



# link

disability magazine

October 2010 | Volume 19 Issue 4

## DUNCAN MEERDING'S UNIQUE DESIGN VISION

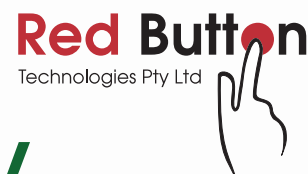
**A WOMAN'S PLIGHT TO EXPOSE  
A HOSPITAL TRAGEDY**

**GILL HICKS ON LIFE AFTER  
THE LONDON BOMBINGS**

**WORK IT! JOBS WITH  
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# inside link

## Cover Story

**12** Young Tasmanian furniture maker Duncan Meerding, who has vision impairment, uses his senses of touch and hearing to influence his designs.



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**Cover:** Furniture designer Duncan Meerding in his studio. **Photographer:** Peter Matthew.  
*Some images throughout the issue are courtesy of stock.xchng.*



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The Federal Government recently released a discussion paper on improved support for Australians with a severe or profound disability, who need supported employment through Australian Disability Enterprises (ADEs).

The discussion paper offered a starting point for a 10-year vision, which would see people with a disability achieving greater participation and inclusion in the community through quality supported employment.

The aim is to help people with a disability have the same opportunities as other Aussies to have a job where possible, participate in the community and have a meaningful life.

As well as ensuring people in supported employment meet their career goals and aspirations, the commercial sustainability of the sector must also be ensured.

In this issue, we visit two ADEs – a salvage yard and a cafeteria – which are already doing good work. Plus, we meet the people behind a forum recently in Adelaide, aimed at getting ADEs to work together and garner public attention.

We also chat with two people with disabilities, who are employed in their own creative ways – a furniture maker and a photo artist. Enjoy the issue!

Carla

Carla Caruso, *Link* editor

➔ Send you event snaps to [editor@linkonline.com.au](mailto:editor@linkonline.com.au)



At Bedford's 65th Anniversary Dinner at the InterContinental Adelaide in July.  
Top: Bedford ambassador Amanda Blair, Colin and Libby Dunsford, and Ted Byrt.  
Right: David Weaver with mum Heather Reid.

## ➔ In the media

Disability was a theme of the 20th annual Catholic Archbishop's Media Citations in Adelaide in July.

*Sunday Mail* photographer Dylan Coker was awarded a citation for his vibrant portrayal of Joh Duffield (below) - a footy coach with a difference. Duffield, 23, hasn't let his quadriplegia stop him from coaching his local football team in SA - the Broughton-Mundoora B-graders.

*Sunday Mail* reporter Brad Crouch also received a commendation for his feature article, *Triumph of a Blind Ambition*, on a sight-giving Third World program. Via the Vision Myanmar project, Australians are helping to give doctors in Myanmar (Burma) the skills and equipment to dramatically lift the rate of cataract operations in the country - the leading cause of preventable blindness.



## Event snaps



## → Refusal on bus

On Wednesday, September 1, I was waiting for my usual connecting bus at 8.50am on King William Street to take me to work. To my amazement, I was refused from stepping on the bus. I have a disability and use a walker, when I need to steady myself, but I can walk unaided for short distances.

The driver said there was no ramp and told me to wait for the next suitable bus. All I required from the driver was to help me fold the walker and I could have stepped onto the bus. It made me feel very embarrassed with busy commuters pushing around me, scrambling to get on the bus. To make things worse, it was a damp morning. Having to wait for the next bus made me late for work.

A bad start to a rainy day, which could have been avoided. People should think outside the square.

Wayne Crabb, SA

## → WE'RE ONLINE!



*Link Disability Magazine* is now on Facebook. Become a fan! Aside from being a bi-monthly print magazine, you can also get regular *Link* updates on everything from news to events and opportunities via our Facebook page.

## Recently on *Link* on Facebook...

Packed to the Rafters *had a great show last night with a brother, who has CP [cerebral palsy] feeling 'lonely'. Good to watch... Pity he is only 'acting' and [them] not having a 'real' [person] with CP playing the part though... – Jacy*

*The four biggest cinema chains in Australia have agreed to install new technology to make at least one screen in each complex accessible for [customers, who are] blind, deaf, hearing or vision impaired - Link*

## → Being a parent carer

Thank you for publishing Estelle Shields' letter in your June issue of *Link* magazine.

How very well she expressed the concerns and worries of us all [as parents of offspring with disabilities] and how honest her assessment of the situation.

My son is 34-years-old and I look to the future with considerable dread. Though, I try not to worry in case that shortens my life and ability to care for him.

Jonty Whitehead, Mount Barker, SA

## → Correct language

I continue to enjoy your magazine, as I have done for years. [However] I am disappointed that on page 24 of the [August] edition, you have captioned a photo with the words, "disabled toilet".

What good would a toilet be if it was "disabled"?

Please use "accessible" in future. Even Central Station toilets have had the correct sign on the toilets there for a LONG time.

"Disabled clients" should be "clients with a disability". Surely, they are "clients" first.

I'd like you to publicise the correct terms e.g. NOT "a disabled person", but "a person with a disability".

I publicise *Link* whenever I get the chance and I'd like people to see the correct terms. Thanks.

Gwenda Hunter, Bathurst, NSW (Ed's note: See our story about language surrounding disability on page 37.)

## → Sailing comrades

I was delighted to read about [late editor] Jeff Heath in the August edition of *Link*. Jeff was a keen sailor of the Access Class dinghy.

Deirdre Schahinger, Mitcham, SA

(Ed's note: Read Deirdre's article on the recent access class world championships in the UK in Sport.)

## Send your letter to the editor:

GPO Box 2100, Adelaide, SA, 5001

or email it to [editor@linkonline.com.au](mailto:editor@linkonline.com.au)

Please include your postal address (not for publication).

**The best letter wins \$50**

By contributing a letter you authorise *Link* to publish it in the magazine or [www.linkonline.com.au](http://www.linkonline.com.au). Letters may be edited for length and clarity. All published contributions earn the author a free copy of the magazine, containing the letter (or current subscribers may specify that they would prefer their free magazine as an extension of their current subscription), provided a postal address is included with the original letter. Your name, suburb and state will be published with your letter unless you specify otherwise.





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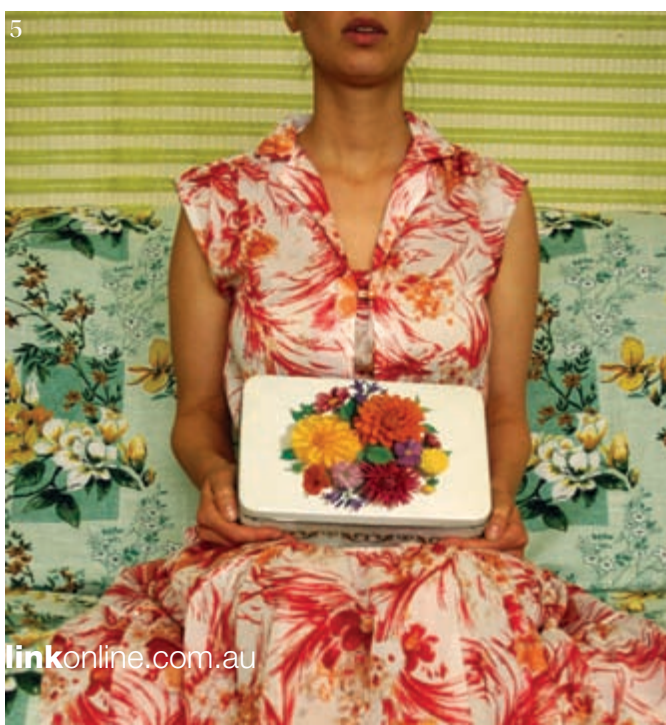
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# The art of being *Feminine*

Adelaide's Annalisa Feleppa didn't fully embrace being an artist until she turned 30.



6

"For my parents, creating art as a hobby was great - as long as I got a real job as well!" she says, laughing.

Still, her love and fascination of vintage and retro items – now seen in her photo art - began way back. "My mother found me to be a challenge as I used to go to the neighbours' to ask for their old

clothes and material. She would become cross with me because I preferred to wear these old, too-big-for-me outfits, rather than the clothes she had bought me to wear!"

When Feleppa was diagnosed with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome at age 20, the focus became about managing the illness, with its many symptoms, and her art fell by the wayside a little.

Later though, Feleppa went on to study visual art at TAFE SA, exhibiting in Adelaide in her first year of study and continuing to do so regularly ever since, chalking up a decade in the industry.

It was during her studies that the 39-year-old first began to nurture a passion for photo art, particularly exploring the theme of femininity in Western culture. "I was so curious and focused on exploring visually this concept of feminine notions that I often started shooting as soon as I got out of bed, still in my pyjamas," Feleppa says, grinning. "I don't have an actual studio. I use areas of my home that I can utilise to construct the images. Many of the images are shot with natural lighting - indoors or outside."

Feleppa is staging an exhibition, dubbed *Notions of Femininity*, at the Queensland Centre for Photography in South Brisbane from October 30 to November 28. The project is proudly supported by the Richard Llewellyn Arts and Disability Trust and B@D Second Hand Caravans. [annalisafeleppa.com](http://annalisafeleppa.com)

Photos:

1. Afternoon Tea Delight series.
2. From The Goddess series.
3. From The Red Carpet series.
4. From The Red Carpet series.
5. An image from her On The Pedestal series.
6. Artist Annalisa Feleppa.




## Sensory delight

ableart 2010 is a 'sense-ational' exhibition of art, produced by people with multiple disabilities including deafblindness (combined vision and hearing loss). It will be on display at the Melbourne GPO, from November 12-19. Run by disability support organisation Able Australia, the exhibition features bold colour pieces and textured paintings. ableart ambassador - artist and comedian Mark Mitchell (aka Con The Fruiterer) - says the exhibition offers art therapy for those involved. "These paintings are not only of contemporary design, they also offer an insight into the world of people, who can't see or hear as we do." The pieces



are available for purchase, with 100 per cent of proceeds going to the artists. [ableaustralia.org.au](http://ableaustralia.org.au)

## Creativity on paper

An exhibition of works on paper by young adults with disabilities, dubbed *Paperworks*, was held in August in Adelaide. The participants were from Tutti's visual arts and design program. (Tutti offers professional experience across a broad range of artistic disciplines to people with a disability.) The exhibition was opened by SA visual artist Laura Wills. 



Above: Jenna May. Photo by Pavlos Soteriou.

## STATE

**Spotlight shines on young performer**

**SA** Jackie Saunders, a performer with Adelaide's Tutti organisation, won the award for Young Person of the Year at the NAIDOC Ceremony in July.

Tutti offers professional experience across a broad range of artistic disciplines to people with a disability. Since 2006, the Wirangu artist has been heavily involved with Tutti Arts, where she performs regularly with her sisters in the choir and also studies drama and visual arts.

Last year, Saunders travelled to the US with the Tutti show, *Northern Lights, Southern Cross*. She's also an accomplished visual artist.



Jackie Saunders, centre, with Jamie and Steve Goldsmith.  
Photo by Philip Griffin.

**Unique retail training program**

**TAS** Five people with intellectual disabilities have taken part in a unique training program, thanks to not-for-profit organisation MEGT.

The program, developed in partnership with Tasmanian community organisation Cosmos Inc, helped students gain their Certificate II in

Retail qualification, using short, classroom-based sessions, focused on interactive, repetitive learning, and work placements. MEGT secured funding from Skills Tasmania for the program, tailored to the needs of those with intellectual disabilities.

Participant Martin Leeson, pictured, enjoyed the experience: "My life has changed so much doing this course."

**Couples sue doctors for failing to detect Down syndrome**

**VIC** Two Victorian couples are suing doctors for failing to diagnose Down syndrome in their unborn babies, according to a report in the *Herald Sun* in July.

Both couples are claiming unspecified damages for economic loss, continuing costs of care and "psychiatric injury". Each says they would have aborted their pregnancies had they known their children would be born with Down syndrome.

In one of the cases, the parents of a girl, born in July 2005, are suing the Royal Women's Hospital, after a doctor failed to detect Down syndrome following testing.

NSW, SA and Tasmania have legislated against such claims, but Victorians can sue for compensation for the continuing costs of raising a child until they're 18, if born as a result of negligent care.

**Indigenous Trainee of the Year gong**

**NSW** Daniel McDonald, below, was named NSW Indigenous Trainee of the Year at the South Western Sydney Region Training Awards in July.

