

# Call to action



Fight Stroke

This is what we need...

**Every year thousands of Australian lives are changed by stroke.**

**Very many people die.**

**For those of us who survive there is a strong chance that disability has forced immediate change upon the way we and our family live.**

**Thankfully some of us have come through with little, or no disability and yet even we are changed, not least because we live life with a fear that stroke may strike us again.**

**Stroke has sent a shockwave through all of our families and our experiences are all unique. Some of our experiences with the health system have been positive but many have not.**

**One thing we all agree is that things can and should be much better for people who suffer or are at risk of suffering a stroke.**

**We believe it's time for change.**

**There needs to be a better way to help people avoid stroke.**

**A better way to treat people who have a stroke.**

**And a better way to help people recover from their stroke and to return as close as they can to the life they had before.**

**As survivors and carers of survivors who live with the impact of stroke every day we are calling on the Australian Government to make changes that will improve the management of stroke in this country.**

**We are calling for action.**

**1** We need the ability to better understand our risk of stroke and what we can do to reduce our chances of having one. This includes more information in the community and from our doctor about what stroke is, the impact it can have, our risk and our risk factors and options and treatments that are available to help us lower our risk.

Many of us thought: "a stroke wouldn't happen to me". We had no idea we were at risk nor that there were things we could do to reduce that risk.

We now know strokes can happen to anyone, at any age, and we think everyone needs to know how severe the impact of stroke can be on your life.

Without knowledge, we are not empowered or supported to change our lifestyle.

Without knowledge we are not able to get the treatments we need to help lower our stroke risk.

With information and understanding we are empowered to better manage our own stroke risk and hopefully avoid the severe impact on life that can result.

**2** We need everyone who has a stroke to know what is happening to them as quickly as possible. This includes being able to recognise the signs of stroke and know what action to take, as well as being seen by health professionals who can quickly determine what is happening and explain this simply.

Having a stroke can be a frightening and sudden experience. For many of us this experience was made even worse because our treatment was delayed.

The biggest cause of delay was from people not recognising the signs of our stroke and then confusion about what to do next. Instead of calling an ambulance some of us thought that the symptoms would just go away. Some of us called family or our GP instead, meaning too much time passed before we got to hospital.

Many of us were not told we'd had a stroke for a long time after it had occurred. This was sometimes because we could not get tests done, or because we were seen by health professionals who were not specialised in stroke care.

If everyone knows how to spot a stroke, what to do when you have one, and can be given this information quickly, then more of us will survive and more of us will get back to the life we had before our stroke.



## Lloyd and Judy Masters

Ambulance officers initially thought Lloyd Masters was having a heart attack.

While waiting in the emergency room his daughter noticed that the right side of his face had dropped and alerted staff.

The doctor failed to diagnose a brain stem clot. His wife Judy says that he was sent to the cardiac ward.

“Several days later a different doctor diagnosed a stroke,” she says

Lloyd spent one week in intensive care before he was well enough for a stroke unit.

One year later Lloyd began vomiting violently. After a scan and several hours in the emergency room he went home. The next day Judy took him to his GP.

“The GP was furious because he had already suffered a stroke and was sent home so quickly,” she says. “The next day he collapsed and it was found that he'd suffered another stroke but still wasn't put into a stroke ward.

“After a friend with medical training told me what to ask doctors he was moved.”

**3** In hospital we need a team treating us that knows about stroke and can make sure we get the right treatment quickly. This team should be able to give us the information and support we need as we adjust to such a life changing event.

We know that the best care people can get comes from health professionals who are expert in their field. We should all be able to expect top quality treatment and access to the right information but many of us didn't get it.

For some of us it was because the team treating us were not experts. Others arrived at a hospital without specialist stroke equipment.

Those of us who missed out on the best care suffered because of delays in diagnosis and treatment. We didn't get the information we needed to help us understand what was happening to us.

If hospitals have the right equipment and if staff are specialised in stroke care then we all have a better chance of surviving and making the best recovery possible.



## Helen Ebzery & Susan Darko

Before their mother's stroke, sisters Helen Ebzery and Susan Darko hadn't considered the impact it could have on their lives.

