# Briefing for the incoming Minister of Health



# **About us**

Stroke Aotearoa New Zealand is the national charity dedicated to stroke.

Our mission is simple; to prevent stroke, improve outcomes and save lives.

We collaborate with Iwi Māori Partnership Boards, our sister NGOs, primary health organisations, hospitals and other community health and social service providers to achieve impactful change.

Our Life Before Stroke services and collaborations raise public awareness of stroke risk factors and provide free blood pressure and pulse checks in the community which are both leading risks associated with stroke. We promote the F.A.S.T message to ensure essential, timely access to acute treatment, deliver workplace stroke prevention campaigns and tools, and advocate for government action to help New Zealanders make healthier choices about the foods they eat. We also advocate for changes to public policy to reduce health inequity across Aotearoa.

In Life After Stroke, we provide the essential community support, information, advocacy and resources needed for people to make their best possible recovery and live their best life after stroke.

Strokes can be devastating for the person who has the stroke, their whānau, colleagues, friends, and employers. We are by their side at this very difficult time. Every year we positively impact and change the lives of many thousands of New Zealanders.



# Stroke by numbers In Aotearoa New Zealand







Strokes happen every year, that's one every 55 minutes

People living with the effects of stroke

1 in 4 of us will be impacted by stroke in our lifetime



\$1,100,000,000

Annual economic cost of stroke in 2020 increasing to:

\$1,700,000,000 •†•†•†•†•†•†•†

PEOPLE AFFECTED IN AOTEAROA



**IN STROKES** 

Māori and Pacific People experience strokes 10-15 years younger

of strokes for Māori and Pacific People occur at working age (15-64 years)

of strokes for other ethnicities working age

# What your government currently funds us to do

The Stroke Foundation relies heavily on the public to fund our mahi, with only 19% of our funding being provided through government contracts. These include:

- Six Disability Information and Advisory Service contracts, through a combination of Health New Zealand / Te Whatu Ora, and Ministry of Social Development. Stroke is the leading cause of serious adult disability, and we use these contracts to part-fund our stroke information and advisory resources, including printed materials and our website. We also have a free 0800 Stroke helpline which is used by individuals, whānau, and clinicians five days a week. This includes expert information to help people navigate the complex health and disability system they are faced with upon discharge from hospital.
- An Employment Services contract to assist stroke survivors who are under 65 and are New Zealand citizens to regain their independence by supporting their return to work. This contract is funded through MSD.
- The FAST campaign contract to raise awareness in priority communities of the early signs of stroke and to urge people to seek urgent medical assistance if they or someone they are with displays any one of these signs; Face drooping, Arm weakness, Speech difficulty – Take action, call 111.

# Priorities for the Stroke Aotearoa NZ

### Workforce

Like all organisations operating in the health and disability system we are acutely aware of the workforce challenges in secondary, primary and community settings. Wherever possible health providers need their workforce to be operating at top of scope. We have identified a significant gap in knowledge and understanding of stroke in primary and community care. We introduced Stroke 101 training to bridge this gap – primarily targeted at the non-regulated workforce, to alleviate pressure on qualified workers.

Stroke 101 provides basic information about the main types of strokes and how they are caused, as well as stroke prevention and life after stroke supports so that people can live their best life after stroke. Surprisingly we have found



that Stroke 101 has also been relevant to the regulated workforce in primary and community care settings. Basic knowledge about stroke prevention and living with stroke is lacking, further adding to the challenges people experience after stroke.

We are also collaborating with our sister charities, Arthritis NZ, Diabetes NZ and the Heart Foundation to develop an NZQA certificate in Long Term Conditions for the non-regulated workforce caring for individuals and whānau in the community. The framework for the certificate has been approved by NZQA, with the intention that it will meet criteria for Equivalent Full-Time Student Funding from Tertiary Education Commission (TEC).

