AUT CENTRE FOR
PERSON CENTRED RESEARCH

01

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.

Care supports people through uncertainty

"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 staff to acknowledge and support them through this time.

When this aspect of care is working well, staff explicitly acknowledge the uncertainty people are feeling. Staff 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. 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. Instead of providing generic information, staff 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. 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.

Supporting people through uncertainty

An example of a positive approach to supporting people through uncertainty

Dave spent 6 weeks in inpatient rehabilitation after his stroke. While Dave and his wife Rachel are optimistic people, they were worried about the possibility of Dave having another stroke. Having someone talk through this with them provided great relief.

"It was [OT] I think that came out and said, 'don't be worried that you will have another one because you are on blood thinners now.' Nobody can guarantee that, but he kind of put our minds at rest."

The OT was a trusted point of contact while in hospital, frequently sharing information about what was happening and always happy to have a conversation. They popped in regularly to say hello, asked explicitly how Dave and Rachel were doing, and, if unable to engage in an in-depth conversation, would always arrange a time to come back. Physiotherapy sessions were similarly supportive.

Dave found the opportunity to talk to trusted staff about his stroke, ask questions and talk about the future even more influential than the therapy activities. Dave and Rachel appreciated the knowledge of his therapists, and the fact that they appeared unhurried and genuinely invested in his recovery. This helped him to feel both reassured and motivated.

"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."

Leading up to discharge, Dave was introduced to the therapists who would visit him at home. He and Rachel knew when to expect contact from the community team and enjoyed a smooth transition home. Once home, Rachel appreciated the frequent phone and in-person contact from the community team.

"I felt they had his back, and nothing was ever a problem, and they used to ring and touch base. You always felt there was somebody out there caring about him."

Moreover, knowing when the next visit would be provided great reassurance in addition to encouragement and motivation.

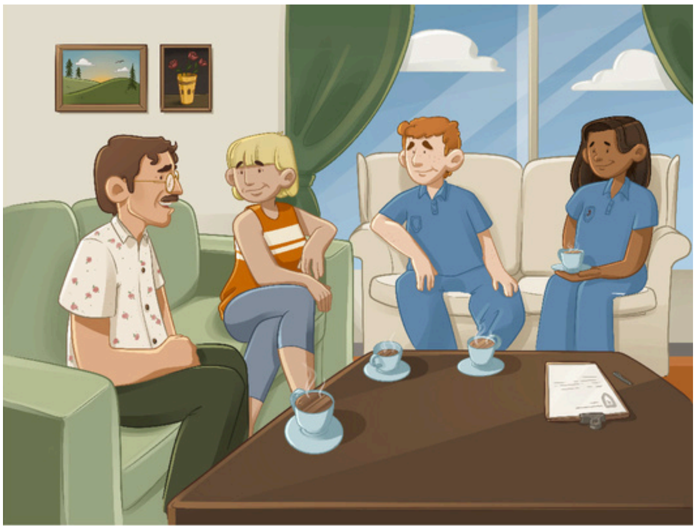
"That is the big one; 'I will see you in four weeks' time'".

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



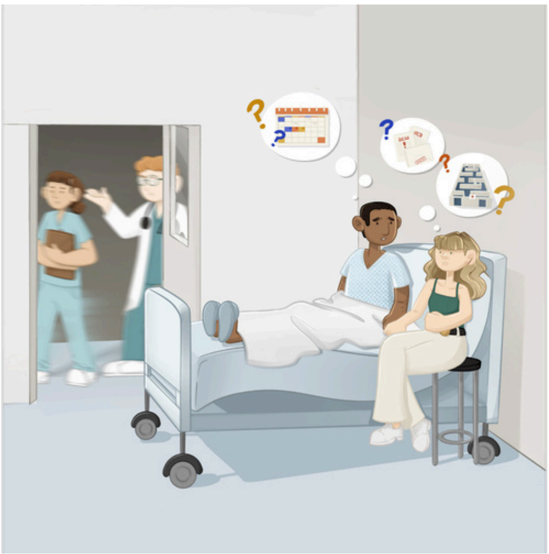
“[Community therapists meet patients on the ward before their discharge home] and we sometimes will get them in to do the home visits with the patients.”
Allied health, Pākehā

"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

Supporting people through uncertainty

What people described when they perceived a lack of support for their uncertainty

- Uncertainty, and the impact of this, is ignored or diminished.
- One-off or unclear explanations are provided, in ways that people can't understand.
- Information is only given to the person with stroke or whoever happens to be there at the time.
- Stroke information is generic, not specific to the person or their context.
- Information doesn't address the areas the person with stroke and their whānau consider is important.
- People don't know what to expect after discharge from hospital.
- People don't receive information about supports available and how to access them.



