NATIONAL STROKE NETWORK

Supporting Psychosocial Well-being After Stroke

Psychosocial Working Group

National Stroke Network
Chairs: Dr Felicity Bright and Dr John Davison
November 2022

AOTEAROA NEW ZEALAND

NATIONAL STROKE NETWORK

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FOREWORD

Kia ora koutou

Across Aotearoa, people experiencing stroke and their whānau have told us about the emotional, spiritual and social challenges that they face in dealing with their life changing events. They also describe the limited resources and assistance available to help them cope with this change. Developing guidance for those of us working with consumers, supporting them though their psychosocial challenges, is a high priority for the National Stroke Network and an important component of the New Zealand Stroke Rehabilitation Strategy.

I am therefore delighted to be able to introduce this kete of knowledge designed to improve outcomes for our whānau living with the effects of stroke. This resource provides clear guidance for services. Through developing pathways for care, ensuring appropriate screening, and assessment when indicated, and timely interventions, we can improve the psychosocial health of people experiencing the effects of stroke. The emotional and social needs of our consumers is a core component of the work of which we all should be aware. This toolkit is evidence based, yet pragmatic, easily understandable and sensitve to the needs of whānau. It is an important step along the pathway and as such should be seen as a living document for all users. Future changes will respond to feedback and ideas that come from its use.

The toolkit is the culmination of a great deal of work from a number of people. The journey to develop this has been disrupted over the last two years. That we have come so far reflects the passion of those involved. I wish to thank everyone who has contributed, but in particular the leadership and expertise of Felicity Bright and John Davison. Your skills, passion and sensitve approach is inspiring.

I also wish to acknowledge the whānau who have shared their experiences. Your willingness to share the stories of your journeys with such openness and trust is humbling. It is now our job to ensure your trust in us is well placed.

Mā tō rourou, mā tōku rourou, ka ora te iwi

With your contribution and my contribution, the people will thrive

Dr Alan Davis

Clinical Lead for Stroke, Te Whatu Ora
Chair, National Stroke Network

EXECUTIVE SUMMARY

> *My life has completely changed. You might look at me and say I'm okay. But I'm really not okay. I know in my head that I'm not okay, even though I'm physically okay. My life has turned upside down. I don't know how to explain it. I don't feel like I'm me. It's hard feeling like I've lost me. The strong, capable, social me.*
>
> 45-year-old woman living with the impacts of stroke

The purpose of this document is to support health services to improve psychosocial care within stroke care provision. The document provides a structured guide for health services developing their psychosocial care pathways, and it provides a resource for clinicians developing their own competencies in supporting psychosocial wellbeing post-stroke.

Psychosocial well-being - the psychological, social and emotional impacts of stroke - has a significant impact on life after stroke. Many people experience difficulties adjusting to their stroke and changes in roles and social relationships. People can experience anxiety, depression, difficulties with regulating emotions and sometimes changes in personality. Poor psychosocial health can impact on functional outcomes, quality of life, healthcare utilisation, and even mortality. Identifying psychosocial issues early and providing information and supports in a timely manner can have many positive outcomes for the person with stroke and whānau.

Everyone in the team has a role in supporting psychosocial well-being. This includes whānau as a key part of the person's team. They bring their own expertise and provide support beyond services. Team members need support to build their confidence and capability in supporting well-being. The well-being of the care team, which includes whanau and healthcare professionals, is also important if they are to be able to support others.

To provide comprehensive care, it is recommended that every stroke service develops a psychosocial care pathway. Whanaungatanga is at the heart of psychosocial care, and within all stages of the pathway, there should be an emphasis on building and strengthening meaningful connections between the person with stroke, whānau, and clinicians. Pathways should be developed with Māori advisors to ensure care is culturally safe and responsive, and that pathways can achieve equity. Whanau should have the opportunity to be involved at all stages of care.

As detailed in this document, pathways should include:

- Processes to regularly review well-being throughout the person's episode of care.
- Integrating of specific psychosocial-oriented questions into disciplinary assessments
- Validated psychosocial screening at least once during an episode of care, and diagnostic and risk assessments if indicated
- A 'stepped care' approach, with proactive supportive care provided to all people with stroke, and more specialised interventions provided as appropriate.
- All services should have access to psychological support, and pathways should exist to ensure timely referral and review by specialist providers.
- Action plans for supporting well-being; support may be provided by whānau, stroke/rehabilitation clinicians, and specialist mental health clinicians.
- Psychosocial needs and care should be addressed within discharge planning and transitions of care, with effective documentation and communication.

This resource is the first in a series of outputs to enhance the effectiveness and consistency of psychosocial supports within stroke services across Aotearoa. This will be supplemented by a series of materials such as: webinars and in-services to build knowledge and skills in psychosocial care; training to provide psychosocial supports at levels 1 and 2 of the Stepped Care model; and a community of practice to share knowledge and practice across Aotearoa. Further refinement is expected as we build our knowledge of how best to provide culturally responsive psychosocial support in Aotearoa.

On behalf of the Psychosocial Working Group
Felicity Bright, PhD and John Davison, PhD

CORE PRINCIPLES OF SUPPORTING PSYCHOSOCIAL WELL-BEING

Psychosocial well-being is everyone's business.

Every member of the team has a role in supporting well-being after stroke.
All team members need the training, skills, support, and supervision in supporting well-being.

Whanaungatanga is the foundation for psychosocial care

Psychosocial care is best provided in the context of a mutual relationship where people feel welcome, known, and have a sense of connection with the person they are working with.

Services should offer proactive rather than reactive psychosocial support

Services should take a preventative and proactive approach to supporting well-being. This includes creating a care environment which is welcoming and engaging for clients and whānau and responsive to different perspectives of health and well-being. Recognising and supporting the well-being of everyone – people with stroke, whānau and staff – is important in creating this nurturing environment.

Every service needs a psychosocial screening pathway and access to specialist psychological supports

People should know how and when to screen, when to refer for specialist support, and how to ensure screening is adapted for those with cognitive and/or communication needs. People's psychosocial needs must be clearly communicated throughout transitions of care.

All team members should be able to provide core psychosocial support, but services should have access to psychology for people who require more specialist support.

Psychosocial care must be culturally safe and responsive

Screening practices, psychosocial supports and broader service provision must be culturally safe and culturally responsive.

Staff need a range of tools in their kete to ensure they explore and acknowledge what may be important for the person with stroke and for whānau, and that they can create an environment that is welcoming and supports connection and well-being.

As services are developing their psychosocial care pathways, they should ensure Māori are involved in co-designing, delivery and monitoring of these pathways.

Involve whānau at the beginning

Whānau are a core resource in supporting well-being. Taking a strengths-based approach, exploring, supporting and building on the strengths and knowledge of whānau, is important.

Psychosocial care should consider how whānau well-being has been impacted by the stroke, and what supports they need to maintain their own well-being. Whānau need to know what services are available to them.

Supporting psychosocial well-being in stroke services

Background and introduction

THE ACTION PLAN FOR STROKE REHABILITATION

All patients with suspected psychosocial needs are screened and where needs are identified, are offered appropriate timely interventions

The Action Plan for Stroke Rehabilitation

The Action Plan for Stroke Rehabilitation [1] has been developed to improve outcomes for people after stroke . Focus Area 2.1 of the Action Plan informs that *"all patients with suspected psychosocial needs are screened and where needs are identified, are offered appropriate timely interventions".* This is a key performance indicator that all services are expected to meet. Given all people with stroke may experience some psychosocial impacts, screening and psychosocial support should be offered to all people with stroke. This resource has been developed to support services in meeting these expectations and in reviewing and developing their psychosocial care pathways .

The need to attend to people's psychosocial well-being

Most, if not all people with stroke experience some psychosocial impacts of stroke as they adjust to this significant change in life circumstances. This can include grief and loss, disruption to one's identity, hopelessness and loss of control, changes in roles and social relationships, and for some, anxiety and depression [2].

Following stroke, many people experience poor psychosocial health. Clinical mood disorders such as anxiety and depression are common. Approximately 25% of people experience anxiety after stroke; this rate nearly doubles when one has aphasia [5]. Around 31% of people experience depression after stroke, whilst the incidence is ~65% in those with aphasia [6]. Poor psychosocial function is associated with poorer functional outcomes, reduced quality of life, higher mortality and greater healthcare utilisation [7, 8].

Psychosocial well-being is multi-faceted and a key contributor to quality of life. Well-being supports engagement in rehabilitation and activities that are meaningful to the person following a stroke. It comes when people have strong self-identity, good social relationships with whānau, friends and other stroke survivors, hope for the future, a sense of purpose and meaning, and a generally positive mood [3, 4]. Te Ao Māori models of hauora describe the importance of holistic understandings of health and well-being, seeing physical, psychological and spiritual health as being entwined [3, 4].

To support people in their recovery from stroke, it is critical that healthcare professionals explicitly attend to people's psychosocial needs. Identifying psychosocial issues and providing supports in a timely manner can have many positive outcomes for stroke survivors and their whānau.

