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Care attends to the emotional impacts of stroke



PEOPLE FEEL HEARD AND SUPPORTED AS THEY NAVIGATE THE EMOTIONAL IMPACTS OF STROKE.

Introduction

Care attends to the emotional impacts of stroke

"The nurse picked up on how my husband was feeling and was always available for a chat."

Family member, Pākehā

The emotional impacts of stroke are common. Many people described deep distress during their time in care. People need healthcare professionals to attune to their emotional experience.

When this aspect of care is working well, healthcare professionals recognise that stroke commonly has significant emotional impacts and are attentive to the emotional responses of people affected by stroke and their whānau and friends. Healthcare professionals intentionally provide opportunities for people to express their feelings if they wish to do so. This is helped when healthcare professionals show genuine interest and availability through unhurried, empathetic interactions. They talk to people about the emotional impacts of stroke and the fact they are common, but also validate the person's experience without minimising it. People and whānau impacted by stroke receive psychologically informed care. This includes access to culturally safe counselling or psychological support if they choose. People are encouraged to access cultural supports from outside stroke services if they feel this would be beneficial. This approach to care helps people to feel heard and supported as they navigate the emotional impacts of stroke.

Attending to the emotional impacts

An example of a positive approach to attending to the emotional impacts of stroke

Alex is navigating the changes that stroke has brought to her life. She has struggled with a loss of independence and experienced significant anxiety since the stroke. Her family have been supportive, but Alex also recalls influential staff throughout her care who were attuned to and supportive of her needs. For example, she remembers a nurse who brought her great comfort on the first night after her stroke.

“She just spent a lot of the night with me. I really was disturbed, couldn't sleep and I was restless, and she just was there, and then she'd say, 'look you're not comfortable, how about you sit on the side of the bed for a while?' and lean on the moveable table thing... she really was marvellous. And she wasn't in a hurry. It was as if 'well no one else needs me, I'm here to help you' sort of thing, you know?”

Small gestures early in care – such as a nurse touching her hand empathetically – made Alex feel cared for at a time of fear and vulnerability. As her hospital stay progressed, Alex appreciated staff who did not try to avoid challenging emotions or difficult conversations, but rather acknowledged her emotional experience.

They would let you say, 'I have had a shitty night' or 'I've had a bloody horrible day' and they will agree with you, or they will let you say it. But then they will say 'well come on then, see if we can make it different' or 'see if we can do this and get you out of here and dressed' or something like that. But they do let you, and the good ones say 'I can understand that' or you haven't had such a good day. Do you think today will be better?' 'Shall we go for a better day today?' I think you can pick those people that you can say that to.”

In addition, she found the seemingly small conversations had 'in between' other activities very supportive. During therapy sessions, for example, her physiotherapist or OT would ask how she was coping and whether anything was on her mind. Alex appreciated the way her therapists prioritised time to listen when she needed them to and they were happy to put their activities to one side to let Alex talk about what she was worried about.

Recommended actions

- The emotional impacts of stroke are proactively talked about so people don't feel they are the only ones feeling this way.
- Healthcare professionals ask how people are feeling, and what they feel would be most helpful for their emotional well-being.
- Healthcare professionals explicitly take time to listen to people and validate, but not minimise, their experience.
- Healthcare professionals are unhurried, and empathetic in the way they engage.
- People and whānau are offered access to social work and psychology support.
- Emotional care is culturally safe, including the offer of culturally grounded counselling and supports.
- Healthcare professionals support people to access the emotional support they need, including from outside of formal stroke services when needed.
- Healthcare professionals have the knowledge and skills to support people through difficult emotions, and the confidence and willingness to have emotionally challenging conversations.
- Healthcare professionals recognise that emotional well-being is not distinct from physical well-being.
- Healthcare professionals understand that emotional well-being is more than the absence of anxiety and depression.
- Healthcare professionals recognise that for many whānau Māori, emotional well-being incorporates attention to wairua (spiritual well-being) and hinengaro (mental well-being).

