



strokeconnect
Sharing, Supporting, Connecting

Stroke Connections

Autumn edition 2015



strokefoundation



You're not alone after stroke

In 2010, Jayson Killick was only 35 years old when he suffered a stroke while driving a taxi. After two months of intensive therapy in hospital Jayson returned home, which is when he said his stroke journey truly began.

"Depression really affected me after my stroke. After I left the hospital I didn't leave the house for two weeks. It was hard to explain to my friends what it was like as they hadn't had a stroke themselves... they didn't know how to approach me," Jayson explained.

Concerned about Jayson's welfare his carer suggested he join the local men's group. Jayson said the group was a turning point in his emotional recovery: "Gradually the men's group got me to the stage where I could talk to people again," he said.

After this positive experience, Jayson tried to find a local stroke support group to connect with others who had been through a similar experience. Unfortunately there wasn't one, so Jayson took matters into his own hands and started a local group to support survivors, families and carers.

Years later, Jayson has maintained his passion to ensure survivors aren't left to cope alone after stroke. He is now helping the National Stroke Foundation test a new online resource for stroke survivors, their families and carers

called *enableme*. The website offers survivors the ability to connect with each other to share experiences, tips and techniques to assist with everyday life. Jayson is one of around 50 stroke survivors and carers who have been helping to test *enableme* ensuring it truly delivers what the stroke community needs when it is officially launched in June.

Jayson said *enableme* would help survivors and carers support each other during the stressful and emotionally-charged recovery process.

"*enableme* will help people learn from others how best to cope with recovery, what to expect and what support services are there to help them," he said.

“ I want to use *enableme* to let survivors like me know they're not alone, there is help out there. They can talk to others and shouldn't be afraid to ask questions. ”

Here at the National Stroke Foundation we are busily preparing to launch *enableme* and we're receiving some great feedback from site testers like Jayson. Keep reading to find out more about this exciting and innovative new resource.



Rich, Di, Jude, Rachel and Jess

Welcome to the autumn issue of StrokeConnections

With autumn being the season of change, we couldn't think of a better time to talk to you about the exciting new things happening at the National Stroke Foundation.

This edition we are proud to introduce *enableme*, a new, free online tool for stroke survivors, carers and family members. *enableme* has been developed in partnership with Bupa Health Foundation and a dedicated group of survivors and carers who have guided us – and pushed and prodded us – every step of the way. You'll find everything you need to know about why and how you can start using this great new website when it launches in June. Visit enableme.org.au

You'll also find a review of stroke survivor Danny Furlong's autobiography 'Flat Out' and some great quilting tips.

This edition marks a change for StrokeConnections. Over the past few years, our mailing list has grown substantially. It is

fantastic to see we are reaching out to even more people, but it also means we need to get smarter about how we communicate with you. This year we will switch to two print editions that will arrive in your mailbox, and other email editions that will arrive in your inbox. We would love to make sure you receive our email edition, so if we don't already have your email address, please get in contact with us by emailing strokeconnect@strokefoundation.com.au or call StrokeLine on **1800 STROKE** (1800 787 653).

If you don't use a computer regularly and don't have an email address, check out our article about diving in to the 'digital age' on page 3.

We hope you enjoy this edition and are inspired to try *enableme* when it launches in June.