About this resource

Supporting well-being requires multiple lines of work: prevention, screening and early assessment and intervention for psychosocial issues. This resource reflects the Action Plan's specification of developing a model of stepped care for use in Aotearoa and is designed to support services to develop and implement a process for ensuring "all patients are screened for psychosocial needs using a validated screening tool and/or psychosocial assessment"[1]. Additional resources to build peoples' confidence and capability in supporting well-being will be developed over time.

We present the resource in five sections:

Development of psychosocial pathways in stroke services.

This section discusses core principles of good psychosocial care that are relevant to all after stroke, including the importance of whanaungatanga, supporting rangatiratanga, and embedding well-being in everyday conversations with people.

Creating an environment that supports well-being.

This section provides an overview of psychosocial screening pathways and an introduction to the Stepped Care model for stroke.

Screening for well-being.

This section presents structured approaches to screening well-being, providing details of recommended screens, and suggestions for how screening can occur.

Action plans to support well-being.

This section provides information about how services can provide supports at each level of the Stepped Care model.

Whānau well-being.

This section presents suggestions for how to support whānau well-being.

This resource is not exhaustive and is a living resource which will continue to be updated over time. We welcome services sharing their resources through the National Stroke Network.

Development of the resource

This resource reflects the work of the Psychosocial working group of the National Stroke Network. The group is comprised of Māori and tauiwi members. They include providers from across from across the continuum of care, academics, community stroke advisors and people with lived experience of stroke. Full details of the group are in the Acknowledgement section . This group developed this document based on multiple reference points: priority setting within the group, a national survey of current practice, a review of the literature and international guidelines, interviews with stroke service leaders throughout Aotearoa, and consultation with subject matter experts.

Creating an environment that supports well-being

CREATING AN ENVIRONMENT THAT SUPPORTS WELL-BEING

Taking a proactive approach to supporting well-being by enhancing the physical, interpersonal and spiritual environment of stroke services will positively impact on people's recovery and their well-being, improve the reliability and effectiveness of our psychosocial assessments and interventions.

Whanaungatanga: 'get to know me before you fix me'

Whanaungatanga, the presence of meaningful connections and relational linkages, is core to engaging and meaningful stroke care [12]. Whanaungatanga should underpin, and run through all aspects of psychosocial care, and requires attention in its own right throughout the episode of care.

Clinicians should invest time in whakawhanaungatanga: engaging and building connections with people with strokes and their whānau. This shows manaaki (care) and aroha, builds genuine relationships and sense of wairua, and helps create a space where people feel welcome and supported and trusting in their clinicians, and comfortable sharing.

Services need to be flexible to ensure that staff have the time and flexibility to build genuine connection is built, and that the key people who need to be involved in screening are there (e.g. whānau).

Incorporating cultural practices in screening processes is one way of creating space for whanaungatanga. Models such as the Hui Process [14] may provide a framework for engagement. This refers to the processes of mihimihi (initial greetings and engagement), whakawhanaungatanga (building connections), kaupapa (attending to the main purpose of the interaction), and poroporoaki (closing the session). It is important to attend to each process before going to the next, whilst also recognising that whakawhanaungatanga is not a 'one off' – there needs to be continued attention to building and maintaining the connection throughout and across sessions.

Correct pronunciation of te reo Māori and other languages is important and will strengthen the ability to communicate and develop a connection or reconnect through this process of whanaungatanga. The use of te reo Māori in conversation, signage and resources also shows acknowledgement and respect for tangata whenua [15].

Te Whatu Ora Whanganui's acute and rehabilitation stroke service take a preventative approach to well-being.

Details can be found on page 47

As the **REACH community rehabilitation team at Te Whatu Ora Southern** developed their screening processes, they engaged with the Māori Health team. working to build time and space for whanaungatanga into their interactions.

Details can be found on page 47

Support rangatiratanga

When people have autonomy and control, it supports well-being. The person with stroke should decide who is involved in their care. It should be made clear that whānau are welcome as active partners in care, actively involved in information-sharing and decision-making.

All staff need to be able to support communication and well-being

All staff should have the skills to communicate with people with aphasia or other communication and cognitive impairments. Communication supports should be readily available on the ward and all staff should know how to use them.

All team members should be cognisant of people's psychosocial needs after stroke and should know what they can do to support them. People should feel confident and competent to provide this support. Team members include non-clinical staff such as ward staff and cleaners.

Whānau: A person's medicine

A person's medicine includes their whānau. Whānau are a source of well-being that are present before, during and after stroke, and "a functional unit of healing" [16].

Whānau hold knowledge of the person with stroke and are an important part of the stroke rehabilitation team. They are often a key source and support of well-being during and after discharge from services. It is important for teams and services to recognise how whānau support the person and also consider the well-being needs of whānau. Furthermore, when one person's well-being is affected, the whānau unit is impacted (see page 33 for more information about supporting whānau).

The physical environment should be welcoming and set people at ease

Enhancing the physical environment supports well-being and people's engagement with services (18). How are whānau welcomed into the space? How are people able to have privacy, time for rest, and space for socialising and daily activities? How are people’s identities evident in the environment through therapy materials, signage, and images?

Encourage people to personalise their environment so they feel comfortable, enhanced mana, greater connectedness, and a sense of at-homeness – e.g., photos of whānau, images of their hobbies, interests, their own clothes, a quilt from home, and easy access to technology for connecting with those important to them.

Māori models of hauora

Existing models that draw from and ground Māori perspectives of hauora include: Te Whare Tapa Whā, Te Wheke, Te Pae Mahutonga and the Meihana Model. These models provide invaluable understandings of hauora when working with Māori post-stroke. In a clinical setting, they can be helpful to:

- Facilitate and guide meaningful engagement with clients and whānau
- Identify areas of hauora that are fundamental to the person and whānau, and potential areas impacted by the stroke
- Guide clinicians in considering aspects of hauora important in supporting psychosocial well-being
- Structure clinical processes (assessments, interventions, and documentation) that are culturally responsive for Māori

Different whānau will draw on different models of hauora. Because of this, it is important to talk with whānau about what supports hauora and oranga (well-being), and work with their whānau, hapu, or iwi models of well-being.