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Person with stroke, Pākehā

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“The nurse picked up on how the person was feeling and were always available for a chat.”

Family member, Pākehā

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“It's good talking to the psychologist, I find... If I talk about stuff and get it off my mind that normally eases my mind – I don't think about it all the time.”

Person with stroke, Pākehā

Attending to the emotional impacts

What people described when they perceived a lack of attention to their emotions

- Physical recovery is prioritised with little acknowledgement of the emotional impacts of stroke.
- People feel their experiences are minimised or dismissed.
- Healthcare professionals appear rushed, inhibiting people with stroke from reaching out to them.
- People feel pressured to mask their true feelings and stay overtly 'positive'.
- Healthcare professionals avoid or 'skirt around' emotionally challenging conversations.
- There is no access to counselling or psychology.
- There is no access to culturally informed, or culturally safe counselling or psychology.



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“Sometimes we tend to not speak the truth because we feel like lots of expectancy. Sometimes we are afraid, or I felt like I was afraid. Because the community rehabilitation team would be ‘oh you are looking good’ after maybe the second, third week they would say ‘oh you are looking much better’ but I felt physically better, but it doesn’t mean to say that I was mentally better. I just sometimes went ‘oh I am good, I am ok.’”

Pacific person with stroke

“Either the staff are too busy or, I don’t know exactly what the problem was, it’s just that... getting to people’s mindset of where they are to understand them, put that work in to... sit down and see where that person’s, state they’re in and then make a plan around that. That’s probably the biggest help people need.”

Person with stroke, Māori

Attending to the emotional impacts

An example of where there were missed opportunities to attend to people's emotions and provide support.

Oliver had an inpatient rehabilitation stay after his stroke. During this time, he became increasingly anxious and low in mood. Despite interacting with staff every day, the depth of his distress was not recognised by others. He admits that he “presents as someone who manages quite well” and so perhaps staff did not see his mood as a priority. However, Oliver was in fact experiencing anxiety and panic attacks.

“I think you are dealing with the feelings and that's all that you can cope with at the time and your mind doesn't go to how can I cope, who could help, or anything like that. You are just focused on getting through that moment.”

Over time staff became aware of Oliver's panic attacks and supported him as they happened. However, he didn't feel supported beyond that point.

“I just sort of got told that this is what they were, anxiety and then they were panic attacks. Well, they don't actually say that, they just said, 'oh you were a bit worried about going [out] and maybe you are a bit too anxious about going home, you know it's a big step' and all this sort of thing. So they didn't actually name it as such.”

While acknowledging that not everyone feels the same way, Oliver would have liked staff to discuss anxiety explicitly and support him with strategies to navigate these feelings in the future.

“For my personality and what I am like I need it labelled and then I can work out ways around it or how to deal with it or what to do with it because they must know that other side of it too.

Well, somebody who deals with your wellness or state of mind must know both sides of it. This is the outcome, and this is what you can do to get around it or these are the systems you can use or find for yourself. Whereas I find that I have had to do it by myself, reason to myself, working out what it might be, working out what I can do. And I have only got a very limited range of things I can do because I don't know much else.”

In fact, Oliver felt he had to hide his feelings in hospital.

“You are not allowed to be pissed off that you had a stroke. The unending positivity that you have to display, 'so what you've had a stroke just get on with it'. Which in itself is what people do, the majority of people must do? I don't know. But it is one thing that we totally get pissed off hearing. 'It's going to be alright, so you've had a stroke'. And it's not. It's not useful.

Whether they do that because they think people will unleash on them, get too emotional and that takes too long to deal with people with that sort of emotion and it's much easier just to say, 'right get on with it, get over it'.”

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 attend to the emotional impacts of stroke.