Best wishes,

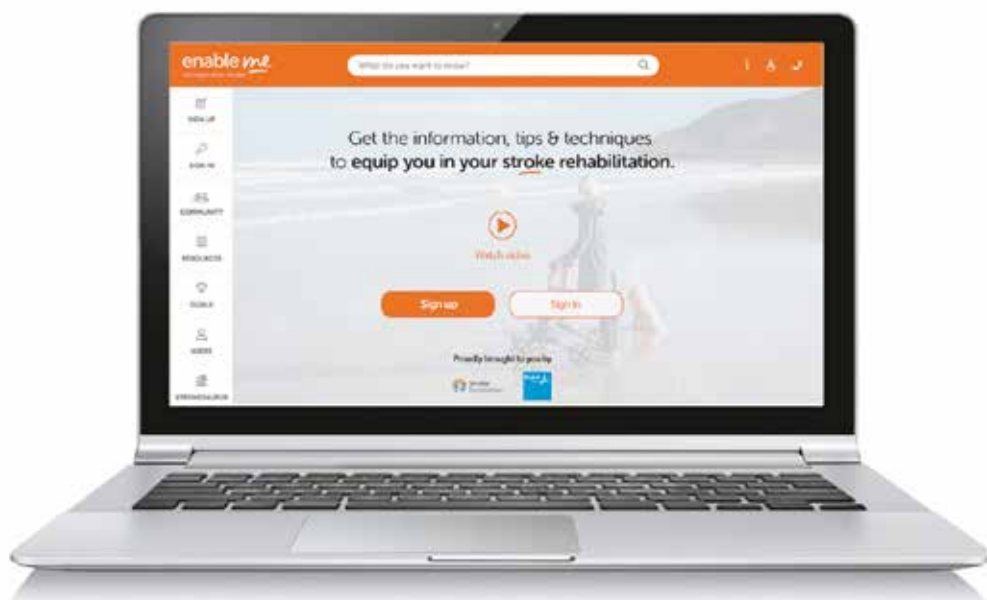
The StrokeConnections and *enableme* teams

strokeconnections@strokefoundation.com.au

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Making the switch: Going digital the easy way



Some stroke survivors have told us they're excited about *enableme* but they don't have a computer and have never used one. If this sounds like you, read on for some handy hints on entering the digital age.

Dipping your toe in the water with computers can be a bit overwhelming – to the point where many people just say 'no, that's not for me.' However like anything else, pretty much anyone can learn how to use computers with a bit of help. Family and friends can be a great source of assistance (especially the younger generation!) but if you need additional support, you might like to consider the following options:

- Your local library, neighbourhood house or community centre are great starting points. They often have computers available for people to use and may even offer training. These services are usually free of charge or only charge a small amount. To find your local library, neighbourhood house or community centre, contact your local council.
- For people over 65, there are a few additional options. Broadband for Seniors is a free program funded by the Australian Government to help senior Australians access computers at kiosks, while building their confidence and skills. There are 1,500 kiosks located across Australia. To find a kiosk near you call their helpline on 1300 795 897.

- The Australian Seniors Computer Club Association can also help you find a computer skills course nearby. The Association runs courses throughout Australia at a low fee of \$10 per hour if you have a Seniors Card, and \$15 per hour for anyone else. To find out more you can call the Association on 02 9286 3871.

Once you've got access to a computer and have mastered the basics, you'll be all set to start using *enableme*. You'll find 'how to' videos within *enableme* to guide you on how to use the site.

To make the most of *enableme*, we recommend you sign up as a registered user. Being a registered user means you'll be able to personalise the site so you can follow people and topics that interest you. You can also set up the site so it meets your individual accessibility needs.

Becoming a registered user is very easy – you'll just need an email address. If you don't have one already you can visit a website offering free email such as www.outlook.com.au or www.gmail.com

This might all seem a bit daunting but with a bit of practice and support we know you'll find connecting online fun and rewarding.

enableme.org.au

enable me

stronger after stroke

enableme.org.au

All about *enableme*

From June stroke survivors, their families and carers Australia-wide will be starting to use *enableme* and we couldn't be more thrilled. We want our StrokeConnections readers to be able to jump right in and start using it when it's publicly launched. So we thought we'd bring you up to speed with what *enableme* is, how you can use it and why you should give it a go.

What is *enableme*?

enableme is a free online resource created specifically for the Australian stroke community. It is a place where you can talk to, and seek support from other people who have 'been there'. It is a place to ask questions, to find the answers you need and to set recovery goals.

It is also a place where you can offer support, encourage others and share your experiences. With *enableme* you are not alone, you are part of a bigger community of people who stand side by side facing life after stroke.

