



A whole life  
left to live

A stroke is a devastating diagnosis at any age, bringing with it the prospect of many months of intensive rehabilitation and the real possibility of permanent disabilities. But for younger people with life stretching out in front of them, physiotherapy can assist them to regain control over who they are and what they can do. Melissa Trudinger reports on the role of physiotherapy in treating younger survivors of stroke.

**W**e think of stroke as something that mostly affects older people. In reality, stroke affects people of all ages. In 2020, 24 per cent of all first-ever strokes in Australia were in people under 54 years of age, around 6580 strokes, and the number of younger people having strokes is increasing.

Young stroke survivors are generally considered to be aged between 18 and 55, although this depends on whom you talk to. Professor Julie Bernhardt (below), a stroke researcher and physiotherapist at the Florey Institute of Neuroscience and Mental Health in Melbourne, says that it can be looked at from two perspectives: biological age and life stage.

'There's no standard definition for young, but after about 45 years of age, people start to have the same risk factors as older stroke survivors. There is something quite distinct about the 18 to 45 or 50-year-old group because of what's happening in their life,' Julie says. 'People who are younger are in that earlier, very busy phase of life, where they're working, studying, having children and developing relationships.'

Unlike older stroke survivors, younger patients have fewer comorbidities (conditions such as cardiovascular disease, diabetes and obesity as well as the physical effects of ageing) and the causes of their strokes differ from those in the older

population—they may be due to heart defects, ruptured arteriovenous malformations or genetic causes. About 50 per cent of strokes in younger people are of unknown origin.

Because stroke is relatively uncommon in younger people, it may not be recognised as quickly and this can be an issue.

'There's a lack of awareness of stroke in the young, which means that people may delay presenting to the health service because they don't recognise that they're having a stroke. Then there's a delay in the health service responding as if they've had a stroke and therefore they may be less able to access some of our most advanced treatments,' Julie says.

There is also a gap between the needs of younger patients and what can be delivered to them in a system designed for older people.

In many cases, young survivors of stroke lack validation of their experience because people, including health professionals, may not believe them when they say they've had a stroke. Additionally, most evidence-based treatments for stroke, and for rehabilitation after stroke, have been tested in an older population.

'The evidence-based treatments we have for an older population,



especially in relation to physical activity and training, may very well apply to the younger population, but we have no young-stroke-specific guidelines. We also have very limited young-stroke-specific evidence, because they make up a smaller proportion of the wider stroke population,' Julie says.

## Does rehab differ in younger stroke survivors?

Rehabilitation doesn't differ that much between younger and older stroke survivors. It's more a question of goals and intensity. Young survivors of stroke usually have very different goals from older survivors—they want to get back to work or university; they might be dating or have a young family; they want to be able to play sport again and have a social life. This affects their rehab pathways and goals. A younger stroke survivor might want to go for a run, play a game of footy with the kids or get back to work. Because they don't have as many comorbidities, they can often work harder and more often than older survivors. They may also be fitting rehabilitation sessions around work or study.

'A lot of clinicians will say it's actually hard to navigate around these young survivors, because they want a life as well as doing their rehab,' says Julie. 'I think we make assumptions that a young person having a stroke will just naturally recover better than someone who is elderly, but it's not necessarily the case. That assumption creates a bias in our health system, which therefore doesn't offer young people the same level of rehabilitation as they might receive if they were older.'

Physiotherapist Dr Gavin Williams APAM, FACP (below), an associate professor at the University of Melbourne, has worked extensively with young stroke survivors as well as patients with traumatic brain injuries at Epworth Hospital in Melbourne, teaching them how to run, ride a bike and swim and helping them return to sports and social activities.

'There's a real focus for younger stroke survivors that's not just the typical pathway of get them up, get them going, walking, transfers and other rehab like that, but is on the participation end of the spectrum. It should



happen with older stroke too; it's just that it seems more devastating for younger people,' Gavin says.

He says it's important to keep the patient's perspective in mind and not just look at it from a clinical point of view.

'They measure loss. They remember what they were moments before their stroke and so they're confronted daily with the things they can't do, whereas we're in the business of measuring the recovery of the things they can do. It's very different. You often hear people say to someone who's 20, 30 or 40, who is starting to walk by themselves after six or eight weeks, "Isn't that amazing?" and you think, "Well, it is amazing for someone who hasn't been able to walk for two months but it's not amazing when you think that this person was playing tennis or netball three months ago".'

Gemma Allinson APAM (above) is a neurological physiotherapist in private practice and at Sunshine Coast University Hospital in Queensland, where she works with stroke patients of all ages. Gemma notes that in younger people there is a huge capacity for neuroplasticity and as a result they are encouraged to do large volumes of rehab to support their recovery, which can look different for each patient.

