



WINTER 2018

mind View

Carers need a fair go



Across Australia, hundreds of thousands of people are looking after parents, children, siblings, partners or other loved ones who have serious and ongoing mental health conditions.

They do it because they feel committed to caring for that person, but they have no training or preparation for the enormous stresses and challenges and sheer physical exhaustion this task requires, day in day out.

This small section of our community disproportionately absorbs the impacts to our society and economy of caring for people with mental ill-health. They do it largely without government or community support.

The Caring Fairly campaign will advocate for a better deal for mental health carers.

Mind's own research¹ shows that in Australia today, at least 240,000 people provide an estimated \$13.2 billion in unpaid support to people with mental illness in Australia each year. ▶ [\(continued on pg 3\)](#)

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Dear friend,

This edition of *Mind View* heralds a new and important direction for Mind as we approach the launch of our first major advocacy campaign, Caring Fairly.

Mind has always supported carers as well as the people who use our services. This is not just because we know that family and loved ones play an important role in the recovery process for people with mental ill-health. It is also because Mind recognises that the wellbeing of carers is important in its own right.

Mind has a long history of providing support to carers through groups, services and resources. This includes our phone services, the Mind Carer Help Line, which answered over 3,000 calls from carers in 2016-2017, and the Carer Warm Line, which proactively reaches out to family members and other carers to check on their support needs (see our story on p8).

Nonetheless, there is only so much organisations like Mind can achieve through individual support services. We and a consortium of other carer support organisations have recognised it is time to take the bigger step of addressing our government, our

employers and our broader community and saying we need to collectively deliver a fairer situation for the people who care for loved ones with mental ill-health.

This will be Mind's first major advocacy campaign since we consolidated our Research and Advocacy division under the direction of Dr Sarah Pollock in 2017. Our organisation was founded in the 1970s when a group of people challenged the lack of care for people with mental ill-health who were being de-institutionalised without adequate support back into the community. Now, again, we need to raise public awareness and mobilise action, this time to help carers.

By taking us into the lives of people caring for a loved one with mental ill-health, this edition of *Mind View* will hopefully begin to raise awareness of the challenges they face.

Thank you to the wonderful carers (and their loved ones) who have shared their stories. I hope that this edition of *Mind View* inspires you to join us on this new journey towards a fairer deal for carers.

I am also pleased to inform you that the Mind Board has appointed a new Chief Executive Officer, Ms Robyn

Hunter, who starts in this role on 4 June. She replaces Gerry Naughtin who, as we previously advised, has moved on after nine years of fantastic leadership to take a position as Mental Health Advisor to the National Disability Insurance Agency. Robyn comes to us with 25 years of management experience, most recently as CEO for Multiple Sclerosis Limited. You can read an introduction to Robyn on p11.

It has been an honour to serve as Mind's Acting Chief Executive Officer over the past few months and I look forward to supporting Robyn, back in my role as Chief Financial Officer, along with the rest of the Senior Executive Group and everyone at Mind, as she takes up the challenges ahead in the coming years.

Warm regards,

Simon Wrigley
Acting Chief Executive



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Many of these people, who don't get paid for caring for their loved ones, have little or no access to paid employment either, because of the demands of their caring responsibilities. For young carers, we are particularly concerned at the acute difficulties they face in accessing education, or otherwise getting a foothold into employment.

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“Mental health carers are undervalued and unfairly treated in Australian society. Change is needed from government, employers, and the wider culture.”

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These obstacles to employment add the stresses of economic insecurity and poverty to the isolation, tiredness and emotional distress that people caring for loved ones with mental health conditions commonly experience.

This year Mind and a nationwide coalition of mental health carer support organisations will publicly launch Caring Fairly, an advocacy and public awareness raising campaign focused on the economic and social rights of mental health carers in Australia.

We believe mental health carers should have equal access to quality work and access to education and that this access should be supported where necessary by fair and improved public policy. Carers should also be appropriately supported for the currently unpaid work that they do.

The Caring Fairly campaign will combine research, policy development, political

advocacy and a public awareness campaign. Its three year goal is to engage government, employers and the public in making changes to legislation, workplace arrangements and community attitudes to achieve a better deal for mental health carers.

