

### Mind's family carer strategy



very one of us needs a supportive network of family and friends for a good life. At Mind, we value families and carers as important partners in the mental health and wellbeing of our clients. We work with clients to strengthen their relationships, and involve family members and others in their mental health support plans.

However, caring for a loved one with serious mental health issues can be very challenging. Many carers find that their own wellbeing is affected through the experience, and we know depression, social isolation and financial problems are all too often realities for carers.

Carers need support – both in their role as carer, but also as people with their own wellbeing concerns.

Mind has made it a key goal to support mental health carers with a suite of services that help them in their journey. Each year we support over 10,000 carers - involving them in our work with their loved one, and providing them with information, advice, referrals and personal support. We have also increased the involvement of carers in our organisational decision-making. These activities largely mirror the expressed needs of families and carers - to be seen and heard; to be included; and to be supported in the task of caring. ► (continued on pg 3)

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# Dear reader,

n this edition of Mind View, we focus on the needs of families and carers of people living with mental ill-health, and Mind's work to support them. Mind wants to be more responsive to the diverse needs of mental health carers. To achieve this, the Board and management have set clear goals and objectives to improve family and carer services at Mind over the next three years. We have set an ambitious work plan and are backing this with additional resources and a focused implementation plan.

We want to offer a suite of support services that carers can access based on where they are in their carer journey. We want to listen more to what carers are saying they want, and think further about our responses. This edition showcases some of the support we already offer, but we are keen to build on this work.

Our Borderline Personality Disorder (BPD) Family and Carer Group is one good example of Mind's support options for families and carers. This group, which meets on a monthly basis, provides a forum for participants to share their experiences and learn from each other. Mind is one of a few organisations offering such a group. For those not comfortable sharing their experience in a group, we also offer face-to-face counselling or support through the Mind Carer Helpline. Details of where to get information about our family and carer support groups and other services such as education sessions, is available in this edition.

Mind is also part of Mental Health Carers ARAFMI Australia (MHCAA), a national network of community organisations committed to improving the lives of families and carers of people living with mental ill-health. The network plays an important role in influencing national policy on mental health carers. On page 4, MHCAA National President, and Mind's representative, Warren Jenkins explains some of this organisation's current work in influencing the responsiveness of the National Disability Insurance Scheme to the needs of mental health carers. Mind is proud to work alongside colleagues from around the country on this important policy and influencing work.

If you, or someone you are concerned about, needs help with a mental help issue, please call our Carer Helpline or Mind Connect for assistance. We are here to help.

I hope you enjoy this edition.

Warm regards,





### Mind Australia

PO Box 592 Heidelberg Vic 3084 | mindaustralia.org.au | 1300 286 463



To contact the editor email communications@mindaustralia.org.au

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With the merger of ARAFEMI Victoria last year, we were made stronger in our ability to support the needs of carers. This includes taking on the Mind Carer Helpline telephone support service, and having ARAFEMI leaders take up senior leadership positions within Mind. With the merger also came funds to be dedicated to building better family and carer support services.

The 'Mind strategy for carers and families' details our goals for the development of services to ensure we are the provider of choice for mental health carers. We aim to:

- · offer a service range that has a reputation for meeting carers' needs
- be known for our consistent approach to family inclusive practice
- · be sought out as a reliable source of advocacy and information for and about carers.

Mind is working to get help to carers much earlier, and for it to be better targeted to their needs.

We know there are many challenges for families and carers of people living with

### Mind's goals in supporting families and carers

Our goals are to:

- deliver specialist services for families and carers of people with mental ill-health
- deliver family and carer inclusive recovery oriented services
- find ways of rebuilding and supporting better consumer and family relationships wherever possible

- provide information and facilitate peer support
- listen to the views and concerns of families and carers and involve them in the planning, development and review of services
- represent and advocate the concerns and interests of families and carers to governments, service providers and the general community.

mental ill-health. Our experience is that, on average, carers find out support is available some three to five years after the onset of a loved one's illness. This alone means carer 'burn out' is a key issue. Mind is working to get help to carers much earlier, and for it to be better targeted to their needs.

