

Submission to the Royal Commission into Victoria's Mental Health System



Submission summary

This year there will be more than 14,000 strokes in Victoria.¹ There are almost 120,000 stroke survivors living in our community¹, many with an ongoing disability. Unless action is taken, it is estimated by 2050 the number of strokes experienced by Victorians will be nearly 34,000 annually¹, and there will be almost 250,000 stroke survivors living in the community.¹

Mood disorders such as depression and anxiety are common following stroke.^{2,3} For many stroke survivors these mood disorders can hamper a return to work, and have a significant social impact.⁴ These effects are often experienced by survivors' carers as well.⁴ Our current health system is focused primarily on physical recovery following stroke. As a result, many Victorian stroke survivors and their families do not have access to services they need for the assessment, diagnosis and treatment of mood disorders.⁵

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, facilitating research and supporting stroke survivors. Stroke Foundation is dedicated to empowering health professionals to deliver high quality best-practice care to stroke patients. We advocate for better systems, processes and resources to help health professionals deliver world class stroke care.

As the voice of stroke in Australia, Stroke Foundation welcomes the Royal Commission into Victoria's Mental Health System. In recent years the State Government has funded a number of innovative pilot projects to improve the clinical assessment and management of mood disorders post-stroke, and Victoria is leading the way nationally in this area. Recommendations outlined in this submission have the potential to improve, and in some cases save, the lives of Victorian stroke survivors, their families and carers. In turn, this will reduce stroke's burden on our community, health system and economy.

Recommendation 1: Victorian Government and healthcare providers to ensure the psychological wellbeing of all stroke survivors is assessed and appropriate support is provided, recognising stroke recovery extends beyond the physical. This includes the provision of telehealth services for patients in rural and regional areas.

Recommendation 2: Victorian Government investment in research focused on the development of an effective post-stroke mood assessment pathway, and targeted interventions for mood disorders following stroke. There is an opportunity for the Victorian Government to leverage off current quality improvement projects in the state.

Recommendation 3: In light of the success of the StrokeConnect Follow-up Service in Queensland, and the recent roll-out of the StOP Program in Tasmania, there is an opportunity for the Victorian Government to invest in StOP, which is focused on helping stroke survivors reduce their risk of subsequent stroke and live well.

Recommendation 4: Victorian Government investment in the world-first 'Return to work' program, to address the current absence of effective resources and support for stroke survivors wanting to return to work.

The impact of mood disorders on Victorian stroke survivors, their families and carers

Mood disorders frequently occur following stroke. One-third of stroke survivors will experience depression², and between 18 and 25 percent will experience anxiety.³ Between 10 and 30 percent of patients will experience post-traumatic stress reactions.⁶⁻⁸ Mood disorders in stroke patients are associated with reduced participation in rehabilitation, higher rates of mortality and increased disability.⁹

Of the almost 120,000 stroke survivors living in our community¹, it is estimated around 30 percent are of working age.¹⁰ In addition, international evidence indicates stroke among younger people is on the increase.^{11, 12}

Currently, Victoria's rehabilitation services are designed to focus on physical disabilities. While we recognise learning to walk and talk after stroke is critically important, there is more to enabling patients to live well after stroke.

A stroke attacks the brain, the human control centre, and its impact extends well beyond the physical.

Families are suffering because stroke survivors are being denied the specialist mental health treatment and care they need to maximise their recovery, and ultimately return to work where appropriate.



One big thing about stroke is a lot of people think (and I myself thought this) it only results in physical disabilities. Not many people realise there's a lot of mental factors that follow a stroke. Most people don't talk about it and I didn't talk about it for quite a while either.

I had the stroke and then I started rehab, and the whole time my mental state was in a really bad way. Eventually it got to the point where I started to have thoughts about taking my own life. One day I hit a brick wall and realised I needed help and things weren't going to be okay if I didn't seek that help.

Luke Webb, stroke survivor.

