Person with stroke, Pākehā

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

Person with stroke, Pākehā

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“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

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Centring people's preferences

What people described when they perceived a lack of considerations of their preferences, and a lack of choice and control:

- People's knowledge and experience is ignored or diminished.
- Whānau Māori perspectives are unheard or overridden.
- There is a lack of interest or respect for the opinions and perspectives of people with stroke and whānau.
- Care feels directed by healthcare professionals and service processes, resulting in people feeling unheard and having to fit the needs of services.
- Healthcare professionals appear too busy to answer the questions of people and whānau.
- When people try to exercise autonomy, this is shut down because of concerns about safety.



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“They have their best intentions but it's like the old, 'well I know what you need and I'll give it to you 'cause I know what you need.' No-one asked me 'what do you need or what would you like?' I wanted to go swimming and they said, 'oh no you can't do that. You can just go and see the psychologist'...”

Person with stroke, Māori

“A major issue was having someone there. You had to depend on them, whenever they were ready to take you to do certain things...Sometimes I'd break the rules because I'd have to wait for a nurse and I'd be sitting on the bed for an hour, maybe two...So I got out of hospital earlier because of what I did.”

Person with stroke, Māori

Centring people's preferences

An example of where there were missed opportunities to centre people's preferences and provide choice and control

Independence and self-drive are fundamental to Kahurangi's identity. It was important to him to use every opportunity to work towards independence after his stroke.

"Lying on the bed, you feel almost helpless. The first two days was probably the hardest, because I had to be taken to the toilet, people had to help me eat and things like that. To get me to the toilet, they put you on the hoist thing and they lift you up, put you down on the seat. Those first two days I was thinking, 'okay, to get out of this situation, I need to learn how to get to the toilet, learn how to shower myself'. These are the things that were in my mind. So, while the nurses were doing these things for me, I was taking note..."

Whilst Kahurangi prioritised practice and self-reliance, the ward strongly prioritised physical safety and required him to have supervision when moving. He found this challenging, reinforcing a sense of dependence and a lack of agency.

"That was always a major issue was having someone there. You had to depend on them, whenever they were ready to take you to do certain things. And they made that quite clear that you had to do it with a nurse, and I had quite a few arguments about that."

He recognised the workload nurses were under and grappled with his deep desire for independence, and his respect for the healthcare team and not wanting to get anyone "in trouble". Over time Kahurangi developed a daily exercise routine which gave him both some control in his recovery, and a sense of achievement. He credits his early discharge to this work.

"Each session I'd do would be an hour and I'd make it longer as I got better...And a couple of times the nurses would see me and say 'Hey, what are you doing, you're not supposed to be doing that, because we're supposed to be with you.' And I'd have a bit of an argument with them. I says, 'Well, are you gonna stand with me here for an hour and watch me walk around and do my thing?' They said, 'Oh, well as long you don't fall.' I says, 'I understand this. I'll make sure that I'm safe and not going past my limits'..."

Kahurangi acknowledged that staff want the best for people but felt the 'rules' of the ward could impede recovery and genuine connection.

"Individually they're really nice, you know 'cause they just want to help you and I don't know where that stops, where they are a person and then they're part of a system and they have to toe the line and never mind about how they feel as a person helping another person, they've got to toe the line and this is your job and these are the policies and regulations that you've got to abide by".

Despite knowing what would be supportive for himself, at times Kahurangi felt he had no control in his care. He feels that staff and services could greatly support people by genuinely listening to their perspectives.

"That's the biggest thing for me is to be heard, and to be heard not from your point of view, listen to me. Listen to me and what I'm saying. Not what you assume I'm saying."

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 centre people's preferences and enable them to have control and autonomy.

- How do you find out about the perspectives and wishes of people with stroke and whānau? How is this shared across the team?
- Do service indicators or requirements get in the way of being able to really engage with people and find out what matters to them? For example, do timeframes for completing initial assessments allow for whanaungatanga first? If not, how might these be changed?
- How are people with stroke and whānau supported to make decisions and plan their care?
- How are the perspectives and wishes of people with stroke and whānau integrated into care? How do you manage it when this doesn't seem to be possible?
- Are there some preferences that seem more difficult to integrate into care? Why is this? Are there ways that things can be done differently to better address these areas?
- What happens if you cannot meet the needs or preferences of a person or whānau impacted by stroke?
- How are you responsive to people's desire to exercise greater control or autonomy as their abilities change?
- What forms of safety are prioritised in your service? Are there times when a focus on physical safety be in tension with cultural safety or well-being?

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

- 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.

Actions to enhance care

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.



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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