How can I use it?

enableme has been purposely built so you can customise the website to suit your goals and needs. There are a range of innovative features you can use to help you achieve your best recovery.

Resources: After stroke the last thing you need to be doing is trawling the web trying to find the information you need. *enableme* brings together thousands of stroke resources all in the one place. We've covered a range of topics from pain management and sleeping after stroke, to the types of strokes and treatments available. We've also included 'Strokesaurus' – a stroke dictionary – to help people navigate the complicated and confusing terminology survivors, carers and families are confronted with after stroke.

Forums and blogs: Do you want to talk to others about a challenge you're facing or something that's on your mind?

“*enableme* has a range of forums where you can connect with other people who 'get it.' It is a place where you can offer tips, cheer people on to achieve their goals and share frustrations.”

You can also blog about your experiences and search for other users' blogs by topics, age, location or name.

Goals: Goal setting is an important part of the recovery process. In *enableme* you can keep track of your short, medium and long term recovery targets. You can meet others with similar goals, share experiences and achievements.

Accessibility: One of the first things you'll notice when you enter *enableme* is the site asks whether you need assistance in setting up the accessibility features. The site has options for increasing the text size, moving text to the left or right, even underlining the first and last words of sentences. Click the 'listen' button to have the words on the screen read to you.

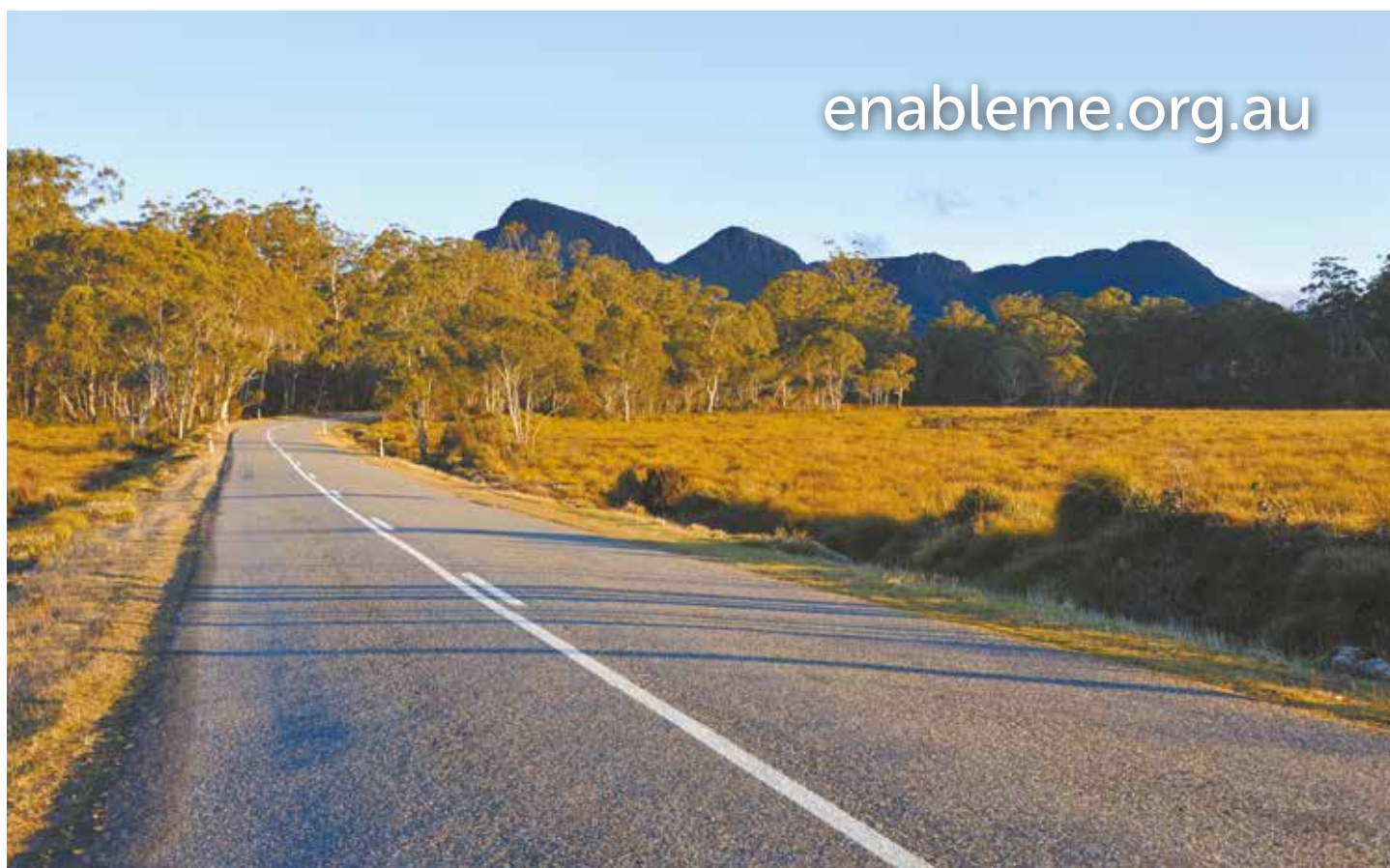
Why should I sign up?