A significant proportion of stroke survivors are dependent on carers, most of whom are informal supports such as family and friends. Carers may accompany survivors to medical appointments, stay with them in hospital, and care for them at home. Carers play a critical role in a survivor's recovery. This support can come at a significant cost, with an estimated 30 to 68 percent of carers for stroke survivors experiencing anxiety or depression.¹³

For many survivors of stroke, their stroke-related disabilities, including 'hidden' disabilities such as mood disorders, can hamper a return to work, and have a significant social impact. These effects are often experienced by their carers as well.

Stroke Foundation, in partnership with Monash University's Stroke and Ageing Research Centre (STARC), and the Stroke Division of the Florey Institute of Neurosciences and Mental Health, developed the 'Stroke Survivor and Carer Needs Assessment Survey'. This survey was designed to determine the needs of community dwelling Australian stroke survivors and their carers at least one year post-stroke. The results of this survey highlighted the significant social and economic impact that stroke is having on the lives of survivors, their families and carers.⁴

Economic impact

In the survey of Australian stroke survivors and their carers, of the survivors who were working prior to their stroke, almost three quarters (71 percent) reported a change in their work activities since their stroke and 57 percent reported that the change was moderate to extreme.⁴ More than one third (36 percent) of survivors reported a loss in income since having their stroke and almost half (48 percent) were receiving some form of benefit.⁴ Of those caregivers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.⁴

A Deloitte Access Economics study commissioned by the Stroke Foundation in 2012, estimated in Australia the cost of lost earnings caused by reduced employment due to stroke in people of working age was \$975 million.¹⁰ In addition, the cost of absenteeism and lost home production due to stroke was estimated to be \$1.14 billion, while the cost of presenteeism (lower productivity while at work) was estimated to be \$700 million.¹⁰ Please note these figures would be higher today as stroke incidence and the cost of living have increased.

Social impact

The survey of Australian stroke survivors and their carers reported for the majority (57 percent) of survivors who had a partner or spouse, their stroke had a negative impact on their relationship, and 34 percent reported this change was moderate to extreme.⁴ Almost one third (31 percent) of carers who were the partner or spouse of a person with stroke reported moderate to extreme changes in their relationship.⁴ A significant proportion of carers reported moderate to extreme changes in their relationships with other family members (20 percent), and with other people outside the family such as friends (32 percent).⁴

Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role reported a moderate to severe reduction in the number or type of leisure activities in which they were able to participate.⁴

In summary, as a result of stroke-related disabilities such as mood disorders, many stroke survivors and their carers experience negative consequences in areas including work, finances and relationships. The impact of stroke-induced disability is also felt by the wider community. A significant proportion of survivors, and the family or friends who care for them, are forced to leave paid work, with some having to rely on welfare payments.

Clive's story

In November 2015, at age 52, Clive Kempson suffered a stroke. He remembers being admitted to hospital, and spending 10 days on the stroke ward while undergoing a battery of tests, all to no avail. No one could tell him what had caused his stroke.

Unable to stand unassisted, with no use of his right arm or leg, and experiencing speech problems, Clive was transferred to an in-patient rehab facility for four weeks. This was a scary time for him, as it became apparent his recovery was going to be a long, hard road, and he worried about what the future would hold.

Before his stroke, Clive was a small business owner, installing and servicing electronic security systems in the commercial, government and industrial sectors. Following his stroke, Clive was forced to decline two contracts his company had been awarded, valued at \$250,000. Clive's confidence and self-worth took a big hit as a result. Clive was now weighed down by thoughts of not finishing projects, letting down clients, money worries and the impact this would have on his family.

It is at this point Clive felt he would have benefited from a consultation with a mental health professional. However, Clive had no contact with a mental health professional at any time during his hospital stays. Clive was never offered mood screening.

Clive's team of health professionals were doing a great job, but they were focused on getting him back to walking and talking.

Once in community rehab, Clive was fortunate to work with a very supportive occupational therapist and physiotherapist, both of whom felt he would benefit from speaking with a psychologist. However, he was told he could not access the services of a psychologist at the rehab centre, and would have to source this himself. Rehabilitation services were focused on the physical.