- What does 'emotional well-being' mean in your team? Is there a focus on mood (and mood disorders), or do you attend to a wide range of emotions that people may experience?
- What information is given to people about how the stroke might impact them emotionally?
- How do you indicate to people that there is space to talk about their emotional experience?
- Are people and whānau consistently asked about how they are coping, and what they feel would be supportive of their emotional well-being?
- How do you integrate what people say would be helpful for their emotional well-being into care? Can people access support from outside stroke services if they feel this would be helpful?
- How do you document factors relating to the emotional well-being of people and whānau?
- In being asked to have more of a focus on people's emotional needs, what thoughts and feelings come to mind? What concerns might healthcare professionals have? What might be needed to help healthcare professionals address some of these?
- Is your team equipped and able to meet the emotional needs of people and whānau? What support and education do you need to be able to provide support for people's emotional responses?
- How do healthcare professionals connect people with more specialised psychological care when needed? Do these more specialised providers need more information about stroke? How do these services provide for those with cognitive or communication issues, or people with limited English?
- How does the leadership of your service show that supporting emotional well-being of people with stroke and whānau is a priority and a legitimate use of clinical time? What messages do healthcare professionals need from their leaders?
- How is the emotional well-being of healthcare professionals supported and promoted in your service?

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

- Challenge how the mind and body are separated in stroke care processes, including building care pathways between mental health and physical health services.
- Build healthcare professional skills and competence in addressing emotional impacts of illness through including these in healthcare professional education, professional development and accreditation standards.
- Utilise existing clinical networks to provide psychological training and mentoring support across services.
- Consider how specialist roles can be created to work across services and districts to provide support for healthcare professionals.
- Build skills and competence in working with the emotional impacts of stroke in professionals outside stroke services. This includes developing providers' skills in working with people with cognitive and communication disorders and ensuring services for those with limited English and from different cultural needs and perspectives.
- Factor emotional and psychological needs and complexity into staffing and workload models.

Actions to enhance care

Service level actions

- Develop resources about common emotional impacts of stroke so people don't feel alone in their experience.
- Build healthcare professional skills and confidence in attending to emotional impacts of stroke through access to professional development opportunities.
- Offer a range of supports for the emotional well-being of staff such as professional supervision, debrief or mentoring opportunities, and access to the Employee Assistance Programme.
- Explicitly integrate emotional well-being into clinical care pathways and documentation requirements. This may include aphasia-friendly well-being screens.
- Allow protected time for social workers to provide grief counselling and emotional support within their role.
- Review the stepped care model of psychological care. Identify the current strengths and gaps in your service.
- Ensure that as a team healthcare professionals are having conversations with people and whānau about how they are feeling, and that these go below the level of "How are you feeling?" to "Why is it that you're feeling that way?"
- Share information about the person's emotions in documentation and team meetings.
- Consider who, within the team, is able to provide emotional support for the person.
- Recognise that people who have pre-existing mental health challenges are more at risk of post-stroke psychological issues. Proactively monitor and support.
- Identify cultural services in your locality that may be able to provide culturally informed emotional support for people.
- Have private spaces available within your service where people and whānau feel able to raise well-being issues.

Actions to enhance care

Healthcare professional actions

- Recognise the value of supporting people's emotional needs. This can be as simple as asking how they are feeling and acknowledging their response. Sometimes this requires a longer time.
- Build time to 'check in' with your patient into your interactions.
- Reflect on the psychological safety a person may feel in their interactions with you. If not with you, are there some healthcare professionals who the person has a stronger relationship with?
- When people are sharing how they are feeling, acknowledge and validate this (e.g. "I hear you're feeling really upset. That must be really hard".) While it can be helpful to normalise this and let people know it is common, it is important that you also validate what that individual person is feeling and sharing.
- Ask about the things that support people's well-being in life beyond stroke. What are the things that usually help them feel grounded, that might give them a sense of peace, or that bring them joy? Work to explicitly ensure that there is space for those things and those people and places within their recovery journey.
- Introduce yourself to cultural support teams in your organisation and learn about their work.
- Consider what training and support you need to support people's emotional well-being. Build this into your professional development plans.



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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