Supporting well-being after stroke

Māori experiences in stroke services

A summary of kōrero with
whānau Māori impacted by stroke

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Wahine Māori
with stroke

“The wairua is our anchor. That’s what keeps us focused and on track with our well-being. If our wairua is not balanced, nothing else is.”

“For me, your guys’ skills and knowledge is in this little weeny piece over here… but for me, mine is about life. It’s not about illness and death, mine is about life. What can we do to improve people’s lives?”

Kaumatua
with stroke

The whakapapa of 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**.

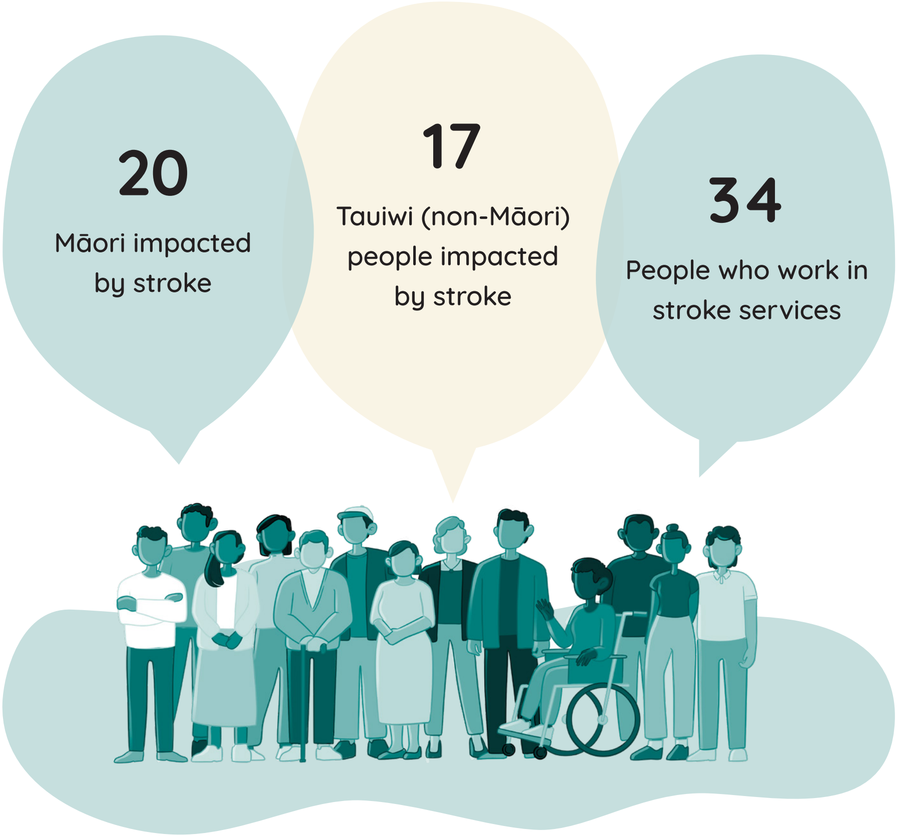
Well-being is important for everyone. It is often affected by a stroke. However, it is not well-addressed by services.

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 whānau Māori about their time in stroke services and how this impacted their well-being.

We spoke with:



Whānau Māori experiences in stroke services

Services could influence people’s well-being after stroke in positive or negative ways.

1.

“You can’t look after the hinengaro without looking after the wairua and the tinana. They all go together”

2.

“I feel connected… and I feel an essence of ‘I’m ok’”

3.

“Know me before you fix me”

4.

“When we engage with whānau, don’t make assumptions. Look, listen and see… Let’s focus on what is shining”

5.

“You can go into a room full of Māori and you just will connect”

6.

“Listen to me and what I’m saying, not what you think I’m saying”

1

“You can’t look after the hinengaro without looking after the wairua and the tinana. They all go together”

Well-being is holistic. It comes from connection – including connection with te ao Māori, te taiao, he tangata – and involves the weaving together of multiple elements which reflect the ‘whole’ person. This includes whānau, tinana (body), hinengaro (mind) and wairua (spirit).

When whānau felt holistic well-being was recognised

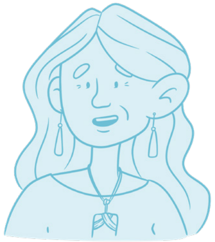
Holistic well-being was supported when people were seen in their entirety, with staff and stroke services valuing all aspects of well-being. This could be through helping people to get ‘back out into the world’ through community activities or arranging for people to visit deeply meaningful places outside of the hospital during their care.

Whānau were clear however, that services needed to recognise that holistic well-being is not their responsibility - well-being often sits within whānau and with communities. However, services must be aware that they can influence a person’s well-being in positive or negative ways.

Stroke services often left people feeling “broken up”

Western ideas of health and well-being meant people felt ‘broken up’ into different, broken body parts and functions. When services focused only on the well-being of the tinana or on the stroke without knowing the person and their whānau, or did not acknowledge the importance of the other aspects of well-being, people were not able to be *well*.

> “It’s when it’s all broken up and things are done separately that people become unwell, and the being is not well”
> Wahine Māori with stroke



2

“I feel connected… and I feel an essence of ‘I’m ok’”

Strokes often disconnect people from their sources of well-being. Rebuilding these connections was important to support well-being journeys. While stroke services could sometimes help this, often they exacerbated the sense of disconnection.