McDonald, who is deaf, studied a Certificate III in Business Administration traineeship, which helped to launch him into a job with the Sydney South West Area Health Service. Of his colleagues, McDonald says: "They make me feel welcome and appreciated."

The local MEGT Australian Apprenticeships Centre works with thousands of businesses across the region. Australian Apprenticeships are a government initiative.





## Is Bendigo disability-friendly?

**VIC** More than 60 people attended a forum, *Is Bendigo Disability Friendly?*, in the regional Victorian city in June.

RigB has been developed as an impartial and independent gatherer of information about the particular issues affecting people in the greater Bendigo community, living with long-term or permanent health conditions. About 20,000 Bendigo locals – or one in five – are said to have a significant health condition.

With much work ahead to address the issues raised at the forum, a follow-up meeting is planned for October 14.

[riac.org.au](http://riac.org.au)

## New captioned phone a bonus for the deaf

**VIC** Life for grandmother Wendy Home, who has a hearing impairment, just got better with the introduction of new captioned phone technology, which has allowed her to speak to her grandchildren.



Home, 62, was one of the first to use the new technology in Australia in July, phoning her pregnant daughter. With the help of an operator trained to understand the speech of people with a hearing impairment, Home learned

that her daughter visited the doctor and “everything is going fine”. The operator repeated what her daughter said and it immediately appeared, voice-activated in writing on the screen of Home’s telephone.

“This means I can talk directly to someone, rather than using SMS or email, and I’ll be able to get an immediate response,” Home enthuses.

Australian Community Exchange (ACE) has copied the technology used in the US and is funding the trial in Australia, where it hopes to roll out 600 of the telephones.

- Jeff Turnbull

## NATIONAL

### Disability groups demand insurance

Groups in the disability sector are joining together to rally for the introduction of a no-fault disability insurance scheme.

The Productivity Commission is looking at the feasibility of a Medicare-style scheme, with a report due for government mid next year.

The scheme would provide things like financial support, therapy, respite and home modifications for anyone with a disability, who needs long-term care.

The newly formed National Disability and Carer Alliance says it’s a “once in a lifetime opportunity”.

### New disability building standards

Federal Labor wants all new homes to better accommodate people with a disability and the elderly.

It released a voluntary set of national building standards in July, aimed at improving the living standards of people with disabilities.

The standards include wider doorways, corridors and turning spaces for wheelchairs, as well as reinforced bathrooms. It is hoped the standards will be adapted across the sector by 2020.

However, they are not enforceable nor extend to other buildings, as recommended by a federal parliamentary committee in 2009. ~

## INTERNATIONAL

### New car designed for those who are blind

**US** A vehicle equipped with technology to allow a person, who is blind, to drive was on display at the National Federation of the Blind’s annual convention in Dallas in July.

The Ford Escape is operated by non-visual interface technology, using a pair of gloves, equipped with vibrating motors, that tell the driver which way to steer.



## Aged care goes state-of-the-art

Amid a growing crisis of a lack of aged care accommodation across Adelaide, one western suburbs organisation has addressed the issue head-on with a major new \$30 million investment at Seaton.

The Society of Saint Hilarion, formed as a community organisation in 1955 by new arrivals to SA from the town of Caulonia in southern Italy, has just completed a stunning new project, The House of St Hilarion, pictured. It initially caters for 107 residents, offering both high and low-care services. It replaces its former facilities at Lockleys and Findon.

St Hilarion chief executive Peter Hill said there has been a particular shortage of aged care that caters for people with special cultural and linguistic needs in Adelaide. "Especially as people get older, they will often revert back to communicating almost exclusively in their original language.

"Approximately 70 per cent of our residents are of Italian origins and this is reflected in the bi-lingual capacity of our staff, the nature of the meals we serve and also our pastoral care program."

Top: Cena, centre, was very happy to move into her new home, with family members on hand to help with the transition.



## Deadly yet discounted: brain injury from falls

Falls – not motor vehicle accidents or assaults – are now the leading cause of traumatic brain injury (TBI) in Oz, accounting for two in five hospital admissions.

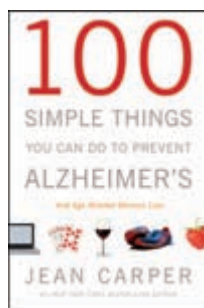
It's due to the ageing of our population. Every year, thousands of older Australians suffer a TBI from a fall. Many will die. Some will survive, but with profound and permanent disability. And, because it is their brain that is injured, they will be affected not only physically, but also in the way they think, feel and behave.

Yet, head injuries in older people are often overlooked. "Australia is heading for a 'perfect storm'", says Nick Rushworth, the executive officer of Brain Injury Australia. "People are living longer. They're being urged to be more active into older ages. This places them at greater risk of a TBI from a fall. And, improvements in trauma care mean they are more likely to survive, but with a greater level of disability."

TBI, like other injuries from falls, is preventable though. Moderate exercise to improve strength and balance, regular reviews of medication and eye checks, improving lighting and reducing hazards around the home have all been shown to reduce the incidence of falls.

## NEW BOOKS


### *100 Simple Things You Can do to Prevent Alzheimer's* by Jean Carper (Little Brown)



When US bestselling author Jean Carper discovered she had the Alzheimer's gene, she was determined to find out if there was anything she could do to help herself. As it turns out, there was quite a lot. In this book, Carper teaches readers how to take simple, effective steps to battle age-related memory loss and prevent Alzheimer's disease. Based

on the latest scientific findings, the book includes such surprising strategies as drinking apple juice, taking care of your gums and even simply trying new things.



Did you know that the average Facebook user is over 50? And, that Aussies spend more time on Facebook than any other country? The book, *Facebook & Twitter For Seniors For Dummies* (published by Wiley), is for seniors wanting to get on-board the social media craze. There's also an *iPad For Seniors* version. As they say, it's never too late to learn! 



### Christmas cheer early on

Children with disabilities have been able to experience an annual Christmas parade first-hand – without venturing far from home.

The Credit Union Christmas Pageant weaves its way through Adelaide's city streets each November. Unfortunately, some are unable to experience the magic due to being isolated by distance or disability.

However, each year the Pageant Royal Family, right, goes on tour to visit children across the state in schools and special needs centres. This year, the tours take in such places as Hewett Primary School Disability Unit, Riverland Special School, Port Pirie Special School and Rainbowland Autism Services.



### New Parliamentary Secretary for Disabilities

Senator Jan McLucas has been announced as the new Parliamentary Secretary for Disabilities and Carers in the new Labor Government, replacing Bill Shorten.

Shorten is now Assistant Treasurer and Minister for Financial Services and Superannuation. Still, in a statement, Shorten said: "You should be assured that my new responsibilities will not dampen my passion for disability and I will continue to argue the case for better treatment of people with disabilities as well as I can."

### SA disability lists explode

A report into disability services in SA has revealed almost 2000 people are on a waiting list for crucial State Government help, with more than 1300 at risk of harming their children or themselves.

The Disability SA report showed that people with disabilities, who are homeless or at immediate risk of harm, waiting for support, had spiked by 55 per cent in the past 12 months.

Dignity for Disability MP Kelly Vincent called for State Disability Minister Jennifer Rankine to resign her portfolio. 

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## A man of mighty vision

A young Tasmanian furniture maker uses his senses of touch and hearing to influence his designs, as **Carla Caruso** discovers.

Furniture maker Duncan Meerding, who is legally blind, looks forward to one day being the “norm”.

The 24-year-old from Hobart has had much media interest - including appearing on ABC TV show *The New Inventors* - in his ability to create furniture using adaptive techniques and technologies, like a talking tape measure.

But, according to Meerding: “I kind of look forward to the day when my story is not the exception. I’d prefer to be the norm. I think in some respects it’s good that I’m getting media coverage, because it’s showing what someone with vision impairment can do. There are plenty a lot of people

out there, who can do things, but I think it’s just often they need the resources to be able to do so.”

Meerding, who began losing his sight at age 18, is vocal about employment opportunities for people with vision impairment. “I don’t see that there’s any real difference to me as a person - my brain still functions exactly the same [as when fully-sighted]. So, I think that’s quite central to my sort of ethos... I think there are probably a few misconceptions in the community about what people with vision impairment can and can’t do.”

Meerding was diagnosed five years ago with the degenerative eye condition, Leber’s hereditary optic



neuropathy, which is passed through the mother and predominantly affects young adult males. It left him legally blind within a year. What he can see now is similar to what you'd see if you put your fists in front of your face and used only your periphery.

“I look forward to the day when my story is not the exception.”

An uncle of Meerding has the same condition, but having it was still unexpected for the young furniture maker. “It also doesn't always affect people, so we weren't expecting it to happen, because one of my uncles had it and one didn't. It's random, even though I've got the gene.”

Meerding says previously simple things, like accessing information, became arduous. “I'd gone from someone who could just pick up a newspaper and read it to someone whose main source of information was basically through radio. [Though] that changed as I got more computer-literate, in terms of using assistive software.”

Meerding had been considering a career as a nurse, after working as a medical orderly in his gap year, but discovered he couldn't get registered with his vision impairment. After hearing about other furniture makers in Melbourne, who'd completed a Vision Australia safety course in power tool usage, he decided to enrol. After that, he chose to alter his humanities university degree to include furniture design, along with history, graduating from the University of Tasmania this year. He has also since received a year-long scholarship to inhabit a studio space at design collective Designed Objects Tasmania.

Much of Meerding's work features curved lines and surfaces, inspired by organic forms found in nature. Working predominately in timber, he often combines hand-carving techniques and bending. Pieces include a bird's nest entrance piece, a lily-inspired lamp, a leaning leaf table, and cracked log lamps.

Meerding uses standard equipment, but employs different aids and strategies, like a talking tape measure and tactile depth gauge. He's also in-tune with his sense of touch and hearing, feeling his way and listening to the machinery. Still, the question has to be asked: does he ever get in harm's way? Meerding responds,

shrugging: “Everyone gets a bit of nips and cuts. I haven't actually had anything too major. I'll occasionally cut myself with the chisel, but pretty much everyone does.”

When he's not making furniture, you'll likely find him indulging his other passion – rock climbing. (There's an outdoor rock climbing wall across from his abode.) When *Link* caught up with him, he was fresh from a rock climbing trip at Victoria's Mount Arapiles, near the Grampians. To accommodate his vision impairment, Meerding will generally follow behind a leader, who will climb from the ground up, with the rope directly attached, while he, as the 'second', will belay the leader.

“There are a few misconceptions about what people with vision impairment can do.”

He's also a keen bushwalker, which is one type of occasion when he'll use his cane. Though, he says: “I don't use it as much as I probably should sometimes. I walk around town without it a lot. But, when I get to alternating surfaces, like bushwalking, it's pretty much a 'must' having the cane, so I don't fall over.”

As for the future? He says: “This [last] half of the year will be quite exciting, because I will be allowed to put a lot more energy into getting my furniture out there.” The nation awaits!

*Duncan Meerding Furniture Design:*  
**[duncanmeerding.com.au](http://duncanmeerding.com.au)** 





# Work it!

Social enterprises are working hard to catch the public's eye and to band together, as a recent Adelaide forum uncovered. **Carla Caruso** reports.

**Left:** Mike Townley, Lyndon Farley and Torry Montgomery at Windmill Hill Salvage. **Centre:** Bedford Group's Katie Williams. **Right:** Finding Workable Solutions' Cass Hissey and Community Bridging Services' Rebecca McBain. Photos by James Elsby.

As far as the eye can see, someone else's trash is being turned into treasure. There are second-hand electrical goods, furniture, building materials, white goods, garden equipment, bric-a-brac and bagged firewood.

Welcome to the Windmill Hill Salvage and Save, located in a picturesque, leafy spot in the Adelaide Hills. Before locals dispose items at the nearby dump, they pass through the salvage yard to see if anything can be recycled for sale – and to see if they can uncover any discarded treasures of their own. Aside from helping the environment and reducing landfill, their patronage, importantly, also helps keep people with a disability in jobs.

The Windmill Hill spot is just one of the salvage yards run by Finding Workable Solutions – a SA not-for-profit specialist employment service for people with a disability and the disadvantaged.

Windmill Hill salvage yard employee Lyndon Farley – among 12 staff on-site – says he loves his job and has been there for about two years. “I like pulling things apart for recycling!”

Fellow colleague Mike Townley has been employed at the yards for about two-and-a-half years. “I’m happy driving the forklift – it’s a good job!”

The salvage yard is just one example of how disability enterprises – or “social enterprises”, as is the new buzz term – can help enrich a community.





