

More than a brother! A young carer story

When S* was just seven years old, his two-year-old brother was diagnosed with Autism Spectrum Disorder and Fragile X Syndrome.

Fragile X Syndrome is a genetic condition that can cause intellectual disability, along with behavioural and learning challenges.

Now 13 years old, S plays a key role in his brother's care and has helped his mum care for him over the past six years. Prior to his father passing away in 2017, S also helped care for his dad.

His daily responsibilities include helping to dress and feed his brother; keeping him calm if something upsets him.

He also helps his mum (who speaks English as a second language) communicate with doctors and other health services.

It's a big responsibility for someone so young. S is bright and talkative, but admits it is sometimes challenging to care for his brother while trying to be a regular teenager.

Balancing school and caring

While S's teachers are aware of



his caring role, his classmates don't know the extent of his responsibilities and he doesn't know anyone else at school who has a caring role.

S enjoys school, but he is often tired and finds it hard to concentrate and sometimes falls asleep in class.

Like many young carers, S doesn't participate in after school activities. He doesn't often see his friends outside school and doesn't have many opportunities to see friends from his primary school.

As much as he wants to spend time with friends, he knows he is needed at home.

Supporting Young Carers

To help S keep up at school, Alfred Health Carer Services provided him with equipment for school and his uniform. We also connected him with mentoring and organised respite for S and his mum.

The team helped the family with NDIS advocacy and planning, ensuring carer supports for both S and his mum were included in his brother's NDIS plan.

Hard but fun

Although it can be hard sometimes, S enjoys helping his mum care for his brother, and they have a special bond.



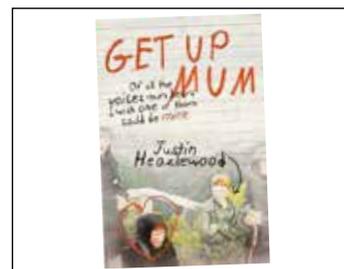
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Carer South News is published quarterly by Alfred Health Carer Services for carers who live in Melbourne's Southern Region.

24 hour Carer Support and Respite



1800 052 222

(freecall except from mobile phones)



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Service providers can
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info@carersouth.org.au

We encourage carers, friends and families to tell us your stories so we can listen to what is most important to you and perhaps share them with others in our community. Phone us on **9076 6439** or email info@carersouth.org.au



Alfred Health Carer Services acknowledges the traditional Aboriginal owners of country throughout Victoria. We pay our respects to them, their culture and their Elders both past and present.



Our organisation values diversity and is committed to providing an accessible service and a safe and respectful environment for our staff and clients.

► 'It's hard but fun,' S said.

S tries to make time for his own interests and is a keen gamer. His favourite games are *Five Nights at Freddy's* and *Gozilla*. A movie buff, S loves cinematography and makes his own videos when he has time, and reviews movies on his YouTube Channel.

S has attended a lot of events with Alfred Health Carer Services, including a recent camp to Phillip Island and a day of trampolining at Bounce Inc.

He really values the friendships he has made with other young carers and said, "it's nice hanging out with friends that I can relate to."

Recognising Young Carers

S wishes that more people understood that young people can be carers too.

He sometimes feels that his caring role is not recognised, and that people don't understand what it's like to be a young person trying to balance school, friendships and caring.

* Name withheld for privacy.

Many young people with caring responsibilities are hidden – they don't know anything different, and don't always seek the help they need.

If you are a young carer, think you might be, or know someone who is, our Young Carer team can work with you to better balance your education and caring role.

You can call **1800 052 222** to speak to the team, or visit www.carersouth.org.au.

On 20 January 2019, Alexandra Gardens will be transformed into a one-stop-party-shop celebrating LGBTQIA+ people and culture for the Midsumma Carnival.

Running from 19 January to 10 February, the Midsumma Festival is Victoria's premier LGBTQIA+ cultural festival, made for and by communities who live with shared experiences around diverse gender and sexuality.

A family-friendly community day offering hours of free entertainment, dancing, sport, food trucks, bars and stalls galore, the Midsumma Carnival is an annual Melbourne tradition and a highlight of the Midsumma Festival.

Alfred Health Carer Services will be joining in the fun with a very special stall at the Midsumma Carnival Day.

If you're planning to attend the Carnival Day, please make sure you drop by and say hello! Our friendly team will be on-hand to chat and answer your questions and will have lots of helpful information available to take away.

Interested in finding out more about Midsumma? Visit www.midsumma.org.au for the festival program.