In taking a proactive stance, we at Mind will honour and acknowledge the huge contribution families and carers made and continue to make in the formation and development of Australian community-managed mental health services. There are some threats to the future government funding of family/carer services, but Mind will strongly advocate for the retention of these support services, and develop new models for ensuring carers have access to the full range of supports they need.

Expressed needs of carers and families To be To be seen and heard included supported

We encourage our staff, service partners, consumers, families and carers to let others know about the Mind Carer Helpline 1300 550 265 and our online carer forum, available through the Mind website, to give feedback, connect and be heard.

# Mental Health Carers ARAFM Australia - advocating for all mental health carers

### In brief:

- Mental Health Carers **ARAFMI** Australia (MHCAA) is a collective of organisations that provide support and advocacy to mental health carers.
- MHCAA believes more leadership, planning and progress is required to improve the lives of people with a mental illness and their families.
- MHCAA will advocate on behalf of carers and pursue an ambitious advocacy agenda.

ental Health Carers ARAFMI Australia (MHCAA) is a collective of organisations that have provided support and advocacy to mental health carers for over thirty-five years. Its members include Mental Health Carers Arafmi Qld, Mental Health Carers Tasmania, Mental Health Carers Arafmi NSW Inc., Mental Health Carers Arafmi WA, Mental Illness Fellowship of Australia (NT) and Mind Australia (who host the national office). Each organisation brings its grassroots experience from across Australia, enabling a powerful overview of mental health carers in Australia.

MHCAA exists to provide a national voice for its member organisations, for their individual members, for all mental health

carers who receive support from our member organisations, as well as mental health carers more generally.

In its capacity as a 'national voice' for mental health carers, the MHCAA advocates for:

- · a strong commitment by government to support mental health carers
- greater support of mental health families and carers upon introduction of the National Disability Insurance Scheme

According to MHCAA president, Warren Jenkins, "One key area of concern for us has been funding uncertainty for carer services at a state and federal level. A recent government announcement, to extend the Mental Health Respite: Carer Support program for a further 12 months, has been a pleasing development."

The MHCAA also has an interest in how the NDIS evolves. According to Warren, "We have both trepidation and hope that the NDIS will improve the lives of carers and families."

An area of concern for the MHCAA has been the level of involvement carers and families have in the NDIS. While carers are acknowledged in the NDIS legislation and rules, it is not yet clear how funding for carer support services will continue under the NDIS.

In recent months the National Disability Insurance Authority has relabelled support previously referred to as 'Tier 2' and clarified what it encompassed. Now termed Information, Linkages and Capacity Building



Warren Jenkins, MHCAA President.

(ILC) the supports to be delivered through ILC include:

- information, linkages and referrals
- · capacity building for mainstream services
- · community awareness and capacity building
- · individual capacity building
- · local area coordination.

"The MHCAA will be reviewing the ILC policy framework to assess whether our concerns about the NDIS have been addressed and if not, we will raise these issues as part of our advocacy agenda," says Warren.

"We have an ambitious advocacy agenda. There is no denying that," continues Warren. "In 2015 our aim is to continue to raise the voice of mental health carers and take their message to the highest levels of government - grass roots to national voice."



### In brief:

- The Mind Carer Helpline evolved from the ARAFMI phone line set up in 1979.
- · A team of 25 trained volunteers work on the helpline.
- Helpline support can be broken into three key areas - information, support and referral.

elping someone navigate a path through mental ill-health as their carer can demand tremendous patience, insight and compassion. On top of the personal challenges is what can seem to be a labyrinth of choices for treatment and recovery support services.

In 1979, the Association of Relatives and Friends of the Mentally III (ARAFMI) stepped into this space offering a phone-in helpline for families needing someone to talk to about their loved one. Around 10 years ago the phone line became a more formalised service after attracting government funding.

From this has evolved the service that is now the Mind Carer Helpline, offering free support and referrals for family and carers of people dealing with mental health challenges.

Twenty-five volunteers are currently rostered to work on the phones. The volunteers come from a variety of backgrounds - many are students of a psychology, mental health or community health course. Others are carers with lived experience. Others are a combination of the above. All new recruits undertake a detailed induction process with training, observation and role-play.

Callers phone the helpline for a variety of reasons. Some just want to talk through issues with another person; others might be looking for more help and don't know where to start. According to Neha Verma, Mind Carer Helpline coordinator, carers "want someone to listen to them and acknowledge their role, validate their story and empathise."

