Supporting well-being after stroke

What impacts on people's well-being in stroke services?

A summary of findings from interviews with people with stroke and whānau

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"Remember you're dealing with a whole person, not just a stroke."

Woman with stroke

"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?"

Wahine Māori with stroke

The background to this work

This booklet was developed as part of the project **Supporting well-being after stroke: A study of experiences, care practices and processes in Aotearoa**.

Well-being is important for everyone. It is often affected by a stroke. However, it is not well-addresesd by services.

We wanted to understand what is important for well-being after stroke, and learn what stroke services could change to better support people's well-being.

We looked at existing research to find out how people experience well-being after a stroke in Aotearoa. We reviewed how well-being was discussed in clinical records in stroke services. We talked with people and whānau impacted by stroke, and with people who work in stroke services.

In this booklet, we share what we have learned from people and whānau impacted by stroke about their time in stroke services.

This research was funded by the Health Research Council of New Zealand.

We spoke with:

What impacts on people's well-being in stroke services?

1.

"I really could not see myself going forward without my whānau"

2.

"As whānau, we need to be looked after too so we can look after them"

3.

"It is a gut wrenchingly emotional time...We should be allowed to be gut wrenchingly emotional"

4.

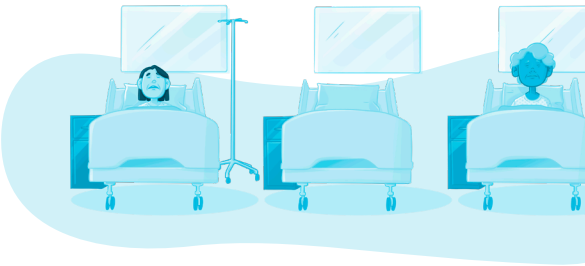
"When you've had a stroke, you don't know what's happening, you don't know where you're going. It's a big unknown"

5.

"The hospital was really foreign"

6.

"The staff were all engaged. They would ask, and they would listen to the answer I gave"



7.

"I've always been a very independent person, so I hated having to ask"

8.

"We don't get told what's available to us while we're there let alone when we leave!"

1 "I really could not see myself going forward without my whānau"

Whānau and friends were the most important source of well-being for many people.

How whānau and friends helped well-being

Connections with whānau and friends were often healing. For some, this involved a big social network. For others, having just one person was important.

Whānau and friends provided practical and emotional support. They worked hard to keep track of information and seek out support for their loved one. They provided comfort, familiarity, motivation and encouragement. They also held deep knowledge of the persons 'pre-stroke' life and context.

Often whānau Māori upheld their loved one's mana in ways that services didn't. They brought Te Ao Māori perspectives, respected tikanga, te reo Māori, providing cultural connections and spiritual support.

People often developed friendships with others in stroke services. These people could become like whānau.

It was sometimes hard for whānau to support well-being

Some people did not have strong whānau connections. This was challenging. Services often assumed people had support, but this wasn't always the case.

The stroke had ripple effects throughout the whānau. Relationships and ways of connecting could change. Multiple generations in the whānau could be impacted.

Whānau and friends also needed support as their own well-being could be affected.

Being a source of support to others

The person with stroke received support from their whānau; they were also a source of support for their whānau. This helped their sense of well-being.

2 "As whānau, we need to be looked after too so we can look after them"

Whānau needed support themselves. They wanted staff to get to know them and to understand their needs as a whānau.

How whānau were included in care

Whānau felt included when staff took the time to build relationships with them. Whānau appreciated staff who sought the perspectives of whānau members, shared information with them, asked about their needs and provided support. This meant whānau could ask questions or talk about issues as they came up.

> **"The nurse was really conscious of how our son's birthday went and how emotional it would be for all of us... She saw the people behind the event, and she would always ask me, 'how are you doing?'"**
>
> Wife of man with stroke

Sometimes whānau felt excluded in care

Many whānau felt their experience and knowledge was not considered, or even welcome. They know the person with stroke best, but staff did not always ask for their perspectives.

Often services placed expectations on whānau without discussion. Staff were not always attuned to the needs of whānau, their well-being and the broader context of their lives. Many whānau faced additional challenges outside of the stroke, however these were rarely explored nor supported by services.

Whānau often drew on their own networks for support, and to support others.

3 "It is a gut wrenchingly emotional time…We should be allowed to be gut wrenchingly emotional"

Many people with stroke felt deep distress during their time in care. They were managing many complex emotions while also trying to 'get through' and take part in rehabilitation. Whānau and friends also experienced emotional impacts of the stroke.

How people's emotions were supported in care

People were more likely to share their emotions with staff when there was a sense of connection. They appreciated staff who asked how they were feeling and took the time to listen and respond.

It was important that staff acknowledged and validated people's experiences, without minimising or dismissing them.