Clive asked for help and accessed a mental health plan with the support of his General Practitioner. With access to sessions limited, Clive was not able to maximise this plan. It concluded and Clive was still feeling lost. With no income he could not continue to access the services he needed. Fortunately for Clive, he stumbled on a free service run by his local council.



Today, Clive is continuing his recovery. He is currently looking for a psychologist who can help him to create new achievable goals. Clive is living independently in a lifestyle community and he is back driving. Clive has been unable to regain the use of his right arm and has not returned to work. However, Clive remains positive about the future and has plans for a new business.

"During my recovery, my mental health seemed to be of less importance than my physical recovery to the health professionals that were treating me, but for me it was just as important to be recovering mentally so I could cope with the physical demands of rehab," said Clive.

Improving awareness of mood disorders for Victorian stroke survivors, their families and carers

Stroke Foundation resources

The Stroke Foundation has developed a wide range of resources for stroke survivors, their families and carers that address the issue of mood disorders after stroke. These resources raise awareness, and help survivors better manage their health and live well after stroke. Key messages include:

- People are at higher risk of depression and anxiety after a stroke.
- Impacts such as communication difficulties (aphasia) increase the likelihood of developing depression and anxiety.
- Depression and anxiety can be treated and recovery is common. The signs of depression and anxiety should never be ignored and people should speak to their doctor.

During Stroke Foundation consultations with working age stroke survivors, returning to work emerged as a significant issue. Survivors told us they needed to work for financial reasons, but beyond that they also valued the intrinsic rewards of work. Survivors felt employers and service providers did not understand the impact of stroke, especially when their disability was not clearly visible. Importantly, there is an absence of effective resources targeted at survivors, employers and service providers, providing the information needed to support people to find their way back to work after stroke.

My Stroke Journey

This resource delivers high quality information to stroke survivors, their family members and carers, and is designed to support care planning and the transition from hospital to home. Stroke Foundation provides this resource to hospitals free of charge.

The My Stroke Journey pack is provided to patients and their families by Stroke Foundation's partner hospitals, and the aim is for all stroke patients to receive this resource before they leave hospital. Importantly, we know from National Stroke Audit data that almost 40 percent of patients and/or families do not receive resources such as My Stroke Journey, which provide critical information on topics such as mood disorders, secondary prevention and recovery.¹⁴

Life after stroke or TIA

This resource is focused on:

- Raising awareness of the signs of stroke and TIA.
- How to reduce the risk of recurrent stroke and TIA.
- How to access allied health and rehabilitation services.
- Where to go for additional information and resources.

An important part of this resource is the information it provides on how stroke can impact survivors, including depression and anxiety.

EnableMe

This is an online resource co-designed with stroke survivors and carers, providing:

- Videos, podcasts and fact sheets on a wide range of topics impacting daily life after stroke, including 'Depression and Anxiety'.
- A community forum to ask questions and share experiences with other stroke survivors and carers.
- A tool to set and track personal goals for recovery.
- An online helpdesk to ask questions of Stroke Foundation health professionals.

Fact sheets

The Stroke Foundation has developed a series of informative fact sheets on various topics in the stroke recovery journey, including one on 'Depression and anxiety after stroke'.

The assessment, diagnosis and treatment of mood disorders following stroke

Victorian stroke survivors and their families are being denied the opportunity to live well after stroke because they do not have access to the high-quality rehabilitation and supports they need and deserve.

The Stroke Foundation National Stroke Audit Rehabilitation Services Report 2018 showed mental health continues to be ignored despite it being recognised by experts as a crucial element of stroke recovery.⁵

Data from the Rehabilitation Audit showed one third of rehabilitation services did not have access to clinical or neuropsychologists.⁵ This was despite the Audit finding 50 percent of patients had some degree of mood impairment.⁵

Access is even more limited for regional and rural Victorians. Many of the health professionals who play an essential role in assessing, diagnosing and treating stroke and mood disorders post-stroke, work predominantly in metropolitan areas.