Development of psychosocial care pathways in stroke services

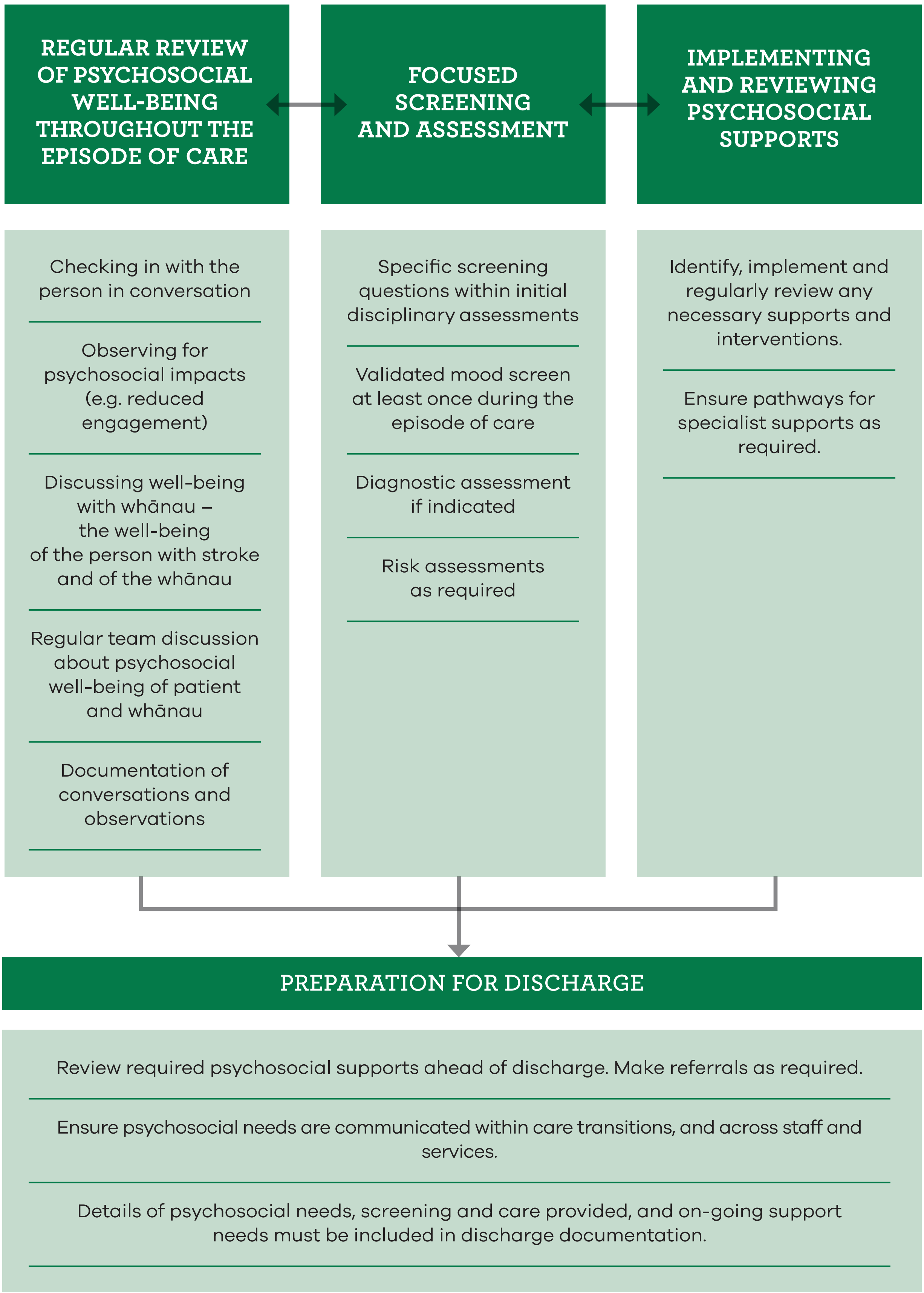
DEVELOPMENT OF PSYCHOSOCIAL CARE PATHWAYS IN STROKE SERVICES

Screening pathways should enable comprehensive screening, assessment, and support processes. These should incorporate a variety of screening approaches, mechanisms for supporting team conversations about well-being, processes for reviewing well-being, clear identification of psychosocial supports within and external to the team (including pathways for referral to specialist service providers), and processes for promoting communication as people transition through services, including information about how people can access specialist psychosocial services after discharge.

Services should develop a screening pathway that is fit-for-purpose for their patient group, service structures, and available supports. In developing a pathway, it will be important to connect with mental health teams within the locality, and with mental health support services in the NGO/volunteer sector.

Rangatiratanga and oritetanga should be at the heart of service development. Pathways for whānau Māori should be Māori led and developed, and ideally, be Māori delivered. Rangatiratanga can be expressed through Māori leadership or opportunities to 'take charge' over the direction and shape of their own organisations, communities and development [9]. At the very least, there needs to be consultation with Māori health services and Māori providers, and proactive monitoring of service provision, experience and outcome (e.g. through audits, feedback from whānau for new services or resources) to ensure equity is achieved.

> Services should develop a screening pathway that is fit-for-purpose for their patient group, service structures, and available supports



COMPONENTS OF A COMPREHENSIVE APPROACH TO PSYCHOSOCIAL CARE

REGULAR REVIEW OF PSYCHOSOCIAL WELL-BEING THROUGHOUT THE EPISODE OF CARE

- Checking in with the person in conversation
- Observing for psychosocial impacts (e.g. reduced engagement)
- Discussing well-being with whānau – the well-being of the person with stroke and of the whānau
- Regular team discussion about psychosocial well-being of patient and whānau
- Documentation of conversations and observations

FOCUSED SCREENING AND ASSESSMENT

- Specific screening questions within initial disciplinary assessments
- Validated mood screen at least once during the episode of care
- Diagnostic assessment if indicated
- Risk assessments as required

IMPLEMENTING AND REVIEWING PSYCHOSOCIAL SUPPORTS

- Identify, implement and regularly review any necessary supports and interventions.
- Ensure pathways for specialist supports as required.

PREPARATION FOR DISCHARGE

- Review required psychosocial supports ahead of discharge. Make referrals as required.
- Ensure psychosocial needs are communicated within care transitions, and across staff and services.
- Details of psychosocial needs, screening and care provided, and on-going support needs must be included in discharge documentation.

Stepped Care model

Universal psychosocial support should be provided to all people with stroke, with more complex, specialist interventions provided if required. This reflects the Stepped Care Model, a model of care that is widely used in mental health and in psychosocial care after stroke [10,11]. It has three levels:

Level One: Care that is offered to everyone and can be provided by all team members

Level Two: Care that is offered to those whose needs are impacting on engagement and everyday life. This can be provided by clinicians with advanced knowledge of stroke and well-being.

Level Three: Care for those experiencing persistent and/or severe psychological difficulties. This is provided by psychologists and psychiatrists.

Not all patients will progress through these levels in a sequential manner. Over the course of their recovery, people may move through the layers several times.

The Stepped Care approach makes best use of best use of the skills of the multi-disciplinary team and utilises more specialist staff for the patients with complex problems that require specialist help [11]. The diagram below shows the Stepped Care model for psychosocial care after stroke.

Stepped Care model for psychological care after stroke

(Gillham & Clarke, 2011)

LEVEL 1

Sub-threshold’ mood changes at a level common to many or most people with stroke.

This can include normal expressions of grief and loss, stress, mood and anxiety, which are mild, fluctuate during the day, and have little impact on engagement in rehabilitation and daily tasks.

Level One support can be provided by whānau, peers, and all of the healthcare team

LEVEL 2

Mild to moderate psychosocial symptoms or difficulties that interfere with rehabilitation or daily tasks.

This may include depressed mood, anxiety and panic, emotional lability, agitation, apathy or loss of motivation, which may contribute to sleep and appetite difficulties and impact on rehabilitation and daily life.

Support with screening, education, brief interventions, goal-setting and problem-solving should ideally engage whānau, and can be supported by non-psychologist stroke specialist staff (with support/supervision by psychologists with stroke expertise) or by clinical psychologists.

LEVEL 3

Severe/persisting psychological difficulties.

These are diagnosable and require specialised intervention, pharmacological treatment and suicide risk assessment, and for which treatment at Level 1 and 2 are not sufficient.

Intervention of clinical psychologist, neuropsychologist and/or psychiatry, ideally with specialist expertise in stroke. Whānau should be involved wherever possible

Psychosocial screening

CORE PRINCIPLES FOR PSYCHOSOCIAL SCREENING

Whanaungatanga is foundational and should be prioritised.

Psychosocial screening – informal or through validated screening tools – occurs best in the context of a mutual relationship where people feel welcome, known, and have a sense of connection with the person they are working with.

Screening occurs in multiple ways and at multiple time points.

Psychosocial screening is not a one-off event.

Screening processes should include a combination of screening approaches; conversations with the person and whānau, observation, structured questions, validated mood screens, and diagnostic assessments where indicated. These all need to be documented.

Mood screens need to be interpreted with caution: combining information from different sources is important for identifying issues and support needs.

Screening needs to be accessible for those with communication differences and impairments.

A number of screening tools have been designed for people with post-stroke communication impairments. Involving speech-language therapists in screening can improve the screening process and outcome.

Whānau, interpreters, and/or cultural advisors should be included for people from culturally and linguistically diverse backgrounds

Screening should consider people's holistic well-being needs.

Within screening, it is important to attend to the different ways psychosocial well-being can be impacted. Formal screening tools commonly focus on depression and anxiety, but other aspects such as adjustment and identity are important to consider as are cultural aspects of well-being.

Appropriate action plans should be developed and implemented.

Observations and results should be shared with the person with stroke, other team members, and with their whānau, if appropriate. These should be documented in discharge documentation.

Action plans need to be developed and implemented in a timely manner and need to be monitored over time.

PSYCHOSOCIAL SCREENING

All stroke services should have a process for screening for psychosocial needs.

Screening helps ensure psychosocial needs are identified early; this can facilitate well-being and improve people's engagement and motivation in rehabilitation.

All stroke services should have a process for screening for psychosocial needs. Screening helps ensure psychosocial needs are identified early; this can facilitate well-being and improve people's engagement and motivation in rehabilitation. Psychosocial well-being should be considered within the initial assessments of all disciplines and monitored in the weeks and months after stroke.

Psychosocial screening can occur through multiple means: conversation and observation, semi-structured interviews, validated screening tools, and diagnostic assessments. All members of the stroke team can screen for psychosocial needs with appropriate training and support. Diagnostic assessments need to be completed by appropriately qualified healthcare professionals (e.g. medical or mental health providers).

Ensuring screening processes are culturally responsive, culturally safe, and engaging is critical to improving equity and better health outcomes. This helps create positive and empowering interactions with the healthcare team, and can help achieve equity for whānau Māori.

Every person with stroke should have a **validated mood screen** in the first few weeks after stroke – although formal screening is not recommended in the first week after stroke. If there are any concerns about mood *after* this time, a validated screen should be completed. Key timepoints when screening may be particularly important are:

- At point of transfer to, or during, inpatient rehabilitation
- Before discharge to the community, or before discharge from community services
- During routine follow-up in primary care or stroke review clinics [14, 15].

People who require further assessment or intervention should be identified early, provided with supports appropriate to their level of need, and referred for specialist support (if required) as soon as possible.

Informal screening: Supportive conversations and observations

Psychosocial well-being should be considered at all times throughout stroke care. Well-being can be reviewed through **conversations** with the person with stroke, their whānau and friends, and via **observation.**

Supportive conversations or observations might be brief check-ins, short chats or extensive discussions. It might simply be a 30 second check in at the beginning of a nursing shift or medical review, a few questions during an initial assessment, an informal five-minute discussion before or after a rehab session, or a longer chat with them or whānau if it appears their mood and motivation is causing them difficulties. These should be two-way conversations, going beyond asking questions to having a conversation about how things are going.