Business as usual at Alfred Health Carer Services

We have recently received enquiries from carers seeking clarification about the services we provide, in light of changes in the service system over the past 12 months.

We wish to reassure you that our services remain available to all carers in Melbourne's Southern Metro Region, and we continue to offer:

- 24-hour phone support
- Useful information, emotional support and advocacy
- Education, events and peer support
- Referral and linkage to services, helping you put the right supports in place
- Services for carers who support someone with an approved NDIS plan

It's business as usual at Alfred Health Carer Services, so if you would like to find out more about the supports available to you, please call us on **1800 052 222** or visit **www.carersouth.org.au**.

Celebrating carers

Carers don't often stop and take time out for themselves, despite being some of the hardest working people in our community.

That's why National Carers Week is so important, recognising carers across Australia.

In October, Alfred Health Carer Services celebrated National Carers Week by holding two great events - a fun-filled Family Day at Melbourne Zoo, and a magical Luncheon in Frankston. These events allowed carers, and their families, time to relax, connect with others, and enjoy a stress-free day out.

Over 400 carers and their families attended the events, enjoying music, entertainment, food and transport all funded by the Victorian State Government.

Nina, who cares for her mother, attended the Zoo Family Day with her sister and nieces, and spoke of the importance of meeting other carers and taking a break from the demands of caring.

"It was such a lovely break from the daily routine and it was wonderful to have the opportunity to attend with my family, it was a very

exciting day for my nieces! It was really nice to meet people who understood our situation, shared our stories," she said.

The connection made between carers was also a highlight of the Frankston Luncheon. Sarah, who cares for her son, enjoyed the opportunity to share experiences and advice with other carers.

"Today was absolutely fantastic, the other carers were very nice and friendly and we swapped tips, notes and hints," she said.



Harris family



Photo credits: Laura Manariti

If you would like to meet other carers, try joining a support group near you. You can download our Carer Support Group brochure from **www.carersouth.org.au/resources** to find a group near you.

Tandem Awards recognise excellence in mental health

During Mental Health Month in October, more than 150 mental health carers, consumers and professionals gathered to celebrate the people in our community who are making a difference in mental health.

The annual Tandem Awards for Exceptional Service to Family and Friends in Mental Health acknowledge those people who are driving change in the way we think about mental health and promoting a family-inclusive approach.

As Tandem CEO, Marie Piu said “The Tandem Awards are a celebration of individuals and services both in and outside of the mental health system, those that are not afraid to be compassionate, and understand that despite quite complex dynamics at times, family and friends are allies in recovery.”

Alfred Health Carer Services especially congratulates Southern region carers, Peter McDonald and Judy Anderson who both won

Lifetime Achievement Awards and Alfred Psychiatry FaPMI Coordinator, Violeta Peterson who won the Jackie Crowe Memorial Award. They are all passionate champions of carers of people with mental illness and are real community heroes!

A highlight of the event was a speech from actor and writer, Arthur Angel, who wrote and directed the short film Boy Saviour, the story of a young boy charged with the responsibility of translating his migrant mother’s innermost thoughts to the doctor while she struggles with her clinical depression.

Tandem is the Victorian peak body representing families and carers of people living with mental health challenges.

To contact Tandem, call **8803 5555** or email info@tandemcarers.org.au

Share your NDIS tips and hints

Does the person you support have an amazing NDIS plan that meets both their care needs and your carer needs? Then we want to hear from you!

We’re looking for carers to share their experiences developing an NDIS plan in our next edition of Carer South News.

We’d like to know what has worked for you, what you would do differently, what resources helped you and your NDIS top tips.

Your experiences can help carers who support people who have yet to develop their NDIS plans, or who are approaching an NDIS plan review. This will help us identify how we can better prepare carers for the NDIS.

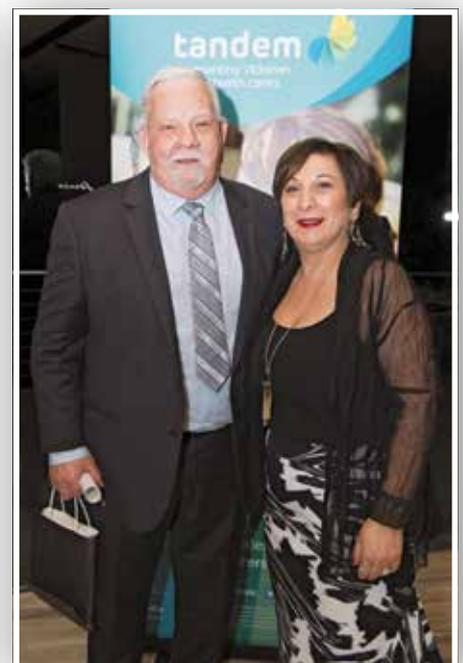
If you’re interested in sharing your NDIS story, let us know! Email info@carersouth.org.au.