There are more than 600 Australian Disability Enterprises (ADEs) nation-wide, employing 19,000 people. The enterprises receive some Commonwealth funding and operate across a wide range of industries, from graphic design, print and metal fabrication to packaging, recycling and landscaping. (SA Group Enterprises, which produces *Link Disability Magazine*, is also a social enterprise.)

Despite the good intentions though, there are some challenges for the sector. On its website, SA Group Enterprises states: "Unfortunately, even with many social changes in community awareness over the last 25 years, ADEs still face many long-standing stereotypes. For example, that they are sheltered workshops and provide cheap, unskilled contracting services and, as a result, they are not generally regarded as providers of skilled, innovative or quality products or services – regardless of being able to demonstrate these competencies."

Another is building up the trust between the varied ADEs and helping each other by working together. Such issues sparked the idea for a forum at Adelaide's Italian Club in July, dubbed *The Spirit of Social Enterprise Forum*. It was hosted by Finding Workable Solutions (FWS) and Community Bridging Services (CBS) - a fellow SA not-for-profit organisation, which provides support for people with a disability in open employment.

Cass Hissey, the relationships manager at Finding Workable Solutions' Mount Barker site, says the forum was sparked

following a meeting between the organisations, including FWS chief executive John Simpson and CBS executive director Freddie Brincat. "I think more so than ever with social enterprises, you have to collaborate and partner together with various other stakeholders to fill the contracts that come up and to be competitive - especially with a regional-type entities."

Hissey continues: "And, that's where the name was born too. It was the 'spirit' of social enterprise, which enables us to create more jobs for people with disabilities. [To ask] how can we, in the spirit of that, collaborate in partnership to bring about that end-result?"

Getting the message about ADEs out to the public is also important for Rebecca McBain, the projects manager at Community Bridging Services. "By using a business that's a social enterprise, you're supporting your community - all members of your community. You're putting something back into that community and you're part of the social inclusion. More and more people are wanting to do that kind of thing - wanting to actually contribute actively to their community."

Hissey adds: "So, the average citizen understands that if they buy something from a social enterprise, it has so much more meaning and depth than perhaps going and buying it from a larger department store."

First to speak at the Adelaide forum was Mark Daniels, the policy and development manager of Melbourne company →

Social Traders. Daniels described social enterprises as social-purpose businesses that trade to fulfill their mission. "Social enterprises are not welfare at all. They're small businesses that deliver outcomes... [and] they operate in every ABS category."

Caroline Crosse, the executive director of Melbourne's Social Firms Australia, also spoke at the forum - and said there is a risk involved in setting up a social firm. "Businesses that operate successfully in the full-profit community cannot always convert into social enterprises. Having a manager who has got the business skills is critical. Business priorities should come first and the social goals sit close behind. There needs to be a balance."

Crosse spoke of non-profit mob Infoxchange Australia and Alpha Autism, who were looking to work together in Melbourne to develop a social enterprise in software testing. "The [autism] population has a high ability to concentrate for a long time and detect flaws in software... There's more demand for software testing, so it's good to be ahead of the curve."

Also at the forum, Louise Gray, the procurement manager for National Disability Services, predicted that there would be more demand for e-cycling services in the future - as in, disassembling unwanted electronic equipment for recycling. "I'm really looking forward to working with e-cycling and perhaps getting the ADE sector to capture that." Though, Gray also said a diversity of ADEs was needed "so there is a scope, all around Australia, for people with a disability to choose where they want to work."

As part of our investigation, *Link* also visited the Adelaide headquarters of not-for-profit organisation Bedford Group, which operates a number of Australian Disability Enterprises, undertaking both local and national contracts in areas such as packaging and horticulture for a mixture of government and commercial customers.

Walking through the site, we could see workers busily putting together show bags for the Royal Adelaide Show, filling fundraising boxes of chocolates, and organising cutlery packets for Qantas international flights.

In the hospitality section, we met with 19-year-old employee Katie Williams, who helps put through 600 hot meals a day for customers on and off-site and has also gained her P plates as part of a life skills course organised through Bedford. (So, next up, she'll be behind the wheel of the catering truck!)

"My favourite part of the job is serving on the cash register and getting to know the customers. Mine's the fastest till!" Williams enthuses.

On the experience she's received, Williams says: "I've always wanted to drive... I get more freedom! [And, one day] I want to work in a restaurant in open employment."

By working together and boosting community awareness, the future certainly looks bright for social enterprises - and employees like Williams.

*For more information on the Spirit of Social Enterprise forum, head to Finding Workable Solutions' site, [fws.org.au](http://fws.org.au), or Community Bridging Services at [communitybridgingservices.org.au](http://communitybridgingservices.org.au). ↻*

## Changing attitudes

US activist/author Dale DiLeo held seminars for not-for-profit disability agency NOVA Employment in July - particularly focusing on psychiatric disability. *Link* spoke to him during his Sydney trip.

**What industries do you think ADEs could particularly tap into?** It's not industry-specific at all. In fact, we urge people not to get locked into thinking that there are certain jobs that people with "labels" can do... It's the job match.

**How can community perceptions about workers with disabilities be changed?** I think most people understand physical and sensory disabilities fairly easily... But, when you start talking about people, who have schizophrenia or Down syndrome and look, talk and act different, that's a little different. They typically underestimate what these folks are capable of... That's what we're trying to do - change attitudes.

For more, visit [daledileo.com](http://daledileo.com).





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## In the swim

Seven Paralympians will compete as part of the Australian swim team at the Commonwealth Games in Delhi, from October 3 to 14.

Multiple Paralympic gold medallist and world recorder holder Matthew Cowdrey, below, is among the seven to compete across six events for athletes with a disability - two more than the 2006 Commonwealth Games in Melbourne.

Cowdrey leads a fearsome contingent of swimmers with a disability – all of whom have competed in at least one Paralympic Games. They include Annabelle Williams, Ben Austin, Ellie Cole, Blake Cochrane, Andrew Pasterfield and Peter Leek.

*Link* wishes good luck to all Paralympians competing at the Games!



Left and right: Matthew Cowdrey. Photos by Mathilde Dusol.

## Ride of a lifetime

Two adventure motorbike riders will set off on a journey across the continent, covering 12,000km in six weeks, starting October 16.

In association with the Anti-Depression Association of Australia, Damian Milo and Bruce Potts, below right, will highlight the seriousness of depression via their tour, starting in Queensland's Maleny.

Potts says: "It is a very exciting time for us. We have already sold the book rights and have joined forces with an award-winning film production company to produce an eight-episode DVD." Follow the trek via [acrossoz.net](http://acrossoz.net).

## Triple threat

Canberra Paralympian Michael Milton reckons the running part of the Noosa Triathlon is likely to be his weakest.

The two-time cancer survivor and multi-gold medallist will compete in the prestigious, annual event - held from October 27-31 - as part of a fundraising drive for cancer research. The event draws more than 8000 competitors for






the Olympic distance course (a 1.5km swim, 40km cycle and 10km run).

Milton's been focusing on running, which he does on one leg and a pair of custom-built, carbon crutches. "I had these crutches made for the [Tasmanian charity event] Mark Webber Challenge and they've also done Kokoda with me. They're light and tough and will be perfect for the Noosa Triathlon. The run will still be my weakest leg - pardon the pun," Milton says, laughing. "Running on crutches isn't as hard as you may think, but it is slow, so I need to be as strong and as fit as I can."

Milton won 22 international medals as a skier for Australia and then competed as a cyclist at the 2008 Beijing Paralympic Games.

"I'm a confident swimmer, thanks to my mum, who made me swim as part of my rehab after losing my leg. I'm pretty handy on a bike and I quite enjoy running. I also love to compete. But my health is my biggest motivator," Milton explains.

He has now been cancer-free for three years and will compete in the triathlon with Team Smiddy who, as part of a wider campaign, is aiming to raise \$750,000 this year for cancer research and services. 



Michael Milton during the 560km Midi-Smiddy bike ride around south-east Queensland.

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# Sail away

**Deirdre Schahinger was among two Aussie sailors recently competing at an international level, as she reports.**

A total of 100 sailors from 10 countries converged on Rutland Water in the UK for the 2010 Access Class World Championships, from June 6 to 11.

Among the 17 Australian entries was Wayne Crabb from Port Adelaide Sailing Club, skippering an Access 3.03 with me (Deirdre Schahinger) from Adelaide Sailing Club as crew, pictured. (Crabb also works at Inprint Design, which produces *Link*.) There were Australian entries in all seven divisions except Access Liberty full servo.

These championships differed from other sailing championships in that over 90 per cent of the competitors had a disability, including physical, neurological, muscular and intellectual. Some sailors used walkers. Some had scooters. Crutches and canes were left behind with friends, and prosthetic limbs were left in the change rooms. Manual and electric wheelchairs were covered up to keep them out of the weather and dry. There were several personal hoists, so sailors could be transferred from their wheelchair into their boat.

The original Access 2.3 dinghy was designed with servo-assisted controls in the early '90s in Melbourne to be sailed by a person with a profound disability. There are now four styles - 2.3 single or double-handed with a single sail, 3.03 with two sails, which can be sailed single or double-handed, the racing single-handed Liberty with two sails, and the 18ft SKUD with three sails, which is the Paralympic two-person discipline. Australia won silver at the last Paralympics in China and two teams have started their campaign for Weymouth in the UK in 2012. (For more on Access, visit [accessdinghy.org](http://accessdinghy.org))

Sunday was practice day for the race management, rather than the sailors. In a light steady breeze, the doubles division, 3.03s (Wayne and I) and SKUDs were in the first race. We got a terrible start, but with some careful body movement by the second leg of the trapezoid course, we had moved up two places and finished 13th.

Day one - the singles, 2.3s, 3.03s and Liberty divisions raced two races 50 to 60 minutes, as scheduled, and the doubles in the afternoon. In a light patchy breeze and learning sail trim from coach Bob Schahinger, we were fifth round the second windward buoy. Then, Wayne noticed the traveller was caught under the rudder and we lost several places as we untangled the traveller. We raced two races back-to-back under an overcast sky, finishing 12th and 10th.

Tuesday's racing was in the morning in light breezes and rain. We got a good start, but were starboarded several times just as we were in a good spot for the windward buoy, so had to pinch and breathe in as we rounded. Rutland Water is a man-made lake and we learned afterwards how to use the waves created by the aerator. We just pipped a British boat on the finish line to come 14th.

“Crutches and canes were left behind with friends, and prosthetic limbs were left in the change rooms.”

The second race was cold and wet. There did appear to be a current and we took advantage of the wind shift. The wind died, the rain poured down and the visibility was poor. We did get a full race in (14th), but the SKUDs had to shorten course. Racing for the singles divisions was abandoned for the day.

We were scheduled to race Wednesday afternoon, but when my and Wayne's carer got back from the laundrette run, the singles had no wind that morning. So, they raced that afternoon and we were able to watch the skilled single-handed sailors get off with a slow start, but a fast finish and Australia was looking good.

Unfortunately on Thursday, I was too sick to sail and rather than Wayne not sail Gerda from ACT was able to take her place. The wind was 16-18 knots with occasional gusts over 20 and drizzle with poor visibility. Gerda is a very experienced



Access Class sailor, so despite the rain and waves and having to bail, they finished 10th in both races.

“Sydney is the venue of the next Access Class Worlds in April 2012.”

Friday was the best day, with sunshine and a moderate breeze and just one race, so boats could get packed up and sailors "cleaned up" in good time for the closing ceremony. Wayne and Gerda came in 7th, giving an overall place of 11th.

The majority of the sailors from most of the countries had been introduced to sailing by their local Sailability ([sailability.org](http://sailability.org)). Sailability is an international organisation that encourages, facilitates and supports people with a disability to go sailing. Many Sailability branches are part of the sailing club activities and sailors with a disability compete in the Access Class on the same course and adhere to the same International Sailing Federation Racing Rules as all other class boats. Sailing is one of the few sports that sailors with a disability can compete in the same race as able-bodied sailors.

The closing ceremony was Olympic style and we got to hear *Advance Australia Fair* twice as Victorian Martin Waller got gold in the 2.3 full servo and 12-year-old Queenslander Angus Macgregor came first in the 2.3s - the largest division with 22 entries. The International Access Class Association flag was formally handed over to Tony Clear, of Middle Harbour Yacht Club - Sydney the venue of the next Access Class Worlds in April 2012.

*Deirdre Schahinger is the co-ordinator of Sailability Adelaide Sailing Club and a committee member of Sailability SA and the International Access Class Association.* ♪





# Tough work

Workplaces can be inflexible and unsure how to support people with mental health issues, writes *Link* reader Catherine.