When you sign up to *enableme* we hope it will improve your life. But what's really exciting is when you join *enableme* you have the power to change the lives of others. We've spoken

to survivors, families and carers who've told us what really helped them after stroke was being able to connect with others in the same situation. As a member of the *enableme* community you can share your experience, hints and tips and make someone else's stroke journey better. And if you're having a rough time, the *enableme* community will be there for you.

We're really proud of the design and features of *enableme* – it's the first resource of its kind in Australia and we know it has the potential to make the often confusing and frightening journey of life after stroke that much easier.

In the next few days we'll be sending you an email with all the information you'll need on how you can get involved with *enableme*. You can also email us at enableme@strokefoundation.com.au and we'd be more than happy to answer your *enableme* questions.



Putting stroke survivors in the driver's seat

Listen

Text read aloud for people with a vision impairment

Strokesaurus

An A to Z guide of language used around stroke. From atrial fibrillation to Webster Pack – it explains key terms in simple language

Tell your story

Create your own blog to tell your story

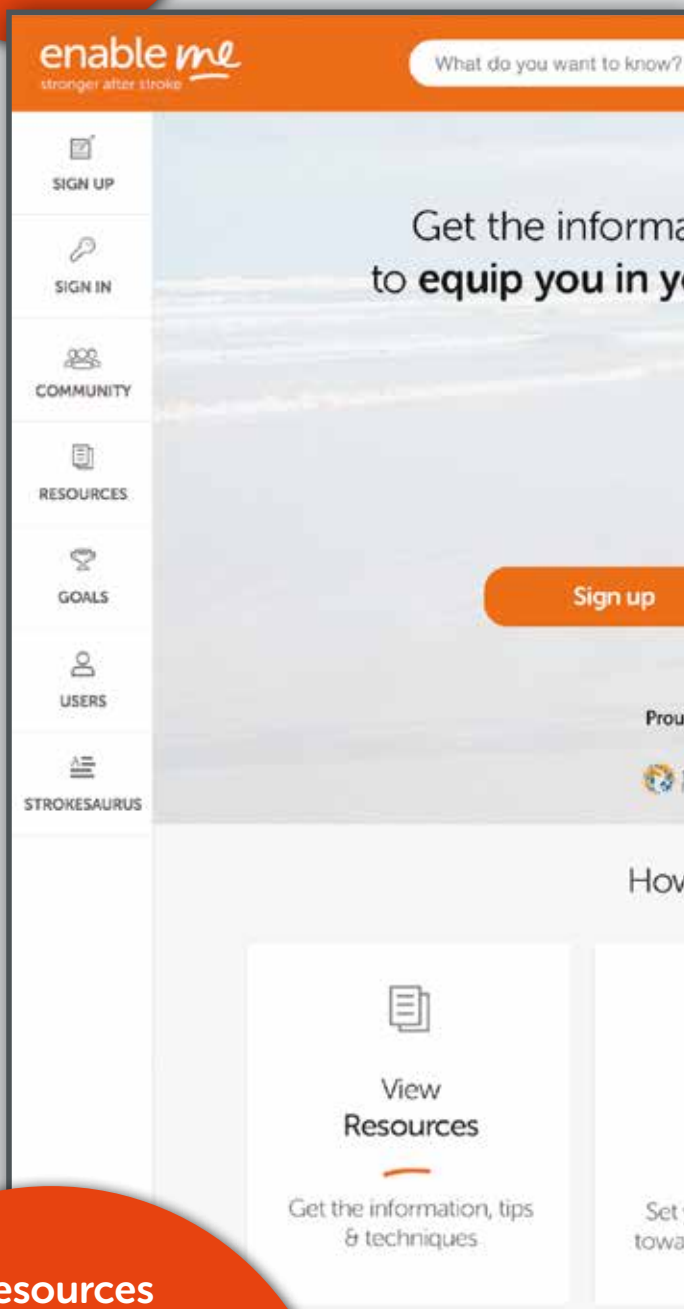
“ [My goal is] to be able to walk along the beach again. ”