In highlighting the above, we acknowledge health professionals are doing their best, and improvements have been made. Between 2012 and 2018 the proportion of stroke patients undergoing assessment for mood disorders rose from 34 to 56 percent.⁵

It is still not enough. Current health systems are designed to focus on a stroke survivor's physical recovery.

Recommendation 1: Victorian Government and healthcare providers to ensure the psychological wellbeing of all stroke survivors is assessed and appropriate support is provided, recognising stroke recovery extends beyond the physical. This includes the provision of telehealth services for patients in rural and regional areas.

Up to 70 percent of stroke survivors experience cognitive deficits^{15, 16}, while approximately one third develop aphasia.^{17, 18}

Ideally, services treating stroke patients should have access to neuropsychologists, or clinical psychologists with an understanding of how to deal with the cognitive and communication deficits that can occur following stroke. Regardless, it is critical all members of the multidisciplinary team are able to recognise mood issues and know how to manage them, even if it means simply referring the patient on to other health professionals using an identified pathway.

In Australia, unlike in Europe and the United Kingdom, there is no published post-stroke mood assessment pathway. In addition, while there is clear evidence for psychological interventions and pharmacological treatment for mood disorders in the general population, the evidence for such interventions in people following stroke is limited.

Cognitive behavioural therapy (CBT) is one of the most established psychological therapies used in the general population; however, to date, studies employing CBT to treat mood disorders post-stroke have had little success. It has been suggested these studies failed to address the cognitive and

communication deficits that can occur following stroke, and that randomised controlled trials employing a modified CBT approach are needed.⁹

Recent Australian pilot projects undertaken to address some of the identified knowledge gaps are outlined below. Victoria is leading the way nationally in this area, and in recent years the State Government has funded a number of innovative pilot projects to improve the clinical assessment and management of mood disorders post-stroke.

Current initiatives in Australia

The development and implementation of a post-stroke mood assessment pathway in the Wide Bay Hospital and Health Service

This project, undertaken in Queensland, was focused on developing and implementing a comprehensive post-stroke mood assessment pathway.

A literature review was undertaken to identify screening tools for depression and anxiety that were clinically valid in a stroke population, effective and efficient, and applicable to acute, subacute, inpatient rehabilitation and community settings.

Two post-stroke mood assessment pathways were developed, one for patients with communication or cognitive difficulties (using the SADQ-10 and BOA instruments), and one for patients without these difficulties (using the HADS-A and PHQ-9 instruments). This pathway was implemented over a 12 month period between October 2014 and September 2015.

Based on evidence from the literature review, routine mood screening was undertaken one month post-stroke unless indicated earlier, and was delivered in conjunction with a clinical interview.

Results showed:

- The rate of mood screening increased by 19 percent.
- Discussions with patients regarding mood increased by seven percent.
- The use of interventions targeting low mood increased by 40 percent.

The interventions utilised were tailored to the patient's needs, and were planned in consultation with the patient. These interventions included counselling, medication, or referral to the mental health team.

Teleneuropsychology in stroke rehabilitation: a pilot project in Echuca Regional Health

Specialist neuropsychologists can provide important assessment and treatment for stroke patients with mood disorders. These services are often limited in regional areas, potentially hindering patient rehabilitation and recovery. Telehealth technology can be harnessed to address the limited access to specialist services in regional areas.

In 2016, the Victorian Stroke Clinical Network funded an innovative teleneuropsychology in stroke rehabilitation service (TNSR) piloted at Echuca Regional Health in collaboration with Monash University. The aim of the pilot was to examine whether TNSR improves clinician assessment and management of patient mood impairments post-stroke and builds capacity within the inpatient regional rehabilitation team.¹⁹

TNSR implementation included development and implementation of policies, procedures and an education program for regional clinicians.¹⁹ A metropolitan-based neuropsychologist provided services via telehealth one day per week. Using a 12-month pre-post implementation design, clinicians were surveyed to evaluate their confidence in and knowledge of detecting and managing mood changes post-stroke, and their TNSR consultation experience.¹⁹