Our discussions across the health sector indicate a strong interest in this qualification from PHOs, Health New Zealand, and other large sector employers such as Aged Care. It has been designed at NZQA L3 initially to enable greater accessibility and is intended to be the first step on a pathway to a higher-level certification in long term conditions, and potentially entry to the regulated workforce.

# Reduce the gap between our two-tier Health system in Aotearoa

When someone has a brain injury caused by an accident, they receive comprehensive rehabilitation and financial support from ACC. A similar brain injury caused by a stroke does not, except on rare occasions where medical misadventure has occurred, or the stroke resulted from an accident. At a time of considerable hardship, stroke survivors experience significantly poorer access to rehabilitation services with lesser and sometimes no financial support. They and their whānau must navigate a complex and confusing health and disability system – all while coming to terms with the challenges of cognitive and physical impairment.

We advocate for the elimination of these inequities across rehabilitation and life after stroke support services; especially where they are heightened by the postcode lottery, and inevitably our most vulnerable communities miss out most. Our vision is for an equitable health system where anyone who experiences a stroke is provided the same level of care and quality services, as someone who receives services under ACC.



### Prevention

With over 9,000 new strokes every year, we estimate that more than 89,000 people are living with the impact of stroke in communities across the motu. And on top of this, there are countless whanau in the community involved in the daily care of stroke survivors, often at the expense of their own employment, health, and wellbeing. Stroke currently costs New Zealand more than \$1,100,000,000 per annum, and this is expected to increase to \$1,700,000,000 per annum by the middle of the next decade. This is an unsustainable trajectory, which must be addressed now if we are going to see the benefit in decades to come. Knowing that up to 90% of strokes are preventable, it is entirely possible to put in place effective prevention measures that will deliver these benefits.

Stroke Aotearoa NZ supports adopting the World Health Organisation's (WHO) recommendations to reduce salt in processed foods, given that salt is the key modifiable factor to reduce hypertension – one of the most common causes of stroke. We also support the introduction of mandatory Health Star Rating on packaged food to help New Zealanders change purchasing behaviour and make healthier food choices.

Our engagement programme with Iwi Māori Partnership Boards and community providers across the motu is specifically designed to help people understand that stroke is not an inevitability in life; that it is possible to reduce risks through healthier living. And that it is possible to reduce risk by early identification of risk factors such as hypertension, receiving appropriate treatment, and understanding the importance of medicines adherence..

We are also taking these prevention messages to industry, through our targeted Health15 health and wellbeing programme.

Stroke currently costs New Zealand more than \$1.1bn per annum, and this is expected to increase to \$1.7bn per annum by the middle of the next decade.



# Summary of our services

The following is a summary of the current services we provide, with a priority focus on high need communities and areas.

### Life before stroke

### Free blood pressure checks in the community

High blood pressure is a leading cause of stroke. However, many New Zealanders don't check their blood pressure regularly due to the cost of visiting their health provider and other barriers. We remove these barriers through our mobile outreach teams, providing over 10,000 free blood pressure checks each year with a focus on high need communities. If people have high readings, they are referred to their health provider for further support. We refer approximately 3% of people we test directly to hospital due to critically high readings – that's 300 people in the last year who were in danger of a major medical event. A further 30% we advise to be retested within one month because of a high reading.

"I had to take a hard look at myself and the diet I've been consuming to deal with work stress. Knowing that I'm at risk makes a difference, because I can do something about it. At my age, getting a free check can be life-changing."

A recipient of our service describes his wake-up call

### Free pulse checks in the community

Atrial fibrillation is a major risk factor for stroke which Māori and Pacific communities experience at a younger age and higher rate than other New Zealanders. To increase awareness, diagnosis, and management, we also provide free pulse checks through our outreach teams. If an irregular pulse is detected, we support that person to ensure they receive follow up with their health provider.

