



Carers

news

Autumn 2015

Work and care

Lessons from the UK

Caring conversations

We speak to carer and award-winning poet, Melinda Smith

Good reads

We review the best-selling *Still Alice*

What's *inside*

- 2 CEO update
- 3 What's happening at Carers Victoria
- 4 NDIS: some common questions answered
- 5 10 ways...
- 6 Tech talk
- 7 Carer stories: a conversation with Melinda Smith
- 10 Policy update: caring and employment in the UK
- 12 Caring around Australia
- 13 Memories: a carer story
- 14 Young carers
- 15 Book review *Still Alice*
- 16 Take a break
- 17 How to choose a counsellor
- 18 Apps for Victorian carers
- 19 Fundraising update

Message from *Caroline*

Welcome to *Carers News* in 2015!

We have now extended *Carers News* to include Carers South Australia and Carers ACT. You will see in this issue that we have an interview with award-winning poet and carer Melinda Smith from ACT, and other information relevant to carers across the country. We are hoping that this extended collaboration will benefit carers across all regions.

Following on from the state election, Carers Victoria continues to work to ensure that the Victorian Government develops a 'whole of government' Victorian Carer Strategy in collaboration with carers across Victoria. Labor has also made a range of promises in relation to the health system, such as public hospitals and ambulance services, which will be welcomed by caring families.

Carers Victoria looks forward to working with the new government to fulfil their policies and improve the lives of Victorian carers and the people for whom they care. We will work with the government to ensure that caring is sustainable in the future and that Victorians have adequate access to housing and support to minimise the financial, psychological and social costs to individuals and families.

From a federal perspective, Carers Victoria has responded to the government's invitation for submissions on our priorities for the 2014-2015 budget. We continue our advocacy work on aged care, disability and mental health reform.



Page 4 of *Carers News* includes some highlights from Bruce Bonyhady's presentation at the Australian National 'Keeping Carers Connected' Carer Conference (run on 16-18 November 2014) on how the NDIS supports families and carers and how carer needs are assessed.

Carers Australia recently invited Madeleine Starr, Director of Business Development and Innovation at Carers UK to speak on the UK experience of carer supportive workplace policies and practices – see page 10 for information on the UK's flexible employment for carers. There is much that we can learn about how Carers Victoria can take a leadership role in advocating on this important issue.

A handwritten signature in black ink that reads 'Caroline Mulcahy'. The signature is fluid and cursive.

Caroline Mulcahy
CEO, Carers Victoria



What's happening at **CARERS VICTORIA**

2015 Young Carer Scholarship program

Carers Victoria is proud to once again offer our Young Carer Scholarship program.

Over 105,000 young people in Victoria are believed to have significant care responsibilities. They may support their mother, father, sister or brother at home because of a disability or illness.

The Young Carer Scholarships give young carers in secondary school the opportunity to apply for assistance with educational expenses as well as extra-curricular activities. This helps young carers participate in school or community activities which enhance their skills, educational achievement, and help them build on peer relationships.

"Over 105,000 young people in Victoria are believed to have significant care responsibilities."

The Young Carer Scholarship 2015 are open from 23rd March–24th April 2015. For further information and guidelines see www.carersvictoria.org.au.

New training session for carers – Geelong or Footscray area

We are delivering a new range of training sessions for carers in the Geelong or Footscray area in March and April 2015. If you are interested in participating, would like to discuss our training programs, or would like to book a session with one of our experienced educators, contact education@carersvictoria.org.au or call 1800 242 636.



Book an education and training session for your carer support group

Why not get in early and book a training session for your carer support group's 2015 calendar? Our educators can provide your group with information and guidance on a wide range of topics. The best part is that we come to you, no matter where you are in Victoria. We also provide specific training for facilitators of support groups, giving you tips on how to successfully establish and manage your group.

If you would like to find out more or book a session with one of our experienced educators, contact us at education@carersvictoria.org.au or call our Advisory Line on 1800 242 636.

Carers Victoria at Midsumma Festival

The Midsumma Festival ran in Melbourne from 18 January–8 February 2015. A celebration of Melbourne's LGBTIQ community, Midsumma is held in the Alexandra Gardens, with a terrific program of events, exhibitions, forums and a pride march. Carers Victoria participated in this year's Midsumma, with a carnival stall.



Carer support group mapping project

Carers Victoria is currently undertaking a project of mapping all carer support groups across Victoria to make it easier to direct carers to their local group. We encourage all support groups to submit their details to the mapping project. Please call 1800 242 636 to add your carer support group details.

NDIS

some common questions *answered*

Bruce Bonyhady, Chair of the National Disability Insurance Agency (NDIA), presented to the Australian National Carer Conference on the Gold Coast in November 2014.

As part of his presentation Mr Bonyhady answered some commonly asked questions about the National Disability Insurance Scheme (NDIS).

How does NDIS support families and carers?

NDIA aims to deliver five key outcomes for carers under the NDIS.

- 1 Families and carers have the support they need to care.
- 2 Families and carers know their rights and advocate effectively for the person they are caring for.
- 3 Families and carers are able to gain access to desired services, programs and activities in their communities.
- 4 Families and carers have succession plans.
- 5 Parents and carers enjoy health and wellbeing.

Who is eligible?

A person must be aged 0–65 years when the NDIS rolls out in their area and meet residency requirements. A person must have a disability/impairment that is likely to be permanent and results in substantially reduced function.

This includes intellectual, cognitive, neurological, sensory or physical or one or more impairments attributable to a psychiatric condition. The support should be required for the person's lifetime.

When will NDIS be rolled out?

