



strokeconnect
Sharing, Supporting, Connecting

Stroke Connections

Winter Edition 2014



strokefoundation



Incontinence after stroke – let's start talking about it

For something no-one wants to talk about, incontinence is pretty common. Over 4.8 million Australians have bladder or bowel control problems.

The National Continence Helpline offers expert, confidential advice on every aspect of incontinence. We spoke with continence nurse advisor, Steve Marburg from the Continence Foundation (pictured above).

Why should people contact a continence specialist if they are experiencing problems?

After a stroke, poor bladder or bowel control can be caused by muscle weakness, changed sensation or feeling, difficulty responding to the urge to go, difficulty dressing or undressing, changes in communication, eating and drinking habits or changes to vision.

Many continence issues can be prevented, treated, better managed or cured, but if left untreated, may become worse or lead to other problems.

Incontinence can be frustrating, embarrassing and distressing and can impact on a person's social activities, work life and sexual activities. It can also lead to depression. A continence specialist can make an assessment about the underlying cause of your continence issues and devise a treatment plan for you.

What advice would you give a person who wants to seek help?

The first step is a small one; speaking to one of the continence nurse advisors on the free, confidential National Continence Helpline. By describing the types of problems you are experiencing, the continence nurse advisor can give you advice over the phone and send you some information. They can also refer you to a continence professional.

What is involved in a continence assessment?

You will be asked to provide some history about your past bladder and bowel control and your present level of control. Your diet, fluid intake, exercise levels and mobility, along with any medications you are taking will also be looked at.

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Anna, Jude and Steph

Welcome to the winter issue of StrokeConnections.

We received fantastic feedback about the last issue, especially the moving story of Erin and Sam Benjamin's new son, Jack. This newsletter is for you, so we really appreciate you taking the time to tell us what you like (or don't!)

One of our Consumer Council members, Adrian O'Malley has done exactly that – he suggested a new column 'What works for me'. Well, it works for us, thanks Adrian and you'll see it in the next issue. Tell us about the products, phone apps, mantras, tricks or nifty gadgets that make you

and your families' lives easier. Adrian's favourite app is 'It's done!'

Applications for the 2014 Stroke Awards have now closed. Thank you so much to everyone who made an application or helped us promote the awards. There are so many amazing achievements and stories in the stroke community and we want to celebrate them! Finalists will be announced in mid-July with winners announced in October.

We are currently finalising our plans for National Stroke Week 2014, so mark 8-14 September in your diary and stay tuned!

Our Fight Stroke campaign continues to gather momentum – we now have over 10,000 members but there's still more to be done. If you haven't already, please add your name at www.fightstroke.com.au

Finally, if you have moved or are moving house, please let us know your new details so we can update our database.

Keep in touch,

Jude, Steph, Simone and Anna

The StrokeConnections Team
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Monitor for kidney disease at home

Cardiovascular disease and chronic kidney disease share common risk factors, such as high blood pressure. Researchers are also discovering that a history of cardiovascular disease is a risk factor for the development of chronic kidney disease (CKD) and vice versa.

KidneyCheck is the first Australian self-management program for people diagnosed with diabetes and high blood pressure. It allows you to check for protein in the urine – one of the first signs of kidney damage – and monitor the health of your kidneys in the privacy of your own home.

For more information visit www.kidney.org.au or freecall 1800 454 363.



Book review

The Twelfth Raven: a memoir of stroke, love and recovery

‘The Twelfth Raven’ begins with Doris Brett and her husband Martin getting ready for an outing with clothes, shoes, food and books packed for every possible eventuality. As she notes: “We are prepared for everything. Absolutely everything. Except what happens.”

This beautifully written memoir explores a life where everything changed in a moment. Martin’s stroke was severe and he was left with significant impairment. It charts the initial shock and confusion, the immediate warnings the couple received against optimism and the satisfaction of a surprising recovery.