enableme community member

Resources

A wide array of fact sheets, videos plus questions and answers on practical day-to-day life issues

- Basic facts about stroke
- Life after stroke
- Information for carers
- Body and mind health



Search

Simple, Google-style search function

Contact

StrokeLine contact details for extra help and information

Accessibility settings

Customise your personal settings to suit your viewing – including larger text size, high contrast or aligning text to suit your vision

“ [I wish to] explore ways to maintain the best health possible as a stroke survivor.”

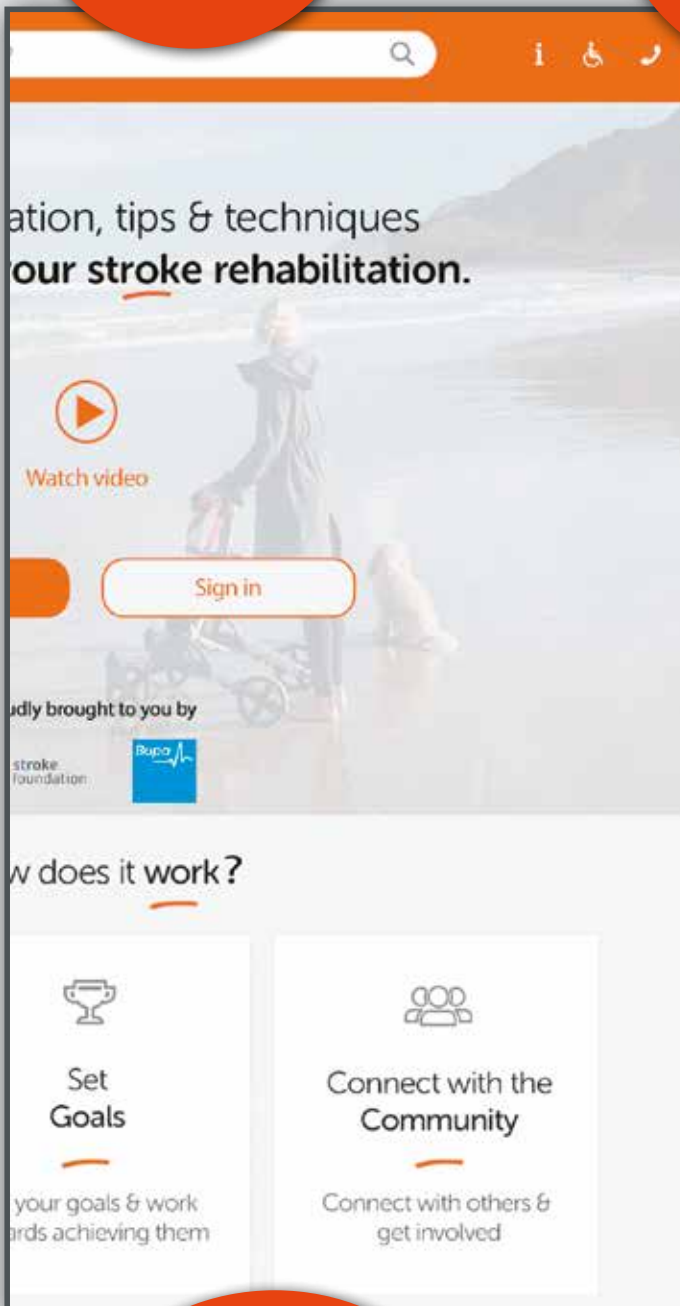
enableme community member ”