There are currently seven trial sites around Australia: The Hunter region of New South Wales, the Barwon region of Victoria, the Perth Hills region of Western Australia, the Barkly Tablelands region in the Northern Territory, South Australia (ages 0–16 only), Tasmania (14–25 years only) and the Australian Capital Territory. National rollout across the rest of Australia is expected to occur between June 2016 and June 2019.

How can carers and families be included in planning?

Assuming they are the legal guardians, carers and families of children with a disability will have a central or lead role in the planning process. For carers and families of adults with a disability, the extent to which they are included will depend on the preference and the decision-making capacity of the person they care for.

Is respite support available under NDIS?

Yes. Following extensive advocacy from carers and the carer sector, respite has now been added as a specific support under NDIS.

What types of supports are funded under NDIS?

The following types of supports may be funded in a participant's NDIA plan:

- daily personal activities
- transport to enable participation in community, social, economic and daily life activities
- workplace assistance to allow a participant to successfully get or keep employment in the open or supported labour market
- therapeutic supports including behaviour support
- household task assistance to allow the participant to maintain their home environment
- aids or equipment assessment by skilled personnel, including set up and training
- home modification design and construction
- mobility equipment; and
- vehicle modifications.

Does the NDIS affect my Centrelink payments?

Not directly. The NDIS provides funding for supports related to a person's disability. It does not provide income or financial support. However, if, as a result of NDIS, a person begins work, or increases their working hours, then this would potentially affect their income support payments. This would need to be discussed with Centrelink directly.

Stay informed

The NDIA website www.ndis.gov.au provides information about how the NDIS works. NDIA also releases quarterly reports that provide an update about the trial sites.

Carers Victoria also releases updates via our free ebulletin, *Voice*. You can sign up for *Voice* on Carers Victoria's website www.carersvictoria.org.au.

10 ways...

to cope with stress

Caring can be a stressful job, and persistent stress has been proven to cause many health issues.

We all cope with stress differently; overindulging in vices such as fatty foods, smoking and drinking can seem like an easy way to cope. However, while these may give short term comfort they may also lead to long term issues. Here are some positive ways to help deal with stress.



2 Apply pressure

A massage can be a great way to relax tense muscles, which can be a physical effect of stress. Applying pressure to specific points on your hands and feet is an easy way to get an effective and beneficial massage.

3 Move it to lose it

Exercise not only helps you cope with stress, but it can also keep your body healthy and release endorphins, which help to enhance your overall feeling of wellbeing. Even a little bit goes a long way.

4 Take a breath of fresh air

Being in nature can be relaxing and invigorating. Even better, sunshine gives you vitamin D which is great for your overall health. If it's hard to get outdoors - get some pot plants, or even some pictures of nature and bring the outdoors to you.

5 Calm your mind

Meditation can give you time away – any day, anywhere! Just 10 minutes a day can be relaxing and refreshing to your mind and spirit. Sit in a relaxing position, gradually relax your muscles one-by-one, empty your mind and take yourself to your happy place.

6 Don't dwell on the negative

Negative thoughts grow and circle in your mind and can make you feel worse. Try looking at things from a new perspective by focusing on the positives and ways you might be able to make things even a little better.

7 Talk it out

Whether it's talking to a friend, a professional, or even writing to yourself in a diary – sharing your thoughts, feelings and day-to-day struggles can help release stress.

8 Many hands make light work

Sometimes getting some help is all it takes to feel less stressed. For a carer it might be regular respite or it could even be as simple as having someone else cook a meal.

9 Escape to a different world

Take time out and experience someone else's story by indulging in a good book or movie.

10 Express yourself

Having a creative outlet such as art, writing or music can be a positive and expressive way to release stress.

New app launched for the deaf, hearing, & speech impaired

The Australian Government, through the Telecommunications Universal Service Management Agency (TUSMA), has launched a new smartphone and tablet app as part of the National Relay Service (NRS).

NRS App, which is now available for free on Apple and Android devices, will enable Australians who are deaf, hearing or speech impaired to easily access the NRS through their smartphone or tablet.

"The NRS app is a world first for relay services. It allows users to access multiple call types through the app as well as allowing them to save commonly used phrases to make calls quicker and easier," said TUSMA Chairman, Mark Darras.

"Demand for the NRS is growing, with usage trending towards accessing the service through online and digital options. Users are embracing the internet based technologies and services available through the NRS."

The app is easy to use and free to download, all you need is an internet enabled smartphone or tablet. NRS App provides quick and convenient access to four NRS service options—internet relay, speak and listen, video relay and captioned relay. People can also store quick phrases in the app to speed up the time it takes to make calls when accessing the internet relay and Speak and Listen service options.

The app is available for download through iTunes and the Google Play store.

ACCAN launches hardship portal

The Australian Communications Consumer Action Network (ACCAN), the peak body for communications consumers in Australia, recently launched an online Hardship Portal – a set of resources to assist people through tough times.



It provides links to the hardship policies of Telstra, Optus, and Vodafone and outlines how to get help and the different options available.

"Any of us might find ourselves in trouble. All it takes is illness, bad luck or even just a short stint out of work. The Hardship Portal is a helpful tool for consumers who are experiencing tough times and finding it hard to pay for their phone or internet bill," said ACCAN CEO, Teresa Corbin.

"While many might not think of themselves as being in 'hardship',

it's important for consumers to know there are policies and guidelines in place to help them when trouble hits."

The Hardship Portal features sections that give consumers contact details and links to other organisations, tips for consumers, and a section with stories from people who have experienced hardship.

If you think you could use some advice on managing your telecommunications costs, visit the Hardship Portal at www.accan.org.au/hardship-home.