You don't need to 'fix' their mood; simply create an accepting and supportive space for them to share, ask questions, and reflect if they wish.

It helps to be down-to-earth, demonstrating care for the person, and being non-judgemental of how they are adjusting to their stroke. You don't need to 'fix' their mood; simply create an accepting and supportive space for them to share, ask questions, and reflect if they wish. Creating an environment where people feel safe to talk and to ask questions is invaluable.

The sooner that difficulties are noticed, or the sooner that improvements are noticed, the more proactive and supportive providers can be.

Be mindful about how questions are framed. This may be particularly important for Māori, Pacific peoples, and those from non-English speaking backgrounds. Use interpreters if needed. Minimise technical words and use more everyday, informal language. More questions may need to be asked both to clients and whānau. When providing information, ensure this is shared in ways, and at times, that facilitate understanding and are responsive to the needs and priorities of the person and their whānau.

Pay attention to changes in mood and behaviour over time. The sooner that difficulties are noticed, or the sooner that improvements are noticed, the more proactive and supportive providers can be.

Checking in about well-being through conversation

Simple questions to explore how people are doing

How are you feeling today? How's your mood or spirits? Is anything bothering you? How are you feeling in yourself?

If integrating Te Whare Tapa Whā into practice, consider questions that address the different elements of hauora:

- Tinana: *How are you feeling physically?*
- Hinengaro: *How are you feeling emotionally - your mood and energy? Is there anything weighing on your mind?*
- Whānau: *How are you and your whānau coping or navigating things currently? Is there anything you are worried about for your whānau? What role do your whānau play in your well-being?*
- Wairua: *How are you feeling spiritually? How would you describe your overall feeling or energy? Is there anything standing out strongly?*

Comment on your observation

You look more (refreshed, motivated, tense, down, restless) than last time – how are you feeling? Is there a reason for this?

Simple 0-10 scales can be helpful. Ask them to comment on the intensity of their mood. 10 reflecting most intense and 1 reflecting least intense.

- *Yesterday you said you were feeling 9/10 in depressed mood and really fed up with life; are you feeling similar today or different?*
- *Before we started this transfer to your wheelchair you were feeling really anxious – 9/10. How about now that we are finished?*

Use people's own language

Pay attention to the words they use to describe their mood: *e.g., "whakamā" "down in the dumps", "tired", "pissed off", "amped".* Explore the reasons for this, and what people think might help. Sometimes, 'simply' acknowledging that these feelings are there is enough, but come back and revisit this at later times.

case study

Example of screening approaches

Te Whatu Ora Counties Manukau's Community Rehabilitation Service uses multiple approaches to screening and supporting well-being that is embedded within car processes. Details of their approach can be found on page 48.

Example of screening approaches

Early Discharge and Rehabilitation Service (EDARS) at Te Whatu Ora Waitematā screens well-being at multiple points during a person’s six week rehabilitation programme, requiring information on the referral form, and holistic screening by alied health and nurses. Details of their approach can be found on page 48.

Simple check-ins with whānau and friends

This has been a big change for you and whānau – how are you coping?

How do you feel [Person] is coping? Do you have any concerns about them?

- Is this mood or behaviour (e.g, quiet, tearful, aggressive) normal for them or new since the stroke?

Observations

Mood and behaviour changes: Are they tearful, tense, glum or agitated OR responsive, motivated, with a sense of humour?

Motivation: Are they motivated and engaged in their own cares and rehabilitation activities? Are they interacting with others?

Sleep, appetite and energy: These can all be affected by a stroke but can also be a sign of mood changes.

If concerns are raised:

- Acknowledge and normalise concerns, be empathetic, and provide a sense of hope
- Discuss with team and with whānau if consenting.
- Consider structured mood screens or risk assessments (see guidelines below)
- Consider referrals to mental health clinicians and/or cultural or spiritual support.
- Document any concerns and actions
- For practical strategies and examples see below sections on *Communication following psychosocial screening and Action Plans to Support Well-being.*

case study

Example of screening approaches

Te Whatu Ora Southern's community rehabilitation service, REACH embed psychosocial screening in their initial interdisciplinary screening form. Details of their approach can be found on page 49.

Screening with structured interviews

Initial assessments completed by any discipline or by an interdisciplinary team should include brief screening questions about client and whānau psychosocial well-being. This ideally includes questions on adjustment, mood changes, emotional lability, behavioural/personality changes and carer stress, all of which are common post-stroke. These should be documented in the patient's clinical notes.

The following questions are recommended:

Recommended questions for IDT initial assessments

1. *How do you feel your stroke/situation has affected your life and well-being (hauora)?*
2. *Have you been feeling down, depressed or hopeless over the last week?*
   Yes / No

   If Yes;
   Does this feeling come and go or does it stay with you for most of the day?
3. *Have you been feeling anxious or having difficulty stopping your worries over the last week or so?*
   Yes / No

   If Yes;
   Does this feeling come and go or does it stay with you for most of the day?

   What is your biggest worry?
4. *Do you find yourself crying or laughing more than you would normally do?*
   Yes / No
5. *Have you or anyone else noticed any changes in your behaviour or personality since the stroke?*
   Yes / No

   If Yes;
   What have you or others noticed?
6. *How do you think your whānau are adjusting after your stroke?*
7. *What do you think might be most important for you and your whānau's well-being/hauora for the next few weeks?*

If any concerns raised from above questions, consider formal mood screen and further discussion about current stressors and goals.

Screening using validated screening tools

All stroke patients should be screened for depression and anxiety with a simple, brief, validated measure at least one time point after stroke. These measures cannot be used to diagnose mood disorders, but they provide a measure of symptoms and severity that can help guide further assessment and intervention.

Some validated screening tools require staff to be trained to administer them.

Things to consider when using validated screening tools

Places of screening: Face-to-face and private. Screening tools are ideally administered with the person face-to-face (rather than simply asking them to complete the form) and in a private space. This has several benefits: greater reliability, confidentiality of responses, reducing distractions and cognitive load, and it allows the provider to explore further if appropriate. If completing the screen in the presence of other patients or whānau, obtain consent before proceeding.

Considerations when screening via telehealth. Screening may need to take place via telephone or other telehealth mediums. As part of the conversation, it can be helpful to check who else is in the room (who might not be visible to you). Check if they are happy having others involved in the connection. If they want whānau involved, encourage them to be visible on the screen. Screening can feel more impersonal, particularly if the person is upset. 'Normal' actions such as passing a tissue or putting a hand on their arm aren't possible. Facial expression, tone of voice, and body positioning can still show empathy and concern.

Whānau involvement in screening well-being. Within the context of screening, it is important to create the space where the person with stroke has choice and control over how screening occurs. One example of this is that people should have choice over who is there when screening occurs. Many will want whānau to be present and this should be supported [13]. If whānau cannot be physically present, technology may be useful in enabling whānau to provide support.

Supporting communication needs. Ensure the person has their assistive devices present, e.g., hearing aids, glasses, microphone and/or communication prompts (see section below on supporting people with cognitive and communication impairments). Where speech and/or language impairments exist, assessments could be carried out in conjunction with the speech-language therapist.

Screening people from linguistically diverse backgrounds. When someone is from a different linguistic background screening must be conducted in the person's primary language with the support of an interpreter. If a person was multi-lingual pre-stroke and is experiencing aphasia, this may impact each language differently. The speech-language therapist will be able to provide advice about screening. It is not appropriate to use whānau as interpreters. However, whānau can provide valuable collateral information to help understand the person's usual mood, their observations of changes in mood and well-being post-stroke, and insight into cultural understandings of illness and of well-being.

Mood screens should be interpreted with caution and guided by clinical judgement. Several symptoms included in mood screens are not specific to mood disorders – they are also common following a stroke and other medical conditions. For example, reduced energy, sleep, appetite and concentration may be symptoms of the stroke itself, or they may be a sign of a mood disorder. Furthermore, people with cognitive or communication difficulties may provide less reliable responses – for example if they have difficulty remembering or monitoring their symptoms, or understanding and expressing how they feel. Take care to use the most appropriate mood screen, identify the best timing of screening, and use clinical judgement to interpret results.

Introducing the screening process

Before screening, explain why screening is happening. Mood and well-being screens are more reliable and therapeutic when clients understand the rationale and feel they can trust their clinicians.

A possible script is: "As you know, a medical event like a stroke can impact not only our brain and body, but also our sense of self and our confidence. As well as monitoring how your body is adjusting to the stroke, we find it helpful to check how you are adjusting to your stroke to make sure we are supporting you as best we can. I would like to ask some questions about how you have been feeling lately – is this ok? Do you have any questions before we start?"

It is helpful to talk about how screening and supporting psychosocial well-being can support people's goals and priorities.

Recommended screening tools[2]

All screening tools have pros and cons. The following mood screens are recommended because they have been validated for people following a stroke, are relatively easy and quick to use, are familiar to providers and GPs within the NZ health system, and they are freely available.

For people without a significant cognitive or communication difficulty

The PHQ-9 and GAD-7 can be administered as a single page form to provide a measure of both depressive (PHQ-9) and anxiety (GAD-7) symptoms. In addition to providing a checklist of mood symptoms, the total score can provide a general indication of the severity of these symptoms, from normal to mild, moderate and severe.