"There was nobody in the family who'd had a stroke so we've never had to deal with it," Susan says.

"The reality is that the other side of stroke can be such a shocking ride."

After initially being told she would have to live in a nursing home, the family fought hard to have her return home and be with their father.

"It was very lonely for him, because it was the first time his wife was away from him," Helen says.

They did their own research and got a second Aged Care Assessment Team to look at their case. It was decided that it would be ok for their mother to be at home with the support of her family.

Now the sisters and their two other siblings divide the task of being their mother's full time carer.

"I would hate to think of what it would be like for someone with no family," Susan says.



## Paul and Wendy Corp

When Wendy Corp suffered a stroke in 2003 her right arm and leg were severely affected and she became aphasic which means her speech and communication skills were lost.

“I went through lots of physical therapy and worked with the occupational therapist, but very little speech therapy,” Wendy says.

“I couldn’t tell doctors when I was feeling sick or ask to go to the toilet. I wasn’t able to ask for help.”

When she left rehabilitation she started day therapy, where again the focus seemed to be on just physical improvement.

Wendy asked if she would ever be able to talk again.

“I cried when I was told that it’s nearly six months since your stroke so you won’t improve much from here,” she says.

Wendy never gave up and had a breakthrough when she discovered the Aphasia speech therapy clinic at the University of Queensland.

“Nine years after my stroke I’m still improving,” she says. “I just wish I’d found this support sooner.”

**4** We need rehabilitation that addresses our personal goals and includes us in decision making. We need opportunities for regular review of our potential for rehabilitation. When formal rehabilitation is no longer appropriate or available, we want to drive our own recovery and need the support and tools to do so.

Losing the ability to do all the things we take for granted is one of the hardest things we have to face as stroke survivors and it is rehabilitation that helps us to get back as close as we can to the life we had before.

Many of us felt like we didn’t get a proper say in our rehabilitation. We felt like it was planned for us and didn’t take into account our personal goals and what we wanted to achieve.

There was also a feeling that we weren’t given the chance to prove ourselves. Assumptions were made too early about how much we could achieve and yet we thought we could do a lot better.

For a lot of us rehabilitation is a lifelong journey and with the right information we want to be able to direct and drive our own recovery for as long as we think we can get better.

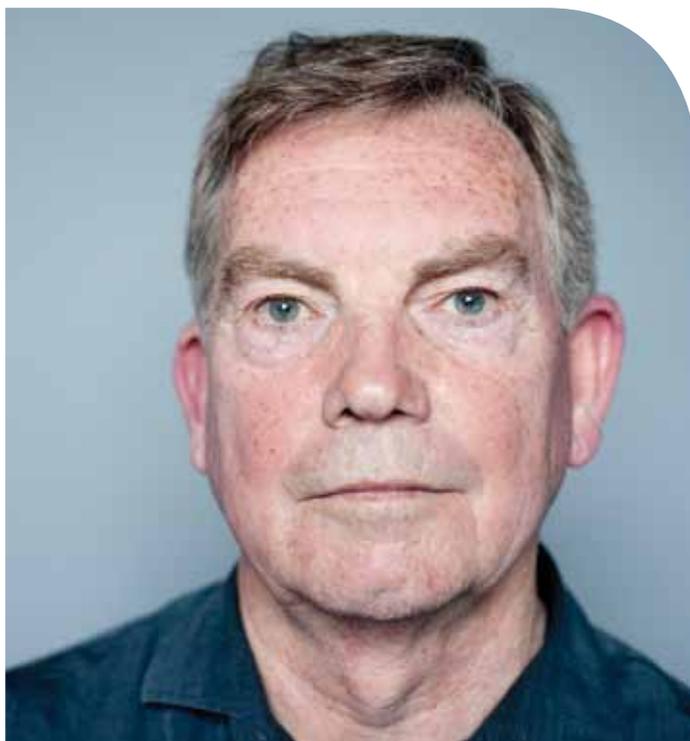
**5** When we go home from hospital we need to feel that we are ready to face life after stroke. Our fears and our concerns need to be addressed. We need information about where we can go and who we can call for help to face the challenges we know are ahead of us.