Staff could support connection to what was important and supportive of a person’s wairua

Some staff helped people connect with what was important to them. This included helping people connect to te taiao and te ao Māori. Some staff made space for whānau to connect together. They also included areas of meaning in therapy activities or helped people to get home to whānau as quickly as possible.

Stroke services are part of “a beautiful non-Māori system” and can disconnect people from what matters

Services often made people feel more disconnected from their sources of well-being.

When services focused on short-term physical recovery and what staff thought was important, they could make it harder for people to reconnect with what was important for their well-being.

Whānau needed space to be themselves as Māori. For some, this meant embracing their identity as Māori. For many, it meant connecting with whānau or going outside. However, few people found such meaningful connections in stroke services.

> “There was just no taking into account that he was the kaikōrero for, you know, an Iwi. How’s he going to be supported to get that back?”
> Daughter of Kaumatua with stroke

3

“Know me before you fix me”

Whanaungatanga (relational connections) with staff was a valuable aspect of care. Whānau described how whanaungatanga could significantly influence their experiences in stroke services.

The power of whanaungatanga

People and whānau valued staff who understood the importance of whanaungatanga. These staff prioritised taking the time to know people and whānau, and importantly, to share of themselves as well. These connections fostered trust and could bring moments of joy into care.

When a strong relationship was built, staff listened to the perspectives of people and whānau and appeared more likely to advocate for their needs.

> “There was just something about their relationship that helped him a lot, like the specialist would acknowledge his capabilities and how it’s a bit harder now, talked about his studies… she talked to him often quite personably, like personal conversation.”
> Sister of tane Māori with stroke

“There’s no ‘Oh how’s your family?’ It’s just business”

Staff often engaged in very clinical ways, rather than connecting as people, and working together with whānau.

People and whānau wanted time to connect with staff and sometimes, to share their stories. However, staff often seemed too busy. People described feeling that they were being moved through services like a “tick box”.

> “Either they’re too busy or, I don’t know exactly what the problem was… they need to get to people’s mindset of where they are to understand them… sit down and see where that person is at and then make a plan around that. That’s probably the biggest help people need.”
> Tane Māori with stroke

4 “When we engage with whānau, don’t make assumptions. Look, listen and see…Let’s focus on what is shining”

People want staff to get to know them and listen to their perspectives. People and whānau want to have a say in their recovery journey.

Including and supporting whānau

People valued staff who took the time to get to know their whānau context, who would “look, listen and see” the strengths within the whānau, and who recognised whānau as a core part of the team.

These staff understood that stroke has ripple effects thorughout the whānau, including impacting mokopuna and wider whānau members. Whānau valued having the support of staff when navigating the changes in their own lives as a result of the stroke.

Whānau often felt excluded and unsupported

Services often focused on the person with stroke, leaving whānau only peripherally involved. Many people felt that staff did not understand their unique whānau context. Many felt their knowledge, as whānau, was not welcome. This could result in services placing expectations on whānau without understanding their needs and capacity, or how they wanted things to happen.

There are many ‘shades’ of whānau with different ways of relating and working together, but services sometimes made assumptions about who would or should be involved in the person’s care. Whānau were not consistently supported in their own well-being, or to take on caring roles.

> “Whānau need someone 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.”
>
> Sister of tane Māori with stroke

5

“You can go into a room full of Māori and you just will connect”

Many people with stroke described feeling disconnected from themselves and others. Meeting other Māori with stroke was a powerful way for people to build their well-being and to develop a sense of community. It was important that stroke services recognise the crucial role of Māori communities in supporting Māori.

Having space to connect

People particularly valued being connected with other Māori, including Māori organisations or sources of support such as marae. These connections helped people feel they could be their whole selves and gave people a sense of belonging.

Having space for whānau Māori to connect with other Māori during their time in services was important, helping them form informal support systems which could continue beyond their time in services.

> “I really enjoy getting together with a group cause I feel assimilated to them and got a connection… it makes me not feel isolated and I can be more myself and be relaxed and not uptight”
> Wahine Māori with stroke

It could be hard to connect in stroke services

Some whānau supported others on the ward and wanted to see staff more commonly introducing whānau to each other to help whānau support each other.

While mainstream Pākehā-led stroke support groups could be useful for some, these often did not provide the space for people to “be Māori” and to connect with other Māori.

> “That’s all they needed was a space where they were all brown faces knowing what each other’s been through or similar, you know and that there’s been a similar lack for everybody of support”
> Daughter of kaumatua with stroke

6 “Listen to me and what I’m saying, not what you think I’m saying”

Rangatiratanga (self-determination) is deeply significant for whānau Māori. The ability of a person or whānau to have their autonomy upheld in determining their own healthcare journey after stroke fosters greater overall well-being.

Honouring rangatiratanga

When people and whānau are able to make choices that are right for them, they are able to enact rangatiratanga.

People described how staff supported this by actively working together with whānau, “fighting their corner”, sharing information and options, helping people to choose what might work best for them, and ensuring they had the supports they needed to enact their choices. Such supports included access to individualised funding, or a trusted contact to ask questions of after discharge from services.

But whānau often describe “battling” to be heard

Some people felt their voices or views as Māori were overridden by staff. Rather than their choices and needs being respected within services, many whānau felt staff expected them to ‘fit the requirements’ of services.

This meant people had to draw on their own whānau or support systems. At times, this resulted in whānau removing their loved ones from stroke services and returning to their homes where whānau felt better placed to meet their needs.

> “Dad 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. So, they agreed with that plan, and we took him home.”
> Daughter of kaumatua with stroke

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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