Overall, data from the pilot supports the feasibility, acceptability, effectiveness and efficiency of teleneuropsychology.¹⁹ Specifically, at 12 months post-implementation:

- Median wait time for a neuropsychology consultation was seven days.
- 90 percent of consultations were held over telehealth (10 percent face-to-face).
- Clinicians' confidence increased for detecting (38 to 71 percent) and managing (0 to 43 percent) mood changes.¹⁹
- A higher proportion of patients were screened for mood issues (19 to 88 percent).¹⁹
- 89 percent of patients were satisfied with their teleneuropsychology consultation.
- 95 percent of clinicians were satisfied with their teleneuropsychology consultation.
- Economic simulations indicate that TNSR service costs (\$1,167 per patient) were approximately half that of an equivalent face-to-face service (\$2,438 per patient).

In summary, the TNSR has successfully addressed a service gap, and is a feasible and economically viable model for increasing access to neuropsychology intervention.¹⁹ The Victorian Stroke Clinical Network is working to improve patient care in regional areas by scaling the TNSR project to an additional three regional health services in 2018-19. The participating regional health services will be provided with access to specialist neuropsychology services via telehealth technology.

Improved Management of Mood Related Symptoms in Stroke Patients: a project in the Royal Talbot Rehabilitation Centre

This project was focused on the development of a mood screening and management clinical practice guideline to guide standardised mood screening. It was led by the Psychology Department at the Royal Talbot Rehabilitation Centre, and funded by the Victorian Stroke Clinical Network. The clinical practice guideline was implemented on two sub-acute wards (Mellor at the Royal Talbot Rehabilitation Centre and Ward 12 at the Heidelberg Repatriation Centre) during a three-month trial phase. Clinical champions were used to consult with relevant clinical staff and discuss the best approach to implement the screening at their specific site.

Clinical staff were provided with education about mood screening and post stroke depression. The SADQ-Hone tool was employed for detecting mood symptoms in stroke patients with cognitive or communication impairment, while the PHQ-9 tool was used for individuals without these issues. Mood screening rates were assessed via a medical record audit pre and post implementation (over a three month period).

The project demonstrated a number of positive outcomes including:

- Effective implementation of the clinical practice guideline and clinical pathway across two wards, resulting in significantly increased rates of mood screening for stroke patients, from 30 percent to 87 percent of admissions, based on medical record audit.

- 50 percent increase in the number of referrals made to clinical psychology or psychiatry services for further assessment and treatment.
- Improvement in staff knowledge.
- Increase in the number of staff members who could correctly identify the prevalence of post stroke depression (76 percent to 93 percent).
- Significant increase (45 percent to 87 percent) in patient reported screening.

This project has been adapted by the Victorian Stroke Clinical Network to develop the *'Increasing Mood Screening in Stroke Rehabilitation'* project. A change package and associated resources will be piloted at one inpatient rehabilitation service. These resources include a clinical practice guideline, a clinical practice pathway, promotional posters and a mood screening presentation. The inpatient rehabilitation service will be supported to use implementation science methodology to test and adapt each change concept to suit their context.

The Identification of Altered Mood After Stroke (IAMAS) project: improving mood screening rates in acute in-patients post stroke in the Hunter New England Local Health District

The aim of this project was to increase the proportion of inpatients with acute stroke that have mood assessed in Hunter New England Local Health District (HNELHD) hub hospitals.²⁰ This study was prompted by results from the 2013 National Stroke Audit Acute Services report, which showed only seven percent of stroke patients in HNELHD hospitals had their mood assessed.

A protocol was developed for mood screening of patients at least five days after admission.²⁰ For patients without communication and/or cognitive problems, the HADS-A instrument was used, while for patients with these issues, the BOA and SADQ-10 observational tools were administered.²⁰

The intervention, which included staff training, area-wide standardised components and localised implementation strategies, commenced in eight HNELHD hub hospitals in July 2014.²⁰ An evaluation of the intervention was undertaken using pre and post-implementation audits. The number of patients assessed relative to those admitted was recorded.