### Support for blood pressure management and healthy lifestyles

People we engage with in the community told us that they would like more support to manage their blood pressure and hauora. 'He Taonga – he taonga koe, he taonga te whānau, he taonga te whakapapa' is a free six-week online programme designed to provide whanau with support to build healthy lifestyles.



# "I am honoured to have been involved in the kaupapa and very humbled at the response it has received."

He Taonga Champion

### F.A.S.T.

People who present to hospital immediately after experiencing the first signs of stroke have a greater chance of survival and improved outcomes. We train communities and workplaces how to recognise the signs of stroke using the F.A.S.T. message. We equip them with knowledge and tools so that they can share the F.A.S.T. message with their community.

"Thank you for this free training, I look forward to sharing this kaupapa in my community e.g. Rugby clubs, marae and schools.

F.A.S.T. Trainee."

### Workplace health and wellbeing

We have partnered with industry to develop a unique free health and wellbeing service called Health15. The service brings advice, tests, and experts directly to worksites making it easier for workers to prioritise their hauora. Employers cover the costs for their employees who need clinical follow-up, including time off work. We also work with these employers to implement initiatives that support healthy lifestyles.

"We were incredibly impressed with the stroke prevention health services provided by Health15. The positive impact on our site team has been remarkable. Despite initial concerns raised by the results, the initiative sparked a transformative change. After the first session, where 55 people completed the tests, 7 took the step of consulting their doctors, leading to necessary interventions such as blood pressure medication. Additionally, 5 people sought free blood pressure vouchers, demonstrating a heightened awareness of their health."

**Southbase Consruction** 



# Life after stroke

## Community Stroke Navigator Advisor (CSN) service:

Stroke Aotearoa has Community Stroke Navigators (Kaiārahi) embedded in communities across the country. Community Stroke Navigators provide information and guidance to help people prevent stroke and navigate the complex health and disability system. They develop partnerships and deliver stroke education programmes in communities. They provide individual advocacy support and deliver face-to-face support when needed to people affected by stroke. Navigators are the front-line of our services in New Zealand. Client feedback about our CSN services includes many comments like these:

"The calls received were of great reassurance. Always at a good time for me mentally. Quick chat with good advice and details greatly aided my recovery thus far."

"My CSN put in place a basic plan on how I could get out and about more, while also connecting me to the local stroke club's swimming sessions, which have been incredible for my recovery.

"I feel grateful for the care I experienced and the assistance from Stroke Aotearoa that helped me to be able to go home."

### Free Helpline: 0800 STROKE

Stroke Aotearoa has a free helpline for people affected by stroke, including people who support the stroke affected community, to access immediate support and guidance. Callers are connected to a Community Stroke Navigator who has the knowledge and experience to answer questions about stroke and navigating the complex health and disability system. No referrals necessary: anyone can call this helpline, including whānau, caregivers, community workers, and health professionals. The helpline is open from 9am-5pm weekdays.



### Stroke101:

Stroke101 education sessions provide an overview of stroke to upskill the health and community workforce to better support the stroke affected community. In just 90 minutes, our 101 training teaches the basics about stroke, stroke risk factors, how to recognise signs of stroke, and how to support people affected by stroke. Stroke101 is designed so that primary health and community workers like Health Improvement Practitioners, Health Coaches, Whānau Ora Navigators, and Health Care Assistants, can confidently work with people affected by stroke, increasing their capability and capacity, and improving wellbeing and outcomes for their enrolled population as well as supporting people to reduce their stroke risk.

### **Take Charge After Stroke:**

Take Charge After Stroke (Take Charge) is a programme designed specifically to increase independence and improve quality of life after stroke. Originally designed by Māori for Māori, it is evidence-based and person-centred.

We deliver Take Charge sessions to stroke survivors in Aotearoa, supporting better outcomes and improved quality of life after stroke.