> "They [health professionals] just about all say, 'every person's stroke is different'. I have heard that so many times. I would like to ask a question and get the answer to it rather than say 'every stroke is different.' That's not really the answer to the question, is it?"
> *Person with stroke, Māori*

> "I didn't really understand a word [the health professionals] were saying...[I could ask questions] but I didn't really want to cause I knew I wouldn't understand what the heck they were about to say."
> *Family member, Māori*

> "It's like you need, like a ward nana or somebody to sit and just go through it all with you and just to actually be that person. It doesn't have to be a medical person – just someone to say, 'hey look you've arrived in this ward, this is available, and this is available...' to try and help you through the situation."
> *Family member, Pākehā*

Supporting people through uncertainty

An example of where there were missed opportunities to support people through uncertainty.

Jack and Christie vividly recall the doctor's words, "you have had a severe stroke." They remember the shock, fear, and overwhelming uncertainty of this time. Christie feels more information in the first few days may have helped her make sense of what was happening.

"There's not a lot of support for someone like me that is a reader, I grab pamphlets and read and stuff like that – we didn't even get a folder or information or anything. It would have been so good if somebody had come down and sat down and said, look, you know, da, de, da, de, da..."

While uncertainty about the future weighed heavily on their minds, Jack and Christie struggled to navigate hospital processes and seek out the support they needed.

"We somehow stumbled across, we kind of stumbled through quite a lot of it."

Both Jack and Christie feel that having someone to guide people through this time would be valuable.

Jack spent a lot of time in bed "staring at the ceiling" during his early days in hospital. This perpetuated worries about the future, and how the family would survive financially. He became low in mood, however both he and Christie felt lost and alone in trying to manage this.

"We just had to fight for every, you know... 'Can we see the social worker?' 'Oh yeah, she's really busy, really busy...'"

As discharge approached they felt both excited and anxious.

"We didn't have any idea of what it would look like on the outside, so I was really worried that [Jack] was going to go from multiple rehab sessions daily, to what – I didn't know."

Their transition home was stressful and disjointed. They were not contacted by the community team for weeks and were not given information about what to expect nor when. Christie followed up and was reassured that the team would be in touch. However, this did not happen.

"I still had to chase her again – no one got back to me. It was really slow...and really difficult. There's not one point of contact, the way that they run it."

The uncertainty of this time was very stressful for the couple as they adjusted to life at home again with their young children. Christie remembers a sense of hopelessness.

"There was a point quite early on when we felt really unsupported and nothing was happening...and I was just like, 'oh my god this is terrible'."

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 people through uncertainty.

- Who is responsible for discussing the stroke, what might happen in care, and what might be possible in the future with people and whānau? Is this a team approach, or the responsibility of particular individuals?
- Do people and whānau impacted by stroke receive consistent messages and information from the team? How do you know what information others have shared?
- Consider how you share information or provide ‘education’. Is this done proactively, or primarily in response to questions or issues raised? Are some aspects discussed proactively, and others not?
- Is information accessible to people who have communication or cognitive impairments?
- Is verbal information supported by written information? What written resources would be helpful?
- How do you know what the person and whānau want to know?
- Is information meaningful and digestible for people and whānau and responsive to where they are at?
- How are whānau involved in these conversations? Have you identified who the key whānau members are, who need to be in those conversations?
- Who are the key service providers you work with? What relationships does your service have with other service providers (internally or externally)?
- How does your service manage and support people across transitions of care?
- What information is your service able to give people about the next stages of their stroke journey? Do you have information and contact details for follow-up services?

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 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 health 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 key worker 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 loss, what to expect, and support options.

Actions to enhance care

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 staff 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 clinician who will work with them where possible. Allow time for whanaungatanga and answering questions.

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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Contact

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