

Supporting psychosocial well-being after stroke

A study of experiences, care practice and processes in Aotearoa New Zealand

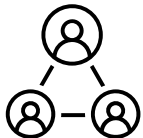
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Researchers: Bobbie-Jo Wilson, Claire Ibell-Roberts, Sandra Yellowhorse

Over the last six months, we have been speaking with people with stroke, whānau, and clinicians working in stroke care to understand what psychosocial well-being means for people, what supports this – in and out of care, and exploring how care might be able to change to better support people's well-being. We have spoken with 25 people with stroke and whānau, and 34 health professionals, service managers and people working in stroke care.

We are considering how well-being is addressed within services and how this 'maps' with the experiences and needs of people with stroke and their whānau. Through this, we are beginning to see what is important in services, and what supports people draw on outside services that clinicians need to be aware of.

Some key findings

Through these conversations, people with stroke have shared what they value in care and when moving forward. We are hearing that:



Whanaungatanga and connection with staff can have a significant impact. Staff who connect with people and whānau on a personal level, recognising who they are, can support people to feel settled. Those who listen, collaboratively problem solve with people and whānau, and take action are seen as allies; they have the power to significantly influence a person's experience of care. Even brief but genuine interactions can lift a person's day – the little things matter.

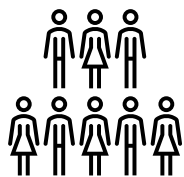


Meaningful connection enhances well-being for people and whānau. These connections may be within whānau or existing networks, or new connections made through the experience of stroke. Many find a particular sense of belonging and acceptance with others with stroke. Services that create space for and foster these connections in ways that are culturally safe and meaningful are highly valued.



Contributing to others is central to the well-being of many. People with stroke support others in a myriad of different ways. Many shared their experience with others to foster solidarity and hope, or to educate friends and family. Others joined health or advocacy groups to strengthen health and community services. One participant explains, "When stroke hit me, I needed supports from all. Awhi atu, when I am strong, I will help others".

There are tensions too. Some of the consistent messages that come through are:



Well-being impacts on whānau, not just the person with stroke. When the well-being of whānau is impacted, this impacts the person with stroke, and others within the whānau unit. The ripples of stroke can be felt widely within whānau. Yet services focus on the person with stroke. Whilst they welcome whānau, there are few services that are resourced to expressly address the well-being needs of whānau.

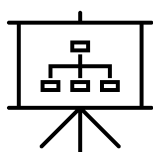


The 'calendar time' of services does not match the 'lived time' of people with stroke. Many services are focused on short-term care. They are often time-bound and are most concentrated in the first months after stroke. Yet recovery is long-term. People's needs change over time, and people want and need supports over a longer period. Moreover, the time bound nature of services can be in tension with prioritising relationships and connection in care practices.

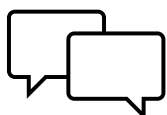


Staff want to do more to support well-being, but struggle knowing how best to do so within their roles. Many staff face time pressures and struggle to identify areas of 'give' to allow for a greater focus on supporting well-being. Some feel time spent supporting well-being prevents working at the top of their disciplinary scope. A lack of specific training and resources in this area, combined with few funded psychosocial supports to refer to can result in staff feeling ill-equipped to effectively support well-being.

Our next steps

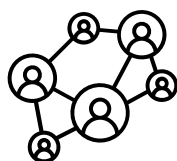


We are continuing our data analysis, **mapping what happens in services** to understand the interactions between care provision and care experiences. This is helping highlight gaps, tensions, and areas of valued practice.



We are **completing interviews** with people with stroke and whānau.

We will be analysing how well-being is captured in **patient records**.



Next year, we will be sharing our findings more widely. We will work with people with stroke, whānau, and clinicians to **identify priorities for service development**.

Sharing our work

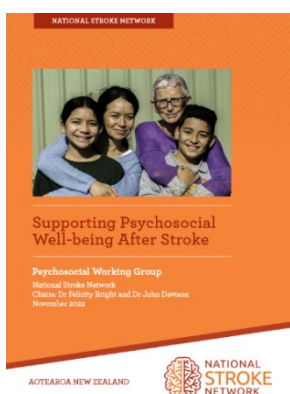
In August, we shared our work at the **Stroke Symposium of Australasia**. The poster we presented is on the next page.



In September, we brought together our students, our core research team, and our kaumatua, Rukingi Haupapa. We drew together the different pieces of the research, exploring how these pieces fitted together. Rukingi suggested kupu to reflect Māori experiences of well-being that we had found in our research.