Essentially the help available breaks down into three areas:

- information about mental illness, the carer journey or legal issues they may need help with
- · support advice about how to communicate more effectively, uncover issues their loved one might have buried

 referral - to either a Mind service or another providers' service.

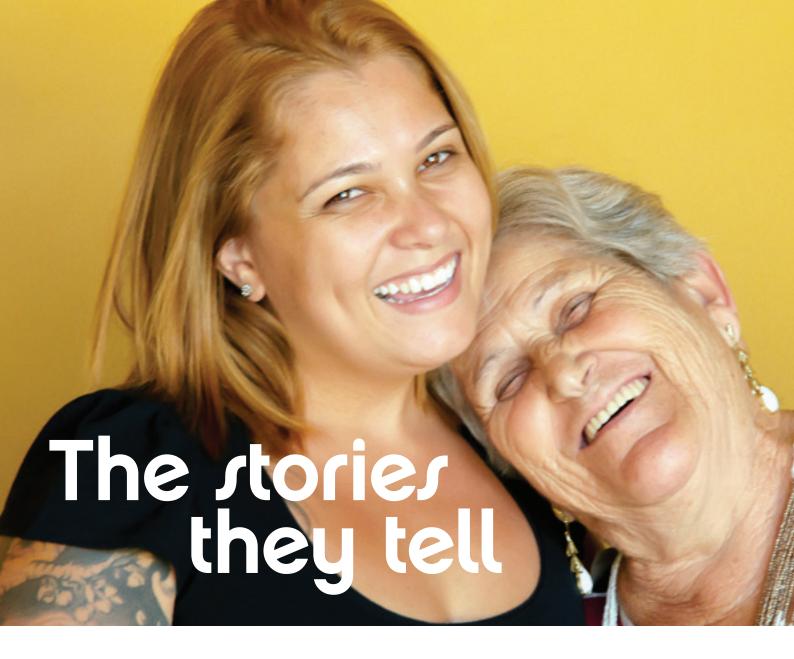
Callers who need some ongoing support can ask to speak to the same person each time they call. Over the page we share with you some carer stories.

> The Mind Carer Helpline 1300 550 265 is open from Monday to Friday, 9.00am - 5.00pm. ■

### Become a Mind Carer Helpline volunteer

Helpline volunteers provide telephone support, information and referrals to friends and family members of people living with mental ill-health. The Mind Carer Helpline operates from Monday to Friday between 9:00am and 5:00pm.

If you are interested in volunteering, please contact the Carer Helpline directly on carer.helpline@mindaustralia.org.au



ince its inception in 1979 the Mind Carer Helpline has supported countless carers. The stories below provide a glimpse into their lives.

### Linda

Linda\* called the helpline after her husband Andrew\* was discharged from hospital following his first episode. Diagnosed with psychosis, Linda was unsure if drug use was the cause. Very upset and crying, she did not know where to go for answers. She had taken off work to support him, further limiting the family's income. Linda was also looking after their three children, the youngest only three years old.

After listening to Linda's story, the helpline worker assisted her to identify two other family members who could be

child-minders while she worked. Linda was very thankful and felt that finally, someone was there to listen to her.

Through the helpline, Linda was also encouraged to think of ways to look after her own needs. As well as identifying activities she enjoyed, a counselling session was suggested. Linda continues to see a counsellor to this today.

#### Anne

Anne\* rang regarding her son Tony\* who had severe depression. Frustrated and fed up, she wanted advice on what to do. She said Tony struggled through VCE and didn't have the energy to keep a job. She felt exceedingly frustrated because he seemed lazy, usually watching TV or playing computer games in his room. Anne felt she

was always there for her son, someone he could talk to, but he always seemed unwilling to communicate.

The helpline worker was able to convey to Anne that Tony did appreciate her efforts even if he didn't say so. She was also told there was a vast amount of information for carers regarding depression. Anne was given information about Mind's education workshops dealing with issues such as challenging behaviours and recovery and hope. Anne seemed grateful there were opportunities to reach out and obtain support. She said it felt better getting everything off her chest.

#### Maggie

Maggie\* was in her 70s and retired with one son living overseas. Her son had a



Counselling was also suggested so she could further explore her fears and concerns. Maggie called back and organised face-to-face counselling.