“Martin was paralysed down his right side, as well as having complete expressive aphasia. He has been making some beautiful furniture since his recovery and I think it’s inspiring for people to see his work – it gives a very vivid sense of the recovery he has made,” said Doris.

The book illustrates how hard-won these gains are. After his stroke, Martin’s health problems are complex and his survival is uncertain for a long time. This story is of a marathon, not a sprint. It details how the challenges of ordinary life continue even as we are gripped by crisis. Things break down, the well partner gets sick and important tasks pile up. Doris is painstaking in her description of the importance of support from family and friends and she doesn’t shy away from the lessons crisis teaches about friends and friendship. Some important friendships fracture, some people drift away,



Martin Brett’s furniture is pictured above.

while other friends step up unexpectedly just when they are needed the most.

There’s a lot of humour in this book and a lot of love. It is a gentle warning about the inevitable codependence that comes with a long marriage. Doris’ description of Martin sitting down to begin to sort out the mess of unpaid bills on his first visit home from hospital is also a celebration of the benefits of that codependence.

Doris’ book is insightful in its depiction of what it is like to rely on a health system that is full of contradictions: lifesaving, expert, yet frustratingly complex and sometimes deeply flawed. It’s comic at times, how hard she needs to push to get even simple information about Martin’s often rapidly changing condition. When the system works well, when problems are picked up and helpers are ‘warm, experienced and communicative’, the relief is profound.

As a psychologist, Doris Brett was well equipped to research her husband’s condition and to consider for herself the evidence about what might help his recovery. Her experience of this, as well as her interest in the emotional side of illness, motivated her to write the book.

“I wanted to share the things we did that were instrumental in Martin’s recovery as well as to explore the inner life of being a carer. I’m a writer as well as a psychologist, so it was natural for me to write about it,” said Doris.

“This is the book that I wanted to read while going through the devastating experience of a loved one’s stroke.”

The Twelfth Raven is out now.

Looking for Dr Right - how to find a good GP

We take a lot of calls on our advice line, StrokeLine, about health issues after a stroke. Sometimes when we ask callers if they have discussed their issue with their general practitioner, there's a long pause and then they answer "Well..."

Having a good GP is important – it is very difficult to manage your general health, let alone your post-stroke health, without one. It may be time to find a new GP if you don't feel comfortable talking to them or if you feel like they're not really listening. If you often find you don't understand the advice your GP gives you, it's definitely time to think about moving on.

Asking neighbours, friends and family for a recommendation is still the best way to go when you're looking for a new GP. There are also websites such as HealthEngine that can help. Check out things such as the GP's location, charges, after hours and visiting services. From there, it's okay to try out a few different GPs before making a commitment. It might also be as simple as switching GPs in the same practice.

How will you know you've found Dr Right? Number one, they'll be a good listener. They'll also explain things clearly, especially when it comes to the different options and why they recommend a particular treatment or course of action. They'll provide you with information about other services and supports that may be able to help you. You'll be confident that they want to work with you to manage your health and make sure you're as well as possible.



When you live in a small town or even on the suburban fringe, choice can be limited. Make sure you get the most out of your GP visit:

- Take a list of symptoms and questions with you, along with a pen and paper to write things down. If it's more serious, and you have someone kind enough to go in with you, that's even better.
- Be realistic about what you can get through in a standard consultation time and book a longer visit if needed.
- Plan to tackle the most important issues first and let your GP know about everything you want to discuss at the start of the visit. GP's often talk about the 'doorknob moment': asking the most important question when your hand is on the doorknob as you leave. Whatever the problem is, remember your GP has heard it many times before.

At the end of your visit, you should understand what might be wrong and if you need any further tests or treatment. You should also be clear about what happens next and what you need to do.

So please, get out there and find Dr Right before it's too late.

More information

'I heart my GP' has a full list of all the websites that can help you find a new GP:

www.iheartmygp.com.au/find-a-gp/

For more information, you can also call StrokeLine on 1800 STROKE (1800 787 653).