'These patients can make huge gains. In my time working as a physio, I've almost never seen a situation where a young stroke survivor was not strongly encouraged to attend rehab when they had ongoing deficits,' Gemma says.

## Special considerations

For many young survivors of stroke, physiotherapy is a huge part of their rehabilitation. During inpatient rehabilitation, physiotherapy sessions may take place two or three times a day, focusing on different aspects of a patient's recovery in each session. Julie says it's important that the rehab leads them towards independently continuing their recovery.

'From the stroke survivor's perspective, they absolutely value the physiotherapist as a lifeline to further recovery, but they also get frustrated because there's a limited time when they might be able to access physiotherapy. We need to make sure that we take a therapist-as-coach approach with young people—treat the impairments, but also start the relationship with the idea in mind that you have to find an independent pathway for this person,





It's okay to shed a tear when they take their first step and to hold them accountable on the days when they feel like giving up.'

Gemma Allinson, neurological physiotherapist

## Creating a one-stop shop for young stroke survivors

Late last year, Professor Julie Bernhardt and her colleague Professor Vincent Thijs from the Florey Institute of Neuroscience and Mental Health were awarded a Medical Research Future Fund grant worth \$9.9 million to set up Australia's first dedicated young stroke service.

Julie says the service will be a one-stop shop for young stroke survivors. She says it's not uncommon for younger stroke survivors to have unmet needs for treatment and care.

'It varies across Australia, but often, once people leave hospital, they may have one follow-up visit with a neurologist at three months. Unlike cancer, where you would have a specialist catch-up or a team catch-up on a regular basis, once you've had this one-off, three-month follow-up, you're often left to your own devices and you need to find a good GP and other ways of supporting yourself for years after the stroke,' Julie says.

The new service aims to address current gaps in the services offered to young stroke survivors, including geographic boundaries, and to better respond to the patients' needs, allowing them to have more control over their long-term care.

'The idea is that we have a common pathway, where people can be referred into the service, and we identify

their unmet needs through a screening tool we have developed for young stroke survivors. Then we create the pathways to try to help them get those unmet needs met. We have a digital platform that is going to be the foundation of the service and we aim to follow people up for at least three years, probably five years, after they've had a stroke,' Julie says.

The new young stroke service will be pilot tested in Victoria and South Australia from early 2023 and the team hopes to eventually roll out similar services in other states. Initially, the focus will be on peer support, psychological needs, memory and cognition problems as well as return-to-work services, but physical needs such as fitness and return to leisure activities will also be developed.

'It can't be done without a diverse team, so we have a lot of different people involved in the project—neurologists, rehab doctors, GPs, all different types of clinical therapists—as well as the consumers, young stroke survivors who are helping to develop the service,' says Julie.

'If there's anyone out there reading this who is experienced in working with young stroke survivors and already offers a service, we'd love to hear about it, because we may refer our patients on to you.'



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Dr Gavin Williams, associate professor at the University of Melbourne



something that empowers them to keep going for a long time, with perhaps touchpoints along the way,' Julie says.

It's also important for physiotherapists to be ready to point young stroke survivors in the direction of the help they might need.

'Young survivors have a lot of psychological and psychosocial unmet needs. They lose friendships; they lose relationships. You can't just address their physical needs,' says Julie.

Dr Natalie Fini APAM, MACP (below), a physiotherapy clinician and researcher at the University of Melbourne, agrees.

'Everywhere I've worked, the physio gym is an energetic place, with people working hard. There's a fun vibe and patients love coming to physio because it's such a positive environment. Because of that, you're often the first person they talk to about something that's bothering them,' Natalie says.

Gemma says physiotherapists need to understand that their patients may be grieving for their pre-stroke life and coming to terms with what they can no longer do.

'It is okay to take the time to build rapport and to have the humility to acknowledge the unexpected nature of the event. To cheer for them on their best days and just stand by them on their worst days,' Gemma says. 'I've always taken a very humanistic approach. It's okay to shed a tear when they take their first step and to hold them accountable on the days when they feel like giving up.'

It's important to include the family as much as possible, Gemma says.

'Having family around can help to foster a collaborative and motivational environment for stroke survivors and can also help to set realistic expectations around stage of recovery for all involved. I also find that linking stroke survivors in with young peer support groups can be extremely valuable,' she says.

Peer group support such as the Stroke Foundation's Young Stroke Project ([youngstrokeproject.org.au](http://youngstrokeproject.org.au)) and the genius network ([geniusnetwork.com](http://geniusnetwork.com)) set up by



stroke survivor Caleb Rixon (above) offer online peer support and community to younger people who may feel incredibly isolated as stroke survivors. They are good resources for clinicians too.