- **PHQ-9 :** Patient health screening tool for depression symptoms with 9 questions, addressing the symptom criteria for major depression, including 1 question about suicidal ideation. View PHQ-9 here
- **GAD-7 :** Generalised anxiety screening tool for anxiety symptoms with 7 questions relating to anxiety disorders and panic. View GAD-7 here

The Hospital Anxiety and Depression Scale (HADS) is an alternative to the above. Users may be required to pay for it. It provides a measure of both depressive and anxiety symptoms, is validated for people with stroke, and is less confounded by somatic symptoms than the PHQ-9 and GAD-7.

Examples of validated screening tools in integrated stroke care. Taiao Ora, the integrated stroke service at Te Toka Tumai completes the PHQ-9 and GAD-7 with every patient, and uses the SADQ-10 or DISCs for people with significant communication issues.

More details of their approach can be found on page 49

For people with communication difficulties

People with aphasia have higher rates of anxiety and depression post-stroke. Screening processes need to be modified to ensure people can fully participate. Some measures have been developed for people who experience cognitive and communication issues, although some people will be able to complete the PHQ-9 and GAD-7 if supported conversation strategies are used (see below). The speech-language therapist plays an important role in decision-making about how screening should occur.

Screening for depression

- The Stroke Aphasic Depression Questionnaire (SADQ-10) is a tool for screening for depression in people with cognitive and/or communication issues after stroke. There is a hospital version and a community version. It is an observational screening, completed by a carer or someone close to the person with stroke.
- The Depression Intensity Severity Circles (DISCs) can be a useful tool for people with more severe aphasia or cognitive impairments. The DISCs is a pictoral scale rating the intensity of depression from the perspective of the person with stroke. It does not provide information on different depressive symptoms but can provide a simple screen for monitoring severity of their self-reported mood state.

Screening for anxiety

- The Behavioural Observation of Anxiety (BOA) is a rating scale completed by a significant other, rating for symptoms of anxiety and may be useful when someone has significant aphasia.

Strategies for supported conversations

- Simplify the language you use
- Use short sentences and pause in between so people have time to process what you are saying.
- Supplement your question with visual supports: write key words and use gesture to convey meaning
- Write down possible responses (or use pictures) so the person can give their response by pointing. Having some laminated response sheets with possible answers may be helpful.
- Ensure the environment supports communication: quiet with no distractions, good lighting, each person is able to see the other.

Screening for psychological risks

Suicide attempts are twice as likely for those with a stroke and are highest in the first 2-5 years post-stroke [16]. Suicide risk factors post-stroke include younger age, post-stroke depression, previous mood disorder or self-harm, higher stroke severity, cognitive impairment, persistent and poorly controlled pain, substance use or withdrawal, and lower education or income [17].

Distress and thoughts of death & suicide are common as people process the reality of their stroke and consider how to resolve challenging situations. They may think or openly talk of death or suicide: ‘I’d rather be dead’, ‘I should’ve died’, ‘I’ve had enough’, ‘there’s no point’.

The risk of self-harm is on a continuum from low risk to imminent risk. Many people will have passive and fleeting thoughts post-stroke such as ‘I can’t cope’ and ‘I wouldn’t mind if I didn’t wake up’. Others can develop more serious considerations of self-harm – with active intent and plan of self-harm. Self-harm attempts can occur with preparation (e.g. stockpiling medications) but can also occur impulsively during a time of distress or helplessness.

It is important to note:

Suicide risk will not be increased by a professional asking about the possibility of suicide.

Healthcare professionals should:

- Be aware of self-harm risk factors
- Take expressions of self-harm seriously
- Be familiar with simple risk questions
- Follow protocol on managing self-harm
- Ensure clear communication with team and senior/expert clinicians

Teams should have contact information for local mental health and crisis teams easily available, both for consultation and to provide to clients and their whānau.

If a clinician is worried about someone’s safety, they must inform the appropriate clinicians involved in the person’s care even if the person requests that they do not do this. This process should be discussed in a transparent and supportive manner. Information that is shared to others should be only on a ‘need-to-know’ basis, unless permission is given from the person.

It is important to note: Suicide risk will not be increased by a professional asking about the possibility of suicide.

Be prepared: Clinicians should have easy access to local mental health crisis numbers for themselves, clients and whanau.

How and when to ask about suicide

Check	*It sounds like you are feeling really down. Have you been having thoughts of death or dying? Have you been thinking of ending your life?*
Be empathic	*This has been a really tough time. It sounds like you have been really upset.*
Plan	*Have you had thoughts about what you might do to hurt yourself?*
Intention	*How likely do you think it is that you would go through with it today / this week? What would stop you from doing it?*
Inform client of responsibility	*I may need to let our doctor / psychologist / senior staff / whānau know what we have been talking about. Anything else you think would be helpful?*
Communicate & action	Inform senior team member to develop support plan. A decision about risk and risk management needs to be made by someone with expertise. Document concerns and plan in notes. If immediate risk concerns, consider: • Ensure safe environment and remove means of self-harm • Contact psychology/psychiatry or mental health crisis line • Observation and monitoring of self-harm expressions or behaviours, agitation, depressed mood, anxiety, and refusal of drink, food, cares or socialising. • Informing whānau or carers and discuss support plan

Screening tools for Māori

The screening tools mentioned are all based on Western constructs of well-being and many are focused on symptoms and diagnoses. A number of Māori measures have been developed which are informed by Māori models of health and well-being, and which are commonly strengths-based. It might be appropriate to discuss screening approaches with the Māori health team, or other Māori advisors to determine what is appropriate for your service .

These tools include:

- Hua Oranga. Hua Oranga is based on Te Whare Tapu Whā. It asks about the different domains of well-being (tinana, wairua, whānau, hinengaro) and has tools to support action planning after completing the measure.
- Te Waka Kuaka explores the cultural needs of whānau experiencing brain impairment. Whilst it has been developed for people with traumatic brain injury, it is relevant for whānau impacted by stroke. **Te Waka Kuaka** has been developed alongside Te Waka Oranga which is a tool for whānau and health workers to share knowledge and priorities, and develop shared purpose and plans that see them work in partnership on the person's recovery journey.

Screening for broader well-being

Conversations about holistic well-being

Having conversations with patients and whānau about the wider domains of well-being may help normalise the psychosocial impacts for people and may help identify issues earlier. This means support can be offered in a timely manner. This section touches on four areas that people identify as important in well-being: adjustment, relationships, hope, and identity. The questions suggested here are not intended to be asked as part of a formal screening process. Instead, they may be interwoven into conversation at different times throughout care.

Adjustment

The process of adjustment is on-going after stroke as people make sense of what has happened, as they continue to experience changes in themselves, and as they engage in different activities. It does not have a specific endpoint [18].

Through conversation, providers might explore how people are adjusting to the stroke – their journey so far, the emotional impacts of stroke, challenges they are having, and what might help them in their post-stroke journey. This may help explore people's insight and adjustment and help you identify areas where further support is beneficial. It is also invaluable to provide reassurance about adjustment being an on-going process where people might feel a mix of emotions – some positive and some negative.

Questions include:

- How have things changed for you since you had your stroke (think: emotions, roles, identity, relationships, roles)? How do you feel about those changes?
- How do you feel you're adjusting to what's happened?
- Is there anything we can do to help you as you adjust to a new life after stroke?

Relationships

Having a sense of connection with others and a feeling of belonging within their social networks is important in well-being. Relationships often change after the stroke; this is particularly common when the person has a communication impairment.

Through conversation, providers might explore if different relationships (with whānau, with friends) have been impacted by the stroke, and if so, how. This may help identify how services can support relationships, through involving friends and whānau, providing information to friends and whānau, and working on areas important to sustaining relationships (e.g. communication, hobbies).

Questions include:

- How has your relationship been affected by the stroke? What is most important to your relationship?
- Has the stroke impacted on your intimacy or sexual relationship?
- Who else do you enjoy spending time with?
- Do you have some relationships that have improved since the stroke? Are there some relationships that you worry might be lost, or negatively impacted by the stroke?

Having hope for the future

The sense of well-being is enhanced when people feel hope and have a positive view of what their future may look like. Low hope can come from multiple areas including low mood, a sense of loss, changes in identity, and a loss of confidence in themselves and in the future. Hope can be built through re-establishing a view of a possible and desired future, positive relationships, and a sense of progress toward things that matter [19]. Processes such as goal-setting can help but it best supports hope when clinicians acknowledge people's hopes and connect short-term goals to people's broader aspirations. This also supports engagement [20].

Through conversation, providers might explore people's sense of hope for the future, what they hope for, and what they would like life to look like. Try not to focus just on what people hope for (specific hopes) but also explore people's broader sense of hope for the future [21]. Through this, providers might identify areas where rehabilitation can support hope and well-being, or where other supports might be useful.