Checking the nation's blood pressure

On 2 April the National Stroke Foundation and our partners the Seven Network, Chemmart Pharmacies and Macquarie Life, started a national conversation about stroke, one that needs to continue.

Over 11,000 Australians participated in Australia's Biggest Blood Pressure Check. Shockingly, around 25 percent of those tested were referred to a health professional as they were considered at high risk of stroke.

2 April also heralded the 2014 launch of the Stroke Solidarity String at Sydney's exclusive Ocean Room. Events like these are an opportunity for us to share the real impact of stroke and garner support from celebrities and key influencers in our fight against stroke. Stroke survivor Luke Webb bought the house down with his singing and fellow survivor William Lo spoke movingly. The Seven Network heavily promoted the Blood Pressure Check on its programs and the entire Morning Show was dedicated to stroke on the day. Plus we received fantastic coverage in Pacific Magazine publications including Prevention, New Idea and Marie Claire. National Stroke Foundation advocate Chris Bath has been a driving force behind the campaign and featured in Marie Claire's photo essay:

"After Dad had his stroke, I kept thinking, 'why aren't we doing something about it, so other families don't have to go through what my family



Channel Seven's Chris Bath is pictured above wearing her Stroke Solidarity String as featured in Marie Claire magazine. Photograph © Hugh Stewart

has been through?' I've been a journalist for 25 years and I can barely remember reading any stories about stroke. Buy the National Stroke Foundation's Solidarity String and help start a conversation around stroke in this country."

Continue the conversation by buying a Stroke Solidarity String today.

www.strokefoundation.com.au/about/string

Wear it, show it, share it.

Share your Stroke Solidarity String photo on social media #fightstroke

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You may be required to undergo some tests to investigate how your bladder is working such as a quick bladder scan, urine tests or keeping a urine diary.

What do you like most about your role as a continence specialist?

I get a lot of satisfaction when I am able to make a clear impact on the quality of a person's life. Incontinence has a big impact on quality of life for people in so many areas – physical and psychological - and can often be the tipping point for someone or their carer going into a nursing home.

If we can help callers to the Helpline with using fewer (or the correct) products, funding assistance, better treatment options, or just acknowledging the difficulties they are experiencing, many callers are grateful for our advice. They are often thankful that there is a “starting point” to deal with the issue. If we can help them manage their problem and improve their quality of life, then that's brilliant.

More information

The National Continence Helpline is a free telephone advisory service staffed by a team of continence nurse advisors who provide information, education and advice to callers. Call 1800 33 00 66 or visit the Continence Foundation Australia website www.continence.org.au

The National Public Toilet Map website and mobile phone app detail the location and details of more than 14,000 public and private public toilet facilities across Australia. Visit www.toiletmap.gov.au for details.

Download the National Stroke Foundation fact sheet on incontinence after stroke from www.strokefoundation.com.au or call StrokeLine on 1800 STROKE (1800 787 653) to be sent a copy.

Support groups news



Support groups in WA go from strength to strength

There are 15 stroke support groups operating in WA, powered by stroke survivors and carers who want to see the benefits of peer support made available to as many people as possible.

Jane McKinley, project officer at the National Stroke Foundation, plays a key role in facilitating a number of hospital-based stroke support groups in WA. “Being based in a hospital makes it easier for stroke survivors and their families to access and connect with the group before discharge.”

Jane believes that stroke support groups play a vital role in linking survivors at various stages of recovery. “Members who are a bit further along in their journey inspire and motivate individuals who have suffered a stroke more recently. After a meeting last year, a couple of new attendees who were still in the hospital made a pact to motivate each other so that they could return home and live independently.” Jane credits the group members with helping all three achieve their aim. “Hearing personal experiences from other stroke survivors who are now back home and living independently provides a source of inspiration and an ‘I can do this’ mentality.”

Jane reports people can be a bit reluctant to attend at first but that the benefits soon become clear.

Jane's groups are just a small part of the flourishing stroke support group scene in WA, with groups operating in many different locations.