A conversation

with **Melinda Smith**



Melinda Smith is an award-winning poet and mother to two young boys, one of whom was diagnosed with autism at three years of age and Type 1 diabetes at 10. She has published four collections of poetry – among them, *First... Then*, which was written about her experiences with autism; and *Drag Down to Unlock or Place an Emergency Call*, which won the 2014 Prime Minister's Literary Award for Poetry.

Recently, Melinda took the time to talk to us about raising a child on the autism spectrum, writing, and inspiration.

Melinda, tell us a little a bit about yourself.

I'm not used to people asking me about myself! I was born and grew up in the central west of New South Wales. I moved around a lot with my family in my early life, but came to rest in Orange. I came to Canberra, where I now live, at 17 for university and I've been here ever since.

I studied Japanese and Law at the Australian National University. As part of that Japanese degree, I got to go live in Osaka for a year and that was fabulous. At the end of university I received a scholarship to the University of Cambridge in the UK to do a PhD, in Japanese History of all things. It turned out I was really burnt out after seven years of studying, so after a year I quit and spent another year with my partner, who had followed me over. The two of us had a working holiday. I came home and decided that I needed to use my law degree, so I finished qualifying as

a lawyer, and got a job in Canberra. Through that I got to go and live in Washington DC for six months, but then came back and decided that it was time to have kids!

And then came your eldest son?

Yes. He was born in 2004 and it was obvious very early that he was really unhappy about being here. If he was awake and he wasn't feeding, he was shrieking like someone was pulling his arm off. And everyone was like, 'Oh yeah, some babies are just like that'. But it had been going for 16 weeks.



Above // Melinda and artist Caren Florance standing amongst their joint work in *Bespoke: Design for the People*, on display at the Museum of Australian Democracy, Canberra. Photo by Mark Nolan of Chalk Studio.

I was losing my mind! I think it was his underlying autism; he was in total sensory overload from the moment he was born. But no one knew that at the time and he wasn't diagnosed until he was three and a half years old.

He was always unhappy. He didn't toilet train easily and he couldn't interact with other children. At mothers group, he would be wrapped around my leg. People would suggest we do outings with the kids, and I was saying, can we just go out at night? Because then I could talk to them, instead of having an unhappy, overwhelmed child wrapped around my leg the whole time.

When I was pregnant with my second child, I took my son up north to visit a friend. We stayed for a week, and it was a total nightmare. It threw all of his behavioural issues into sharp relief and made me see it through someone

else's eyes and go, this is not just a difficult child – there is something going on here. My friend mentioned the word 'autism' to me, and I thought – what is that? Isn't that when they can't talk? I didn't know anything about it. I googled it and everything about Asperger's syndrome was like ding-ding-ding in my brain. Fast forward through lots of trips to paediatricians and child psychologists and we got a diagnosis.

"My friend mentioned the word 'autism' to me, and I thought – what is that?"

The therapists we then worked with could actually get him to sit down and concentrate on something for longer than one second. They did just all the stuff that needed to be done.

He continues to have very challenging behaviours. The last 10 years have been trying to manage those challenges, as well as bring up his younger brother, who is a funky little specimen. Then S was hospitalised last year with type 1 diabetes and our lives got even more challenging ...

Balancing work and the demands of caring must be difficult...

It was difficult to find time for paid work. I often found I was logging on at night to finish off work. I had already made the decision to give up paid work for a while and then I won this prize [The 2014 Prime Minister's Award for Literature]! That's replaced my income for two years, so I can concentrate on my writing and looking after my family properly. That's the biggest gift I ever could have wished for.

How, and why, did you start writing?

I've always written as an outlet. I started to do it more seriously in the year I was doing my PhD. I did a little creative writing course while I was in Cambridge and what came most naturally was poems. So I figured that was my natural genre and I started to save them up. When I came back to Australia, I started sending them out to publishers. It was around 1998 when I started to publish things in Australia.

For my fourth book there was a new poetry publisher starting up [Pitt Street Poetry], and I admired a few poets they had on their books. I was lucky enough to have a manuscript land with them and that's the manuscript that turned into the book that won the award [*Drag Down to Unlock*]. It was life-changing for me, really. I've been gifted this time. It's enormously wonderful.

What inspires you to write?

My inspiration comes from stuff we all go through: love, loss, birth, death, even the small annoyances of daily life. It's about being open to things and willing to experiment. It is also partly about the discipline of making time and being open to catch things when they arrive.

It's like rain falling from the sky – if you never go outside, you're never going to get wet. You do have to be sitting in front a piece of paper with a pen regularly, so you get a chance to catch those good ideas when they come.



Melinda signing books // Photo by Angus Kendon.



Photo by Melinda Smith.

You've written about your experiences as a carer, and your son's autism. Was that a natural progression or a deliberate choice?

Kind of both. *First... Then* kicked off when he was about eight. We got from eight to nine and a half with him in a reasonably happy space, and we were able to breathe out for a while.

"I had been thinking about writing some poems about having a child with autism. It was an extraordinarily fruitful time, and great therapy for me."

But I not only wanted to write through the experience as therapy for me, but to let other people know that they weren't alone and to articulate the things we all go through as autism carers—and to do it in a way that was short and memorable. One of the poems got taken up in a big way, and I felt I had achieved my purpose at that point. I'm really glad I wrote that book and I'm glad that the poems spoke to the people who read them.

Do you have any words of wisdom or advice for other carers?

Oh wow! I'm still working it out! Everyone says this to you, and you never believe it, but I'll say it, too: things will get better. Your child is on a different developmental path, but they are still learning and growing, and you need to try to find a way to help them learn in the way that they learn. But most parents of autistic kids have that said to them over and over again! Really, there is hope, even with all of the challenges, that you can contribute in some way outside your own family. If you can find an outlet like poetry or art, you can have a life apart from your caring that will be enriched by your caring. You have a lot more to say when you've had to make the kinds of sacrifices you have to make as a carer. Your experiences are important. Your voice is valuable.