Questions include:

- What is most important to you right now? Do you feel hopeful about the future? Why is this?
- When you think of yourself in (specified amount of time), what would you hope to be doing? What do you hope to be like? What might help build your hope for the future?
- What might help you feel more confident that the things will be okay in the future?

Identity

People's identities are ever-changing, but these changes can be particularly disruptive or unwelcome after a stroke. Many strands of what makes a person who they are are disrupted – a loss of roles or activities, a sense of disconnection to their body or to their pre-stroke self, a loss of connection to others. A loss of identity is particularly common for people with aphasia [22]. One Māori stroke patient described stroke as impacting on their "'whole āhua'… one's presence, being or identity." [23]. For many Māori, their cultural identity is crucial in supporting well-being – through reo, whānau and communities – and this needs to be acknowledged and supported [24]. It is important for services to respond to who the person is and tailor rehabilitation to their personalities, interests and their identity, acknowledging their personhood and mana in interactions and care, and seek to build people's confidence and sense of self [24, 25]. Supporting people to engage with others, and in activities that support their identity, is important.

Through conversation, providers might explore what helps people's sense of self. This might be through questions around what they enjoy doing, what makes them 'them', where they feel most contented and have a sense of belonging. It is important to delve beneath simply what people do and explore why they do it and why they enjoy it. It is also important to not assume that someone's pre-stroke identity is their desired identity. Following stroke, many work through a process of adaptation and change, and their identity is ever-evolving [26, 27]. Exploring what matters, what brings meaning and purpose, and what they want to be and be doing in the future is important.

Questions include:

- Tell me about yourself. How would people who knew you before the stroke describe you? What are the things you enjoy doing?
- Tell me about the situations where you feel you are most able to 'be yourself'? Why is this? Is there anything about you that you would like to change?
- If you think of yourself in six months time, what do you want to be like?
- What helps you feel good?

Validated screens for holistic well-being

The measures above have been used extensively to screen for mood disorders in people with stroke. However, broader measures of quality of life can provide understandings into other areas of well-being that are commonly impacted by stroke.

Measures that may be useful include:

- Stroke Impact Scale is a holistic self-report tool of multi-dimensional stroke outcomes, including physical, communicative and cognitive function, mood and role functions. It also asks people to rate their recovery from stroke.
- Stroke Specific Quality of Life Scale is a patient-centred outcome measure intended to provide an assessment of health-related quality of life for people with stroke. Like the Stroke Impact Scale, it is a multi-dimensional measure of stroke impacts across physical and cognitive function, communication, mood, personality, roles, and self-care.
- The Stroke and Aphasia Quality of Life Scale (SAQOL-39) has been developed specifically for people with aphasia . This is based on the Stroke Specific Quality of Life but has been adapted to make it easier for people with aphasia to understand and provide their answers using a range of communicative modalities.
- The Warwick-Edinburgh Mental Well-being Scale is not a stroke specific scale but provides insights into positive mental health.

Communication following psychosocial screening

After screening, findings need to be discussed with the person with stroke, their whānau (if appropriate and consenting), and with other members in the team.

Communicate with the person with stroke, whānau and team.

It is important to share your observations and screening results with both the person and those involved in the persons' care. Consider their confidentiality: only share information that is relevant to their care and goals.

Communicate with client and whānau

Summarise simply: e.g., "It sounds like you have been feeling really down recently and you feel this is impacting on your daily life and relationships."

Empathise: "This must be hard for you"

Normalise: "Adjusting to this change in life and building our confidence and sense of self can take time. It is common to feel up and down after a stroke".

Educate and provide hope:

- *"We know our mindset is important when recovering from a stroke. When we feel down or anxious, this can impact on our energy and motivation, our enjoyment of life and our relationships. It can also start to impact on our rehabilitation and recovery. It can even impact on our symptoms, because our brain focusses more on what is not working – pain, discomforts, weakness, speech difficulties etc. Have you noticed this?"*
- *"There are things that you and we can do to help. If ok with you I want to check in regularly with you (and whānau) about this. In the meantime, is there anything you think would help?*

Check with whānau: Any concerns or recommendations for the client's well-being (if relevant and client consenting).

Communicate with team

Document: Place copy of mood screen in notes; make brief comment in notes to inform team that screen is completed and general results. e.g.,

- *"Mood screens PHQ-9 and GAD-7 completed: Scores fell in normal range for depressive symptoms but severe range for anxiety symptoms. Reports not sleeping well and particularly worried about stress on partner. Plan: Discuss in IDT meeting today and develop shared goals for addressing stress and sleep.*

Team meetings (MDT meetings, Rapid Round meetings, Nursing handovers).

- Provide brief update on screening and check other providers' perspectives. Team can reflect on any concerns with motivation, engagement, safety, sleep, appetite etc.
- Team can also discuss any strengths or positives so that all of the team can build on these (e.g., *James really appreciates having a plan on his calendar for the day and an afternoon siesta and seems happiest when friends drop in).*
- Discuss action plan (see next section).

Action Plans

ACTION PLANS FOR DIFFERENT LEVELS OF THE STEPPED CARE MODEL

Level One: Support provided by the team, whānau, and others with stroke.

- Make space for people to connect with their cultural identity.
- Involve whānau.
- Acknowledge and normalise the psychosocial impacts of stroke.
- Watch and wait: keep monitoring well-being through observation, conversation and team meetings.
- Build therapeutic relationships, creating space for trusting relationships and on-going kōrero about well-being.
- Focus on people's strengths and strategies they have used successfully in the past.
- Engage in goal-setting and problem-solving.
- Provide information and education. Let people know where they can get support.
- Support people's existing social networks and help them connect with new social networks.

Level Two: Support provided by the team with advanced training and support

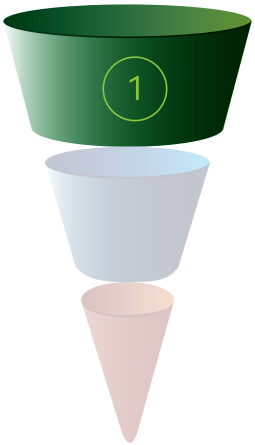
- Complete more comprehensive mental health screening and assessment.
- Provide psychologically-informed interventions such as Motivational Interviewing or Solution Focused Brief Therapy.
- Engage in goal-setting and problem-solving.
- Focus on people's strengths and strategies they have used successfully in the past.
- Ensure adequate sleep, diet, exercise and fatigue management.
- Consult with psychology.
- Consider anti-depressants.
- Connect the person with psychosocial education groups.
- Provide details for on-going mental health support.

Level Three: Support should be provided by specialist psychologists and/or psychiatrists.

- Refer for psychological or psychiatric assessment or intervention.
- Monitor psychosocial risks and commence intervention as indicated.
- Provide details for on-going mental health support.
- Consider anti-depressants.
- Ensure psychosocial needs are clearly documented as people move through stroke pathways, and provide information about how people can access specialist support as required.
- Provide clear plans for supporting the patient once they are 'sub-threshold' (level one on the stepped care model).

ACTION PLANS TO SUPPORT PSYCHOSOCIAL WELL-BEING

There are a number of things that can be done to support psychosocial well-being. Some of these apply for everyone and reflect a proactive, preventative approach to supporting well-being. Others are more specifically targeted depending on the extent and severity of the person's needs.



Level 1:
'Sub-threshold' mood changes at a level common to many or most people with stroke

This can include normal expressions of grief and loss, stress, mood and anxiety, which are mild, fluctuate during the day and have little impact on engagement in rehabilitation and daily tasks. Note that support can be provided by whānau, peers and all of the multi-disciplinary team.

Action plans can include:

Acknowledging the emotional impacts of stroke is valuable. Regardless of whether the person is currently experiencing any issues, knowing that this is common after stroke can help provide reassurance; it can also mean that people are not surprised if they have challenges later.

Continue to build and focus on therapeutic relationships. Whakawhiti kōrero: within interactions, continue to create space for care and discussion about the different impacts of stroke. The small connections can make a significant difference to people during a challenging time.

'Watch and wait': No immediate action required, but continue to monitor well-being via observation, conversation and multi-disciplinary team meetings.

Attend to how clinicians and the service demonstrate manaakitanga. Consider how people are welcomed as guests into the stroke services.

Build on people's strengths. Explore how they have coped with stress or difficult situations in the past – what has helped, who has been able to provide supports?

Practice active listening – listen for what people say, what they don't say, what comes through in their tone of voice or body language. Acknowledge this. Try and allow time for conversation so they don't feel rushed and that they know you are interested in listening. Respond in ways that encourage them to keep sharing.

Normalise, don't minimise people's issues. Providing reassurance that their reactions are common is valuable. In doing this, signpost where people can get informal support, who they can talk to, and where further professional help can be found. The team can normalise the role of psychologists in supporting adjustment and rehabilitation.

Identify key whānau who should be involved in people's care and keep conversations open with them. They often know their person best and know what is normal and not normal for them. They can help alert you to signs that the person might be struggling or might need additional support. Normalise things for them as well, and help them know how they can ask for support for their whānau member, and for themselves. Ensure that whānau are involved in decision-making if the person with stroke wishes.