We invite our readers to learn more about the difficulties and inequities faced by carers of people with mental ill-health in this special issue of *Mind View*. ■

Carers are invited to tell us your own story to help the Caring Fairly campaign demonstrate to Australia why carers need a fairer deal.

Contact campaign manager John Foley at **john.foley** @**mindaustralia.org.au**

¹ *The economic value of informal mental health caring in Australia 2017*, Mind Australia, The University of Queensland.

Karen's story

Karen* knew from the beginning that she needed help with her first child, but she struggled to get people to listen. Her daughter Lisa* needed constant attention. She was hyperactive, constantly on the go, had no attention span and was walking at seven months.

"I had to put her on a lead or she would just run out on the road. And of course there were all the looks and comments you'd get from people when they saw her with a lead," Karen says.

It wasn't until two-year-old Lisa pushed Karen's newborn baby off a balcony that Karen could get medical professionals to acknowledge that her daughter's hyperactivity was anything more than the 'terrible two's'.

Lisa was diagnosed with Attention Deficit Disorder but the medication she was prescribed "turned her into a zombie". When Lisa was five, a behavioural specialist helped manage her behaviour enough to get her off the medication and to make attending school possible.

Sadly, Lisa and Karen's problems were far from over. Lisa had been cutting herself since she was 10 but she hid it from Karen until she was 18.

"I wasn't in good shape"

"She was confiding in a school counsellor rather than coming to me," Karen says.

"I wasn't in good shape so she didn't feel like I was a stable person to confide in."

Karen was herself suffering from depression – but her unsupportive ex-partner made the situation worse.

"I had a horrible partner who didn't believe in mental health diagnoses. When I was diagnosed with depression and finally got treatment, he flushed my medication down the toilet and told me to get over myself."

Lisa left home to attend university but she couldn't cope with the pressure; her self-harming escalated and she finally opened up to her Mum and told her she had been diagnosed with Borderline Personality Disorder.

All parents are carers and parenting is a challenging role for anyone, but when a child has a serious mental health condition the consequences for those who care for them are often lifelong and profound.

“When she told me everything she’d been through it was devastating but also very cathartic. There were lots of tears and hugs but the self-blame and guilt was terrible,” Karen says.

Lisa is now in her late twenties and lives away from home in another town, but Karen’s responsibility and concern as a carer continues.

“Lisa stays indoors at her home and is very isolated. She thinks and talks about suicide a lot and she still self-harms. She also dissociates, so we get calls to come and find her because she’ll be in the middle of nowhere and not know where she is and we have to ask her to identify things she can see around her and come and find her.”

Caring and paid work

Throughout the experience of caring for her daughter, Karen’s already difficult situation has been made worse by the difficulties of getting or keeping paid work.

“When Lisa was young, it was difficult to work because it was hard to find someone to look after her,” Karen explains. “That’s because it was difficult to afford care and also because it was hard to find someone to take care of a hyperactive child.”

Even when Lisa was at school, Karen found it difficult to find regular and meaningful work that had the flexibility and understanding to help her juggle the needs

of caring for Lisa. Karen found that even when she got a job it was difficult to keep it because she felt very overwhelmed and unable to cope.

“I’ve had to resign”

“I was just being pulled in so many different directions by my caring responsibilities. At most of my jobs, all my leave has been used as carers leave. I have even called in sick and lied so that I could attend to my caring responsibilities. I’ve had to resign from work before because I couldn’t cope and wasn’t looking after myself.”

Not having her own income also meant she was financially reliant on her partner, which put additional strain on their already difficult relationship and the family as a whole. They have now separated and Karen has a new partner but he is also suffering from depression – and a serious health issue – and she now cares for him also.

Turning her experience into a positive, Karen now works professionally as a carer support worker. It means her manager is understanding about her responsibilities at home but it has also increased her caring responsibilities.

“I work in mental health in the caring area and then I come home to another two clients, my daughter and my partner. Lisa’s on the phone with her problems and it is really emotionally hard. I have my own stuff to deal with too,” Karen explains.

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“I’ve had to resign from work because I couldn’t cope and wasn’t looking after myself.”