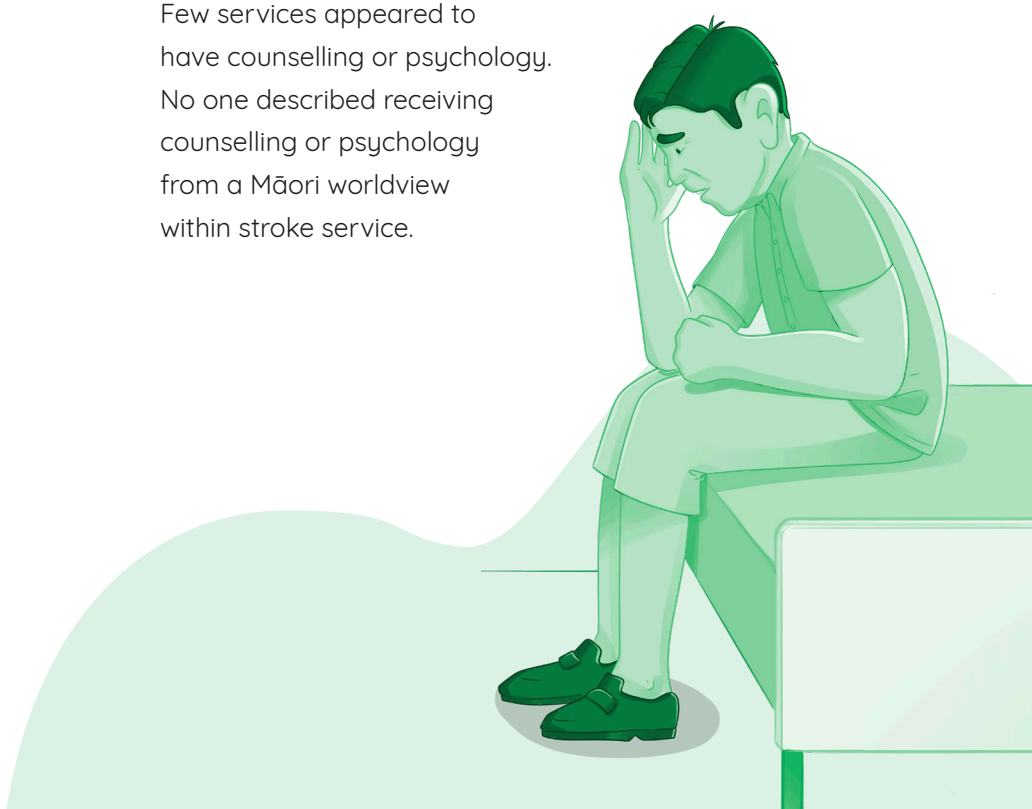
Some people found it useful to be offered access to counselling or psychology. Whānau Māori described how this needed to reflect Māori worldviews, addressing hinengaro (the mind) as well as the wairua (the spirit).

Sometimes it was hard to talk about emotions in stroke services

Services did not consistently address people's emotional needs – or even ask about them. Staff often appeared very busy, and did not seem to have the time nor interest to ask how people were feeling. Conversations and therapy often focused on people's physical needs.

When people talked about their emotions, they could be told their feelings were normal or not serious enough to get support. This could make people feel worse. They wanted staff to recognise the impact the stroke was having on them.

Few services appeared to have counselling or psychology. No one described receiving counselling or psychology from a Māori worldview within stroke service.



4 "When you've had a stroke, you don't know what's happening, you don't know where you're going. It's a big unknown."

People felt uncertain about the cause of their stroke, whether it would happen again, and what their future might look like.

Things that helped people to manage uncertainty

It was helpful when staff acknowledged the uncertainty people felt, made time to talk about it, and provided information that responded to this uncertainty.

For example, people wanted information about the stroke. This helped them to make sense of why the stroke had happened. People also wanted information about what might happen in their care, their possible recovery, and what life might look like in the future. This helped them to look forward to the future and to have hope.

It was important that information responded to the questions and concerns of people with stroke and whānau.

But sometimes stroke services increased the uncertainty people felt

Sometimes staff did not address people's uncertainty. They were not necessarily available to have conversations about the stroke and the future when people felt ready. People wanted information to be repeated. Whānau were often not present and the person with stroke had to pass information on.

When people raised worries about the future, sometimes staff gave responses that downplayed their uncertainty, or didn't seem comfortable having these conversations, perhaps because they were uncertain.

Some whānau Māori felt that information did not meet their needs. For instance, they worried about how the stroke might impact their wairua and their ability to engage in roles they held within their community. However, staff mainly focused on physical recovery,

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"The hospital was really foreign"

The hospital environment could be confusing, stressful and confronting. It did not always provide a welcoming environment.

Things that helped people to feel settled

People felt more settled when they knew who the staff were, what was happening, why and when. People appreciated staff who introduced themselves and explained their role. Having a daily or weekly timetable was useful.

People felt more settled when they were with others with stroke, with people of similar ages, and when they could connect with others from their culture. These things all helped them feel a sense of connection and belonging.