Judy Anderson with Marie Piu, Tandem CEO



Violeta Peterson with Gabrielle Williams MP



Peter McDonald with Marie Piu, Tandem CEO

Mental health NDIS access support

...a new way to get help accessing NDIS services

People living with a mental illness can now access additional support to access the NDIS.

Subject to eligibility criteria, the Mental Health Community Support Services (MHCSS) Intake Services will now be able to assist people with a mental illness to understand, engage with and complete the NDIS access process.

How can they help?

- Assist you to gather supporting evidence and complete the Access Request form
- Liaise with health services and general practitioners/private psychiatrists
- Collect and collate additional evidence, if required by the NDIS, to ensure timely completion of the access process
- Follow up with the NDIS on the status of the application



- Assist you to understand and seek a review of the NDIS decision or appeal the decision.

To check your eligibility for this service, please contact the MHCSS Intake service provider in your area:

EACH

Local Government Areas:
Greater Dandenong, Cardinia,
Casey

Contact: **1300 033 224** or
NDISAccess@each.com.au

Neami National

Local Government Areas:
Bayside, Glen Eira, Kingston,
Port Phillip, Stonnington,
Frankston, Mornington Peninsula

Contact: **1300 379 462** or
intake@neaminational.org.au

Improved NDIS support announced on World Mental Health Day

On World Mental Health Day in October, the Australian Government announced a new NDIS Psychosocial Disability Stream that will offer improved assistance for people with a mental illness.

The new Stream will support people with a mental illness to access and develop their own individual NDIS plans in order to receive relevant community based support.

The Psychosocial Stream will employ specialised planners and Local Area Coordinators and develop better linkages between mental health services and the National Disability Insurance Agency (NDIA) staff.

A key focus will be a positive recovery-based planning approach with recognition of the episodic nature of mental illness.

If you care for a person with a mental illness and are looking for support to connect them to the NDIS, or if you would like to learn more about the supports available to you, call the Alfred Health Carer Services team on **1800 052 222**.

Have an NDIS meeting booked? Call us first!

Did you know that people who participate in NDIS pre-planning tend to get better outcomes?

Our team can help you with NDIS access, pre-planning and appeals and help you navigate the new system to ensure you achieve the best outcome for the person you support.

Our team can support you to:

Develop a Carer Checklist

The Carer Checklist, developed by Carers Australia, prompts you to describe the support you provide, including what you are doing, how often and how it affects you.

Write a Carer Statement

A Carer Statement helps the NDIS planner understand what you do now, and the role you wish to play in the ongoing care of the person you support.

Understand how to appeal

Occasionally, an NDIS plan may not deliver the anticipated result. In these situations, you have the option of appealing the outcome to try and get the right supports in place.

Review the Plan

If the person you care for is due for an NDIS plan review, consider giving us a call to talk about any additions or changes that you would like taken into consideration at the review. You could consider additional funding to make sure you can take regular breaks and look after your own wellbeing.

To talk to our team about the NDIS, call **1800 052 222**.

Young carers take a well-earned break

When we think about carers, most of us think of an adult caring for a partner, child or parent. And while this can certainly be the case, anyone can be a carer, at any age.

In fact, of Victoria's 736,600 carers, more than 71,000 are young carers.

Alfred Health Carer Services' Young Carer team helps carers aged 18 and under connect with other young carers, have fun and take a break from caring, and recently hosted two action-packed events.

Adventuring on Phillip Island

Canoeing? Tick. Little Penguins? Tick. Archery? Flying Fox? Adventure maze? Tick, tick, tick!

During September, 16 young carers spent three nights away from home attending a fun-filled camp at Phillip Island Adventure Resort.

The camp included lots of activities that encouraged the group to step out of their comfort zone, have fun and make some new friends.

Highlights of the camp included watching the Penguin Parade, visiting at the A Maze'N Things adventure park, and dinner out in Cowes.

The group left the camp with new friendships, new experiences and lasting memories – and for one young carer, it was 'the best thing I have ever done!'

“ I will remember all the friends I made at the camp ”

Time to BOUNCE!