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Caring is complicated

Karen’s family history may be more complicated than most, with the additional traumas of an uncaring partner and Karen and her new partner’s own mental health challenges. It nonetheless demonstrates how caring for a family member with serious mental ill-health can compound the challenges that all families face – from finances and relationship problems to the health and wellbeing of other family members.

Most specifically, it illustrates the particular obstacles carers face in gaining and keeping paid employment. *Mind View* spoke to many carers in the development of this special issue and all had similar stories to tell about how caring impacts on their ability to work and bring income into the home. Mind is proud to participate in the upcoming campaign to get better support and employment outcomes for the thousands of people in Australia who care for loved ones with mental distress. ■



Stock photo. Posed by models.

Mind View thanks Karen for generously agreeing to share her story with us. The Caring Fairly campaign will be launched in Winter 2018.

* Names have been changed for privacy reasons.



Stock photo. Posed by models.



About Caring Fairly

Caring Fairly is a new national advocacy and awareness raising campaign focused on improving the economic, social and cultural rights of mental health carers.

Mental health carers are structurally undervalued in Australian society. We recognise that change is needed within multiple spheres: from government, employers, and the wider culture.

Caring Fairly is led by Mind, and supported by a nationwide coalition of organisations that support mental health carers, including Mental Health Carers Australia, peak bodies, and other major national non-government organisations.

What do we hope to achieve?

Caring Fairly's three-year campaign goals are to:

- influence and improve legislation and public policy arrangements for mental health carers
- Influence and sustainably improve employer behaviour and workplace practice for mental health carers
- raise public awareness on this issue. ■

For more information, visit caringfairly.org.au

In a carer's own words

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“No one chooses to become a carer for a child who develops mental health problems; we do not learn how to parent someone who is in so much distress, and whose behaviours are so extreme at times.”

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“If I had to point to the most frightening thing about being a carer, it would be this. When we feel like we can't cope, we see homelessness, despair, and suicide for our loved one. There is this constant background hum.”

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“We need carer friendly policies at work, consistent and available peer support and case management for the whole family, and not just in times of crisis when the family is no longer able to manage, but offered so that crises can be avoided or navigated better.”

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“We need to be offered a break when we need it, just like every other working person gets.”

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Carers: what the research tells us

Most have no training

Carers provide their loved ones – usually their partners or children – with emotional support and psychosocial care. Most of this is done without the benefit of the training and support systems that are available to professional health care workers.



Almost half of all primary* mental health carers have been doing what they do for 10 or more years.

* The primary carer = the person who provides the most care.

Respite needed

Carers are telling us they need respite and emotional support and that they have poor mental and physical wellbeing as well as feelings of hopelessness, exhaustion and isolation.

60 hours on standby

Primary mental health carers also spend an additional 60 hours 'on standby' when they need to be available to drop everything if something unexpected happens. Because of the way people's mental health fluctuates, carers often have no idea when they'll be needed or for how long.

Nearly 40% of all carers are unable to work

due to their caring demands, while primary carers have less access to education and employment than other carers.



Diagnoses

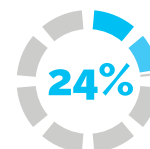
Carers are caring for loved ones with diagnoses of:

- Major depression
- Bipolar disorder
- Anxiety disorders
- Schizophrenia and other psychotic disorders
- Personality disorders
- Eating disorders
- Behavioural disorders.

Each week they provide an average of 36 hours of support.

This caring is also done with no pay and, in 43% of cases, no form of support from Centrelink.

Only 24% receive a Carer Payment.



You can read the full report at <https://www.mindaustralia.org.au/informalcaring>

Pictured: Liz on the phone



The Mind Warm Line: personal carer support

People who care for a loved one with a mental health condition find themselves thrown head first into this challenging situation without any warning or expertise and have to figure it out as they go along.

That's why Mind introduced the Mind Warm Line, a very personal phone support line for carers whose loved ones are using Mind services. So personal, in fact, it is just one extraordinary person, Liza Staios, a qualified community health practitioner, at the other end of the phone.

Liza has put her 16 years of lived experience as a carer and over 20 years of experience in retail customer service to good use by training as a community mental health

practitioner to provide this special service for other carers.