To find out more about stroke support groups, contact your local state stroke association or call StrokeLine on 1800 STROKE (1800 787 653).

Survivor story



The emotional side of stroke recovery

Barbara Cafagna was 35 when she started experiencing excruciating headaches. After initially being treated for sinusitis, dehydration and even tension headaches, she suffered a stroke five weeks later.

“I was lucky in one way as the strength in my left side came back relatively quickly so physically, I felt fine and people couldn’t tell I’d even had a stroke,” said Barbara.

“It was the emotional recovery that I found hardest - I used to be so confident but my personality had changed a little and my confidence was down.

Becoming a StrokeSafe Ambassador last year was a turning point for Barbara, she is one of a team of 150 volunteer ambassadors nationwide who speak with community groups about stroke and the signs of it.

“I really didn’t deal with the emotional side of my recovery until I did the StrokeSafe Ambassador training. The training made me realise the massive impact that my stroke had on my emotional well-being, and helped me face my fears of public speaking. Doing the training, I also discovered there were resources and literature to deal with the emotional side of stroke recovery – it helped me feel validated. I really wish I knew more about that when I was discharged.”

Three years after her stroke, Barbara moved from Perth to Kalgoorlie for her partner’s work. Like many stroke survivors living in rural communities, she has felt isolated, especially without a stroke survivors group to attend.

“The after effects of my stroke probably compound the isolation I feel being without

family and friends. I make a real effort to keep in touch with them whether it’s by Facebook, text or an old fashioned phone call – it makes such a difference.”

Like many stroke survivors, Barbara credits her partner with being an instrumental part of her recovery.

“He was amazing – there were days when I was really cranky and he would help me through it just by being there for me. I learnt that it’s normal to feel like crap and not yourself. Be open and honest with your partner and family, don’t just fob your feelings off and don’t be scared to ask for help.

“Remember, people are doing things for you because they want to, not because they have to.”

More information

It is very normal to feel sadness and grief in the time shortly after the stroke. However, if these feelings last more than a few weeks, it may be time to seek help.

To order a free DVD that features stroke survivors and a health professional talking about emotions and depression after stroke, call StrokeLine on 1800 STROKE (1800 787 653).

StrokeSafe Ambassadors deliver information sessions about stroke. We are currently looking for new Ambassadors in Albany, Northam and Narrogin in Western Australia, Adelaide, Geelong, North and North West Tasmania and in Hobart.

If you would like to express interest in being an Ambassador, please contact Meg Werner or Michelle Adamson on 1800 STROKE (1800 787 653) or email volunteer@strokefoundation.com.au

Keeping
active



Yoga after stroke

Yoga, an ancient practice originating from India more than 2500 years ago, aims to unite and balance the mind, body and soul through physical postures and breathing.

There are many reported health benefits and anyone can practice yoga as there is a style to suit everyone. Traditional yoga postures can be adapted to meet the needs of individuals and can be completed in standing or sitting.

If you're thinking of trying yoga after a stroke, it's important to contact the yoga teacher prior to attending a class to discuss your specific needs and to help decide if private classes or group session are more appropriate.

Some useful questions you may like to ask the teacher are:

- What are your qualifications?
- What experience do you have in teaching people with injuries or health concerns?

- What level is the class aimed at and what do I need to bring?

Research about the general health benefits of yoga is emerging, including studies specifically on yoga and stroke. Whilst yoga isn't covered by Medicare, there are a number of private health funds that do provide rebates.

Stroke survivor Karen says "Yoga helps to get me out of my head and into my body. The breathing and meditation practiced in yoga assist me to calm central post-stroke pain and to decompress the sensory overload in my brain. The two sides of my body feel and function differently to one another and yoga postures help me to understand and reduce this asymmetry."

To find out more about yoga following stroke or to get help locating a suitable class or teacher please visit

www.yogaaustralia.org.au
or call **StrokeLine on 1800 STROKE (1800 787 653)**.



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