The Young Carer team got into the Carers Week festivities with a day of trampolining at Bounce Inc in October.

A group of young carers participated in a ninja-warrior style circuit challenge, working as teams to overcome obstacles and win the day's bragging rights!



The day concluded with a team lunch where they celebrated their personal and team achievements.

On a day filled with action and excitement, the young carers made sure they took the time to get to know each other and share their caring stories.

At the end of a very busy day, they left feeling energised and connected with other young carers. They even coined a newfound motto to sustain them in their caring roles ... "when it all gets too hard, you just keep bouncing!"

Out and about for Carers Week!

The Alfred Health Carer Services team was out and about during Carers Week, hosting an information stall at The Alfred Hospital.

The team spoke to hospital staff and visitors, to help raise awareness about the supports available to carers in the region.

Alfred Health Chief Executive, Prof. Andrew Way (pictured with Communications Officer, Nicole Oliver) stopped by to say hello during the week.

He expressed Alfred Health's continued support for carers, emphasising the need for carers to reach out to get the help they need.

If you would like to arrange a presentation or information stall for an upcoming event or your workplace, please contact our events team on **9076 6644**.



More locations for Residential Day Respite in 2019

Being a part of our local community is important for everyone, however can be a challenge for older people as their support needs increase.

Older people living at home can enjoy regular company and companionship, social outings and gentle exercise by getting involved in one of the day respite opportunities offered at a number of participating facilities.

The 'Residential Day Respite' program offered by Alfred Health Carer Services is currently operating at nine locations. It is expected to expand to an additional 16 locations throughout the Southern Metropolitan Region in 2019.

Day Respite is a great option for participants, offering regular, all-day connection and involvement with others. It also allows carers to take a regular break with peace of mind, knowing the person they support is part of structured and engaging activity in a safe environment.

Residential Day Respite is offered through the Commonwealth Home Support Program, so to access this program a referral from My Aged Care is required.

We can support you to arrange this referral, please call Alfred Health Carer Services on **1800 052 222** to speak to our team.

Why we care: Michelle shares her story with Caulfield Hospital staff

For Michelle, the realisation that she had become a carer was sudden and unexpected.

Her husband Blair had been diagnosed with Dementia in 2017, which explained some of the changes they had noticed in his behaviour. However, Michelle hadn't thought of herself as a carer until she came home one day to find Blair hadn't eaten, dressed or done anything since she left the house.

Caulfield Hospital staff were privileged to hear Michelle's caring story during National Carers Week. The theme of the week was *why we care*, dedicated to sharing carer stories.

During a Question and Answer session with Sue Leake, Coordinator of Alfred Health Carer Services' Aged and Dementia Carer Support Program, Michelle reflected on her experience with the health system after Blair was diagnosed.

At the time of his diagnosis, Michelle wasn't given any information about support for

herself as a potential carer. Initially, she and Blair had to manage on their own.

As time went on she recognised she needed some additional support and arranged an Aged Care Assessment. The assessor identified that Michelle could benefit from some carer support and respite and connected her with Alfred Health Carer Services. This is when things started to change for the better.

Michelle attended Creative Ways to Care, a seven-session program run by Alfred Health Carer Services. The program encourages carers of people with dementia to use meaningful activities for pleasure and purpose, creating enjoyable shared experiences for the carer and the person they support.

An activity she found particularly helpful was creating conversation cards on topics Blair enjoys. She used the cards when their grandchildren came to visit, which helped Blair share his interests with his grandchildren and create special family memories.

As a result of the support from Carer Services, Michelle is now linked into regular support groups and activities, which help her connect with other carers and take a break from her caring role.

She also talked about the importance of clinical staff ensuring carers are part of the conversation when they develop ongoing care plans.

Her key message to Caulfield staff was to listen to carers, respect care relationships, and help people with dementia remain at home for as long as is possible and practical.

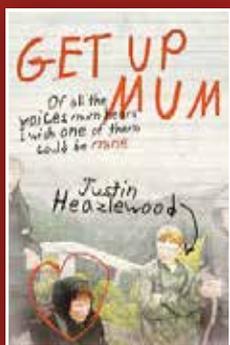
"Hospitals can be frightening places for people with Dementia," she said.

"Often, the best place for people with Dementia is at home, and carers know this better than anyone. It is important for clinical staff to speak to carers to get a true understanding of the care needs of someone with Dementia, and include them in decision making."

We would like to extend our sincere thanks to Michelle for sharing her story during National Carers Week.