But people and whānau often felt unsettled

It could be hard to understand the different roles of staff and what to expect each day. Often people were not told what was happening and why, and they did not know what would happen next in their care. This increased the stress people felt.

People felt isolated when they had little in common with others around them. Clinical spaces could feel 'sterile' and unwelcoming. Hospitals were seen to be designed for Pākehā, with no reflection of te ao Māori either in how services were offered and in terms of the physical environment.

Being able to connect with staff from the same culture often helped people more settled.

6 "The staff were all engaged. They would ask, and they would listen to the answer I gave"

People wanted to be understood as individuals in their whānau context, and with unique preferences, priorities and things that matter in life.

Things that helped people to feel seen as individuals

People valued staff who got to know them and asked what they wanted to see happen in their care. It was useful when staff shared different options and helped people and whānau to choose what would work best for them. This helped people have a say in their care and it felt like a process of shared problem-solving.

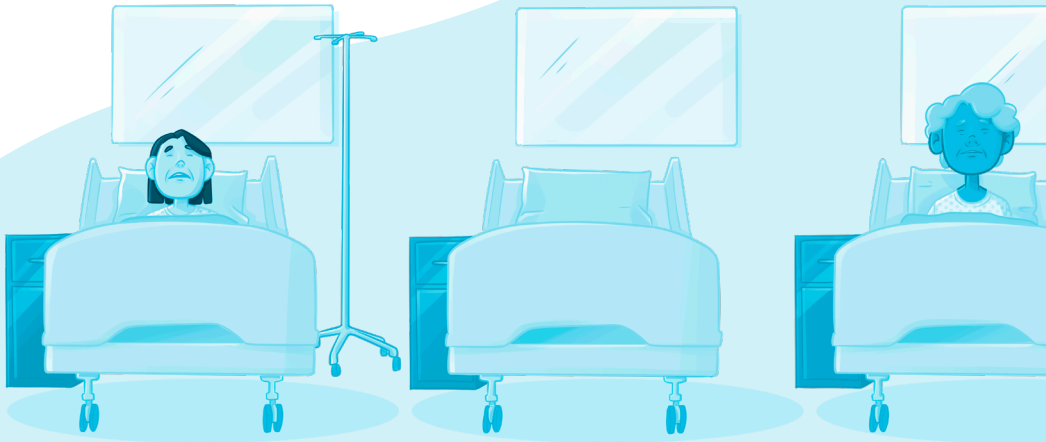
People felt their preferences were heard when staff took the time to hear what was important to people, and made sure these were at the centre of care.

> **"What I really liked about the community team, it's all about the... 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?"**
>
> Man with stroke

Sometimes people felt disempowered by health services

Sometimes people felt like "just another person with a stroke".

This happened when staff did not ask for their perspectives, but instead focused on what staff thought was important. These were often the things that needed to happen before discharge. People sometimes felt that they had to 'just go along' with how things were done, with little choice or input.



7 "I've always been a very independent person, so I hated having to ask"

Independence was important for everybody but could be difficult to achieve in stroke services. It was hard being reliant on others. Many people described working hard to regain their independence.

What supported people to be independent

People valued staff who encouraged them to give things a go. They valued staff who pushed them – but also gave them support to do this successfully.

It was motivating for people to receive feedback; this helped them see the progress they were making. People appreciated staff who recognised the effort they put into their recovery, and the strengths that they were drawing on.

It was difficult to maintain independence in services

Often the strong focus on physical safety could make it hard to practice tasks independently. Many people spent long periods waiting for assistance while in hospital. This reinforced feelings of being dependent on others. People wanted to be supported to 'test themselves' and 'give things a go', even if there were some risks associated with this.

> **"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."**
>
> Tane Māori with stroke

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"We don't get told in hospital what's available to us while we're there let alone when we leave!"

It was hard to get information or support, both in the hospital and after discharge. This left some people isolated. Because of this, whānau and friends were essential. They helped people to find information and navigate stroke services.

Things that helped people to have a smooth healthcare journey

People appreciated being included in decisions about what would happen, and being regularly updated on the plan of care.

People said it was easier to discharge from hospital when they knew what to expect. This included having contact details and timelines of follow up services.

Transition from community services went well when people could choose when services would finish and were given a point of contact for the future if needed.

Being connected with other services in the community was valued.

> **"We kind of stumbled through quite a lot of it"**
>
> Woman with stroke

Often people felt left to manage alone

Services were commonly short-time and inflexible. This meant that often people did not have access to the right services at the right time for them.

It was hard to understand what services were available and how to access them. Some were difficult and expensive to get to.

People and whānau often had to find support themselves. They wanted a navigator to support them from early in their stroke care to help them understand and access the services they need at each stage of care.

We thank everyone who has
shared their experiences with us.

More information about our study can be
found via the QR code or on our website:

https://cpcr.aut.ac.nz/our-research/psychosocial-well-being-after-stroke

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