Paradoxically, many young stroke survivors do very well in the early stages of their rehab, while still an inpatient, but their quality of life can suffer as the rate of progress drops off, especially once they return home, says Gavin. This may lead them to seek more rehabilitation as an outpatient or even years later from their old rehabilitation clinic or from a private practice.

'Early on they're optimistic because they think, "Okay, I'm going to get better" and then they realise not much has improved since they left rehab,' he says. 'You can still do very effective rehab in the chronic phase. They're more engaged because they've been living in the community and so they know what's most important to them.'

One aspect of treating young stroke survivors that might not be immediately obvious is setting them up for the many decades they have ahead of them, emphasising good fitness habits and regular exercise. Natalie says that a focus on the quality of movement is essential in young stroke survivors, who may have 40, 50 or 60 years ahead of them. Sometimes the impairments caused by the stroke—for example, spasticity or severe weakness—can result in problems that surface years later and abnormal movement patterns may also cause problems, such as an increased risk of osteoarthritis or chronically damaged joints.

'If someone has a stroke at 30, they might live another 60 years. If they move with poor quality—for example, hyperextending their knee so that their knee snaps back when they walk—that's going to do a lot of damage to their ligaments over 60 years of walking. Their knee's likely to deteriorate and be at risk of needing a replacement sooner than it will if we can teach them to walk with correct movement patterns,' Natalie says.

'Don't forget to look at the whole person. They've had impairments and not just from a physical perspective—there's often cognitive, speech and language and emotional impacts, so think holistically. Above all, don't underestimate what they will be able to do,' says Natalie.





The people who gave me a range of expectations, they got the best out of me.'

Caleb Rixon, stroke survivor



Caleb Rixon underwent extensive physiotherapy after his stroke.

## Coming to terms with a life-altering event

Caleb (Cal) Rixon's life changed during a gym session when he was 24. A musical theatre performer, he was about to go on tour with the musical *Chicago* when a grade five subarachnoid haemorrhage stopped him in his tracks. He ended up in an induced coma, having major surgeries to relieve the pressure on his brain and resect the issue, and when he eventually came to, he had a paralysed vocal cord, couldn't swallow, had severe diplopia (double vision) and had significantly reduced strength, control and sensation through his left side.

Cal spent more than five weeks in ICU before being moved to a rehabilitation hospital closer to home and then spent two years in outpatient rehabilitation. He still has ongoing issues more than 14 years after the stroke, the diplopia and vestibular dysfunction causing balance issues, among other things.

'It's not to say that I've been crippled by it, but every step since is very conscious. I've not taken an unconscious step for the past 14 years,' he says.

Thanks to his professional career in musical theatre, Cal was physically fit before the stroke. He says that it took him quite a while to come to terms with the fact that he was never going to rejoin the tour or return to his old life treading the boards as a dancer and singer.

Cal is thankful that his physiotherapists treated him as a whole person during rehabilitation, not just a collection of impairments to fix, and partnered with him in discovering his new capacity. Sadly, some other clinicians were not nearly as supportive or tactful and were even dismissive of his concerns. About six months after the stroke, his neurologist bluntly told him that his voice and his gait would never improve.

'I was like, all right, bitch, watch me do a catwalk outta here,' Cal says.

It's a moment he's never forgotten that has informed his approach to his recovery and his life after stroke.

'The people who gave me a range of expectations, they got the best out of me. I fought hard and I had to have a big realisation and release [about leaving the Broadway dreams behind], but it was very quiet and it was very private and I'm fine because I have reframed my position as a storyteller,' Cal says.

'I think hope is the most powerful currency we can have. And I think when people rob you of that hope or try to peck at it based on their ego or their ignorance or their fear or even them thinking that they're giving you the thing to butt back against, good on them, but they're now a footnote of my story.'

Cal's drive to tell his story of survival and to hear the stories others were telling led him to start the *genyus* network, which provides an opportunity for younger stroke survivors to connect with others who have been through a similar experience.

'Every single person wants to share their story and they also want to share that story to help out the next person,' Cal says. 'I realised that my narrative was about finding people just like me. That's where *genyus* network was born.'

'It's a safe space for people touched by trauma to connect and share and celebrate. And really build that capacity, build social confidence to take on leadership, start conversations. You know, one of our mottos is "find inspiration, be inspiration",' Cal says. 'So much is sitting within those who have a living experience that they can share to help someone else or to help themselves, and it goes untapped because that person is framed as a recipient. *Genyus* has a vision of a world where every person touched by life-changing trauma is empowered, emotionally resilient and connected.'