



strokeconnect
Sharing, Supporting, Connecting

Stroke Connections

Summer edition 2014



strokefoundation



Introducing the Valentine family

Max Valentine suffered a stroke at the tender age of 10 weeks. His mother Faith has allowed us to share his story. Max, now three years old, has just welcomed a new baby sister, Silvie (pictured above with her big brother) into the Valentine family. Faith updated us on her second pregnancy and how Max has been coping post stroke.

“In March of this year, we discovered I was unexpectedly pregnant. I hadn’t planned on having any more children, because Max alone is quite a handful. But, I honestly think everything happens for a reason and already this little girl has healed me in places I never knew were broken. Max now has a little sister, Silvie. We speak about her a lot and he loves helping me get her things ready,” said Faith.

On a day-to-day basis, looking after Max as well as her newborn daughter can be quite difficult for Faith.

“Things I would never have suspected, like feeding himself he [Max] finds hard and he struggles to maintain focus. He is going through a very ‘challenging’ stage’. We are going swimming a lot because that’s one of the only

things I can do where I can keep up with him!” said Faith.

Along with the lows come the highs and according to Faith, Max has the kindest of spirits.

“We also share some beautiful moments together and I frequently see glimpses of a very sweet, caring little boy. A few days ago, I got home from work completely exhausted, Max told me to lie down, close my eyes and go “nigh nigh”. Then he tucked me into bed, gave me a kiss and left me to sleep. It’s moments like this, where I see that my words really are sinking in and it gives me the strength to keep going,” said Faith.

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Jude, Jess, Simone and Katherine

Welcome to the summer issue of StrokeConnections

This edition has a very personal feel to it. We introduce you to young stroke survivor Max Valentine and his family and share their heartfelt story before providing you with a wealth of information on the personal impact of stroke on survivors, their families and their relationships.

We also take this opportunity to announce the 2014 Stroke Award winners for each of the four categories.

On a technical side, we have some great tips on how to avoid falls, slips and trips post stroke.

As the the end of year fast approaches, we offer joyous season's greetings and a happy and safe new year to yourself and your loved ones.

Best wishes,
Jude, Simone, Katherine and Jess

The StrokeConnections Team
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Introducing enable me

Stroke survivors, carers and their family and friends all face a common challenge: how to get from stroke beginner to stroke expert fast. Having access to information, tools and support is vital to participate in your initial treatment and to move on to manage your own recovery.

Enable me is a new website being developed by the National Stroke Foundation in partnership with Bupa Health Foundation. Enable me will assist with the 'how' of life after stroke. It will feature information, resources and interactive tools to allow people to do things like set goals and celebrate achievements. The site will also

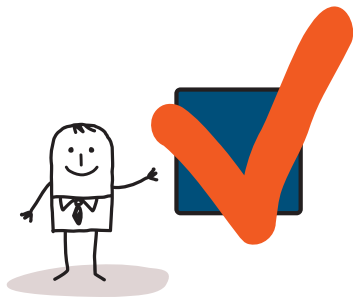
enable me
stronger after stroke

connect survivors and carers, allowing them to share their experiences, tips and techniques. It will be easy to use and is designed to be accessible for everyone.

Enable me will launch next March so stay tuned. If you aren't online and you're thinking about it, now might be the time to get on to it! Once enable me launches, we'll be featuring stories on how to use it. We want to make sure as many people as possible get the benefits.

You can also follow our progress at:
www.strokefdn.squarespace.com

It works
for me!



Share your tips and tricks with the community

A new column to share advice on what makes your life easier. 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.

Sitting still in one place for a long journey is really bad, everything sets and when you go to move nothing wants to cooperate. Early on in my recovery my physio told me if you must take a long trip, then make sure you stop every hour and do five laps around the car. I didn't manage to stop that often, but I did stop as often as we could and I did those laps. The first one is always really slow but as you unkink you get faster.

Heather, stroke survivor

In the morning I exercise my leg in bed, I lay on my back and bring my knee up to my chest about 25 times before I get out of bed. I find this helps me walk better through the day.

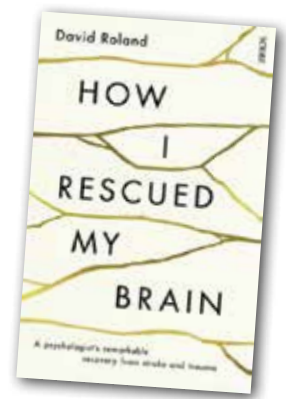
Eddie, stroke survivor

This edition's \$50 Coles Myer gift card winner is Eddie who has sent us a long list of great tips.

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

Sharing, Supporting, Connecting

Book
review



How I rescued my brain - David Roland

As a forensic psychologist David experienced many struggles of his own. He had spent years working and supporting clients who were battling with mental illness.