I've had to deal with mental illness for the majority of my life. I have Obsessive Compulsive Disorder and I was first diagnosed with this condition in my early teenage years. The hardest times have definitely been in adulthood in trying to hold down employment.

My first job was in retail when I was 16, where I worked on a part time basis while I was at School and TAFE. On completion of my course I continued at the same company on a full time basis. I moved from the stores into the head office and then, back into a store as manager. This was a big step for me mentally as I knew the successful running of the store was based on me remaining well.

All went well for quite a few months, until one day everything just got the better of me, and I became very unwell. The only other people at the store were casuals, who I couldn't rely on to run the store.

I called my area manager one day in a distressed state and asked him to come in and take care of the store, as I was very unwell. He suggested I have a week or so off to help get myself back together (his words). This suggested to me my illness was something I could control.

Once I came back to work, I managed really well, but I still didn't have the additional support I required and I was worried the same thing would happen again. An increase in the wages budget would have been ideal so I could have hired someone a full time person instead of having multiple casuals and part-timers that I felt I couldn't rely on. In the end, I thought it was time for me to move on and find something more suitable for my situation.

I applied for a few administration jobs as I wasn't quite sure exactly what I wanted to do next. Finally, I was contacted by a company for a job as a report generator and account coordinator and was successful in my application. Along with my contract and employee information, I was sent a medical form to complete. I was reassured this form was confidential and would only be seen by the company doctor. I was skeptical about providing the details of my condition. However, I thought it was the right thing to do and in addition if I became unwell and had not disclosed details of my condition it could be grounds for dismissal.

The first few months were great, as I had a great group of girls to work with but, unfortunately after a few months I became unwell. My boss seemed to try and understand my condition and for the first few times I came into the office in tears she

was supportive of me but after a while she started to become very irritated.

One weekend, I went away to Sydney with my girlfriends and took the Monday off as annual leave. Unfortunately, I was really depressed for most of the weekend and on Tuesday, when I was supposed to return to work, I was still very depressed, but I thought it best to go into the office, so I wouldn't get into trouble.

When I arrived in tears, my boss automatically assumed I had a big weekend and I just didn't want to be at work. After some discussion, I went home and called my psychiatrist. However, she couldn't see me for a couple of days, but she could clearly tell how unwell I was and offered to write me a certificate for the day.

“I learned how to put a big grin on my face even when, underneath it, I was feeling terrible.”

On the Wednesday, my boss requested I fill out an annual leave form for the Tuesday. Confused and vulnerable, I did what she asked. It wasn't until the next morning, when I came in with a certificate from my psychiatrist was she willing to tear up the annual leave form. My psychiatrist also offered to speak with my manager and provide her with any information regarding my condition and how I could be best supported but my manager declined her offer.

I had approached the human resources department after that incident, as I had done on many other occasions, but they were unable to assist me. A couple of months after that incident, my manager was still making my life pretty difficult, so I resigned.

The next position, I was hired for was recommended to me by a friend. I was very excited when I was accepted for the job as the company seemed to have much to offer. As a receptionist, I was the face of the company and learned how to put a big grin on my face even when, underneath it, I was feeling terrible at times.

Sometimes I would find myself running into a spare meeting room to have a quick cry, and then run to the bathroom to fix my make-up, before heading back to my desk. The HR team was very helpful and supportive and we often spoke about ways to try and find more flexible working conditions for me, but it was difficult to find a solution.

Between taking time off for my doctor's appointments, being physically sick a couple of times a year and having a day off here and there due to my depression, I believe it all became far too hard for the company to accommodate.

I was really eager to keep my position, because I found it challenging and interesting. But, I was advised that my time out for appointments was having an impact on the business. As →

my psychiatrist does not work out-of-hours, I would, wherever possible, work through my lunch breaks to make up the time. I provided a medical certificate for time I needed off for appointments and for sick leave.

During my 18 months at the company, my medication went up and up. The side-effects were dizziness, stomach aches, agitation and sedation. I really struggled to get out of bed every morning as every day was really hard and something to conquer.

“Every day was really hard and something to conquer.”

I had it in my mind that I could be like everyone else, managing to go to work and live a normal life. Unfortunately, I was late one too many times, so I was dismissed. I have now realized owing to my condition and the nature of the workforce, I am probably going to always struggle finding suitable employment which can provide me with the support and flexibility I require.

I have always worked hard in my jobs with good organisational skills, being able to meet deadlines, providing good ideas for improvement, making processes more efficient and having plenty of creativity to go with it all. My colleagues always enjoyed having me around as I am naturally a very friendly and fun person. I'm very good at hiding how I'm feeling around people and, as I have found so are many people who have depression.

I'm now on sickness benefits through the government, which pays about one third of what I was earning when I was working full time. That in itself has been difficult for me get used to. I now feel the best I have in ages without the pressures of work. In time, I will go back to work, but I'm so disheartened by my past experiences that I am afraid of how I will cope. The work place has little understanding of people with mental health issues and how they can be supported to remain well and continue to be productive.

What is worse for me is that I don't really have any references, because I have always left on less than satisfactory terms. I want more than anything to get back into the workforce and make my contribution to society. I have dreams and aspirations just like everyone and I hope someday I can fulfill them.

I don't doubt that in the past 10 years or so mental illness has become a lot more recognised as a real illness, but I can't help wonder if it was something that was more visible, like a physical injury, or more easily understood, like diabetes or asthma, whether I would be in this situation.

If I wasn't as fortunate enough to have such a good support network as I do, from my family, psychiatrist and friends then I would have found it much more difficult to cope. I feel for those who aren't as lucky as I am. 🌀

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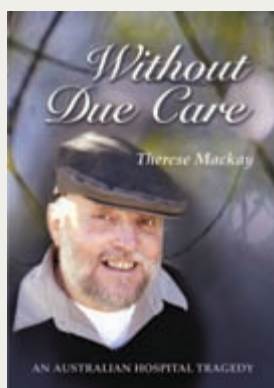
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## How could they do this to him?

Therese Mackay is the author of *Without Due Care: An Australian Hospital Tragedy*. It's a story of what she calls her husband Don's "shocking medical abuse and death at the hands of the diseased and unaccountable Australian health care system." This is her book's first chapter.



In another desperate attempt to end the cruel, painful farce that was being played out in the hospital's intensive care unit, Don had again bitten through the ventilator tube in his mouth, trying to end his living hell.

"Help me."

Those two words haunt me as I write this today, more than two years since his death. He looked directly at our daughter, Melissa, and me and on the outrush of trapped air, when the tube was bitten through, came his awful plea.

Melissa and I will live with those words inside our heads for the rest of our lives. The reality of Don's desperation and his pleading for help still makes my chest hurt. It is the same for Melissa. This is hard to deal with. That particular night, when I tried to sleep, my heart felt like someone had sawed through it. I lay there raw and bleeding. Hopeless. Helpless. Useless.

“No doubt most of them go home at the end of each shift with no idea.”

We couldn't do anything to help Don, apart from killing him outright in front of them, and that was something we just couldn't bring ourselves to do, no matter how bad things were. I felt terrible guilt over this inability to act. I could have done it, and gone to jail. I can imagine the headlines, *Woman Kills Disabled Husband*. But, the spirit in me couldn't face it, and so the tragedy was left to play itself out.

As before, the alarms went off and we were hurried out so doctors could reintubate Don. And, on it went like that, for another five weeks.

If Robin Cook, the author of medical horror stories, had written a novel based on the torment Don endured without choice, he could not have matched the reality of what happened inside the chaos, grime and cold detachment of that major hospital. No one would have considered it credible. People don't really believe that it can have been that bad. Most can only take in the bits and pieces you can tell them.

In Cook's horror novels, there are always one or two villains, deranged doctors or nurses or whatever; but what caused Don's death was no aberration of humanity, no psychopathic doctor or demented nurse. The real horror I carry within me these days is that Don wasn't brutalised and killed by evil, dark forces.

No, his suffering and death were caused by entirely ordinary doctors and nurses, most of whom I would not recognise again. No doubt most of them go home at the end of each shift with no idea what their lack of compassion, cleanliness and sense of responsibility meant to vulnerable patients like Don.



This attitude carries right through. No one can be pinned down. No one is accountable, no one responsible. This is becoming 'hospital culture' in NSW, and it chills me to the bone. At times, when I was inside the Sydney hospital and since, it was as if we were all characters inside George Orwell's *1984*.

“Last night, my beloved husband died again in my nightmare.”


Despite everything, this book is written in a spirit of hope. I am an optimistic person by nature and for me the glass is always half-full. The hope I have in writing this is that all those ordinary people responsible for Don's care in that grimy, chaotic, dysfunctional hospital may read this and realise what happened, how so many of their actions made him suffer and the effect on those of us who loved him. My hope is that each doctor, nurse and bureaucrat who reads this and understands will act differently in future, so that others can be spared the shockingly bad medical and nursing treatment Don received.

Last night, my beloved husband died again in my nightmare. I dreamt I woke up beside Don in our bed. He is suffering and drenched in sweat. I say to him, "I'll get you out of all this." I pick him up like a baby, even though he is taller than me. In dreams, all things are possible. I carry him out to the lounge room to show our daughters and my sisters that he is still here, still alive, although he is once again dying. We still have him.

They can't see us. Don and I are like ghosts. So, I take him out to the big lounge chair on the verandah, and we sit together. I feel and hear his breath, feel his beard, face and skin, and then the breaths stop again.

He is not suffering any more. I know that. My head knows that, but my heart lies open and wrecked as if it has been cut and hacked apart with a chainsaw. Don's deplorable treatment in a NSW public hospital in May 2007 caused his death. He has received no justice to date.

Melissa, Alison and I, who will grieve for his suffering for the rest of our lives, have been denied justice. This book is my testament. Every single thing I write here is the truth, as confirmed by the medical notes and the evidence of other witnesses.

Without Due Care: An Australian Hospital Tragedy is self-published. For a copy, email [tmackay@tsn.cc](mailto:tmackay@tsn.cc) or via post: Therese Mackay, PO Box 248, Port Macquarie, NSW, 2444. Cost is \$27.99, plus \$6 postage. The book will be officially launched at NSW Parliament House on October 20. 



**Opposite page:** Author Therese and husband Don share a happy moment.

**This page:** Therese and Don at Aberdeen, NSW, in 1973. Don at Belmont Caravan Park in NSW in 1976. Don with daughters Melissa, left, and Alison at Oxley Beach, NSW.



# On the move

There are positive and negative outcomes when older people move from disability group homes to residential aged care, as **Ruth Webber** reports.





Moving to residential aged care is often an anxious and difficult time for older people. However, the transition can be especially difficult for older people with intellectual disability.

In addition to common problems, such as deteriorating health and mobility, older people with intellectual disability are likely to be younger than most other residents in an aged care facility. Their interests may well be different.

They are likely to be the only person with intellectual disability in an aged care facility or one of a very small number. Because of the time in which the majority of older residents grew up, other residents may feel afraid of them or uncomfortable with them.

Aged care settings have been generally described as inappropriate and likely to have negative consequences for older people with intellectual disability. However, recent research in Victoria\* provides insights into how relocation from a disability group home to residential aged care can have positive as well as negative effects, and some understanding of what contributes to different outcomes.

At the same time, important questions remain about the impact of moving to aged care and individual experiences may vary considerably.

This article briefly describes the stories of two people, who moved from a group home to residential aged care in the past year or so. They were part of a larger study, which explored the experiences of older people in disability group homes. Names and some identifying details have been changed.

Tony moved to aged care soon after he turned 65 because of deteriorating health and increasing mobility problems. His family chose a facility with previous experience of residents with intellectual disability. Tony's behaviour was closely observed and the director worked with staff to ease his settling in. The director discussed with staff why he became frustrated, how his frustration might be avoided, and effective ways of responding when he became angry or punched someone.

For some time, a staff member from the disability organisation visited Tony each week. The group home provided detailed notes about his history and behaviour, likes and dislikes and suggested strategies to encourage him. However, this was not always read by all staff and at least one wrong assumption was made. An aged care worker commented: "I had no idea that Tony could walk. I asked the lady who comes to visit him, and she said, 'Yeah, he walks'... We go through the care plan and we can miss something... when she [the visitor] talks about Tony, we get information we can use..."

As a result Tony was given a specific walking program. On the whole, his family and the aged care staff believe that after an initial period of settling in, he is relatively content. However,

he tends to stay in his room or occasionally spend time with another resident.