In the weeks just before the Prime Minister's Literary Awards results were announced, my son's behaviour and mental state took a severe turn for the worse, and I myself had trouble coping. I called on the services of a Carers ACT counsellor, who was fantastic and who let me vent and problem solve at my own pace during our free sessions. I feel it is important to mention this. I am not some kind of superwoman. I need help sometimes just like the rest of us.

Melinda's latest award-winning collection of poems, *Drag Down to Unlock or Place an Emergency Call*, is available from Pitt Street Poetry for \$25 pittstreetpoetry.com/melinda-smith.

Melinda also blogs www.melindasmith.wordpress.com, and all of her autism poems are available to read for free on www.circlequirk.wordpress.com.

The UK: flexible employment for carers

A win-win proposition

There are not many people who doubt the benefits of caring and carer supportive workplace policies and practices. The issue, however, is not always given much media, political or policy attention. Carer Associations around Australia support flexible workplace arrangements. As part of learning from successful models overseas, Carers Victoria recently invited Madeleine Starr, Director of Business Development and Innovation at Carers UK, to speak on the UK experience. In this article, Robert Gruhn, Policy Advisor at Carers Victoria, and Colleen Sheen, Senior Policy Adviser at Carers ACT, summarise the key issues from Ms Starr's presentation on carers and employment.



Above // Madeleine Starr, Director of Business Development and Innovation at Carers UK.

Key global policy drivers for carer friendly practices

In the UK (as in other Western nations), an ageing population, as well as changes in family structures, mean that more people are combining caring and work responsibilities. Currently, there are 6.5 million carers in the UK—about one in eight adults. Of them, almost 50% have given up working to care for a family member.

As many companies recognise the value of retaining organisational experience, there has been an increasing interest in implementing carer-friendly policies, not only in government, but in private and other sectors. Ms Starr's presentation started with an overview of the UK's

policy and legislative response from 1999, when the Labor government implemented a new framework through the *National Carers Strategy* (Caring about Carers) and *Employment Act 2002*. As the issue gained bipartisan support, the strategy was 'refreshed' in 2010 by the Coalition government focusing on education and employment opportunities. The recent *Equality Act 2010* and *Care Act 2014* enabled carers to request flexible work arrangements and provided protections from workplace discrimination and harassment.

Key to success – employers for carers

Ms Starr noted that the key to the UK's successful campaign was not only the strategic partnerships

between government and not for profits (NFPs) but also the central role played by private businesses and employer organisations.

In 2000, a campaign led by Carers UK culminated in *Employers for Carers* (EfC), a membership forum of global and national employers aiming to raise awareness of the benefits of flexible employment. EfC also aims to support carer-friendly policies, provide practical services, information and tools for managers and employees and facilitate peer support networks in the workplace.

Further, an EfC leadership group was created to work in partnership with government to inform policy and influence practice. Carers UK's role is to provide the specialist knowledge, information and advice on carer issues.

The economic case for being an employer of choice

For Carers UK and other advocacy groups, having the ability to argue wider economic benefits and to make a well-developed business case is also crucial. Implementing flexible workplaces provides multiple benefits to employers and employees.

Organisations led by flexible work principles can become and remain employers of choice (recruitment) and are more likely to keep skills and experience (retention). In addition, they improve employee engagement and



“Ms Starr stressed the four R’s: Recruitment, Retention, Resilience and Results to generate a ‘win-win’.”

productivity (resilience) which leads to improved performance (results).

The advantages are also shown through the positive impact on individuals and families in terms of financial wellbeing and work-life balance. Importantly, employers can take a lead role in providing flexible external support services for staff. One example is the innovative use of technology to facilitate employees to work and care remotely, with past UK studies showing great productivity gains.

One of Carers UK’s key strategies was to undertake research that provides an evidence base to prove the positive impact of carer-friendly work practices. Several pilots are now underway that measure the impact of providing information, advice and support to both employers and working carers, including workplace support or flexible and affordable local services (eg. homecare and respite).

Ms Starr concluded by stating that EfC is now seeking to create a global network of organisations working in this area. Her visit to Melbourne

reminds us to take a leadership role in advocating on this important issue and to become part of the increasingly global EfC network.

Update on Australian context – emerging issues and opportunities

In Australia, although governments recognise the importance of unpaid care, carers continue to face significant barriers, including:

- Lack of flexible employment options
- Lack of alternative care options that are reliable, high quality and affordable
- Financial disincentives to enter the paid workforce.

All members of the Carer Associations network have consistently supported carers’ rights to request flexible work. A recent joint campaign, including carer peaks, unions and employers, has resulted in positive changes. After a review in 2011–12, the *Fair Work Amendment Act* was expanded to include the right of carers to request flexible work. As part of these reforms, we advocated for an appeals process to be provided for carers in cases of refusals to provide flexibility; however, to date there is no such process. Recent proposals by the Australian Human

Rights Commission also included noteworthy proposals, such as a ‘carer credit scheme’ so that carers not in paid work can still accrue superannuation.

Carers Australia recently launched its new *Work and Care* initiative at a Parliamentary Friends of Carers meeting at Federal Parliament House, with Ms Starr and several politicians participating. This campaign represents a further important step to gain wider public attention and to achieve concrete workplace improvements for carers to more easily combine employment with their caring responsibilities.