"Listening, acknowledging and validating her concerns, the helpline worker helped Maggie identify options for supporting her son while looking after herself."

Grace\* was 55 years old and her 24 year old daughter Julia\* had just moved away to live with friends interstate. Grace called the carer helpline after a friend recommended she talk to someone.

Grace spoke a lot about her daughter Julia; how she became involved with drugs to cope with the depression she had since high school, the suicide attempts in her younger teens, and her recent hospital stay due to drug-induced psychosis. Grace said it seemed like she had done nothing but worry about her daughter for the last ten years and now she spent a lot of her time alone, feeling sad and not doing anything.

The helpline worker talked with Grace about activities she liked and sent her a Mind calendar of carer events and activities, along with information about a local cooking group - which Grace later attended. Grace finished the call talking about a group of ladies who went out for lunch once a month. Although Grace was always invited to join them, she had never attended one. After speaking to the carer helpline worker, Grace felt encouraged to join them.

\*Not their real name

traumatic past. His father suicided, his girlfriend overdosed and he had seen many psychiatrists and psychologists over the years.

Maggie had spent around \$1 million supporting her son's lifestyle as he moved around the world, initiating business ventures and ideas that never came to fruition. Sadly, while Maggie felt she had enabled his lifestyle, if she pleaded she could not afford it he belittled her, was rude and made her feel guilty until she gave in. As a carer, she was anxious about the future and worried for him. Maggie was also exhausted. Her greatest fear was that he may suicide and she could not live with that.

Listening, acknowledging and validating her concerns, the helpline worker helped Maggie identify options for supporting her son while looking after herself.

### Volunteer stories

#### Maureen

she's had has equipped her to take these calls and provide support, but that bring up issues that resonate

Helpline is a great way to help put

#### Roshini

which she has volunteered on the helpline have greatly assisted her professional growth as a psychologist. really helped me build confidence and develop the skills and knowledge to

can be tricky when trying to connect with people seeking help and advice. Working on the Carer Helpline has done a lot to hone her listening skills. The ultimate pay-off is the satisfaction she gets from hearing she that challenge."

### Carers' online forum shares knowledge In brief: • The Carers Forum is a partnership of mental around Australia, led by SANE Australia. a safe, supportive environment where

ince August last year, worried carers have been logging on in growing numbers to a web forum offering sympathetic and life-affirming support from those who know best - their peers.

Pioneered by SANE Australia, the forum works as a partnership between mental health organisations around the country, including Mind. By late February, the forum had logged 27,922 visitors who viewed 301,102 pages and contributed 9,671 posts.

Uncertainty and exhaustion underline many of the posts to the carers' forum, with headlines such as: "not sure how much longer I can do this" and "feel like I'm living in purgatory". But the responses are warm, supportive and understanding, because they come from people who have been down the same road; people who know from personal experience how lonely and difficult it can be caring for someone dealing with mental ill-health.

SANE's Online Community Manager, Nicole Thomas says, "They get to talk to people who have been in similar situations, supporting and helping each other out."

The most common theme in the carers' forum is around getting help. "Carers are closely focused on the person they are caring for but sometimes it's only when they get onto the forum that they realise they also need support. They often don't give themselves permission to think about that."

A team of moderators works each day to ensure the environment is welcoming and respectful. Emma McLachlan is the Mind moderator and attests to the popularity of the platform. The moderators assess each contribution to the forum before it is posted to ensure the tone of the exchanges remain helpful and positive.

Like many of the moderators, Emma is a carer herself and feels the peer input keeps the conversations fresh and relevant. She enjoys participating in the online forum and says, "You often get information from other people you wouldn't know existed otherwise. Also when you speak to a carer you get knowledge that doesn't come from textbooks."

> Log on to mindaustralia.saneforums.org

carers can share their

 A team of moderators ensure the forums remain welcoming and

• The Carers Forum is

homepage of the

Mind website.

accessible from the

respectful.