Goals

- Set and keep track of short, medium and long term recovery targets
- Meet and encourage others with similar goals to share experiences and challenges

Community

- Forums to ask questions and share experiences about recovery or life after stroke
- Connect with support groups around Australia
- Tips, reading lists and technology to help your recovery



Meet the *enableme* team



As you've probably guessed, delivering *enableme* is one of our key priorities at the National Stroke Foundation and we've been working hard to get it up and running. Richard Cullen and Diana Kerr, pictured above, from the communications team have been heavily involved in the creation of *enableme*.

Rich Cullen is the project coordinator for the site and has been working on *enableme* right from the start. You might know Di Kerr as the voice behind the National Stroke Foundation's social media. Di has also taken on the role of community coordinator for *enableme* and will be your main contact when you sign up.

We sat down with Di and Rich to get their insights into *enableme* and what they hope it can achieve for the stroke community.

What does *enableme* mean to you?

Rich: It is a well-used saying but *enableme* really is a one stop shop for stroke survivors and carers. It provides a wealth of information and resources. It will become the largest online stroke community in Australia, which is pretty exciting. *enableme* users will be able to create and track goals and browse through an extensive dictionary of stroke terminology that we call 'Strokesaurus'. Of course the greatest resource in *enableme* is its users – stroke survivors, their families and carers. Everyone has something to offer, from those at the start of their stroke journey to those who have walked down that path and want to help others. We purposely built *enableme* in consultation with

stroke survivors and carers to ensure users will have the tools and resources to equip themselves in their stroke rehabilitation.

What is your role in the project?

Rich: I am the project coordinator for *enableme* and have overseen it from when it was just an idea through to building the website itself. I am very proud to have seen it through to where it now is and I think of it as my second baby! It has provided a few sleepless nights but also great pride in seeing it take its first steps.

Di: My role is the community coordinator for *enableme*. Essentially I'll be the main contact or go to person from the National Stroke Foundation for people when they're using *enableme*.

Why do you think *enableme* is important?

Di: I have been managing the Foundation's other social media communities, including Facebook, since 2010. I have watched our Facebook community develop into a space where people connect, share information and ask questions about what they are facing after their stroke. *enableme* will be an extension of that community and will act as a 'library of stroke' where people can get the latest information right at their fingertips.

Rich: One of the first lessons I learnt from survivors was that all strokes and survivor experiences are different. It is incredibly challenging to translate this to an online experience for all stroke survivors, when every stroke and life experience is different. I am confident *enableme* will provide the most

personalised, resource rich and supportive community for stroke survivors in the world.

How is it different from existing supports for stroke survivors?

Rich: The challenge for a stroke survivor navigating the web has always been how to find the information most relevant to me. *enableme* is designed to suggest relevant information to the survivor rather than the survivor having to struggle to find it. There are lots of organisations producing great content but if a survivor doesn't know about it, they will never find it. Essentially what we've done with *enableme* is flip the age-old problem so the most relevant information finds the user, not the other way around. *enableme* collates resources from all around the web. People using *enableme* can choose to follow the topics most relevant to them. And importantly they will be told when new information about that topic is shared on *enableme*, which will make it a lot simpler for them to stay up to date.