When David learnt he had actually suffered a stroke himself he then commenced an incredible journey to find out how to survive through the challenging recovery period. David is a very intelligent human being who discovered so much about himself. It is remarkable in how he has laid himself bare for all to see at this most vulnerable time of life.

David explores the complexities of the mind, consciousness and neuroscience and relays it in a way everyone is able to understand.

Stroke affects every element of a person's life. David proceeded on a journey to 're-wire' his brain. He sought advice from doctors, neurologists and researchers, yoga therapists, musicians and many other people to assist in restoring his 'sense of self'.

He explored many different pathways to aid in his recovery. David struggled with waves of anxiety and depression. He had to fight through and overcome many hurdles along the way.

This is David's account of the incredible strength and sheer determination to overcome the odds. I hope that you will find it as inspiring as I have. I became so engrossed in the journey that I found myself responding to the emotional waves that David was describing!

I encourage everyone to read it!

Reviewed by Jane McKinley, Project Officer WA.



Relationships after stroke

Relationships Australia is a leading provider of relationship support services for individuals, families and communities. They aim to support all people in Australia to achieve positive and respectful relationships. This edition, we are pleased to profile Val Holden, pictured above, from Relationships Australia talking about navigating life and relationships after stroke.

How can a sudden health crisis like stroke affect a couple's relationship?

Couples often have to adjust to a different kind of relationship. One partner may not be able to do all the things they used to and if they are severely affected, one partner may have to become the carer for the other. This completely changes the relationship dynamic.

A severe health crisis brings up strong emotions like fear, anger and grief. The person may not be able to return to work which adds financial stress to the relationship as well. A health crisis can also change the way people think about each other, thoughts around how much do I really love this person or their level of commitment to each other often come up.

How can counselling help?

Individual counselling can help people feel heard and give them a space to explore their own emotions around this crisis. This reflection can make things clearer for themselves and will help them to not bottle up emotions that may explode over the partner.

Individual counselling is also helpful for the client who has not suffered the health crisis when the other partner is unable to participate in counselling due to health issues.

Couples counselling can give a safe space for the couple to hear how this has affected each of them and give them understanding and skills to help each other deal with this crisis. Counselling can help the couple understand the impact of this sudden crisis and help them understand the emotions of guilt or stress and the negative affect this may have on the relationship. Couples can also help each other to deal with this transition in their relationship and come to an understanding of its impact on each of them.

Through counselling, clients can come to a better place in themselves which will help both of them accept and move forward from the place of crisis.

What happens during counselling at Relationships Australia?

People are encouraged to explore their feelings and emotions in a safe place where problems and issues can be understood. Counselling can help people gain clarity, exploring a wide range of possibilities, options and the possible consequences of actions. People report feeling supported, acknowledged, respected and valued throughout the counselling process.

Any advice for someone whose partner is reluctant to go to counselling?

They can access counselling themselves and this will ultimately impact on the other person as change in one person in a relationship will affect the other. Also sometimes when one client accesses counselling the other person can see the positive change and can be encouraged to attend.

How long have you worked at Relationships Australia and what do you like about it?

I have been with Relationships Australia since 2006 working as a relationship and family counsellor, gambling help counsellor and a clinical supervisor within this time. I enjoy working with families and couples helping them to explore their relationships to achieve their goals and sustain healthy and happy relationships.

Call Relationships Australia on 1300 364 277 or visit www.relationships.org.au

Stroke Awards 2014

Winners announced

Seventy-two people were nominated for an award this year, what an amazing effort!

The judging committees, made up of health professionals, industry experts and media personalities spent June reviewing the nominations. They have been unanimous in their thoughts that every single person nominated deserves to be commended.

Thank you to everyone who nominated someone or who were nominated – you are all unsung heroes of stroke.

We are extremely proud of the calibre of finalists for the 2014 Stroke Awards.

Congratulations to all this year's winners.

Pictured at right from top,

Fundraiser of the Year winner Dan Englund with Sally Phillips (left) and Libby Dunstan (right).

Improving Life After Stroke winner Jayson Killick.

Creative Award winner Barbara Gabogrecan with her husband Peter.

Stroke Care Champion winner Kelly Gerrard.



Coping with the trauma of stroke

Trauma is one of those words we hear a lot but we're not always sure what it means. The word itself is defined as a serious injury or shock to the body, as well as an event that causes distress and disruption. Trauma often comes from crisis, especially where we believe we or another person may die.

Everyone's experience of stroke is different however one thing that is universal is its sudden and serious nature. Stroke is by its very nature traumatic for both stroke survivor and their loved ones.

Having said that, it's also true everyone's experience is unique and many people will not consider trauma as part of their stroke experience. Even for those that do, their experience of trauma will be unique to them. There are many different responses to traumatic experiences and they can include:

- Emotional effects: feelings like disbelief, shock, numbness, anxiety, sadness, guilt, helplessness, guilt, anger and shame. Mood swings and also common.
- Cognitive effects: trouble with memory and concentration, as well as flashbacks, recurring dreams or thoughts
- Physical effects: being easily startled and hyper vigilant, as well as having headaches and pain, sudden sweating, heart palpitations and changes in sleeping and eating patterns.