### In brief:

- Mind offers carer specific workshops.
- The core workshops are structured to provide carers with progressively more information.
- All the workshops are run by facilitators and co-facilitators who are qualified trainers with lived experience as a carer.
- The carer workshops provide information, strategies and peer support.
- Carer workshops are offered in Bundoora, Cheltenham and

eing a carer of a loved one dealing with mental ill-health presents many challenges. What do you do? What do you say? How do you say it? Should you say nothing? Many carers speak of walking on 'egg-shells' not knowing the 'right' thing to say or do. To help carers begin to answer these difficult questions Mind offers free education workshops.

Mind's core workshops are structured to provide carers with progressively more information. They begin with Building carer resilience, followed by Challenging behaviours and end with Recovery and hope. According to Family Services Educator, Susan Preece, "You can do them in that order, or do just one of the three. The three together does take the carer along the path of recovery." In 2015, new workshops have been introduced to complement the existing core - Getting off the rollercoaster and A family affair.

Getting off the rollercoaster explores how to maintain healthy relationships between family members so that everyone is treated with respect. The workshop examines ways family members can stay connected and communicate constructively when relationships are strained.

A family affair explores how different members of a family respond to a loved one dealing with mental ill-health; including siblings, parents, offspring (children of the person with mental ill-health) or partners. While all may have a caring role, each brings a different perspective to their loved one's recovery.

All the workshops are run by facilitators and co-facilitators who are qualified trainers with lived experience of being a carer. While the workshops have been run for over ten years, no two workshops are the same. "While we have refined the workshop content over the last ten years," says Susan, "each and every workshop is tailored to address the needs of the people in the room."

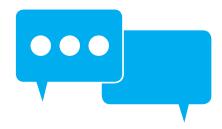
Carers attending the workshops come from all walks of life and are of all ages and carer roles - parents, siblings, partners and friends. Some come looking for specific information and caring strategies, others are seeking support and connection. What they all receive on attending a carer workshop, is peer support. "I wish I'd known about these workshops earlier" is feedback received most often.

According to Susan Preece, "Carers, like the people they love, are the most brave and resilient people I know and deserve to be supported. Education is just one way we can support them."

Education workshops are currently being offered in Hawthorn, Cheltenham and Bundoora. For more information about the carer workshops contact the Mind Carer Helpline, **1300 550 265**. ■

> To download the latest Carer Workshop calendar go to www.mindaustralia.org.au/ education

### In brief



Mind recently won the tender from the Cairns and Hinterland Health Service to operate a Prevention and Recovery Care (PARC) residential service in Cairns. PARC offers a unique setting for consumers to start their recovery journey and resume their role in the community by providing coordinated, recovery oriented treatment and support. Partnering clinical mental health services with a recovery

### Mind opens service in Cairns

service, PARC enables consumers with severe mental illness to receive clinical intervention and treatment and active support for their recovery in a safe and supportive setting. Mind is the largest provider of PARC services nationally, and a leader in residential mental health recovery oriented services. The Cairns PARC is expected to open in April 2015.

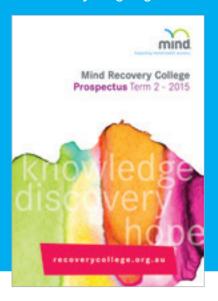
### Mind Recovery College launches new website and moves location

The Mind Recovery College has now launched its own website. The website features all the upcoming courses and resources to 'get inspired'. According to Mind Recovery College Director, Dianne Hardy, "It's wonderful to see the Recovery College website launched. In time we hope to see it become a great source of useful information and inspiration for students, staff and anyone else wanting to learn more about mental wellbeing. The College and the website are very much about gaining insights from people who have been on their own recovery journey."

In other Recovery College news, the college's head office

has moved. No longer based in Heidelberg, Victoria, the Mind Recovery College has moved to 4-10 Jamieson Street, Cheltenham - opposite Southland. Most of the College staff will work from these premises and there will be three learning spaces and a resource centre. Many of the College's Melbourne courses will be delivered from Jamieson Street.

For a full prospectus of upcoming Mind Recovery College courses go to the Recovery College website www.recoverycollege.org.au



### Mind Community Conference

On the back of a very successful Community Conference last year, Mind is happy to announce the Community Conference 2015. Like last year, two events will take place – one in Melbourne on 7 May at the MCG and one in Adelaide on 14 May at the Stamford Plaza.