Tony's story shows positive effects of informed management, staff efforts to understand his behaviour and access to detailed information from the disability group home.

Walter was in his late 60s when he moved to residential aged care. He had had limited use of his right side for many years and was falling more often, hurting himself, having seizures and becoming much more frail.

When he moved to aged care, he had an extensive health and nutritional assessment, and his medication and risk of falling were reviewed. Measures were taken to reduce injuries if he fell. He was placed close to the nurses' station and his diet was changed to reduce his weight.


Diagnosis and treatment of a urinary tract infection considerably improved his incontinence. In Walter's case too, the disability group home provided a "wonderful journal, with every detail, including [that of] management if he gets annoyed ... it's got all his specialists, every meeting, everything he's done".

Aged care staff and family say Walter has adjusted well. He still has falls but is hip-protected and has fewer injuries. However, he is confined to areas where he can be supervised. His story shows how the medical focus of care in a residential setting can improve aspects of health and quality of life and result in more effective management of some risks.

Residential aged care and disability group homes have a different focus of care. In aged care, residents undergo a comprehensive health assessment and health and treatments are closely monitored. Nursing staff can identify conditions that may not have been previously identified, and they may discover previously diagnosed conditions not treated effectively. The outcome is likely to be better management of chronic health conditions and improvements in non-chronic conditions. There are also structural differences between residential aged care facilities and disability group homes, with consequences for people as they age.

On the other hand, moving to aged care tends to increase social isolation of older people with intellectual disability. In aged care, they tend to be in a room on their own, somewhat isolated from other residents, or they spend time with staff.

In summary, both positive and negative outcomes are possible for older adults moving from a disability group home to residential aged care. A more detailed knowledge of the overall picture would contribute to improving outcomes for more people.

*\*The study was a three-year project. The three researchers were Professor Ruth Webber (Australian Catholic University), Professor Chris Bigby (La Trobe University) and Professor Barbara Bowers (University of Wisconsin-Madison).* 

# Room rescue

What happens when you have a nightmare living room? Call in the renovators!

A Perth woman, with Multiple Sclerosis (MS), has won a living room makeover competition, as judged by TV personality Kerri-Anne Kennerley.

Amanda Smith, aged 42, scooped the \$10,000 makeover prize from home furnishings and design brand Laura Ashley in July, thanks to an entry from her stepmother, Wendy Smith.

Her stepmum wrote:

*"Amanda manages to live alone in a unit with wonderful assistance from carers, the MS Society and the Silver Chain. [But] she is on a disability pension and is unable to afford any refurbishing. Amanda rarely leaves her unit, so it would be lovely if she could have her life brightened up with a living room refurbishment by Laura Ashley."*

Smith took out the overall prize, as well as coming third in the public choice category. And, she couldn't be happier with the win: "I'm very grateful for this opportunity. It's the best thing that's happened to me all year. I never win anything!"

At the age of 25, Smith was diagnosed with Multiple Sclerosis - a disease that affects the central nervous system

and can interfere with the transmission of nerve impulses throughout the brain, spinal cord and optic nerves. An estimated 18,000 Australians have MS. Its cause and cure remain elusive.

*"I never win anything!"*

The living room makeover will certainly brighten Smith's days, being a central spot, where she enjoys entertaining friends and tuning into Foxtel.

For further inspiration to decorate your living room, head to [laura-ashley.com.au](http://laura-ashley.com.au). 



**Top:** Amanda Smith in her living room before the makeover. **Bottom:** 'Brighton Beautiful' decor for spring/summer from Laura Ashley.



## Chocolate cupcakes

Monique Kleine, behind Adelaide food and event planning biz Confetti Design, says “you can never go wrong with the classics” when it comes to cupcakes.

“This is my never, ever fail chocolate cupcake recipe. I recommend using a good cocoa - Cadbury is the best kind from the supermarket. But, if you are in a gourmet food shop and they have Dutch-processed cocoa, get some and give yourself a treat!”

### Q&A with Monique Kleine

#### Why do you love cupcakes so much?

They're so easy to put an individual and personal spin on, compared to a cake. A cake can usually carry just one theme, whereas you can theme a dozen cupcakes with different elements.

**Tell us about your link with the Women's and Children's Hospital Foundation in Adelaide, which you recently organised a fundraising high tea for at The Highway Hotel.** My younger brother and sister, who are twins, were born at the hospital and they were looked after so well in the special unit they were put in when they were born. I've also supplied some cupcakes to the foundation for a function a few months ago!

#### Describe what it has been like growing up with a sister with autism.

Melinda is 21 this month. She gets bored very quickly and can throw tantrums if she doesn't get what she wants! Her autism is milder than the people she went to school with, so I am thankful that we have it easier than most. But, it's still difficult at times!

[confettidesign.com.au](http://confettidesign.com.au) 



### Ingredients

- 110g butter (room temperature or softened)
- 2/3 cup of caster sugar
- 1 teaspoon of vanilla essence
- 2 eggs, lightly beaten
- 1 cup of self-raising flour
- 1/3 cup of cocoa
- ½ cup of milk

### Method

- Preheat oven to 180°C or 160°C fan-forced. (I always recommend getting an oven thermometer. They are roughly \$8 from places like The General Trader.)
- Cream butter, sugar and vanilla with an electric mixer until all are thoroughly combined. Add eggs and mix until just combined.
- In a separate bowl, sift the self-raising flour and cocoa. Add half the flour and cocoa mixture in with half of the milk, and mix. Repeat with the remaining half.
- Spoon into cupcake cases and bake for 15 to 18 minutes or until a skewer comes out clean. If you have a couple of moist crumbs clinging on that's fine - the heat in the cupcake will finish the cooking. So, they're ready!

**Tip: In summer months and warm environments, you may need to add 5-10g more butter, so the cupcakes don't dry out while cooling!**

# Survival instinct



Photo: Telegraph Media Group 2009/Martin Pope

Gill Hicks lost both legs from below the knee in the London bombings of July 7, 2005. The former South Australian – now London-based - has learned to walk again using prosthetic legs. She has also since swapped the architectural design world for her own charity, M.A.D. (Making A Difference) For Peace. *Link* spoke to her during a recent trip to Oz.

**How have you managed to turn a terrible incident into something positive?** [While] losing both legs is not anything you can imagine for yourself in the future... I think, for me, because I came so very close to losing my life altogether that being alive firstly, and then, secondly, being completely Gill [still in mind], how amazing is that! I was clinically dead really for over half an hour, so even that I managed to pull through without any brain damage - the whole story could have been a hell of a lot worse. So, I'm just so thankful, grateful, appreciative, all of those things... Even feeling pain or disappointment or anything that's negative is still a signal that, well, I'm alive!

**When did what happened really hit home?** I think for me it really was coming back to Australia for the first time and that realisation that I'll never step foot on Australian soil again. I'll never walk on the beach. I'll never paddle at the water's edge. Because this was *home*! I've lived in London for 18 years, so London is kind of an adopted home, but this is 'home home' and you think, "Oh no, that's it! I'll never be able to do that. It's gone." It's also then that process of beginning to understand that I'd never recover. That this is a very



permanent situation... My life now will be about a series of adapting and adjusting as I go.

**Why did you go with prosthetics legs and not a wheelchair?** I think it's absolutely down to that personal feeling - some people get on [well] with prosthetic legs and some find the wheelchair is a better option for them. For me, it was absolutely prosthetic legs. I didn't find the wheelchair easy for me. I just get too frustrated. My head works faster and I think, "Ooh, I can't get up here or I can't do this or I can't do that"... I currently have [prosthetics with] hydraulic ankles that move, which I'm trialling. They're called Echelons. They're amazing! They're the closest thing to how a normal ankle would move... I can move side-to-side and go up and down steep hills!

**Since the bombing, you're now going through a divorce with husband Joe Kerr. Ever think "why me"?** Well, I made the decision to leave the marriage, [but] no, it's all very positive. I think it's about taking the view - and particularly just from the marriage front for both of us - that life is so precious and yes, we've given very, very solemn vows to each other, but equally it's to allow that... things have changed and our lives have gone on different paths... Everybody needs to make sure that they're doing everything they possibly can to be as happy as they can, because [life] is so precious and it's such a short time that we're here.


**Any thoughts on getting back into the dating scene?** Can you imagine it - positive Aries girl, no legs? No, I think I'll concentrate on world peace for awhile [laughs]!

**"I was clinically dead for over half an hour,"**

**You did 435km for the sponsored walk, *Walktalk*, in the UK. Next you're contemplating climbing a mountain?**

Yes, that's on the cards at the moment! We're looking at the logistics and just doing a reconnaissance of ideas. So, there's lots of research at the moment - "is it possible and should I be doing it?" But, it wouldn't [occur] for probably two years. The symbolism with that there is no mountain too big that we can't overcome. The training for that is starting to be seriously discussed. So, watch this space!

**What's been your proudest achievement over the past five years?** I'm still absolutely 'me' and I'm also really proud that I've been able to choose to be a survivor... It's that sense of being proud that I've done things with my life despite everything's that happened. I've approached those things without the hatred that led to this happening to me in the first place. I'm proud that I've been able to not ever have a moment of feeling that I wanted an "eye for an eye".

For more on M.A.D. For Peace, visit [madforpeace.org](http://madforpeace.org). 

Problem with your  
telephone, mobile phone  
or internet service?



The TIO may  
be able to help.

The Telecommunications Industry Ombudsman is a free and independent dispute resolution service for people with complaints about telecommunications or internet services.

If you have tried to resolve a complaint with your phone or internet service provider, but are not making any progress then contact the TIO.

Website [www.tio.com.au](http://www.tio.com.au)

Freecall 1800 062 058

Freefax 1800 630 614

TTY 1800 675 692

Interpreter service 131 450



Telecommunications  
Industry Ombudsman

## Hip hop hooray

First Flight Crew is an eight-piece hip hop outfit, managed by Accessible Arts' creative program coordinator for western Sydney, Alison Richardson. She says: "First Flight Crew is about reaching new audiences outside of the disability sector and bringing to them an explosion of beatboxing, rap, dance and projections."

The crew - formed in 2008 and taught by Aussie hip hop artist Morganics - has performed everywhere from Sydney hip hop festival Platform 3 to the Powerhouse Museum's recent '80s exhibition.

On being a crew member, Ana Nguyen says: "We want to give the voiceless a chance to [tell stories]!"

For more, head to [facebook.com/FirstFlightCrew](https://facebook.com/FirstFlightCrew) or [aarts.net.au/westernsydney/first-flight-crew/](http://aarts.net.au/westernsydney/first-flight-crew/).



Chris Dyke and Digby Webster of the First Flight Crew.  
Photo by Alison Richardson.

## Textbook romance

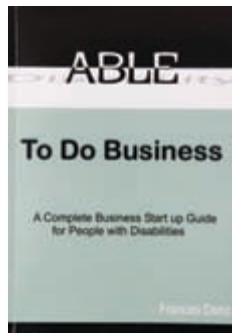


US couple Michael Davoli and Anne Miller have had their love life immortalised in Julie Leto's book, *Hard to Hold* (HCI Books). The tome is part of a new literary genre, known as "faction", where writers use slightly embellished versions of real-life stories to create fiction. Davoli, who has a mild form of Tourette syndrome, spoke to *Link* about it.

**How did your relationship come to be written about in a book?** We were married in August 2009. Our wedding

## Books

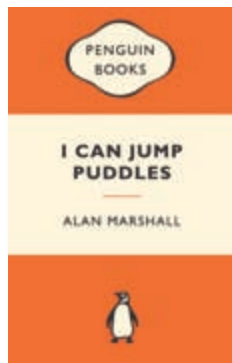
***ABLE To Do Business* by Frances Denz (Bassdrum Books)**



*ABLE To Do Business* is a comprehensive, empowering guide for people with a disability, who wish to start their own business. Using real-life examples and success stories, this book demonstrates that not only is it possible to successfully start up in business, but also to take control of your life and live it your own way.

The author, who initially trained as a nurse, developed cancer at 18 and for the next 29 years was unable to work fulltime. To earn money, she developed various small enterprises, from a tourism safari park to having free range hens. [bassdrumbooks.com](http://bassdrumbooks.com)

***I Can Jump Puddles* by Alan Marshall (Penguin)**



*I Can Jump Puddles* is an autobiography of Alan Marshall's early life in the early 1900s. It's set around the time Marshall got poliomyelitis - or 'polio' - which paralysed the muscles in his legs. Marshall still made use of his legs though via crutches, his 'billy-cart-come-wheelchair', riding a horse again, and even swimming. Marshall's world is of the Australian countryside, brimming with bush men, farmers and tellers of tall stories. The book's best suited to younger readers.