For more information on the Australian context and on legislation ensuring a number of flexible work arrangements and employment standards, read the *Carers Victoria Carers News Summer 2014* edition.

www.carersvictoria.org.au/file-assets/magazine/carers-news

Resources and contacts

- **Carers UK:** www.carersuk.org
- **Employers for Carers:** www.employersforcarers.org
- **Carers Australia, Work & Care Initiative:** www.carersaustralia.com.au
- **Contact your local Carer Association on 1800 242 636.**

Regional, rural & remote

Australia's country carers. There are more than two million Australians living in regional, rural and remote areas across the country – and more than 360,000 of those Aussies are carers.

Country carers share many of the challenges faced by metropolitan and inner regional carers, however, the work of a rural carer is becoming ever more challenging with an increasingly ageing population, lack of accessible services, lack of recognition, and carers themselves reporting even lower wellbeing standards than metropolitan carers.

Country carers report poor health

Carers are more likely to report lower wellbeing standards than people without caring responsibilities no matter where they live. However, the gap between carers and 'non-carers' in regional, rural and remote areas is certainly larger than in metropolitan areas, with 22% of rural carers reporting fair or poor health compared with 17% of non-carers in the same regions.

Strategies for wellness

- If you're able, visit your GP and talk to them honestly about your mental and physical health. There is very little a GP hasn't heard before – they're well-equipped to help, and will be able to assist you to find further support.

- Manage, don't react. The worst thing you can do for yourself is let your health deteriorate to the point where you feel in crisis, especially when it can be difficult to access or get to emergency services. Be brave, honest and proactive in managing your own health problems – it's not selfish, it's practical.

The trials of travel

Carers living in rural and remote areas are twice as likely to report having difficulty accessing services like doctors, telecommunications and government agencies than carers living in major cities. Distance from services is the primary reason for this difficulty – it is hoped as more services become digital-savvy and internet access continues to rise across the country, that this will facilitate better access for rural carers.

Get closer to your communities

- There are a number of resources – some of which are listed below – that can help you even when you can't travel. From government resources to community groups, there are people out there who want to support you – let them know you're there.

- Make the most of the networks you do have. 84% of carers living in outer regional and remote areas say they personally know someone whom they could contact for information or advice. While not a substitute for services and supports, strong personal networks can make the challenges of caring easier to tackle.

The rising cost of being a rural carer

Carers living in rural areas are statistically more likely to experience financial hardship than those living in major cities. There are many reasons for this, including higher travel expenses, costs incurred in service provision in rural or remote areas, lack of access to government services like the Department of Human Services, and higher rates of unemployment.

Cope with the cost of caring

- **Be aware of what's out there for you.** With a lot of patience and some savvy, you can find out a lot about what payments and reimbursements you are entitled to, and what services exist that may help you. For example, did you know that every state and territory in Australia offers a Patient Assisted Travel Scheme? Check out some of the resources below to find out more.

Your local Carer Association

1800 242 636

National Rural Health Alliance

www.ruralhealth.org.au
or (02) 6285 4660

The Country Women's Association of Australia

www.cwaa.org.au

Rural and Regional Health Australia

www.ruralhealthaustralia.gov.au
or 1800 020 103

Statistics sourced from Carers Australia and Australian Institute of Family Studies research paper, *The Tyranny of Distance*: http://www.carersaustralia.com.au/storage/20091007_Tyranny%20of%20Distance.pdf

Memories

a carer story



It was as ephemeral as the tendrils of mist hovering over water meadows in the sharp winter sunshine. This is how I saw the early changes, when I did not want to believe what was happening to my husband, yet I feared the early stages of dementia.

The other image hovering close was that of my mother-in-law, curled up in foetal position in her chair barely able to acknowledge our presence. I lived some months with these two images, hoping it was just illusion, but at the same time paralysed by the thought that one day it could be my husband in that chair.

Eventually the mist cleared and reality came. He had been and still is a keen bushwalker, but when he failed to find the rendezvous three times in a row, we both realised that something was wrong. The fact that he also recognised he was having memory difficulties, made our initial trip to the doctor much easier.

I now realise there is a long, and sometimes hard, road to travel but we are able to enjoy our (gradually limited) life. I could only see the end, not the journey. Now the journey absorbs our life. I know anything could happen, but my energies and time are spent on making the present as stimulating and pleasant as possible for both of us.

This is the challenge of positive caring. I built on the things he enjoyed: walking, cycling, the outdoors, classical music, good food, and theatre. So we have climbed mountains, visited Norfolk Island, enjoyed walking on our own and with his club, whose members have known him for years. Even though he

cannot talk with them, their welcome is always warm. In the bush there is a role reversal because I am the weaker walker, so he is at my side on the uphills, and he becomes the carer. This is so important in maintaining his self esteem.

"We so often think of what we are giving that we easily overlook what is given to us."

We have learned the joy of watching a magpie with her chicks strut along the veranda; we have been thrilled by the brief appearance of a delicate cactus flower; he often points out the antics of a dog or child at play. In his way he is trying to help me recognise the little pleasures of life. We have found the depth of true friendship, and I have learned to respect my family because they have shown me compassion and matter-of-fact support. I have met some heroic carers.

I cannot deny there are moments when the going gets tough – you wish the man you have known for so long is there, but it helps not to think of it too much. The two images have receded and the present is so much more important... because the rewarding moments will linger longer in my memory.

Story by Margaret Baulch

This story was reproduced from Caring Matters (Carers Victoria, 2003)

How to build *self confidence*

Not everyone is born with a strong sense of self assuredness. Sometimes it can be hard to develop confidence, whether it's because of personal experiences that have caused you to lose confidence or you're suffering from low self esteem.

There are a couple of handy things you can do to build your confidence. Some of these are just little changes to your frame of mind, and others are things you have to work on for a bit longer to get used to them.