The proportion of admitted patients that received mood assessment was shown to increase from eight percent before the intervention, to 20 percent post-implementation.²⁰ Approximately 50 percent of patients were discharged before Day 5 of admission, precluding them from undergoing mood assessment. Importantly, the impact of this intervention was sustained, with results from the 2015 National Stroke Audit Acute Services report showing that 26 percent of patients within the HNELHD had their mood assessed, an increase of 19 percent on the 2013 Audit results.

Stroke Foundation's Stroke Outreach Program (StOP)

Stroke Foundation's StOP Program, which is currently being delivered in Tasmania, provides planned, individualised and coordinated education at a key point in an individual's stroke journey. It targets stroke survivors post-discharge from hospital, when they are highly motivated to act but often lack the knowledge and skills needed to effectively reduce their risk of subsequent stroke and live well. It provides mood screening, and promotes attendance at outpatient appointments and connections with primary care, to ensure ongoing medical management.

StOP has two key components:

1. Education and support for hospital clinicians.

This support enables health professionals to deliver targeted secondary prevention education and recovery planning – including advice on mood disorders – for every patient with stroke, every time.

2. Contact with the stroke survivor from a Stroke Foundation health professional within 21 days of discharge from hospital.

StOP will increase the number of stroke survivors screened for risk and vulnerability, including mood disorders, and provide connections to appropriate services.

A similar Stroke Foundation program has been running in Queensland since 2011, and has delivered excellent results for stroke survivors in that state. The StrokeConnect Follow-up Service provides an independent, specialist health professional to support stroke survivors following their discharge from hospital. This ensures all stroke survivors, their families and carers are connected with, and supported to access the information, resources and services they need to prevent recurrent stroke and manage their recovery. A recent evaluation of the program showed²¹:

- Ninety-six percent of participants evaluated were satisfied with the program.
- Ninety-five percent of participants evaluated agreed it was helpful.
- Seventy-four percent of stroke survivors engaged with the program reported they had since adopted a healthier lifestyle, with benefits including improved mental health.
- Stroke survivors engaged in the program demonstrated increased utilisation of services from general practitioners and other health professionals, with the greatest utilisation seen with psychologists.

Other initiatives that will address existing gaps in service delivery

'Return to work' Program

Stroke strikes in an instant, often changing the lives of survivors and their loved ones forever. This year alone stroke will devastate thousands of Victorian families, and international evidence shows the number of working-age people impacted by stroke will increase over the coming years.⁹

Importantly, current health and social services systems are not designed or equipped to help younger stroke survivors.

The world-first 'Return to work' program would support the specific needs of Australia's increasing number of working-age stroke survivors. It would maximise not only their physical recovery, but their psychological recovery, post-stroke. The program would equip working-age stroke survivors with the skills and support they need to actively engage with the community and optimally, to return to work.

This program would deliver:

- A specialised working-age stroke rehabilitation clinic run by some of Australia's leading minds in stroke rehabilitation, piloting cutting-edge stroke recovery interventions.
- Online training resources supporting health professionals to respond to the specific needs of working-age stroke survivors.

- Targeted resources to empower working-age stroke survivors and their families to live well after stroke.
- Specialist resources and individualised support for stroke survivors and their employers to aid a return to the workplace.

This program would empower working-age Victorian stroke survivors to maximise life after stroke. Survivors would be supported to grow and thrive, to get back to work and contribute to the community. This program would reduce stroke's burden on families, the community and government.

Recommendation 2: Victorian Government investment in research focused on the development of an effective post-stroke mood assessment pathway, and targeted interventions for mood disorders following stroke. There is an opportunity for the Victorian Government to leverage off current quality improvement projects in the state.

Recommendation 3: In light of the success of the StrokeConnect Follow-up Service in Queensland, and the recent roll-out of the StOP Program in Tasmania, there is an opportunity for the Victorian Government to invest in this program.

Recommendation 4: Victorian Government investment in the world-first 'Return to work' program, to address the current absence of effective resources and support for stroke survivors wanting to return to work.

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