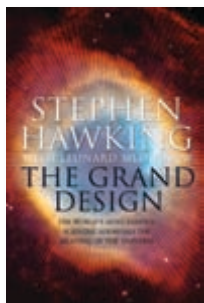
story appeared in *The New York Times*' vows column two weeks later. Around December, we received an email via Facebook from HCI [Books] asking us if we were interested in having our story told as a romance novel. It took us about two weeks before we realised that they were serious!

**What has the reaction from family and friends been like?** At first, everyone laughs, but then when they hear the details they are all so excited to read the book. They all want autographs and some want copies with certain scenes blacked out! It's been a great thing to share with everyone.

**Tell us why the book is called *Hard to Hold*.** I have Tourette syndrome, which is a neurological disorder that causes chronic muscle twitches. Because of the almost constant twitching, Anne and I have to sleep with our backs to each other, so I don't accidentally kick her in the middle of the night. So, as you can imagine, I am very hard to hold. That is what the book title comes from. Just once I would like to be able to fall asleep with her in my arms.



***The Grand Design* by Stephen Hawking & Leonard Mlodinow (Bantam Press)**



In the last 30 years of his life, Albert Einstein searched for a unified theory, which could describe all the forces of nature in a single framework. But, the time was not right for such a discovery.

In this ground-breaking, new work, however, Hawking and writer Leonard Mlodinow have drawn on 40 years of Hawking's own research to reveal an original and controversial theory. Regarded as one of the most brilliant theoretical physicists since Einstein, Hawking has a motor neurone disease - amyotrophic lateral sclerosis - that has progressed over the years and left him almost completely paralysed.

**DVD**

***Can You Sound Like Me?* by Kathryn Keiper**



Music and speech therapy meet video modelling in a new tool designed to develop communication skills for children with developmental delay and disability, including autism, Down syndrome and cerebral palsy. Chew Chew Chatter is a new, Australian, educational DVD series, created by paediatric speech

pathologist Kath Keiper. The first DVD in the series, *Can You Sound Like Me?*, includes 15 original songs and is designed for children with a cognitive age range of birth to six years.

**[chewchewchatter.com.au](http://chewchewchatter.com.au)**

**Goss**

- Club Cool, now in its 12th year, is an ongoing, socially integrated, musical event, held the third Sunday of every month at Adelaide's Governor Hindmarsh Hotel, in collaboration with Arts Access SA. Club Cool offers a friendly, inclusive environment, with a mix of people with a disability, their friends, families and carers, as well as the broader public. The next dates are October 17 and November 21, with a gold coin for entry.
- Not-for-profit disability employment agency Nova Employment was inundated with filmmakers' contributions for its *Focus on Ability Short Film Competition*. Nine short films across three categories were shown at a special event in August. The winners in the Open Entrant category and the Australian Schools Category each won \$5000. They were Bates Drive School for Specific Purposes and DanceAbility. Student winner Jack Noble also won \$1500. **[focusonability.com.au](http://focusonability.com.au)**
- The name, Nicole Taylor, occurs in popular author Sophie Kinsella's latest book, *Mini Shopaholic* (Bantam Press), as a result of an auction in aid of The Children's Trust in the UK. The Trust provides specialist care for children with severe disabilities and Taylor provided a generous bid.
- Theatre company Brink Productions has become the first in South Australia to provide live captioning for its production, *Harbinger* (dubbed "Hitchcock meets *True Blood*"), which showed at the Space Theatre in August and September. The Captioning Studio was employed for two of the shows, enabling patrons with hearing impairments to better engage with the performance. 

**TV special**

British internet doco series *The Specials*, following the lives of five housemates with learning disabilities, won the Best Reality gong at the 14th Annual Webby Awards. The series was both the winner overall and the 'people's voice' winner in that category. *Link* interviewed housemate Sam, 22. **[the-specials.com](http://the-specials.com)**.



*The Specials* cast Lucy, Sam, Megan, Hilly and Lewis at the 14th Annual Webby Awards.

**How was your Big Apple trip for the Webby Awards?** New York was great - it was amazing. We went to Times Square and the Statue of Liberty and they've got loads of big shows there.

**What was it like seeing yourself on-screen for the first time?** I was nervous and shocked at first. I remember the pub scene with the karaoke - drama!

**Fave episode from the show?** My favourite is episode 10, when we're on holiday in Malta and things happen with me and Megan.

**Will there be more shows of *The Specials*?** We hope so. We're looking for funding. A message to my fans in Australia - I love Australian girls!

## Bedford Recognised with National Business Innovation Award



Bedford Chief Executive Max Dyason and employees Andrew Norman and Rebecca Sargeant receive the prestigious award from then Parliamentary Secretary for Disabilities and Children's Services - the Hon Bill Shorten

Bedford's innovative approach to providing vital services to South Australians with disability has been recognised at the annual National Disability Enterprises Excellence Awards held in Melbourne on 6 September.

Bedford was named winner of the ADE Business Innovation Award, which acknowledges disability enterprises focused on building career paths for their supported employees and providing sustainable work through new and viable business opportunities.

Bedford Chief Executive Max Dyason said the award acknowledges Bedford's ability to develop strong relationships to deliver optimum employment outcomes for South Australians with disability.

"We're extremely grateful for the Federal Government's support and are proud to be recognised at these awards amongst some of the nation's finest disability service providers," Mr Dyason said.

"As South Australia's most diverse provider of services for people with disability, Bedford has engaged in partnerships with businesses across a range of sectors to allow employees to realise their full potential."

Bedford has developed partnership arrangements with companies including Bunnings, Canberra Investment Corporation (CIC), Delfin Lend Lease, Robern Menz and Carter Holt Harvey Woodproducts Australia – providing stable employment opportunities in multiple industries across the State.

"Bedford now supports over 3,000 people with disability across metropolitan and regional South Australia, due to the

strength of these partnerships," Mr Dyason said.

"The longevity of many of these relationships reflects both the capabilities of people with disability, and Bedford's commitment to training and quality systems which ensure our disability enterprises maintain extremely high standards of work and professionalism.

"We're extremely grateful for the ongoing support these local and national businesses provide that allows us to deliver the best possible opportunities for people with disability."

This is the second time Bedford has been recognised at the National Disability Enterprises Excellence Awards, having won at the inaugural award ceremony in 2008.

The awards recognise, encourage and promote the significant contribution that disability employment services make in improving the lives of people with disability across Australia.

\*\*\*

Bedford prides itself on its progressive nature and commitment to innovation within the state's disability sector. Its service offering is broad – providing employment and training for people with disability or disadvantage through its furniture, hospitality, horticulture, packaging and various regional Australian Disability Enterprises (ADE's) or in community based employment through CareerSystems. In addition, life skills education is offered through its Day Options programme and key residential services in metropolitan and regional communities.





## What's in a name?



The language we use to describe disability affects the way we see people with those disabilities, reports **Anthea Skinner**.

Cripple. Freak. Retarded. Lunatic. Differently abled. Deaf and dumb. Spastic. Midget. Handi-capable...

The language we use to describe disability has changed a lot over the years. Words that used to be benign descriptions of symptoms or conditions have been abandoned as offensive and replaced with new terms, like “person with a disability” or “vision impaired”. Why do words about disability keep changing, and are we destined to replace them with each new generation?

The disability community is not the only minority group that has changed its name over time. Both the African-American community and the gay community have continually re-branded themselves as positive words become used as insults in the mainstream. I’ve watched it happen before my own eyes...

When I was young the word, gay, had been embraced by homosexuals as a more positive description of their lives than terms like queer or dyke, but when I talk to young people today, they use the term, gay, in the same way as words like stupid or boring.

Andrew Peacock’s recent comment that you’d need to be “handicapped not to appreciate that this [Labor] government was dissolving...” reminded us that words about disability are regularly used as insults.

Some people are trying to rehabilitate words that have gone out of fashion, embracing them to describe the pride they take in their difference from the mainstream. There are growing “Freak Pride” and “Mad Pride” movements. Comedian and host of TV’s *No Limits*, Stella Young describes herself as a “stropky cripp”.

I’m aware of the power of language surrounding

disability because I have a badly-named condition. I have chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). The slash in the middle is a hint that no one can agree on what to call it.

The ME part of the name refers to the suspected cause of the illness back in the 1980s when it was first described. It turned out to be wrong. As a result, the term, CFS, was added, describing the most obvious symptom, chronic fatigue.


Unfortunately chronic fatigue is a symptom of a lot of conditions, including overwork, and doesn’t describe the myriad of overlapping symptoms experienced by someone with CFS/ME. This has led to some mind-numbing comments when I explain my illness to people: “That’s not a real disability...” “I had a touch of that last month...” “I’d love to have that, I need a rest...”

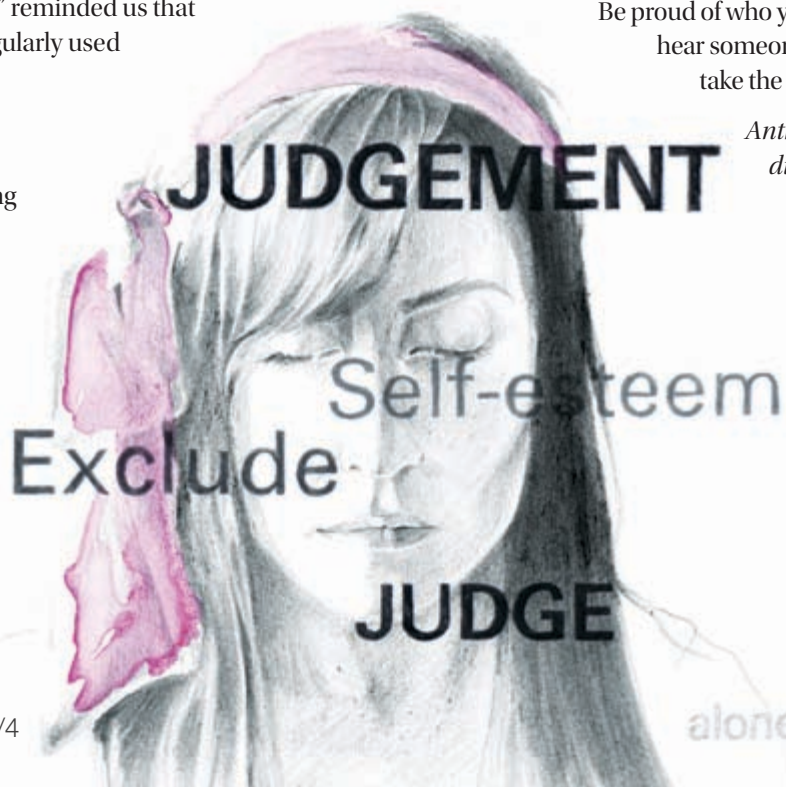
“Why do words about disability keep changing?”

One family member told me CFS/ME wasn’t an illness, it was “a lifestyle choice”. Next time I choose a lifestyle, it will be one without chronic pain, hallucinations or random stabbing pains in my rectum! I’d like to see CFS/ME renamed after its Japanese title, Low Natural Killer Cell Syndrome. Makes it sound like a Manga cartoon character, don’t you think?

How do we ensure that the words we use to describe ourselves today don’t become the insults of tomorrow? The only answer is education. As long as the world sees people with a disability (or any minority) as being less than equal, our names will continue to be hurled as insults.

Be proud of who you are and next time you hear someone take our names in vain, take the time to correct them.

Anthea Skinner was diagnosed with CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) and Meniere’s disease as a teen. She is a postgraduate student at Monash University’s Conservatorium of Music and gives regular talks on disability issues. 





# Travel time

**Accessible travel consultant  
Bruce Mumford recounts his  
family's experiences on holiday  
and offers some tips that should  
be useful for anyone travelling  
with a disability.**

## **Packing**

After researching a range of places to go for a rather special birthday present for my wife, I decided on a ramped seaside cabin at a tourist park on the NSW South Coast.

We knew that the area of Durras Lake was great for a range of abilities, but from previous experience had found that there was only one really suitable cabin at the resort we had previously stayed - and it was booked out.

I looked at photos and plans of a very reasonably priced cabin at the nearby Lakesea Caravan Park at Durras Lake ([lakesea.com.au](http://lakesea.com.au)) and internet contact with the managers found them friendly and helpful, so I took a punt and booked it. As it worked out, I couldn't have been more satisfied.