1 Look at what you've already achieved

Sometimes it can be easy to focus on what you haven't done. It's easy to lose confidence if you feel like you haven't achieved anything. Focusing on stuff you have done - big or small - can help you gain perspective on all your talents and abilities.

Write down a list of all the things you're proud of in your life. Think of things you have achieved, whether it's getting a good mark on an exam or even learning to ride a bike. Keep this list close and add to it when you do something you're proud of. When you're low in confidence, pull this list out and use it to remind you of all the awesome stuff you've done.

2 Think of things you're good at

Everyone has strengths and talents, what are yours? Have a look at the Reach Out fact sheet on strengths and work out how you can build on yours (<http://au.reachout.com/what-are-strengths>). Recognising what you're good at and trying to build on those things can be a really valuable way of building confidence in your own abilities.

3 Set some goals

Set some goals and aim to achieve them. By proving to yourself that you can get stuff done, you'll prove to yourself what you're capable of achieving. They don't have to be big goals; they can even be things like baking a cake or planning a

night out with friends. Just little things that can be ticked off a list and help you gain self confidence in your ability to get stuff done.

4 Talk yourself up

You're never going to feel confident if you have a negative commentary running through your mind telling you you're no good. Think about your self talk and how that might be affecting your self confidence. The Reach Out fact sheet on self-talk (<http://au.reachout.com/what-is-self-talk>) provides handy tips on self talk to turn your negative self talk around.

5 Get a hobby

Try to find something that you're really passionate about. Do you like playing footy? Like building model trains? Think of some of the stuff you're really interested in and commit yourself to giving them a go. Finding stuff that you're passionate about will help you find the stuff that you're good at. Chances are, if you're interested or passionate about a certain activity you're likely to be good at it as well.

This content was adapted, with permission, from the ReachOut.com fact sheet *How to Build Self Confidence*. ReachOut.com is Australia's leading online youth mental health service, where you can get the help you need, where and when you need it.



Book review

“With a master storyteller’s easy eloquence, Lisa Genova shines a searing spotlight on this Alice’s surreal wonderland. You owe it to yourself and your loved ones to read this book. It will inform you. It will scare you. It will change you.” Julia Fox Garrison, author of *Don’t Leave Me This Way*.

Alice Howland is a successful Harvard professor and happily married 50 year old woman with three grown children. Juggling a busy life style she puts down her memory loss to either being stressed, signs of menopause, or simply growing older.

On her daily run in her local neighborhood, she suddenly finds herself completely lost and disorientated. She realises that something is seriously wrong and makes an appointment to see the doctor.

After a series of tests she is diagnosed with early onset Alzheimer’s dementia. Her husband John, a cancer scientific researcher, is devastated and tries to cope by throwing himself into a search for a cure.

Written in the first person, *Still Alice* gives the perspective of someone living with Alzheimer’s. The novel chronicles her battle with the disease – how she scrambles to develop strategies to fight and retain her sense of self and self worth.

There are very poignant scenes, which take you through a rollercoaster of emotions. From humour – finding the book she is currently reading in the microwave – to extreme sadness, when she is no longer welcome and her opinion is no longer valued at a university presentation.

Living in the moment, she scrambles to enjoy and memorise everything she can before it is gone. Through moving scenes, *Still Alice* navigates the transition of Alice’s changing relationships with her family, as they transition into caring roles in their daily lives.

“Still Alice is inspirational, realistic, thought provoking and challenging.”

“This is the clearest and most truthful piece of fiction I have read depicting living with Alzheimer’s. You accurately describe the feelings and actions of both persons, together, entangled in this dance with Alzheimer’s Disease. Thank you for writing this story.” Chuck Jackson, diagnosed with Alzheimer’s, age 50.

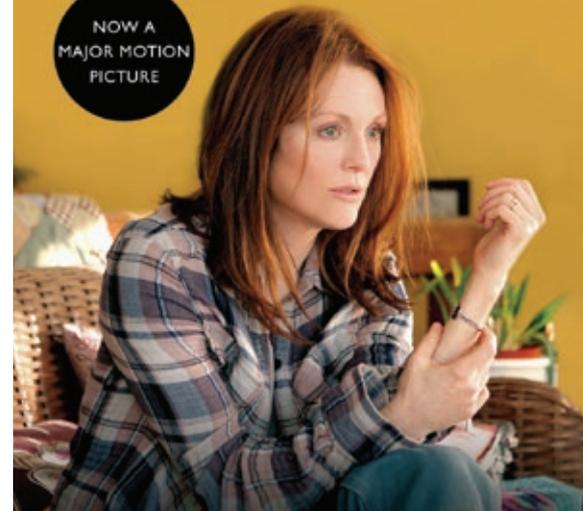
LISA GENOVA

‘A remarkable and utterly absorbing read’ *THE AGE*

NEW YORK TIMES BESTSELLER

STILL
ALICE

NOW A
MAJOR MOTION
PICTURE



About the author

Lisa Genova has a degree in biopsychology and a PhD in neuroscience from Harvard University.

She started out as a self-publisher before landing a six-figure book deal with Simon & Schuster and making *The New York Times* Best Seller List.

Still Alice is now a feature film, starring Julianne Moore, Kristen Stewart, Alec Baldwin, Kate Bosworth and Hunter Parrish. Julianne Moore won a Golden Globe Award for the ‘Best Performance by an Actress in a Motion Picture - Drama (2014) for *Still Alice* and has been nominated for an Academy Award 2015.

Genova, L. (2014). *Still Alice* 1st Edition (Simon and Schuster) is available as an ebook from the Amazon Kindle Store, \$9.90 on www.amazon.com.au.