"Sometimes carers can be worried about whether they are handling things the right way or doing the right thing," Liza explains. "They can be dealing with situations they have never had to think about before and so they don't always feel confident they know the best way to react or respond."

As a carer herself, she can both empathise with the experience of feeling overwhelmed and also offer the wisdom of her own long experience.

"The fact that I have lived experience of being a carer for my son, who has serious mental health challenges, really connects

with carers and gives them the confidence to open up and talk about what's worrying them," she says.

"Carers go through all the ordeals of their loved one's episodes of relapse and recovery, challenges with trying different medications and with making sure their loved ones are taking their medications. They can be worried about where their loved ones are in the community at any given time. I understand all these worries and stresses."

Mind already provides the Carer Helpline (1300 554 660), which provides over-the-phone counselling and information about the range of services Mind has for carers – and your loved one does not have

to be using a Mind service to access this support. The Mind Warm Line was launched in 2016 to provide even stronger support for carers by proactively reaching out to people whose relative or friend is receiving our service, to provide peer support, information and referrals.

“Being a carer can be such an emotional experience and talking to someone who has walked in your shoes can help you see and handle things more clearly,” Liza says. As well as lending an understanding and compassionate ear, Liza can help provide clarity and problem solving.

“People who are just plain tired from caring for their loved one can get very stressed and emotional from the pressure they are under and find it hard to communicate with the different agencies they have to deal with – they can feel very disempowered,” Liza says.

“One of Mind’s NDIS consultants recently referred a carer to me who was very distraught and overwhelmed. She was anxious about having to share her son’s financial details to receive his NDIS funding. Through the Warm Line service, I was able to reach out to her and take the time to really listen to her concerns and find out why she was feeling so distressed.

“Once she started to feel at ease I was able to go through the documentation with her. She was able to take in the information, ask questions and together we were able to clarify the situation.

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“Carers go through all the ordeals of their loved one’s episodes of relapse and recovery, challenges with trying different medications and with making sure their loved ones are taking their medications.”

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In the course of doing so, Liza discovered this carer had no support system – her whole life was focused on caring for her son, which is why she was so overwhelmed. “I was able to explain the importance of self-care for carers. I invited her to attend a support group and referred her to other events in her area, which gave her the opportunity to be linked with other carers.”

Liza also acts as a go-between between carers and support workers. “I find a lot of carers have a limited knowledge of what the workers do for their loved one and that is something I can explain to them,” she says. “Our support workers are fantastic but they are so busy supporting the person with the mental health challenge that it’s good to have someone who can liaise with both them and the carer.”

Liza also links carers with financial support, going through a checklist with them to see what financial support they are getting and link them with any they are entitled to but are not yet accessing.

Liza finds operating the Warm Line enormously rewarding. “The challenges,

Mind’s Warm Line service supports carers to clarify their own needs and to build connections and supports in the community.

emotions and feelings experienced by carers are very real to me. I know I am helping people but it also feels like an amazing privilege that people share their experiences and let me into their lives.” ■

Any carer whose loved one is using Mind services can access our Warm Line by getting in touch with a staff member or by calling the Carer Helpline (1300 554 660).

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“Being a carer can be such an emotional experience and talking to someone who has walked in your shoes can help you see and handle things more clearly.”

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In brief

Mind staff appointed to Victoria's Mental Health Tribunal

Mind staff Erandathie Jayakody and Anthony Stratford have been appointed as community members of Victoria's Mental Health Tribunal. Erandathie is the Team Leader of Mind's Consumer and Carer Participation Team and Anthony is our Senior Advisor for Lived Experience. The appointments were made by the Governor in Council and are for a term of five years. They join Mind's Principal Research Fellow, Dr Lisa Brophy of the University of Melbourne, who has been reappointed in the same capacity.

It is great to see that people with lived experience are being included in the Tribunal, which is an essential safeguard under the Mental Health Act (2014) to protect the rights and dignity of people with mental ill-health. Amongst its duties, the Tribunal determines whether proposed compulsory mental health treatment for individuals meets the required criteria as set out in the Mental Health Act.



Pictured: L-R Erandathie Jayakody and Anthony Stratford.