The events are open to all current and past Mind carers, consumers, volunteers and staff and will include presentations, activities, workshops, stalls and entertainment. The conferences provide an opportunity for participants to make new connections and celebrate how we work together as a community.

An awards ceremony will also be held at each event to recognise outstanding contributions to the Mind community.

#### Victorian event

Thursday 7 May 10:00am - 4:30pm Melbourne Cricket Ground, Melbourne **South Australian event** 

Thursday 14 May 10:00am - 4:30pm Stamford Plaza, Adelaide

Registrations are now open.

### Living well - mental health reform in NSW

Living well, published by the NSW Mental Health Commission, outlines a reform of the current mental health system in NSW from one predominantly focused on treatment via hospitalisation, to one of hope of recovery through community support, thus giving those with a lived experience of mental illness a voice.

This report tells the story of mental health in NSW from the perspective of people who live there. As the NSW Mental Health Commissioner himself describes it, "The pages that follow present a powerful and at times emotional case for a new generation of mental health reform in NSW – one that puts people firmly at the centre."

The report has been well received by mental health advocacy groups across the country.

To download the full report go to the NSW Mental Health Commission website www.nswmentalhealthcommission.com.au

### New independent mental health advocacy service

Victoria Legal Aid has reached an agreement with the Department of Health and Human Services to deliver an independent mental health advocacy service.

This new service is the first of its kind in Victoria and will support the goals of the Mental Health Act 2014.

It is a serious step for people to be detained and to receive psychiatric treatment against their will. It is vital that people subject to compulsory treatment have a say about their treatment, care and recovery, are supported to express their treatment preferences, and have their wishes considered, respected and where possible, followed.



Independent advocates employed by the new service will help people diagnosed with a mental illness and who are receiving involuntary treatment to have a voice in decisions about their own treatment, care and recovery

The independent mental health advocacy service is not a legal service.

Many details of the new service are still being worked out, and in the early stages Victoria Legal Aid will be talking and listening to mental health consumers, and the services that already support them, to learn more about what is needed.

## responsibilities in health issues paper released The federal government has re

Roles and

The federal government has released an issues paper laying out the development of Australia's health care arrangements since Federation. The paper outlines the pressures on current arrangements and canvasses questions about how the current split of roles and responsibilities between the Commonwealth and the States and Territories could be changed to alleviate them and lead to improved health for all Australians. It sets out options for reform which will form the basis of a White Paper which will be released in 2016.

The issues paper considers several important questions:

- What is the appropriate role of government, as well as non-government and private providers, in health care?
- What should we change in the allocation of roles and responsibilities between the Commonwealth and the States and Territories to improve the health of Australians? Why?
- Should any roles be shared? If so, which ones, and how can they be clarified and coordinated to minimise overlap, duplication and blame-shifting and improve service delivery?
- What aspects of our health care arrangements involving the Commonwealth and the States and Territories are working well and should be maintained or extended?

To read the full document go to the Reform of the Federation White Paper website www.federation.dpmc.gov.au

### Consumer and carer guide to Advance Statements now available

Advance Statements under the Mental Health Act in Victoria – Carers and Consumer Guide is now available on the Department of Health's website. Advance Statements were introduced along with the new Mental Health Act.

Advance Statements document what treatment a person dealing with mental ill-health would like in case they require compulsory mental health treatment. Treatment means the things used to relieve the symptoms and distress caused by being unwell.

In the event that a client receives a compulsory mental health treatment, doctors and other people in their treating team have to consider what treatment they would like, including preferences they have written in their Advance Statement.

Advance Statements are not required to be considered if the individual is receiving voluntary treatment, but it could still



be a useful way to let doctors know what treatments they prefer.

The information provided is for people who may be thinking of preparing an Advance Statement and for those who may be helping someone write up their Advance Statement.

The carer and consumer guide is available for download from the Victorian Department of Health website www.health.vic.gov.au

#### **DONATION FORM**

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

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

Email

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 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.

ABN 22 005 063 589 MVA15



### Run for mental health recovery.

Join Team Mind to support the recovery of over 7000 people living with mental ill-health.

Run Melbourne Sunday 26 July 2015 5km - 10km - Half Marathon

Champion entries available now. Visit www.mindaustralia.org.au or phone 03 9455 7989



Supporting mental health recovery



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