It is available in paperback, \$21.25 on www.booktopia.com.au, and may also be available from your local library.



Nourishing mushroom soup

Ingredients

- 2 tablespoons olive oil
- 20g butter
- 1 large brown onion, finely chopped
- 2 garlic cloves, crushed
- 600g Swiss brown mushrooms, sliced
- 1/2 cup dry white wine
- 2 1/2 cups chicken stock
- 300ml pure cream
- 4 slices prosciutto, chopped
- Crusty bread, to serve

Method

Heat 1 1/2 tablespoons oil and butter in a saucepan over medium heat. Cook onion, stirring, for 5 to 6 minutes or until softened. Add garlic and two-thirds of the mushrooms. Cook, stirring occasionally, for 5 to 7 minutes or until mushrooms are just tender. Add wine. Cook for 2 to 3 minutes or until almost evaporated. Add stock. Cover. Bring to the boil. Reduce heat to low. Simmer, stirring occasionally, for 15 minutes or until mushrooms are tender. Season with salt and pepper. Remove from heat. Using a stick blender, blend until smooth. Increase heat to medium-low. Add cream to mushroom mixture. Cook, stirring occasionally, for 6 to 8 minutes or until heated through (don't boil).

Meanwhile, heat remaining oil in a saucepan over medium high heat. Add prosciutto and remaining mushrooms. Cook, stirring occasionally, for 3 to 5 minutes or until mushrooms are tender and prosciutto golden and crisp.

Divide soup between bowls. Top with prosciutto mixture. Serve with bread.

Recipe adapted from taste.com.au

Take a break

Take 10 trivia

We know to take care of our bodies, but our minds need a workout, too. Take 10 with our 10 trivia questions – not only is it great for your brain health, but who knows when a little tidbit of trivia will come in handy!

- 1 Would you find your philtrum under your nose, tongue, or chin?
- 2 What is the floral emblem of Australia?
- 3 Which song finished second to *Advance Australia Fair* in the 1977 referendum to choose a national song?
- 4 What does the acronym SCUBA stand for?
- 5 Who was the first Australian born governor general?
- 6 By area, what is the smallest country on the planet?
- 7 What country is home to Mount Everest?
- 8 The Spanish Steps are found in which city?
- 9 What was Elvis Presley's first hit in 1956?
- 10 How many unpaid carers are there in Australia?

Sudoku

	7			1	8	5		4
		5		7			8	3
	8		2		4		9	7
6	5	2	4					
7		1	8				4	5
4	3			9		2	7	
8	2			4	3			
5			9			4		8
3		4				9	5	

9	7	6	3	1	8	5	2	4
2	4	5	6	7	9	1	8	3
1	8	3	2	5	4	6	9	7
6	5	2	4	3	7	8	1	9
7	9	1	8	2	6	3	4	5
4	3	8	1	9	5	2	7	6
8	2	9	5	4	3	7	6	1
5	1	7	9	6	2	4	3	8
3	6	4	7	8	1	9	5	2

- 1 Under your nose – it is the vertical crease between your nose and upper lip
- 2 The golden wattle
- 3 *Waltzing Matilda*
- 4 Self contained underwater breathing apparatus
- 5 Isaac Isaacs
- 6 Vatican City
- 7 Nepal
- 8 Rome
- 9 Heartbreak Hotel
- 10 More than 2.7 million!

How to choose a *counsellor*

We may need the assistance of a professional to help us at different stages of our lives. Carers Victoria's Carer Counselling Service has a network of counsellors from different professional backgrounds.

All of our counsellors are required to be registered with their relevant professional organisation; however, there is often confusion about our different professions.

Counsellor

Counsellors can help with different problems including stress, conflict, and relationship difficulties. Counselling can help with providing strategies and skills for daily living and generally focus on managing a specific problem or situation.

Psychotherapist

Psychotherapists can help with exploring deep-rooted problems that disrupt someone's life on a consistent basis. Psychotherapists support change and healing at a deep level.

As counselling and psychotherapy are not regulated by law it is important that you choose a professional who can demonstrate their training, experience and professional membership.

Social worker

Social workers are trained to have a dual focus on individual wellbeing and 'systemic' issues that may create barriers to wellbeing. For example, a social worker will work to identify what your individual stressors may be, and also consider the impact of your family circumstances and the community

you live in. Social workers who have done additional training and who are registered with their professional body are often registered for Medicare rebates.

Psychologist

Psychologists specialise in human behaviour, concerns of the mind and interpersonal interactions. They can assist with managing psychological disorders and improving wellbeing. Psychology is a regulated profession in Australia, meaning that people who call themselves psychologists must be registered with the Psychology Board of Australia and must adhere to certain standards to maintain registration. Most psychologists are registered for Medicare rebates.

What to look for

- **The 'fit'.** Feeling comfortable with your therapist is the most important component of any talking therapy.
- **Speciality.** Mental health professionals use different approaches and specialise in different issues or client groups. Speciality impacts on the 'fit'.
- **Qualifications/ Accreditation.** Find out what their professional background is and what professional association they belong to.
- **Reputation.** Ask around. Personal recommendations can help.

Different ways of accessing counselling

Meeting one-on-one with a counsellor is the most common method of counselling. However, there are other ways to access counselling:

Telephone and online (Skype)

counselling are good alternatives for individuals who do not have the time or capacity to attend counselling in person. Additionally, some people have found that talking to a counsellor from home makes them feel more relaxed, safe and in control.

Group counselling is where a counsellor facilitates a group of individuals with similar experiences/issues (eg. carers of ageing parents, loss and grief) in discussions. Sharing experiences and feelings within a group can help reduce isolation, validate individual experiences, and enhance peer support.