Leaving hospital and going home after a stroke was a very frightening time for many of us. It was hard to know if we were ready for the challenge of caring for ourselves outside the safety of a hospital.

Often we were scared because we didn't know what to expect. We were scared that our recovery might stall and we were scared that we might not be able to get the help we needed if something went wrong.

This wasn't the experience for all of us and for some survivors, going home was a positive experience. It was positive because they were given a good discharge plan; they were able to ask questions to allay their fears; they were informed about support services; they were reassured that they wouldn't be forgotten and that someone would contact them to check on their recovery.

This should be the experience for everyone.



## Stephen Cousens

When Stephen had a stroke in 2006 he was living alone.

When he was discharged, he couldn't read names or numbers or sequence tasks. He couldn't talk on the phone or understand messages and struggled with processing information and responding.

He had no formal discharge assessment and was told that he needed to arrange to have someone stay with him. His sister came from interstate for a short time and received only basic information about stroke and how to support him.

He was not referred on to any rehab services and was told he needed speech therapy but it was not available.

Six months later community rehabilitation became available and he received psychological and speech assessment. Stephen was diagnosed with depression and identified as a high suicide risk. He then had speech therapy and sessions in daily life training.

Friends still help him with communication and he attends support groups for people with communication difficulties following stroke.

**6** When we go home, we need help to adjust to life after stroke; to find the right people and services in the community to help us with our recovery and to enable us to drive our own recovery. This needs people to better understand the disabilities that are associated with stroke. Many of us will need additional support in this adjustment and help in other areas, for example, return to work and financial assistance.

Life after stroke is different for all of us. Some of us transitioned very well and made a quick recovery when we got home from hospital but many of us have needed extra help to adjust to our changed life.

Our needs, our disabilities, our priorities and our life circumstances are all unique but the one thing we do have in common is a burning desire to get to our own version of a happy and fulfilling life.

For some of us it's been about returning to work, but for others it's been re-learning to walk. Whatever our personal goal, it's important for us to know that help is available and crucially that we know how to find it.

While our different needs are met in different ways and by many different organisations it would be ideal if we could access information about services and support from a central source.

**7** We need emotional and psychological support at every step of our journey. It needs to be offered to all of us. This support can take many forms and may not always be provided by the health system.

The impact of stroke on us, on our families and work colleagues and friends is immense.

Our response to stroke varies from person to person, but at every stage, we have questions, fears, loss and sadness.

Stroke can be a very lonely place and getting support to answer our questions, to support us in our recovery and to help us adjust to our new lives, is vital.



## Emma Gee

Emma Gee was 24-years old when she had a stroke caused by a congenital defect in her brain. She initially felt trapped.

“I felt very lost. I couldn’t go backwards to my old job and my old life, but there was nothing to go forward to.”

It took her about a year to accept her stroke.

“I think it took me about a year of grieving before I could feel that it (stroke) does happen to young people and it’s even more important that it is spoken about because people aren’t aware.”

Emma says her physical and emotional progress wasn’t balanced.

“I was offered anti-depressants initially, but I didn’t feel like I needed them.

“I think that a lot of health professionals saw it as something that medication could fix and they wanted to move onto the physical side of my recovery.”

Emma is now content with the direction her life is taking. “Life is full of meaning now which once it lacked.”

**8** We need regular updates and information on what has happened to us and on our progress, at every stage of the journey, starting immediately. We need to be included in decisions about our recovery rather than simply being told what will happen.

None of us were prepared for a stroke. All of a sudden our lives were put on hold while we faced the challenge of recovery and yet we did not know what to expect or even what questions we should be asking.

We all wanted to know how stroke had affected us and what we could expect on our stroke journey. We also wanted the health professionals to treat us as part of the team. It was our fight but many of us didn’t feel like we had any control of it.

Those of us who were given clear information about our stroke, about the treatment we were receiving and the options that were available to us felt in control of our recovery.



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