Summer read: *Get Up Mum* by Justin Heazlewood

It's 1992 in Burnie, Tasmania and 12-year-old Justin lives alone with his mum. When she is well, Mum is perfect. She knows he likes his carrots raw and his toast cooled, and she knows how to soothe his growing pains.



But when she is sick she cries uncontrollably and never gets out of bed.

High school is on the

horizon and Justin is bursting with adolescent energy. But his mum's mental illness hangs over him like a shadow and he feels the need to grow up fast.

Told with youthful exuberance, *Get Up Mum* is a wildly endearing, entertaining and incredibly powerful memoir about love, family, and coming-of-age.

About author Justin Heazlewood

Justin Heazlewood is an award-winning writer, musician and comic.

As the Bedroom Philosopher he has released three albums including the ARIA-nominated *Songs from the 86 Tram*. He was a senior writer for Frankie for five years. His first book, *The Bedroom Philosopher Diaries*, was published in 2012 and his second book, *Funemployed*, was published in 2014.

You can buy *Get up Mum* in paperback format for \$29.99, or as an e-book for \$9.99 on www.affirmpress.com.au/publishing/get-up-mum.

In your words

This poem was sent to us by Mary, a carer involved with the aged and dementia team. It tells her story of caring for her mother after she was diagnosed with Dementia.

Life in the bubble

*We've been in this bubble my mum and me
For almost five years we haven't been free
to go where we want or choose what we will
Whether exotic or run of the mill
We've been in this bubble my mum and me*

*For Mum it began with getting more muddled
Where are my keys? What are they for?
What meal am I up to? Have I eaten...not sure...
There are so many things I just can't recall
Hunting always for purse and for shawl.
A domino effect of losses ensured
Memory, independence, and home was lost too
Abilities to comprehend, fine motor skills
Writing, and reading and swallowing pills
So many losses but what can you do?*

*For me it began with helping a bit
A meal or a shop or in fact just to sit
with Mum in her home and then moved into ours
The bubble was forming around us by now
Consciously chosen, naively at first
Sustaining of life and quality too
Many the benefits, restrictions were few*

*The years as they passed became harder for both
For Mum there was fear and dementia it sucks!
For me the bubble constricted and all was impacted
social life, music and shopping curtailed*

*Thinking for both, so neither one failed
Was she hot, was she cold, hungry or bored
Where has she gone? Please help me Lord.*

*Lindsay's been great and others helped too
My depth of feeling and love for Mum grew.
We became joined on this treacherous path
Brief respite I found as the bubble stretched out
as someone else entered briefly to be
Mum's companion and help but soon I could see
that reliance on me was growing too much
I found that too, became something which sucked.*

*We are near the end of this journey together
The bubble will burst and Mum will be free
To join her parents, brother...and friends she will see
To be at peace and be happy and not to need me
The bubble will burst and I too shall be free.*

*But even now as we begin to part
There is great sadness within my heart
For the bubble was special and precious and good
And I am thankful and grateful that I really could
Love you so much and although soon to depart
I will hold you forever deep in my heart...
We've been in this bubble my mum and me...
Joined at the hip my mum and me
Safe in the bubble, now safe to be free.*

We thank Mary for sharing this beautiful and very personal poem with us.

Mary received support from Alfred Heath Carer Services to develop an ongoing care plan via the My Aged Care Commonwealth Home Support Program. The plan included weekly respite for her mother,

ongoing home support services, and linked Mary into carer support groups.

If you have a story, poem or artwork that you would like to share, please call **9076 6439** or email **info@carersouth.org.au**

Birthday Wishes can come true!

When you wish upon a star....

A huge thank you to Little Dreamers, who made one young carer's birthday dreams come true in November! After learning that a young carer wasn't planning to celebrate her birthday due to financial pressures, the Alfred Health Carer Services Young Carer team spoke to Little Dreamers about making her birthday wish for a 10 Pin bowling party come true.

Little Dreamers were more than up

to the task, and set about planning a fun-filled day with lots of bowling, arcade games, decorations, party food, lolly bags and a dedicated party host! To keep the sugar-high going, they even organised a delicious ice-cream cake to be delivered on the day of the party.

Thank you so much to the Little Dreamers Dream Experience team for arranging such a magical day.

The Little Dreamers Dream Experience Program provides

opportunities for young carers to make their dreams come true, and create life-long memories.

For more information about the program, visit **www.littledreamersonline.com/programs/dream-experience-program**