### Returning to Work:

Returning to work after a stroke can be a daunting prospect, and employers can sometimes need assistance to put the supports and processes in place to help someone to regain their independence after stroke, through employment. Our service helps both the stroke survivor, and the employer navigate this difficult time, co-developing modified employment arrangements and graduated return to work plans which allow individuals to ease back into their working life and ensure their employment is sustainable long term. On occasion when returning to previous employment is not possible, we help stroke survivors consider their options and find alternative employment within their new capabilities. This service also ensures that the stroke survivor's rights as tāngata whaikaha are upheld under New Zealand law.

### **Online Café:**

Stroke Aotearoa runs a monthly "online cafe" meeting. This free online event helps people connect with others affected by stroke from the comfort of their own home. Each session covers a different topic relevant to stroke and recovery, and there is an opportunity to ask questions and share experiences.



### **Stroke Education Groups:**

Stroke Aotearoa runs group community education sessions for anyone affected by stroke. These sessions cover a range of topics and provide an opportunity for participants to connect with others affected by stroke in their community.

### **Affiliated Stroke Groups:**

People who have been impacted by stroke are united for mutual support through a range of volunteer-led groups across the motu. As well as enabling people to share experiences and help each other, the groups encourage social activities and organise outings.

"I no longer felt I had been forgotten. I now have monthly support and socialise with our local stroke group with other survivors. Thank you so much."

### Rehabilitation support:

We connect clients to a range of therapies throughout the motu. These include speech and communication therapies, physiotherapy, occupational therapy, hydro physio, and art therapies.

### Support for tamariki and rangatahi:

Stroke Aotearoa partners with youth ambassador Edna Swart to create videos and online resources that answer young people's questions about life after stroke. Children and teenagers can also call the free 0800 What's Up (0800 942 8787) Helpline operated by Barnardos to talk to a counsellor who has been trained about how a stroke can impact a young person's life.

### Information:

We provide a database of free resources to help whānau and communities reduce their risk and rebuild their life after stroke. These are available in a range of formats and languages.

The book Life After Stroke is readily available in hospitals and through our CSNs.



# **Advocacy**

- We advocate for all New Zealanders to have access to best evidenced clinical diagnosis and excellent acute treatment to reduce harm caused by stroke.
- We advocate for system changes that make it easier for communities to reduce their stroke risk and achieve their aspirations after stroke.
- We provide individual advocacy support through our CSN and RTW services when clients face barriers to accessing services.
- We advocate to decision makers to remove cost and access barriers to a regular blood pressure and pulse checks to reduce stroke risk.
- We advocate for the public health benefits of government mandated salt reduction targets for processed foods, as well as the Health Star Rating on packaged foods so people can be helped to make healthy food choices.
- Our Lived Experience Advisory Panel (LEAP) brings expert lived experience knowledge to the centre of our advocacy work, extending across the stroke continuum. LEAP members are a diverse group of stroke survivors, carers, and whānau, representing gender, culture, age, and location. The Panel gives a strong voice to the interests and viewpoints of our stroke community, providing lived experience leadership to guide and influence our mahi.
- Stroke Aotearoa is part of Health New Zealand's National Stroke Network supporting a vision where "All people living in Aotearoa at risk of stroke, and those that have suffered a stroke, will have access to an equitable, accessible, cohesive, and people-centered system that improves their health and wellbeing"



# **Our mission:**

To prevent stroke, improve outcomes, and save lives.

# **Our vision:**

Is for a New Zealand where:

- significant steps are taken to reduce the number of strokes
- everyone understands and responds to the key risk factors
- anyone affected by stroke is supported and empowered.

# **Our values:**

### Kaitiakitanga

Guard and protect stroke survivors and help people learn to detect and manage stroke risks early.

### Manaakitanga

Care for others and be inclusive to everyone. Act with integrity and treat people with respect.

### Rangatiratanga

Enable people to be decision makers over their own health and wellbeing to achieve their best health outcomes.

### Whānaungatanga

Connect as a whānau and work together in everything we do to make a significant difference.



# We welcome your contact through the following channels:

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