Looking to the future, goal-setting, and seeing markers of progress is important in helping people feel a sense of progress, hope, and possibility. It also helps build a sense of competence. Talk about what matters to people – what brings them joy, meaning, and satisfaction. Find out why these things matter. Goal-setting should overtly orient to what is meaningful to people in their life beyond stroke. Building in indicators of progress helps people objectively see progress when it might be hard for them to feel that they are progressing.

Provide simple education and resources (verbal, written, and pictoral) for people about well-being and adjustment. Make sure this is reviewed before discharge.

Facilitating social supports and networks can help support well-being. Social networks often reduce after a stroke, particularly when the person has communication impairments. Working proactively to maintain existing relationships, and to help people develop new relationships (e.g. with others with stroke) can be helpful.

Provide culturally safe care.

If someone identifies a strong connection to a cultural identity, explore what is important for supporting them – for instance, spiritual practices, language, culturally-based approaches to healing (e.g. mirimiri, acupuncture) – and together consider how these might be supported in stroke services.

Level 2:
Mild to moderate psychosocial symptoms or difficulties that interfere with rehabilitation or daily tasks

This may include depressed mood, anxiety and panic, emotional lability, agitation, apathy or loss of motivation, which may contribute to sleep and appetite difficulties, and impact on their rehab and daily life.

Action plans can include:

Further assessment by non-psychology stroke specialist staff, ideally with oversight/supervision by specialised stroke clinical psychologists or mental health clinicians. This should include an individualised review of the client's current difficulties and history of mental health difficulties and treatment, discussion with client and whānau of their perceptions of their symptoms; and identifying relevant strengths, coping strategies and goals for supporting their psychological well-being.

MDT members with additional competence in psychological care can provide: Brief psychological interventions such as Motivational Interviewing, Solution Focused Brief Therapy, Take Charge. Many of these interventions have been adapted for people with post-stroke communication impairments.

Consultation and referral to psychologist if available. Clear pathways for referral to psychologists need to be in place and the stroke services need awareness of optimal utilisation of psychology services.

Provide advice and information to support adjustment, goal setting and problem solving

Draw on strengths: How do you normally cope with stress or with difficult situations in the past? What helps? Who can you draw on to support?

Ensure adequate sleep, nutrition, exercise, fatigue management and environment: e.g.,

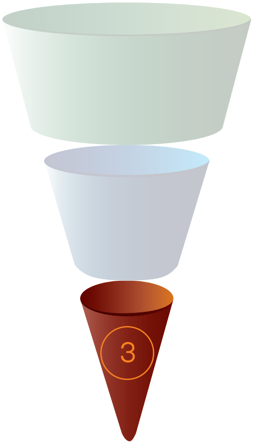
- Monitor diet and consider increased prompting and support as required.
- Monitor sleep and provide information and support for sleep hygiene
- Consider more structured fatigue management plan
- Ensure regular exercise, adapted for client's physical ability
- Consider if the environment can be improved, e.g., more sunlight during day, less noise, better company, headphones and earplugs available

Antidepressant medication should be considered with clearly defined and accessible management plans to review or stop medication.

Consider referral to chaplain or cultural services

Actively encourage to attend psychosocial education groups if available, or consider developing these within your service. These groups may focus on issues such as grief, adjustment, or goal-setting.

Provide contact details for local mental health crisis numbers and Helplines to client and whānau. Some Helplines have texting options which can be easier for some clients with expressive language difficulties; services such as Relay can help people with communication difficulties connect with these mental health services.



Level 3:
Severe and/or persisting psychosocial difficulties which are diagnosable and require specialised intervention, pharmacological treatment and suicide risk assessment and for which treatments at Level 1 and 2 are not sufficient

These require the intervention of clinical psychologist, neuropsychologist and/or psychiatry, ideally with specialist expertise in stroke.

Action plans can include:

Referral for further assessment and treatment. In the *inpatient* this might include *inpatient* psychologists or liaison psychiatry. Clear referral and triage pathways should be in place to prioritise urgent reviews. In the *community* setting this might include referrals to *community* mental health, psychologists within the community stroke rehabilitation team, GP referral to subsidised/free (only available to some GP clinics), or referral to private psychologists or psychiatrists.

Regular monitoring of psychosocial risks, for example expressions of self-harm, increased alcohol or substance use, relationship conflict or abuse, or self-neglect. If concerns, discuss these with client, whānau and team as appropriate. Only share pertinent information.

Provide contact details for local crisis and helplines to client and whānau. Some helplines have texting options which can be easier for some clients with communication difficulties.

Antidepressant medication should be considered with clearly defined and accessible management plans to review or stop medication.

Psychosocial needs should be considered in the ongoing management and collaborative care plan. Psychosocial needs for clients and whānau should be clearly communicated in transitions between service, e.g., in discharge reports, handovers and referrals. Include a route for ongoing support by stroke service teams or the voluntary sector once the patient is subthreshold

Develop and enhance relationships between mental health teams and the stroke service

Whānau well-being

CORE PRINCIPLES FOR SUPPORTING WHĀNAU WELL-BEING

Identify who significant whānau are

Don’t make assumptions about who the key whānau are for the person with stroke. Ask. The key people to connect with may or may not be physically present, but will need to be included in discussions about people’s on-going care and support needs.

Recognise that the well-being of whānau is impacted by the person’s stroke

Stroke impacts on whānau through changes in roles, relationships, finances, and through other changes in everyday life.

The well-being of whānau needs to be attended to within the episode of care.

As a minimum, whānau should be asked about how the stroke has impacted on them, how they are coping, and what supports they need.

Whānau need to be provided with information and support

The impacts of the stroke neeed to be acknowledged and normalised.

Help connect whānau with the support they need. This may be through the social worker, their own GP, or through other organisations.

Provide written and verbal information, and help people connect with useful information sources.

Stroke has a ripple effect that extends beyond the person who has had the stroke.

Considering whānau well-being

Recognising psychosocial impacts on whānau

Stroke has a ripple effect that extends beyond the person who has had the stroke. Whilst the focus of stroke services is primarily on the person with stroke, their well-being is entwined with the well-being of their whānau. Whānau – partners, children, mokopuna and others in the wider whānau network – can experience significant life changes as a result of the stroke [28]. Changes in relationship are common, such as a partner taking the role of carer, and changes in how people relate , such as changes in communication, cognition, behaviour, and sexuality. Pre-existing relationship challenges may be exacerbated post-stroke. Carers, who are most commonly whānau members, are at increased risk of depression and anxiety [29]; this can persist for a number of years post-stroke [28]. Given all of these things, considering the well-being of whānau is important.

At the same time, it is important to recognise that every whānau is different. Don't make assumptions. Explore who are the important whānau members for the person with stroke.

Considering whānau well-being

The psychosocial needs of families and carers should be considered in rehabilitation. At a minimum, whānau and carers should be supported to identify and discuss the impacts of stroke and their post-stroke needs, including the supports they need as they care for their whānau member [30]. Screening may also consider their level of coping and risk for depression [14]. This screening should ideally take place around each transition point and be repeated throughout the episode of care.

A designated staff member who has a relationship with whānau members should, through conversation, explore the impacts of stroke on them and their whānau, how they are coping with the stroke and its impacts, mood, and support needs. It is often important to have these conversations in a private space; if they don't need to worry about being overheard by others (including the stroke survivor), this may mean whānau feel freer to talk about their own experiences. This conversation should be documented and resulting actions detailed and followed up.

Questions might include:

- How is the stroke currently impacting on you?
- How is the stroke impacting on your wider whānau?
- Have you got other stresses in your life at the moment?
- Are you noticing any changes in behaviour or personality? How are you coping with these?
- How do you look after yourself during this challenging time?
- What might help you and your whānau as you adjust to living with the effects of stroke?
- What is most important to you right now?

Screening should also consider the ripple effects of stroke – how it might impact on people within the wider whānau unit. This can include considering how the stroke impacts on the person's role within their whānau and the inter-generational impact of the stroke on others (e.g. how mokopuna are impacted).

What do you do if carer well-being issues are identified?

Appropriate actions may include:

Acknowledge the impact of the stroke on whānau.

Recognise the important role they play and reassure them that their reaction is common. Normalise the psychosocial impacts of stroke for both the stroke survivor and their whānau.

Refer to social work or psychology for support.

Provide information about people's practical concerns. Resources may be found on the Stroke Foundation website, through international Stroke organisations, or through blogs or books by whānau members who have navigated this journey before.

Provide information about what services are available during and after the episode of care and give verbal and written information about how they can access them.

Connect whānau members with support services such as the Stroke Foundation of New Zealand.

Groups for whānau members can be a useful resource to help people feel connected to others who are having similar experiences. These groups may be part of your service or they may be provided by others (e.g. Stroke Foundation).

Support the person to connect with their GP.

Provide a notebook and pen and encourage whānau to write all current challenges, identify what they have control of currently and can change, what is their priority, and who can they draw on for support.

Formal screening of carer well-being

More structured tools are available for screening for carer burden are available. However, there are pros and cons to this. Before engaging in formal screening, consider what you will do with the information. Are there supports available? Who might you refer on to? Often conversation and demonstrating a genuine interest in how people are doing is the best approach.