For the stroke survivor, trauma can go undetected. “The emotional roller coaster hit and the experiences I encountered particularly in the first couple of weeks after were overwhelming. I had nowhere to go and no one to talk to, no one had spoken to me about what to expect or how to get help. I felt like I was going crazy or perhaps already there.” says Kerry. Elizabeth’s experience was hard for her to cope with. “For some time after I had flashbacks and was very fearful of another stroke. I am still somewhat anxious and have bad dreams about another stroke”.

For the people close to the stroke survivor, the personal impact can get lost amongst all the demands. People spend much of their time alone at the hospital. They are responsible for staying in touch family and friends and meeting with health professionals, all the while providing practical and emotional support to their loved one. Sarah, whose partner had a stroke, said “It took me a long time to process the fact he almost died. I was busy, busy, busy, doing everything perfectly and being reasonable but inside I was a bloody mess.”

So what helps? For some people, taking time in a safe place to experience the emotions

Stroke support groups

is helpful. Just be angry, scared or sad while remembering these are normal reactions and it will get easier.

Taking opportunities to talk about it helps a lot. It is common to feel you don't want to burden your loved ones with your problems, especially if they have already been supporting you in other ways. However it is important to remember most people want to help. Stroke survivor Elizabeth told us "My husband is very supportive which has been my greatest asset in recovery."

Finding someone professional to talk to can also help, especially if you feel it's just too hard, or it's been going on too long.

Beyond talking, it is surprising how helpful leisure activities can be. When you can, doing the things you enjoy will help. "I am actively engaged in life - mixing with friends and travelling. I try to always have something to look forward to, although I still have many challenging physical problems." says Elizabeth.

Glen, who had his stroke many years ago, found "managing trauma after stroke requires accepting what has happened, focussing on turning a new page, setting goals and taking up the challenge to move on. Time is a wonderful healer but it requires determination, focus and planning to move on and this is certainly no easy task."

Just as the effects of trauma are individual, the methods that will help us manage it are very much our own. It is important to remember it will get easier in time, and to allow yourself time to recover from trauma in your own way. You can call StrokeLine to talk it through on **1800 STROKE** (1800 787 653).

Bringing the joy

"Whenever I come to the group, it's a joy to come," says Norma Carson, speaking of the stroke support group in the Melbourne suburb of Sunshine. "I always leave there with a smile on my face."

For many stroke survivors such as Norma, joining a stroke support group means enjoying times with peers who share and understand their various experiences. Here they can make new friends, share a laugh, gain confidence and be inspired by each others' amazing stories.

If you have been affected by a stroke, your local support group would like to support you regain your best post stroke quality of life.

"It's an uplifting experience to be part of a group," adds Norma. "It's a positive thing. We don't sit there just talking about stroke. It's not a doom and gloom thing. It really makes you appreciate life more."

There are general peer support groups across Australia as well as some groups for particular age groups and interests. In Victoria, New South Wales and South Australia, state stroke associations play a key role in setting up and supporting groups. In these states, the state stroke association can provide you details of support groups in your area. For other states, get the details of groups in your local area by calling StrokeLine on **1800 STROKE** (1800 787 653).



Keeping active

Stay on your feet and stay active

Falls, slips and trips can affect anyone, especially if you have had a stroke. Unfortunately, stroke is a major risk factor for falls. In fact, between 50-70% of people who return home after a stroke sustain a fall. Having a fall can be incredibly disabling – loss of confidence and injuries can lead to a loss of independence. The good news is you can take steps (pardon the pun!) to reduce your risk of falling – tackle falls so you can stay active after a stroke.

Top tips to prevent falls:

- Keep yourself mobile. You may need to see a health professional such as a physiotherapist to improve your level of physical activity,

strength and balance. Groups such as Tai Chi and balance programs run in many local areas – this is a fun and social way to reduce your risk of falls.

- Check your medications. Some types of medications can increase your fall risk. Speak with your doctor about a review of your medications and health problems.
- Wear supportive footwear and keep your feet healthy. If you have foot problems or need advice about footwear, a podiatrist may be able to help you.
- Check your vision. Have your vision checked every two years through an optometrist, orthoptist or ophthalmologist.
- Eat a healthy diet and drink plenty of fluids. A healthy diet is important for general health and strong bones. Your doctor may recommend vitamin D and calcium supplements.
- Make your home environment safe both inside and outside. This might involve removing clutter and slip/trip hazards as well as ensuring adequate lighting.

To find out more about falls after stroke and discuss falls prevention, call **StrokeLine on 1800 STROKE (1800 787 653)**.



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