L->R: Caitlin Thomas, Karina Delemont, Felicity Bright, April Reid, Rukingi Haupapa, Claire Ibell-Roberts, Olivia Grigg

Felicity and BJ, together with our students Caitlin and Karina, travelled to the **Awahi Mai Stroke Trust wānanga** at Te Whetu o te Rangī, in Welcome Bay, Tauranga. We spent three days as ringawera, helping in the kitchen and connecting with whānau. Awahi Mai have supported our research from the start, and it was great to support *their* mahi, and to share our study progress with them. A real high point was the launch of Sandy Hiakita's book "Life beyond limitations". Sandy experienced a stroke 48 years ago, when she was 19 years old. She was newly married and 7 months pregnant. In her book, Sandy shares her journey in her own words, reflecting on her experiences of stroke, and what helps her live a life beyond limitations.



Our work has contributed to the recently published National Stroke Network guide: **Supporting psychosocial well-being after stroke**. This work was led by our Principal Investigator, Dr Felicity Bright, with Dr John Davison (Te Whatu Ora Te Toka Tumai). Our Māori lead, BJ Wilson (Ngāti Tuwharetoa) supported the development of this resource.

This resource can be found on the NSN website: strokenetwork.org.nz/rehabilitation

To **find out more** about this research contact Felicity Bright (Principal Investigator) at felicity.bright@aut.ac.nz, or email wellbeing.study@aut.ac.nz

EXPERIENCES OF PSYCHOSOCIAL WELL-BEING IN AOTEAROA

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Background

Psychosocial well-being is critical after stroke. It impacts on stroke outcomes and is often a marker by which people judge their quality of life and extent of recovery after stroke. However, it is not consistently addressed in stroke services.

This research programme seeks to understand what matters for psychosocial well-being after stroke in Aotearoa, how it is experienced and addressed in stroke services, and to identify how things may be done differently. The starting point for the research was two literature reviews to understand the core elements and enablers of psychosocial well-being in Aotearoa.

Methods

Guided by He Awa Whiria (Braided Rivers model), we explored Māori and non-Māori experiences of life after stroke, as detailed in existing literature, examining how these experiences could inform understandings of well-being in Aotearoa.

Review 1: A qualitative metasynthesis of stroke survivors' experiences of stroke (Māori and non-Māori), drawing on 19 articles. Led by Felicity Bright (Pākehā). Analysis using reflexive thematic analysis.

Review 2: A narrative review of whānau Māori experiences of stroke, drawing on 6 articles and 5 theses. Led by BJ Wilson (Ngāti Tuwharetoa). Analysis using rangahau Māori approaches of noho puku (reflection), whanaungatanga (seeking connections) and kaitiakitanga (guardianship).

Discussion

- Well-being is unique to an individual, deeply relational in nature, and influenced through connection with people, culture and community. All of which need to be supported.
- Cultural differences in well-being are evident. Well-being for Māori has wider integrations with whānau and culture, and is unique for each whānau.
- Many factors that enhance well-being are not currently supported in services. In fact, some may be negatively impacted by existing care practices and processes.
- This review can help clinicians and services reflect on how well-being is addressed and identify areas for discussion and support.

Scan this code to take you to our research website, where more information about our research is available:



General experiences of well-being in Aotearoa

STRONG CONNECTIONS

Having strong connections with family, old friends and new friends who have also had a stroke, helps provide a sense of belonging.

STABLE IN THE PRESENT

Having a general sense that things are okay at the moment helps people find balance, stability and hope amidst uncertainty, challenge and loss.

SENSE OF SELF

Having a self-identity that reflects the past, present and future (who they were before the stroke, who they are now, and who they want to be) grounds people.

A VISION OF THE FUTURE

Having a vision of a possible future, and a sense of moving toward this desirable future, gives people hope and purpose.

Whānau Māori experiences of well-being

WHANAUNGATANGA AND NGĀ HONO

Having a sense of connection and belonging within one's whānau and wider community, and places of meaning, supports well-being.

WAIKUA AND MANA

Having one's mana acknowledged and upheld influences the sense of waihua and overall experience of well-being.

KO AHAU

Feeling connected to one's personal cultural identity as Māori, and this being recognised and supported, helps ground people.

RANGATIRATANGA

Whānau feeling a sense of autonomy and control over their health recovery journey enhances their personal and collective well-being.

We thank our advisor, Rukingi Haupapa (Te Arawa, Ngāti Whakaue) for identifying kupu that reflect the experiences of whānau Māori



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