But, before we left, we had to pack. From experience, I've learned to double check that I've taken all essential items as forgetting some of these can really ruin your holiday. It also made things difficult for the rest of the family, who wasted a lot of time trying to help me later. So, prepare a checklist – and double check you've actually packed it!



Your list might include:

- Medicines and remedies
- Continence aids and supplies
- Necessary mobility aids (for both inside and outside)
- A high-visibility vest, flag, extension cord, charger, tarp and tools for the above
- Bathroom accessories (see below)
- Poncho, torch, mobile phone, reading material, maps, DVDs, fashionable hat, compass, emergency beacon, water-purification tablets (my wife always pooh-poohs this, but they'd be handy if travelling to Pakistan right now), and perhaps you'll find a bit more space in your vehicle for a kitchen sink... (Also, be aware that no matter how many times you go over your packing list, there will always be something obvious you'll forget. But don't worry - you'll remember it once you arrive at your destination!)

## Travelling

So away we went in our lovely new accessible car, which had plenty of room, due to my hiring mobility aids at our destination. I avoided carting a scooter and walking frame with me (we used to tow these in a trailer) by hiring one from a wheelchair supplier in Ulladulla, recommended by the local tourist office.

Peter, the owner, was exceptionally helpful and actually delivered and picked up the equipment, saving me enormous amounts of effort and worry -and space! We then found that a luggage pod on the roof gave us plenty of storage.

When travelling, try to make sure your continence and other needs are set up as best you can on or near you to reduce unnecessary stops. It's a trauma for everyone to have to stop and fish out an essential item from the bottom of your suitcase, which is packed in the pod above your car below three or four other cases, which have been carefully wired with anti-theft booby traps.

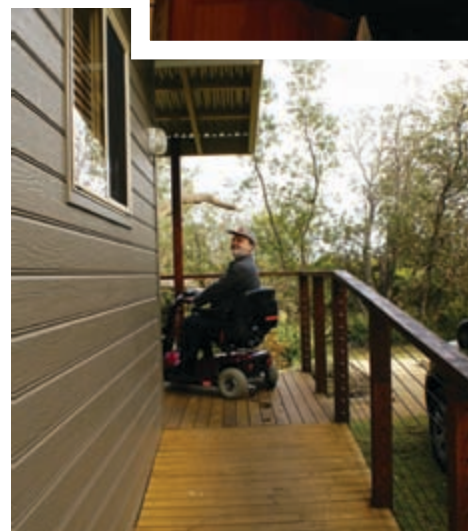
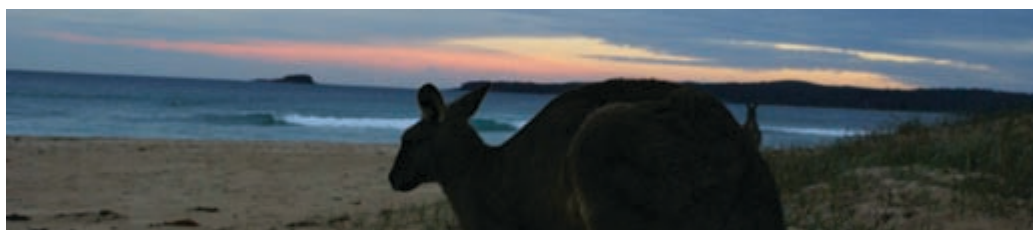
## Arriving

We arrived after a couple of hours drive at our three-bedroom ramped cabin, which was roomy and set in quiet and attractive surroundings, with kangaroos and lorikeets our regular visitors right outside.

“The suitcases are carefully wired with anti-theft booby traps.”

Although the interior was not fully set up for disability access, the managers, Sam and Scott, were very receptive to suggestions for modifications to make it a fully accessible cabin and they were very willing to help in any way they could.

When settling in try to keep things you will regularly need close to hand within a small area, so you don't have to be constantly moving around looking for stuff. →



**Opposite page:** Lakesea Park is at the centre of this scenic spot. **Clockwise from top L:** A roo on the beach near the cabin. Bruce jokingly trying to prise up the kitchen sink for packing, while wife Louise looks on. Bruce breakfasting on the verandah. The cabin entrance ramp.

In selecting accommodation, we've found it important to have separate bedrooms, because a good night's sleep is essential if you're travelling – especially for the driver. And, a cabin with more bedrooms usually doesn't cost a lot more.

Staying in caravan park cabins allows you much more room and is a lot less expensive than motel or hotel rooms. Travelling outside peak periods and mid-week also makes things a lot cheaper.

The bathroom is an area that always requires caution when travelling. Making sure there is a shower that is not over a bath and is easy to get in is essential for me.

I also take a 'soap bag' that keeps the soap in a porous bag on your wrist and prevents the potentially disastrous consequences of dropping it while washing (this and many other useful accessories for people with a disability, I got at Pelican Manufacturing, [pelicanmanufacturing.com.au](http://pelicanmanufacturing.com.au)).

Taking an anti-slip mat with you is also a good idea and, if you don't put too much weight on it, one of those suction cap grab rails available at most hardware stores, could also be handy. Once at the destination, I always ask for a plastic chair for the shower. (They're nearly always available, but you can check on this before you leave).



**Above:** The author's seaside cabin. **Below:** The author's car at Depot Beach, near where he stayed.

## Enjoying

Lakesea Park was a breeze to travel about in my scooter and Durras Lake township itself was great to get around. As there was hardly any traffic, I could hear cars coming from miles away and the main pedestrian traffic were kangaroos.

They even had a cycle path built through the bush long before such things became popular in bigger towns.

The only thing to remember if out in the country is that it can be a long way to decent shelter if caught out in a rain squall – and I wished I had packed a decent poncho instead of the ripped garbage bag I used!

“I entertain the wildlife, while the family goes on vigorous bush and beach walks.”

The great thing about our cabin was not just its great setting, but also the wide verandah, which allowed plenty of room for my scooter to be charged overnight as well as providing a comfortable spot for me to relax, read and entertain the wildlife, while the rest of the family went on vigorous bush and beach walks.

## Leaving

My family will tell you that you should find out the planned departure time and start preparing early. I'd like to be fast and efficient, but unfortunately I know that I never am now (perhaps I never was).

Before you vacate the premises, make sure you've packed all essential items and checked for medical equipment left in bathroom, chargers still plugged into sockets, clothes etc left in cupboards and drawers, mobility devices left outside, grandfather clocks left in the hallway ...

Next article, we go further afield! I am currently planning a trip for us all to the Great Ocean Road. The family is crossing their fingers that my navigational abilities will not make themselves too obvious.

## Useful contacts

### Tourism offices

[ulladulla.info](http://ulladulla.info)

[eurobodalla.com.au](http://eurobodalla.com.au)

[shoalhavenaccess.com.au](http://shoalhavenaccess.com.au)

### Wheelchair hire

There's a great range of companies who will hire out mobility aids. Try Googling "wheelchair hire" and the location you need.

For this trip, I used: Peter Kierzkowski, Everything Ulladulla Pty Ltd T/as The Wheelchair Factory South Coast, 67 Camden Street [P.O. Box 404], ULLADULLA, NSW, 2539. [wheelchairsthcoast@bigpond.com](mailto:wheelchairsthcoast@bigpond.com).

And, there's me at: [blmumford@exemail.com.au](mailto:blmumford@exemail.com.au). 🌀



# The musings of Peter Coulter

Photo: stock.xchng/juliosstock



**Peter Coulter** ponders the benefits of music, red meat – and beer.

## Music & veg

If vindication were needed, this is it. Music has positive effects on the brain and is a road to some communication with people in a vegetative state.

Though, I was not in a vegetative state subsequent to my accident, I was for a period of six weeks in a coma. While in this state, a friend played classical music on his violin and I responded in manifold ways - keeping time, moving and blinking. I came from a complete coma to a responsive state and after being reintroduced to my best friend, Barney the bear, I regained consciousness.

A study has now shown that people in a vegetative condition can alter their heart rates in a predictable manner, which parallels that of normal controls. This indicates that despite severe and widespread brain damage, the areas of the brain responsible for emotional response are left intact.

“We have long known that smoking ourselves is harmful, but not to dead meat.”

This was the findings of a team at the Santa Anna Institute in Crotone, Italy, who played four pieces of classical music to 16 healthy volunteers. They then repeated the experiment with nine people, who were in a vegetative state. Uncovered was that the music affected the heart rates of both groups in the same way – pulling at their heartstrings equally.

## Red meat - it's good for you

Once again, we are finding that anything artificial is not good for us. What a surprise. Highly processed foods have long been known to have unwanted effects - white sugar, sauces, purified extracts and many others. Not only the purified and processed foods, but anything to which these are added.

Recent research has discovered that red meat is not the killer dieticians once thought it to be, but what we do to it that makes it bad and that not only salt is the culprit. Preservatives, many chemicals and even the old favourite, smoking, are now thought to be harmful.



We have long known that smoking ourselves is harmful, but not to dead meat that we treat in this way to preserve it!

The American Heart Association says processed and cured red meats are seriously bad for the heart, recommending one serving a week - at most.

How often do we need to be told and with what reinforcement? “Artificial is bad and natural is good, take what nature provided to us and enjoy it for what it is.”

## Beer kills arthritis

Ever since it was invented, man has been looking for a good excuse to drink more beer (as if we ever needed one). Now, it seems that there is legitimate cause for indulging and it might even save the medical community money on other less enjoyable cures. I've known it for years and now I am vindicated - beer is good for you! Well, at least arthritis.

Frequent drinking of alcohol may ease arthritis. In a study of 873 people with arthritis, those who drank on more than 10 days per month had less damage to joints and 30 per cent less pain and inflammation than teetotal people. Alcohol may actually act as a mild analgesic and dampen the immune system, according to newscientist.com.

It would appear that I will never get arthritis and, if I do, I will never be likely to feel it. ~

# Fresh produce

Julia Farr Group chief executive officer  
**Robbi Williams** ponders the Productivity Commission's inquiry into disability care and support.



Faced with the unavoidable fact that our disability support systems are failing people, the Australian Government has referred the matter of 'Disability Care and Support' to a body called the Productivity Commission.

It seems odd, don't you think? What do you think of when you hear the term, productivity? Hens laying eggs? Miners bringing up the coal? Sweat shops

banging out the T-shirts? It's all wrapped up in our minds along with life-sucking terms, such as indexing, audit, capitalisation and depreciation. The word comes from the realms of industry, finance and economics, and its use is typically confined to regular appearances on the ABC's television program, *Lateline Business*, industrial relations negotiations, and company annual general meetings.

But the word, productivity, is not typically used in the conversations that most of us have about the things that matter in our lives, like having a home, going about our day, having friends, having enough money to live on, recreating, finding love, and so on.

You are unlikely to hear someone deploying the word, productivity, in relation to their home plumbing or their clothes storage. Similarly, words other than productivity will be chosen to describe a day at the beach or the state of a romance. Friendship is rarely assessed in terms of that friend's productivity, which is probably just as well, because some friends may choose to opt out of any such audit.

We can conclude, therefore, that such everyday matters of home, love, belonging, and participation, are important to all of us, and conversations about them do not draw upon the concept of productivity. Yet, here we are having a really big conversation about the way people might be supported in the future, and we have framed the conversation within something called 'productivity'.

This is not to say that the work of the Productivity Commission won't be worthwhile. Indeed, we can hope that the work will be productive (there, I've used the word in a proper sentence). I also emphasise, here and now, that

I am glad the Productivity Commission is working on this topic and I am hopeful that something good will emerge. It just seems odd that we are using the concept of productivity to examine how we might better support people living with disability in lifestyles – a topic that doesn't typically draw on this rather industrial word.

This isn't just me being fussy about words. Words carry great meaning, and the words that we choose can set the context for how something is explored. When we place a disability support enquiry into the context of productivity, this can have a significant influence on the way the issues are discussed and understood.

When we take words from the industry and apply them to the topic of disability support, there is a very real danger that we create an industry view of people's lives, and that people living with disability become commodities within that industry.

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## Whose productivity are we trying to understand here?

Our current funding arrangements reinforce this – people living with disability and other vulnerable citizens become translated to units of production, such as respite hours, bed days, and, program placements.

When this happens, we run the risk of losing sight of people as individuals and instead re-framing people as collections of tasks that need to be performed, or as the unfortunately phrased 'bums-on-seats' to achieve contract quotas. This 'bums-on-seats' approach to productivity is evident, whether service agencies like it or not, in a range of disability support models, such as shared living group homes, supported employment enterprises, or congregate care day programs.