“**Di:** Talking with others who 'get it' can be very motivating and peer support is essential to recovery. I like to think of *enableme* as a really big local support group.”

What has been the most challenging aspect?

Di: Waiting for it to go live, I am very impatient ;)

Rich: 'When will it be ready?' tends to be the comment I hear most and not just from Di! The need for an online tool such as *enableme* is massive – it's long overdue. The main challenge is to ensure we are building a tool that meets a long list of needs. One of our main priorities is making sure *enableme* is accessible as well as usable by allowing users to customise the site

to suit their individual needs. We have worked with stroke survivors and carers at all stages to ensure we meet this challenge and the feedback so far has been encouraging.

What kind of feedback are you getting from stroke survivors and carers who are testing *enableme*?

Di: I have spoken with many of the survivors and carers who are helping to test *enableme* and the feeling in the group is very positive, which is fantastic. One comment from a stroke survivor really stood out to me as it shows why *enableme* is so important. Neville told us: "I've been looking at this [*enableme*] for a couple of hours and I think it's outstanding. I did have trouble finding my way around at first, but once I found the necessary parts, I have been amazed at what I've seen. I've actually learned a lot and realised where some of my problems have come from. This will give me an opportunity to get some help. Considering how much I've learned tonight by looking at *enableme* is amazing, especially when I'm almost five-years post stroke!"

“**Rich:** At the end of the day it is about those individual wins. It has been humbling and educating in equal measure to meet so many stroke survivors, carers, friends and family. Listening to their needs and creating ways to bridge the gaps they face in using technology has driven me in creating *enableme*.”



‘Flat Out: an unusual autobiography’ by Danny Furlong

I was going to call this review “The return of Alvin Purple” until I realised no one remembers who Alvin Purple is anymore. For those not lucky enough to have been around in the 1970s, Alvin Purple was a blockbuster Australian movie about a charming young man who was always a hit with the ladies. If you do remember Alvin Purple and if you’ve ever wondered what would happen if a bloke like Alvin had a stroke and became a non-verbal quadriplegic confined to an electric wheelchair, this book is definitely for you.

The 1970s was a very, very different time to now and after reading this book I have no doubt that Danny Furlong, pictured above, is a seventies man. His book *Flat Out: an unusual autobiography* certainly lives up to its title. This book left me speechless, so perhaps it’s best if I use Danny’s words to describe it:

“Imagine yourself as a physical guy, an ex-commando and skydiver, who has a stroke for no known reason and loses nearly everything but your mind and – thankfully – your sexuality. You awaken from a coma to a gruelling, yet often funny, rehabilitation. You lose your marriage and are separated from your children. Finally, new love, and you become a parent once more. This is the true-life story of Danny Furlong’s extraordinary journey from active life to the depths of mute quadriplegia, to the highs of life within that quadriplegia.”

Danny offers readers an audacious, funny and often touching account of his life before and after stroke. Throughout the book, readers gain

an insight into Danny’s journey, from learning to communicate to his discovery that stroke hadn’t robbed him of the things that made him himself.

This is a funny, honest and well-written book. Danny doesn’t shy away from anything in telling his story of how he regained as much of himself as he could, including his self-respect.

If you’re easily offended, this book probably isn’t for you. If you can’t help but admire a lovable rogue, then give it a go.

Flat Out: an unusual autobiography is available on Amazon.

You can also visit www.dannyfurlong.com


World Continence Week 22–28 June

Many stroke survivors experience problems with bladder or bowel control after a stroke. Incontinence can be distressing and embarrassing, and can seriously impact the lives of survivors and their carers.

World Continence Week runs from 22–28 June and marks the launch of the Continence Foundation of Australia’s major project for 2015 – *Carers Count: support for continence management*. There are 140,000 Australians living at home who need help with bladder or bowel control problems. Their carers are twice as likely to report stress-related illnesses and they suffer an estimated productivity loss of \$2.7 billion annually.