However, if the service wishes to screen for carer well-being, some screening tools are:

- Bakas Caregiving Outcomes Scale
- Caregiver Strain Index.
- Zarit Burden Interview.

Case Studies

PREVENTATIVE APPROACH TO PSYCHOSOCIAL CARE

Te Whatu Ora Whanganui's acute and rehabilitation stroke service takes a preventative approach to psychosocial well-being. They endeavour to prevent psychosocial distress by identifying risks and issues and addressing these early. Whānau are considered a critical component in well-being and are invited to take part in care from the start of the person's journey. All disciplines attend a rapid review each morning. In the rapid round, well-being is discussed, including staff observations of mood, eating and drinking, sleep and general engagement. Each patient has a holistic assessment during admission which also covers all of these areas. If concerns are raised during daily rounds or at any point during the person's care, the team develop a plan to monitor and address issues. A psychologist runs a weekly whānau session. The psychologist completes screening as required, and provides early intervention as needed.

SUPPORTING WHAKAWHANAUNGATANGA

As the **REACH community rehabilitation team at Te Whatu Ora Southern** developed their screening processes, they engaged with the Māori Health team. Their key learnings from this were to focus on building the connection with the person. This impacted on several things.

- They prioritise building relationships and engagement. As a community team, they are based in people's homes, making it easier to connect through people's environments. They have found that it is often in these conversations, that they find out about people, what matters to them, and how things are going.
- While psychosocial screening is meant to be completed on the first visit, they will sometimes do this on later visits. This ensures they prioritise relationship-building and try and follow the lead of patients and their whanau as to when they are ready to engage in these conversations. The team also revisit psychosocial needs with patients and whānau at other key planning and review visits, such as the mid-way review and final review/discharge visit.
- While the screening form is useful for the provider, it can be a barrier for the person with stroke and their whānau. Māori Health advised the REACH team to focus on completing screening through conversation and complete the form later.

COMPREHENSIVE APPROACHES TO SCREENING

Te Whatu Ora Counties Manukau's Community Rehabilitation Service include the PHQ-4 as part of the initial IDT assessment. It used to be recorded on a separate form, but they found that incorporating it into the initial assessment form prompted staff to do it routinely. Before implementing the PHQ-4 into routine practice, their psychologist provided training about how to ask questions and score responses and gave information about what would trigger a referral to psychology. The PHQ-4 is supported by a wide-ranging initial assessment which prompts providers to explore people's general well-being and to ask about carer stress and well-being, and by providers' observations of the person and their whānau. Staff use a range of strategies to adjust screening for people with aphasia or significant cognitive issues. These include joint sessions with the SLT, use of Talking MatsTM resources to aid understanding and expression, and use other communication supports such as whiteboards to write key words and to help people communicate their responses. When working with Māori stroke patients, staff involve whānau in screening. These initial screenings are discussed at the regular IDT meeting. The template for the meeting also reminds staff to identify people's cultural needs and to discuss sex and intimacy with the person.

The Early Discharge and Rehabilitation Service (EDARS) at Te Whatu Ora Waitematā screens well-being at multiple points during a person's six week rehabilitation programme. The referral form for the services requires referrers to provide information about psychosocial well-being. Whilst this was primarily intended as a safety screener, it helps highlight issues around vulnerability, isolation and social supports, prompting and prompts the referrer to identify issues and consider these before the person is discharged home. It also means that the EDARS team have a better picture of who is coming into their services and who may be particularly vulnerable. The questions ask if the person is a primary carer for others, if they are a vulnerable adult or at risk of abuse or neglect; if they are socially isolated; and if there are any concerns about the person's relationship.

This is supplemented through the nursing and social work screens. Their RN completes a comprehensive screening with every patient in the first week of rehabilitation. This includes asking questions about cognition, memory, mood, depression and anxiety. They ask about changes in body image, spiritual distress, feelings of grief and lost, and ask about the person's adjustment to the impacts of stroke. In week 2 or 3, the social worker completes a phone screen for every patient. Through conversation, they explore mood changes to identify if there are any issues. Psychosocial issues are also commonly identified through the team's goal-setting process. The goal-setting tool, the Schedule for the Evaluation of Individual Quality of Life (SEIQOL), prompts people to identify the areas of life most important to them, and uses this to help identify specific therapy goals using Goal Attainment Scaling. Talking about what matters most in life provides an opening for people to raise issues related to their psychosocial well-being.

COMPREHENSIVE APPROACHES TO SCREENING

Te Whatu Ora Southern's community rehabilitation service, REACH, embeds psychosocial screening in their initial interdisciplinary assessment form. Rather than having specific questions to ask patients, they have areas for discussion with associated prompts. These include topics such as 'social situation' with prompts that staff should explore, such as family, neighbours, relationships, intimacy, roles and pets. The form requires that they identify the person's living situation, whether they feel socially supported or feel socially isolated or lonely, and a prompt to provide details about the person's mood. Other areas explored include the person's cultural and spiritual beliefs and values, their hobbies and interests, work and productivity, fatigue, support systems and transport. Whilst their initial screening is long, it can be broken over several sessions and is helpful in identifying psychosocial issues early.

VALIDATED SCREENING TOOLS

Staff in **Taiao Ora, the Stroke service at Te Toka Tumai Auckland** complete screening with every patient. The keyworker completes the PHQ-9 and GAD-7 with every patient. This is done with the patient, not left for them to do alone or solely with family support. If the person has significant communication difficulties, they may use the SADQ-10 or the DISCs. These assessments are often completed in conjunction with the speech-language therapist. This structured screening is supplemented through disciplinary based assessments, and patient and family questionnaires which cover areas such as personality, hobbies and carer stress and expectations. The findings of these are discussed in the IDT, which is attended by a psychologist, where a plan is developed. The service audits mood screen completion on a monthly basis.

FURTHER RESOURCES

General resources

Stroke Foundation of New Zealand www.stroke.org.nz

NSN Rehabilitation Action Plan https://www.strokenetwork.org.nz/rehabilitation

The National Stroke Network https://www.strokenetwork.org.nz/

New Zealand well-being research. There is research underway exploring how people experience well-being after stroke in Aotearoa, and how services can enhance well-being. Updates on this can be found at:
https://cpcr.aut.ac.nz/our-research/psychosocial-well-being-after-stroke

Te Pou is the national workforce centre for mental health, addiction and disability. They have developed a number of resources to help build cultural awareness and competency. The Te Pou module on working with Māori can be found here:
https://www.tepou.co.nz/initiatives/lets-get-real/working-with-m%C4%81ori

The Health and Safety Quality Commission have produced a report *Ngā whānau Māori wheako ki te tauwhiro pāmamae me te whakaoranga | Whānau Māori experiences o major trauma care and rehabilitation.* Many of the recommendations in this report are relevant to those with stroke.
https://www.hqsc.govt.nz/resources/resource-library/whanau-maori-trauma-care-rehabilitation/#related

Inform Me, the Living Guidelines for Stroke care in Australasia address different aspects of well-being. These include mood, communication, transitions in care, sexuality, and support. This information can be found in the living guidelines:
https://informme.org.au/guidelines/clinical-guidelines-for-stroke-management

The Canadian Stroke Best Practice Guidelines provide detailed information about supporting people after stroke.

Guidelines on supporting people in transitions and participation in care can be found here:
https://www.strokebestpractices.ca/recommendations/managing-stroke-transitions-of-care.

Guidelines on supporting mood after stroke can be found here;
https://www.strokebestpractices.ca/recommendations/mood-cognition-and-fatigue-following-stroke

Creating an environment that supports well-being

Resources on whakawhanaungatanga in trauma and rehabilitation are available on the Health Safety and Quality Commission website: https://www.hqsc.govt.nz/assets/Our-work/National-trauma-network/Publications-resources/whakawhanaungatanga-1pager-WEB.pdf

Working with people who have communication impairments

Useful resources to support conversation can be found here: https://www.strokenetwork.org.nz/events/practical-tips-for-improving-communication-with-people-with-aphasia

Whānau well-being

An overview of Māori models of health
https://www.healthnavigator.org.nz/clinicians/m/m%C4%81ori-models-of-health/#Overview

Inform Me, the Living Guidelines for Stroke care in Australasia address carer needs and supports. This information can be found in Chapters 7 and 8 of the living guidelines:
https://informme.org.au/guidelines/clinical-guidelines-for-stroke-management

The Canadian Stroke Best Practice Guidelines provide detailed information about screening, assessment and support for carers. These can be found here: https://www.strokebestpractices.ca/recommendations/managing-stroke-transitions-of-care/supporting-patients-families-and-caregivers-following-stroke

ACKNOWLEDGEMENTS

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We would also like to thank those who shared their expertise with us:

Vanessa Trotman, Te Whatu Ora Waitematā

Ayesha Qurashi, University of Otago

Amanda Van Elswijk, Te Whatu Ora Whanganui

Kate McKenzie, Te Whatu Ora Southern

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