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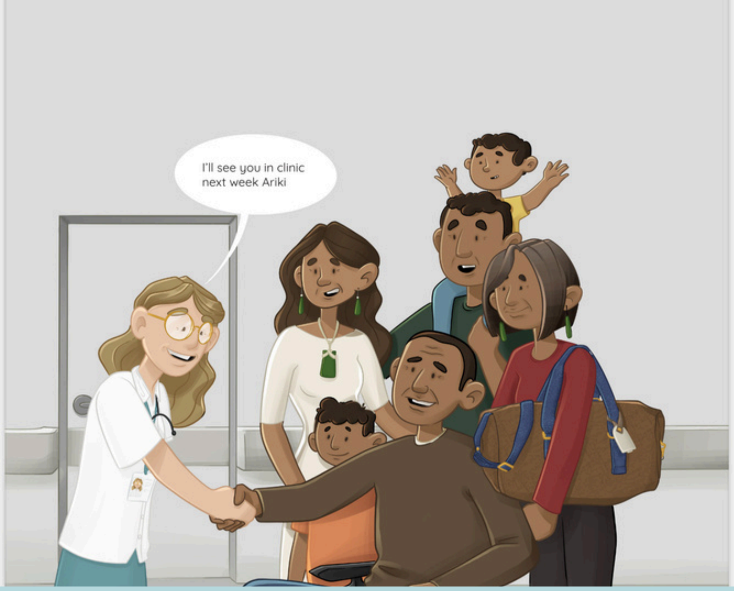
Care responds to the strengths and needs of whānau and friends



FRIENDS AND WHĀNAU ARE RECOGNISED AS PART OF THE CARE TEAM. THEIR PERSPECTIVES AND KNOWLEDGE ARE WELCOMED. SERVICES RECOGNISE THAT FAMILY AND WHĀNAU HAVE THEIR OWN NEEDS WHICH MAY REQUIRE SUPPORT AND PROACTIVELY ADDRESS THESE.

Introduction

Care responds to the strengths and needs of whānau and friends

"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."
Person 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.

Supporting the strengths and needs of whānau and friends

An example of a positive approach that responded to the strengths and needs of whānau

Ariki's whānau immediately wrapped around him after he had a stroke. His communication and memory were impacted by the stroke, and the hospital was an unfamiliar environment. Ariki was surrounded by strangers in a space where there was no reflection of te ao Māori. His daughter Kiri describes how the whānau felt it was important that Ariki move home as soon as possible to heal.

"Once he was out of the like immediate danger zone, we felt he needed to be back in his own environment. He needed to be home, he needed to be back in his own, 'cause he just was looking around like it was, he didn't know where he was, it was really foreign...So for us to get him home, so long as it was safe, that was what we thought was best for him."

As soon as he was medically stable, his whānau sought to take Ariki home. Whilst this was sooner than the healthcare team would have proposed, Ariki's team, and in particular his specialist, listened to and supported the wishes of the whānau. The healthcare team arranged outpatient care to ensure that Ariki was able to access specialist follow up and rehabilitation in a way that worked best for the whānau.

"He had a wonderful specialist at that time...she was amazing and because dad was only young when this happened...he wasn't old...he had a really great specialist who agreed, there was no reason why, you know, he couldn't go home and just come to everything as an outpatient. Yeah so they agreed with that plan and we took him home."

Ariki values the decision his whānau made for him.

"My daughters knew that there was nothing valuable for me to stay in the hospital, so I was taken home and when I got home, one of the daughter's families had moved in with two children. My children just automatically thought that it would be better for me surrounded by our whānau rather than me being up in the hospital for two or three months with strangers that I have no idea who, you know..."

Kiri felt supported by the specialist not only during Ariki's hospital stay, but throughout his outpatient follow up, and indeed, even after Ariki's care finished.

"She said 'but if ever there's anything comes up contact me Kiri, happy to go back into it.' So there's something there that's, yeah, she was an excellent source for me."

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.