Mind gets four big ticks

Mind has just passed its latest accreditation assessment with flying colours. Accreditation is a process of rigorous independent external review and examination every three years that allows Mind to demonstrate we meet the following four relevant agreed national industry standards for mental health:

- Quality Improvement Council Standards
- National Standards for Mental Health Services
- Victorian Human Services Standards.

Meeting these standards demonstrates that we meet (and mostly exceed) minimum objectives of safety, quality and performance in our products and services. Achieving accreditation gives consumers – and funding and referring agencies – the confidence that services we provide are safe, appropriate and reliable.

We are proud to announce that the Mind Equality Centre has also achieved the new Rainbow Tick accreditation, a great achievement in its first year of operation.

The Rainbow Tick Accreditation Program supports organisations to understand and implement Lesbian, Gay, Bisexual, Transgender, Intersex and Queer (LGBTIQ) inclusive service delivery, and provides assurance to LGBTIQ consumers and staff that an organisation will be responsive to their needs.

Mind is committed to ensuring that all our services provide a welcoming environment and experience for everyone, so hopefully the Rainbow Tick will be a standard we can achieve more broadly across the organisation in the future.

Tandem Awards 2018 nominations

Do you know a service or person who has significantly improved the experience of family and friends supporting people with mental health issues in Victoria?

The **Tandem Awards 2018 for Exceptional Service to Family and Friends in Mental Health**, now in its third year, recognises individuals and services who demonstrate a family inclusive approach and compassionate work practices in the mental health system.

Awards information and nomination forms can be downloaded from the Tandem website at tandemcarers.org.au

Nominations are open until 31 August 2018.



Mind welcomes our new CEO

Ms Robyn Hunter has been appointed the new Chief Executive Officer for Mind Australia and starts in this position in June 2018.

With 25 years of management experience, Robyn's career spans senior roles in corporate strategy and planning, operational management, project management and health service management.

Robyn is a highly experienced CEO who is skilled in leading large and complex organisations, managing cultural change and building collaborative and enthusiastic teams.

Robyn has most recently held the position of CEO for Multiple Sclerosis Limited, a position she has held since March 2013 when she was promoted from Chief Operating Officer. Robyn's formal qualifications include: Masters of Business Administration, Melbourne Business School and

Bachelor of Applied Science, La Trobe University.

We would like to welcome Robyn to Mind and assure her of our support as she takes up the challenges that are ahead in the coming years. Thank you to Acting CEO Simon Wrigley who has held the reins during the recruitment process and returns to the role of Executive Director, Business Services.



Mind partners in new Queensland PARC centre

Mind Queensland State Manager Denise Cummings and Queensland Service Development Manager Steve Morton joined the Board of Wide Bay Hospital and Health (WBHH) on a site visit of a Prevention and Recovery Care centre under construction in

Bundaberg Queensland. Mind is proud to have been chosen by WBHH as their non-clinical partner in this 10 bed facility, which will help meet the region's high need for short term care for people with mental ill-health.

DONATION FORM

Make a real difference to the lives of people recovering from mental ill-health.

You can donate by credit card online at mindaustralia.org.au at

Home page > About Mind > How you can support our work

or by using the form below.

I would like to make a tax deductible donation to Mind (Donations of \$2 or more are tax deductible)

monthly quarterly half yearly

annually one-off

Amount

\$25 \$50 \$100 \$200 Other \$

Payment options

Cheque/money order: made payable to Mind Australia Ltd

Credit Card: VISA Mastercard Amex

Credit card no.

Expiry date /

Name on card

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Getting involved

Please contact me or send me further information on:

- fundraising opportunities
- remembering Mind in my Will
- upcoming events
- workplace giving

Please return the completed form to:

Fundraising
Mind Australia Limited
86 - 92 Mount Street
PO Box 592
Heidelberg VIC 3084

The personal information we collect on this form will be used to track and manage donations and for marketing purposes. This information may be disclosed to other members of the organisation or third parties who do things on our behalf where it is required or allowed by law or where you have otherwise consented. You can access your personal information we have collected, if we have retained it, by calling the organisation.

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Help for carers

Sometimes you just need to talk to someone who understands.

Call our professional, caring staff for free over-the-phone counselling and information about services for carers. (Your loved one does not have to be using a Mind service to access this support.)

**The Mind Carer Helpline
1300 554 660**



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