Listing of Associations

AASW (Australian Association of Social Workers)

www.aasw.asn.au

ACA (Australian Counselling Association)

www.theaca.net.au

PACFA (Psychotherapists and Counsellors Federation of Australia)

www.pacfa.org.au

Psychology Board of Australia

www.psychologyboard.gov.au

For further information on Carers Victoria's counselling services please call our Carer Advisory Line on 1800 242 636.

Apps

for Victorian carers



Out & About

Villa Maria's award-winning *Out & About* – *Accessing Your Community* app is now available to download on Android.

Designed to assist people with a disability or mobility limitation, their families and carers, *Out & About* helps people find accessible venues and events across Melbourne. It's all about finding accessible opportunities to connect with your communities and have a great day out.

"Venues include theatres, cafés, restaurants, galleries, beaches, parks and gardens. Events can include concerts, festivals, exhibitions and more."

Users can filter information based on accessibility needs, leave feedback to help other users and rate the venue by answering two simple questions.

Villa Maria's Executive Manager Marketing, Rebecca Ryan, says the more people who use the app, the more useful it will be to everyone. "With the app

now available on Android, more people can have access to this information and suggest other events and venues that could be included," she said.

"As a community powered tool, it's a great way for people to inform other users about the accessibility features of places and events around Melbourne and regional Victoria."



The app is already available through the iTunes store and has been downloaded for iPhone more than 2,500 times, with more than 2,000 events and venues listed. With the move to Android, the app is expected to grow significantly, giving users even more information and choice when heading for a day out.

Out & About is available for free from the Google Play and iTunes stores.

Stop Here

A new app will help commuters who are vision or hearing impaired to never miss their station.

Developed by Metro in partnership with Vision Australia, Blind Citizens Australia, VicDeaf and Guide Dogs Victoria, *Stop Here* uses location technology to provide push notifications to inform commuters when they are approaching and arriving at their station.

The app tracks where a person is on the network and sends alerts via *see, hear or feel* – a notification on screen, a noise alert or through vibration – when the user is nearing their desired station.

Metro Trains CEO, Andrew Lezala said it was part of Metro's ongoing improvements to customer service.

"We want to make travelling by train as easy as possible for all of our customers and are continually looking at ways we can use technology to improve our service," Mr Lezala said.

"Many of our customers rely heavily on our trains and public transport to get around and *Stop Here* is another step in making our customer information timely and reliable."

Stop Here is available for free from the Google Play, iTunes and Windows stores.

Sue Fincham & Melbourne High School

In 2013, SBS's *Insight* profiled young carers – or, in their words, “some awesome kids doing some pretty grown-up stuff”. After watching this special feature, Sue Fincham felt compelled to support young carers and kindly reached out to Carers Victoria to see how she could help.



Not only did Ms Fincham decide to make a generous annual donation to the Young Carers Scholarship Program, she also established a bursary to provide recognition and support to young carers at Melbourne High School (MHS), a school very close to her heart.

The bursary aims to provide young carers with the opportunity to increase participation in the MHS community while alleviating some of the financial pressures associated with caring. Now in its second year, two bursaries are provided annually and are used to cover expenses such as fees, uniforms, books, excursions and co-curricular activities.

Ms Fincham has met with both bursary recipients and continues to communicate with them.

“They are both wonderful young men who are coping with so much – going to school and all the challenges that presents as well as the daunting role of being a carer for their mothers. I have a huge amount of respect and admiration for them both and I am pleased to hear from them that the scholarships have made a difference to not only their lives, but also that of their mothers.”

Through her ongoing benefaction Ms Fincham will have a very positive impact on the lives of young carers, their education and their families, both through MHS and Carers Victoria.

We would like to thank Sue Fincham for her incredible generosity and ongoing support of the young caring community.

There are many different ways to support Carers Victoria. You can join the growing number of supporters who have donated, volunteered their time, named Carers Victoria in their will or shared their stories with us. To find out more please call 03 9396 9562.

Did YOU know

The Victorian Carer Card

With all the carer support programs it can be hard to know what's out there, and whether it's right for you. Here is an initiative that might be helpful for you – and remember, you can always call the Carer Advisory Line on 1800 242 636 to find out about more supports that would suit your caring needs.

The Carer Card was launched in 2010 by the Victorian Government as part of their work to recognise the invaluable contribution of carers. The Carer Card offers discounts and benefits for unpaid primary carers at over 1400 businesses, venues and attractions around Victoria. Cardholders also get free public transport on Sundays, and discounted entry to State Government venues like zoos, museums, and festivals.

To be eligible for a Carer Card you must be:

- a resident of Victoria
- the primary carer of a person with a disability, severe medical condition or mental illness, or someone who is frail aged or in need of palliative care. Foster, kinship or respite carers may also be eligible.

You can confirm your eligibility by:

- providing your Centrelink Customer Reference Number (CRN) or your Department of Human Services Vendor Number if you receive a carer payment or allowance, or
- having a medical professional verify your eligibility.

For more information on the Carer Card, visit www.carercard.vic.gov.au, or call 1800 901 958.



The quarterly magazine of Carers Victoria.
ISSN 1445-6761 2015 // Issue No 1 (autumn)

Editor // Lisa Green, Davina Noakes

Graphic Design // Blick Creative

Contributors // Davina Noakes, Kate Outhred, Kate Topp, Lisa Green, Robert Gruhn, Colleen Sheen and Anna Tedesco.

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Carers Victoria is supported by the Australian Government, Department of Social Services. Visit www.dss.gov.au for more information.

Carers Victoria acknowledges the support of the Victorian Government.

ARBN 143 579 257 Inc No. A0026274M



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