As part of the project, the Continence Foundation is launching several resources including a carers’ booklet, dedicated web pages and videos supporting carers of people with incontinence.

Carers are also encouraged to phone the National Continence Helpline on 1800 33 00 66 or visit continence.org.au for advice, referrals and further information.



More than anything Wendy wanted to talk again

Supporting our work

enableme was inspired by the stories of stroke survivors, their families and carers. These stories tell of a void in support survivors face when they return home from hospital after stroke. Survivors asked us to fill this void by giving them something to direct their own recovery.

Before her sudden stroke, Wendy Corp, pictured above with husband Paul, was a vibrant 60-year-old with a rewarding career as a theatre nurse. Wendy's stroke robbed her of her communication skills and left her with severe physical disability.

For Paul and Wendy, information about stroke was hard to come by, even during that traumatic first day in hospital. "I knew very little about stroke. I was worried sick and I was told to go out to reception and read a brochure," Paul said.

After her stroke all Wendy wanted to do was talk again. But she couldn't physically tell hospital and rehabilitation staff that talking was more important to her than walking.

Six months after her stroke Wendy managed to ask if she would ever be able to talk again.

"I cried when I was told, 'it's nearly six months since your stroke so you won't improve much from here.' I couldn't even put two words together," Wendy said.

After a lot of trial and error, Wendy and Paul finally found an aphasia speech therapy clinic

where she could get the specialist help she needed.

"This was a big turning point in my life. The clinic has helped so much with my speech."

Wendy and many people like her are the reason we have created *enableme*. It is designed to empower stroke survivors and their families to take control of their recovery.

Paul said he wished *enableme* had been around at the time of Wendy's stroke, "I can envisage what a hell of a difference it would have made if it had been around at the time and I was directed to it."

Launching *enableme* has only been made possible thanks to the support from founding partner Bupa Health Foundation. With so much more to do, we are also calling on the public's support to ensure *enableme* becomes a true online community of stroke survivors across Australia.

If you are interested in supporting our work to deliver projects such as *enableme* you can visit www.strokefoundation.com.au/donate

“ I can't believe I was told I wasn't going to get any better, Wendy said. ”



**It works
for me**



Share your tips and tricks with the community

Do you have advice for other stroke survivors, carers and family members on gadgets, apps, tricks or techniques to make life easier? Best tip published wins a \$50 Coles Myer gift card.

Having a hobby like quilting can be a fantastic creative outlet and can even help you lower stress levels. But for many stroke survivors with mobility issues, activities such as quilting and sewing can be challenging. Stroke survivor Lisa, pictured above, has recently returned to quilting 18 months after suffering a major stroke that affected the left side of her body. Lisa loves to make quilts for family, friends, new babies and even the odd one for herself. She has shared her tips, tricks and recommended gadgets that helped her get back into quilting one-handed using her sewing machine.

- An AccuQuilt fabric cutter assists with cutting fabric in a range of different sizes and shapes.
- Lisa uses special plastic clips instead of pins to hold the fabric together. She found the fabric clips at her local quilting shop – the brand that Lisa uses is Sew Easy, but you can also get them from Clover.
- Lisa suggests using a magnet to hold the fabric in place when placing it under the foot of the machine before pulling the lever down to start sewing.

Lisa said achieving goals like learning to quilt again has helped her recovery.

“There’s nothing I can’t do or won’t try. A positive attitude is key and I have a wonderful supportive and loving husband and family,” she said. Pictured here is Lisa’s amazing ‘recovery quilt’, the first quilt that she made after her stroke. We think it looks incredible!

Congratulations Lisa, you are this edition’s winner of our \$50 Coles Myer Gift Card!

Email your ideas and tips to strokeconnect@strokefoundation.com.au or call **StrokeLine 1800 STROKE (1800 787 653)**.



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