Supporting 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

Supporting the strengths and needs of whānau and friends

What people described when they perceived a lack of attention to the strengths and needs of whānau and friends:

- Staff do not introduce themselves nor get to know whānau or friends.
- Staff assume the roles that whānau will play in the person's care.
- Whānau members are only peripherally included in information sharing, and don't feel able to ask questions.
- Family meetings are dominated by staff and the agendas that matter for the service.
- People do not feel prepared for family meetings.
- Whānau are only included in therapy activities and care when they happen to be there.
- Staff don't seek out the perspectives of whānau, nor recognise their strengths.
- Staff don't understand the broader context of whānau lives, and the wider impacts of stroke on them.
- Services are not resourced to support whānau needs.

"The fact that no one had actually been with my husband, family wise when he was told that if he had surgery he could become a 'cabbage'. And to this day nobody spoke to me, not a doctor, nobody. I got little snippets from the nurses, but I saw no doctor, nothing, and we were visiting him every day and there was no mention, I was just going on what he had been told."
Family member, Pākehā

"There's too much expectation that ok, a family member can take care of the person, but that family member probably needs to work to help support the rest of the family so if we take care of the person that can't, who doesn't get paid well then, you know...money's needed."
Family member, Māori

Supporting the strengths and needs of whānau and friends

An example of where there were missed opportunities to respond to the strengths and needs of whānau and friends

Liz supported her cousin Don after his stroke, spending many hours with him throughout his hospital stay. She assisted with his personal cares, practiced therapy tasks, and tried to bring a sense of normality to his days. It was very important to Don's whānau that he return home after his hospital stay.

"I believed that if he was in his...in the hospital it was useless, too many people, too many doors, too many this and that, there was no way his brain was going to settle until he was home and had to work in his own home environment."

Prior to his stroke Don was working full time and was actively engaged in his community. Although he now needed significant care, Don's whānau knew that returning home would support both his recovery and his long-term well-being. However, they were not able to provide all the care that he needed. The whānau discussed how they would work together to support Don, and what support they would need from the service. They shared this plan with his healthcare team.

"We had a talk and I said 'what he would want is... I think it would work this way' and the idea was put forward. So, at this initial meeting which had every man and his dog...there was the doctor, there was a social worker...there was a whole lot, there was the OT, physio, but they all were just coming, and I understand it, coming from a money base and they said...'no' that wasn't possible. I said, 'so what's possible?' He goes, 'oh, well a nursing home'."

Don's whānau knew that residential care would be detrimental for him, and so they again discussed how they could manage as a whānau. They discussed a new plan with the healthcare team that would require less input. However, again they faced resistance. A long "battle" followed. Throughout the process the whānau did not feel that staff listened to their perspective nor engaged in genuine discussion. Rather, they felt that staff had already decided what was appropriate for Don.

Eventually the whānau were able to try taking Don home with support. As Liz and the whānau anticipated, Don flourished and the support he required from the service reduced significantly over time. Whilst he still has the help of carers, he can lead his own life with their support. He has reengaged with his community and now provides support to others experiencing health issues. Liz worries about the expectations that services place on family and whānau, often without knowing the wider context. She would like to see services listening to and engaging in conversation with family and whānau about what might work best for them.

"I think it'd be good for them to have an advocate available that is able to sit and talk and say, 'hey, these are options, and you don't have to accept what's given to you if you have another plan'. So, they need someone available that can discuss how they might want to see things happening."

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 respond to the strengths and needs of whānau and friends.

- How do you identify and get to know whānau members and friends of a person with stroke?
- Are whānau seen as part of the care team? What helps this happen? What gets in the way? Are whānau asked how they want to be involved in care?
- How are whānau involved in information sharing and decision-making?
- How do you learn about the wider context of whānau lives and how this might impact on their needs, and the needs of the person with stroke?
- How do you learn about the impacts of stroke on whānau and friends, and what support they may need?
- How are whānau and friends talked about in documentation?
- How are family meetings structured? Are they an opportunity for genuine two-way conversation?
- Who has power and control in family meetings? Think about who decides there needs to be a meeting, who sets the agenda, who speaks when (and about what).
- In what ways do you assist whānau to connect with their own support networks?
- Are there opportunities to introduce whānau to each other for peer support?
- How do you currently consider the well-being needs of whānau members or friends?
- What resources and services exist for whānau and friends? How do you help people to access these?
- Are there unused spaces in your service that could be used to create welcoming, engaging spaces for people and whānau?

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

- 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.

Actions to enhance care

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).

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

For questions, comments or feedback, please contact:

Associate Professor Felicity Bright
felicity.bright@aut.ac.nz