So the question is, whose productivity are we trying to understand here? What is the dominant meaning behind the current Productivity Commission enquiry into disability care and support? There are a number of possibilities. For example, it might be that the government is trying to understand the relative productivity of the public funds we are setting aside for disability support. Or, it might be that we are trying to understand the productivity of the government and non-government agencies that are formally involved in the lives of people living with disability.





Let's explore each of these in turn. First, if the dominant conversations that emerge in the enquiry are about the relative productivity of the public funds used for disability support, then much of the debate and deliberation might be about the relative efficiencies of the formal arrangements, the reduction of purchase overheads, and the incremental improvements in the number of units (bed days, program places) that might be purchased for people living with disability. This all sounds productive, but we cannot necessarily assume that this activity will extend to the positive impact on people's lifestyles, or how such outcomes are understood in personal and practical terms.

Second, if the dominant conversations that emerge in the enquiry are about the productivity of the government and non-government support agencies that are formally involved in the lives of people living with disability, then much of the debate and deliberation might be about issues of financial sustainability, of workforce training, of benchmarking and service standards. While such topics will feel meaningful and productive to the agencies concerned, we cannot necessarily assume that any incremental improvements in these areas will necessarily extend to a positive impact in people's lives.


There is a third way to understand productivity in this enquiry, and that is the extent to which people living with disability are taking their place as active citizens in our

communities, as valued contributors to community life and to the economy. It is hard to be productive when you are not actively involved, and it hard to be actively involved if you are excluded and separated. Our communities are built on the idea of interdependence and mutual support, which assumes that each of us will make a productive (i.e. valued) contribution to community life, in return for similar considerations.

---

### It is hard to be productive when you are not actively involved.

So the true meaning of the Productivity Commission's enquiry should be on how we might best support people living with disability to be active, valued members of our communities, because that is the essence of our role as citizens. This interpretation of productivity in the enquiry will help move us away from arrangements that place people living with disability as passive recipients of welfare, and towards arrangements that are anchored upon active citizenship.

Perhaps it would have helped people's understanding if this enquiry was taking place within a Citizenship Commission, but Australia doesn't have one of those. But, we can be hopeful that the Productivity Commission shapes its deliberations and recommendations around the goal of active citizenship. That could be very productive indeed. 

VISIT [TELSTRA.COM.AU/DISABILITY/CATALOGUE](http://TELSTRA.COM.AU/DISABILITY/CATALOGUE), CALL 1800 068 424 (VOICE),  
1800 808 981 (TTY) OR EMAIL [DISABILITY@ONLINE.TELSTRA.COM.AU](mailto:DISABILITY@ONLINE.TELSTRA.COM.AU)

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## US: Meditation 'rewires the brain'

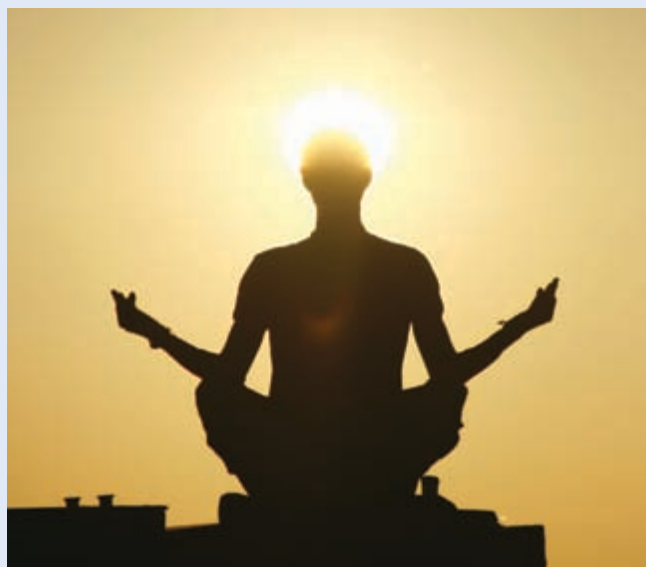
Meditation can help a person find peace by rewiring the brain, research has shown.

Just 11 hours learning a meditation technique, called Integrative Body-Mind Training (IBMT), produced dramatic changes in the brains of volunteers at the University of Oregon in the US.

An area of the brain called the anterior cingulate may be especially affected by meditation, the scientists believe. Deficits in this region have been associated with disorders such as dementia, depression and schizophrenia.

IBMT, adapted from traditional Chinese medicine in the 1990s, is practised by thousands of people in China.

- John von Radowitz



## Aussie scientists in stem-cell first

Australian scientists have taken the world a step closer to effective stem cell-based treatments for now incurable diseases.

Researchers at the University of NSW have found a way to generate stem cells from human skin - known as induced pluripotent stem (iPS) cells - without introducing the risk of troublesome "foreign DNA".

Associate Professor Kuldip Sidhu's laboratory is collaborating with the university's School of Psychiatry to produce stem cell lines for Alzheimer's, Huntington's and Parkinson's diseases. Though, Dr Sidhu said it was still too early to say whether iPS cells would totally replace the need for embryonic stem cells which are - more controversially - harvested from human embryos.

## UK: Autism brain scan developed

British scientists have developed a 15-minute brain scan they hope could be used to detect autism in children, cutting both the time and cost of diagnosing the disorder.

Researchers from the Institute of Psychiatry at King's College London in August published details of the technique, which has been tested on adults and shown to have 90 per cent accuracy in detecting autism.

Children are presently assessed through a lengthy process, with a confirmed diagnosis rare before 18 months.

The new technique involves taking pictures of the brain with a magnetic resonance imaging scanner. The scans are reconstructed into 3D images and analysed by computer software, programmed to spot hallmarks of autism in the structure of different brain areas.

## Israel: Sniff-controlled technology on its way

People with severe disabilities may soon be able to use their noses to write, drive a wheelchair or surf the Internet, thanks to a device developed and tested by doctors in Israel.

The device harnesses sniffing - or breathing in and out through the nose - which involves the soft palate on the roof of the mouth, according to a study published in July.

Scientists from the Weizmann Institute of Science and Tel Aviv University in Israel worked together to develop a way to convert sniffs - which the device measures as nasal pressure - into electrical signals.

The device consists of a small cannula, like the tubes used in hospitals to deliver oxygen to patients, which sits at the opening of the nostrils and is connected to a small pressure sensor. Sniff-controlled technology is still in the development stage, but the institute has applied for a patent.

- Karin Zeitvogel

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# A night of the senses



Aroma jockeys and vibrating dance floors were just a few of the features of a music event in Sydney in August, reports **Alyssa Gill**, of IDEAS NSW.

The queue outside Home nightclub in Sydney's Darling Harbour gave the first hint that SenCity Australia was no ordinary music event.

Outside any nightclub, you expect laughter, gossip and chatter. However, at SenCity this pre-party communication

took place a little bit differently – using Auslan [sign language]!


SenCity is an international travelling event, which offers people with hearing impairment the opportunity to experience music through the shaping and manipulating of all senses. Combining a creative repertoire of 'sign' singers (an entertainer's helping hands), fragrances designed to stimulate the nose, a vibrating dance floor (which allowed people to feel the rhythm), a fondue fountain for taste, and massive TV screens featuring animations and strobe lights, the senses were certainly "sense-ationalised".

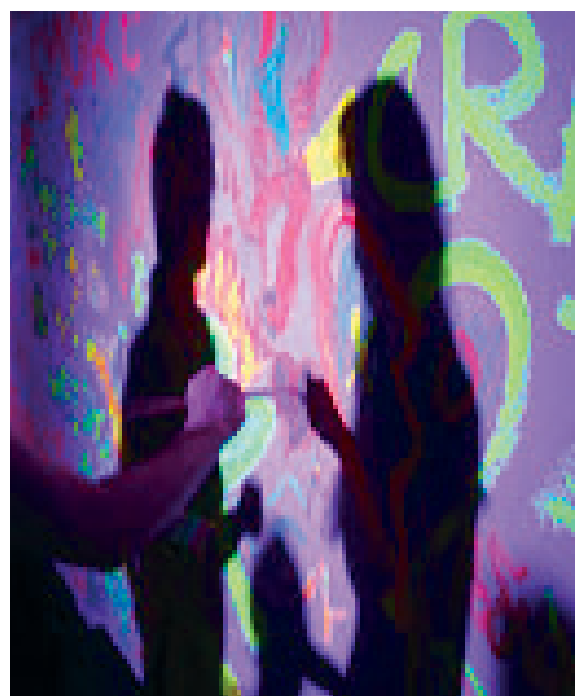
I attended the event as a representative from IDEAS NSW, an organisation that provides information for people with disability through the free-call number 1800 029 904

([ideas.org.au](http://ideas.org.au)). IDEAS was the sole corporate partner to the night, giving 20 lucky people the chance to experience all that SenCity had to offer. It was a great opportunity to support the occasion, with a focus on fun and accessible quality entertainment.

The entertainers on the night, from far and wide, were talented in their abilities to keep the night going and the people dancing. Aussie band Bluejuice was like a cannonball of energy with their combination music style of hip hop, rock and electro. Other entertainers included the amazing drum line from Samba Ninja, DJ Doom from Bang Gang, Carina Hagg, and Supersede.

Possibly the biggest feature of the night was the performance from Finland artist Signmark, the first-ever person, who is deaf, in the world to sign a record deal with an international label. Supported by his speaking translator, Brandon, Signmark truly demonstrated that people with hearing impairment can sing and dance.

The array of emotions around togetherness shared on the dance floor leaves hope that it won't be the last time SenCity hits Australian shores. 





### **Cerebral Palsy Charity Golf Day**

22 October 2010

Lake Karrinyup Country Club WA

Kathy or Sam, (08) 9443 0276

samantha.thiele@tccp.com.au

### **The Nepean Disability Expo**

22-23 October 2010

Penrith Panthers Pavilion, Penrith

www.nado.org.au

### **YMCA Weekend Escapes**

Camps for adults with disabilities

29-31 October – Mt Evelyn, VIC

camping.victoria@ymca.org.au

### **Opens Minds Melbourne Cup Fundraiser**

Supporting people with mental illness, intellectual disability or aquired brain injury

2 November 2010

The Strand at Rugby Quay, Brisbane

Josie Loth - frm@openminds.org.au

www.openminds.org.au

### **2nd Annual International Arts and Health Conference**

16-19 November 2010

University of Melbourne, VIC

www.artsandhealth.org

### **2010 West End Mighty River Run for Novita**

22-26 November 2010

Loxton - Waikerie - Blanchetown - Swan Reach -

Mannum - Wellington

www.novita.org.au

### **Australasian Mobility Conference 2010**

24-26 November 2010

University of Sydney, NSW

www.guidedogs.com.au/amc2010

### **Connect! 7th Annual Disability Arts Party**

1 December 2010

11am-2pm

Dunstone Grove, Stepney SA

www.nostringsattached.org.au

### **International Day of People with Disabilities**

3 December of each year

www.idpwd.com.au

### **'Come and Try' - Bike/Trike Clinic for Novita**

13 December 2010

Regency Park Centre, South Australia

margaret.parkin@novita.org.au

www.novita.org.au

### **Inclusive Basketball**

For people with physical or intellectual disability

YMCA Kensington Community Leisure Centre, SA

7pm Wednesday nights

kensington.sa@ymca.org.au

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Lrellis@sunshinehome.net.au

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### **Rural and Remote Australia**

11th National Rural Health Conference

Perth, WA

13-16 March 2011

www.ruralhealth.org.au

### **5th International SRV Conference**

21-23 September 2011

Canberra, ACT

srvconference@koomarri.asn.au

www.koomarri.com.au



**Are you a young adult living with disability that would make an awesome mentor...?**

**Are you aged between 16-30 and living with disability?**

**Do you have a positive and determined outlook on your life and live in South Australia?**

**Do you have a few hours a week to spare?**

If you've just said 'YES' three times then we would really like to hear from you. The Julia Farr Youth Group (a young group of adults living with disability) has developed a mentor program for children and adolescents aged 11-16 also living with disability (or otherwise known as mentees).

As a mentor, a person will have the opportunity to be involved in training, developing new skills and the worthwhile opportunity to empower a younger person living with disability.

We are also interested in hearing from interested mentees and their families. So please pick up the phone and contact Georgie at Julia Farr Association on (08) 8373 8313 or email georginae@juliafarr.org.au

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## Are you a (you may tick more than one box):

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☐ carer/family member      ☐ government organisation  
☐ health worker      ☐ other please specify \_\_\_\_\_

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