

Mind's approach to working with families and carers

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Acknowledgements

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"We aspire to a situation where all families and carers can get the right information, support and service at the time and place that best suits their needs."

- Gerry Naughtin, Chief Executive, Mind

Contents

Purpose	4
Context	5
Who are families and carers?	6
Core principles	8
Practice	10
1. Carer welcome and identification	13
2. Staff are carer aware	14
3. Confidentiality and sharing information	16
4. Carer champions	17
5. Information and engagement	18
6. Support	20
Moving forward	22
References	23

Purpose

Introduction

Mind is a community managed specialist mental health service, which has been supporting people with mental health issues, their families and carers for nearly 40 years. It provides a diverse portfolio of services to a broad range of people including young people, older people, people from culturally and linguistically diverse communities, indigenous communities and families and carers. Our approach is directed by the overall values of the organisation: client focus, making a difference, integrity, hope, creativity and innovation.

Mind's goal is to respond to the impact of mental ill-health on the wellbeing of families and carers in their own right, and work with carers as partners in care. This document demonstrates Mind's commitment to families and carers, and provides an overview of Mind's approach to working with families and carers (Mind, 2010).

Policy context

Family centred and inclusive practice, where families and carers are seen as partners in care, is central to modern mental health policy, practice and service delivery.

This document outlines our adherence and commitment to the guidelines, legislation and best practice for working with families and carers (Carer Recognition Act, 2010; Department of Health, 2010; Victorian Mental Health Act, 2014; South Australian Mental Health Act, 2009; South Australian Carers Recognition Act 2005; Government of South Australia, 2006; Queensland Mental Health Act 2000).

Objectives

The objectives of this document are to:

- guide our model of practice for working with families and carers at both an organisational and individual practitioner level
- promote a shared understanding of our model of working with families and carers across the organisation.
- provide a communication tool for promoting our best practice for working with families and carers.
- provide an opportunity to communicate to families and carers what to expect from Mind.
- raise the benchmark for community managed mental health services in Australia on how to work with families and carers.



Context

In 2014 Mind released their *Strategic plan for working with families and carers of people with mental ill-health.* A key activity of the strategic plan was to develop 'Mind's approach to working with families and carers' (Mind Australia, 2014). The objectives of Mind's strategic plan for working with families and carers of people with mental ill-health include:

- Be a leading provider of services for families and carers of people with mental ill-health.
- Provide information to families and carers and facilitate peer support.
- Deliver family and carer inclusive recovery oriented services (where services are focused on the person with mental ill-health).
- 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.

The following principles guide Mind's approach. We will:

- acknowledge and respect the role and expertise of families and carers
- invite family members and carers to be part of the client's recovery process and life support network
- recognise family and carer needs for information, support and services in their own right as well as in their support role
- ensure that organisational processes, planning, service delivery and development, and monitoring and evaluation are informed by the expertise and experiences of families and carers
- develop community awareness of the issues facing families and carers of people with mental ill-health
- work alongside families and carers, and those that work on their behalf, to ensure that we not only build better services but influence changes at the local, state and national levels.

"Mind has a strong commitment to supporting families and carers of people with mental ill-health. We believe that families and carers are central to a recovery approach to mental health. Strategically, we want to progress better supports for families and carers, lead practice change and advocate more powerfully on behalf of carers." - Mind (2014)

Who are families and carers?

Carers

Carers of people with a mental health issue may include family members, partners, friends, neighbours or anyone whose primary relationship with the person concerned is a personal, supportive and caring one. We recognise families and carers may not live with the person they care for. The focus of this guide is for unpaid carers and families of people with mental ill-health (Mind, 2014).

Did you know that:

- Carers provide emotional, practical, physical, psychological support.
- Carers may provide care a few hours a week or everyday.
- Carers may be parents, siblings, partners and ex-partners, step-parents, children, grandparents, cousins, aunties, uncles, friends, housemates or neighbours.
- Carers are diverse in age, gender, cultural background, and socio-economic status (ABS, 2012).
- Some people do not identify as a 'carer' (Carduff, et al. 2013; Molyneaux, et al. 2011).

"Mind provides a place for carers to meet, learn and share their experiences, tears and laughter as they soldier on in their caring role - with support from Mind to help looking after themselves."

- Mind Family and Carer Reference Group member





Core principles

Mind will achieve better collaboration and partnership with carers in their, and their loved one's journey through mental health services.

Our work is guided by Minds' Model of Recovery Oriented Practice and a human rights approach to social and community supports (Mind Australia, 2012).

We have a commitment to International best practice and we endorse the use of the Triangle of Care and The Carer Life Course Framework when working with carers and families.

A human rights approach

All people are entitled to the supports they need to function as citizens. Carers enjoy rights, as related to their special status as 'carers'. The Preamble of the UN Convention on the Rights of Persons with Disabilities (2007) states that, "family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities".

Mind understands carers require the right supports and environment to survive and thrive (Clements, 2013). Mind upholds the rights accorded to carers and incorporates these rights into service delivery.

The Triangle of Care

Mind endorses and enacts The Triangle of Care which describes a collaborative relationship between professionals, the client and carers. The Triangle of Care supports many carers' wishes to be thought of as active partners within the care team. The link between the professional and client often defines the service, but in most cases, the bond between client and carer has pre-existed (Carers Trust, 2013).

The key elements to achieving the Triangle of Care

Mind aspires to achieve the six key standards outlined in the Triangle of Care, to enable better collaboration and partnership in the client and carer's journey. These are outlined below.

The six key standards are:

- 1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- 2) Staff are 'carer aware' and trained in carer engagement strategies.
- 3) Policy and practice protocols regarding confidentiality and sharing information are in place.
- 4) Defined post(s) responsible for carers are in place.
- 5) A carer introduction to the service and staff is available with a relevant range of information across the care pathway.
- 6) A range of carer support services is available (Carers Trust, 2013, p.3).

Our approach relies heavily on these throughout this guide.

Service user



The Carer Life Course Framework

We have endorsed the use of the Carer Life Course Framework within our services. This framework identifies six phases of caring that most carers go through, and provides information, support and resources for each stage. Through utilising the Carer Life Course Framework, our staff can help break down common feelings of isolation and fear and describe the journeys and experiences of other carers (Pagnini, 2005). It also helps us to develop the right supports and services for carers. Becoming aware that 'something is just not right' is the first stage of the carer journey. Families and carers may be the first one to try to find help. Education, support and information are important tools as families and carers navigate treatment and support options.

Once carers confirm the presence of mental ill-health, carers will need the support of people (such as Mind staff and other carers) who understand what they are going through.

Over time, carers and families may need respite from their caring responsibilities. Looking after their own wellbeing and that of the whole family is vital if they are to continue caring over the long term. We understand what carers go through and we are here to help.





Practice

Our commitment to building effective relationships with families and carers

In order to establish sound relationships with family members and carers, each staff member at service level aspires to:

- be an effective communicator with families and carers
- be professionally competent to engage and work alongside families and carers

- be genuinely respectful of diversity; welcome each family member and carer and honour cultural and social diversity
- demonstrate commitment and compassion and be sensitive to the emotional needs of family members
- strive for equality and partnership with families and clients
- · be a champion on behalf of families
- build trust with families and carers by listening non-judgementally.

Supporting families and carers at different life stages

- We acknowledge all families and carers are different and diverse.
- We understand caring is a dynamic experience and changes over time.
- We will be responsive to the profile of families and carers and their life stages.

"Mind recognises the diversity of carers in the community and is there to provide support, education and understanding."

- Mind Family and Carer Reference Group Member.

What is expected from our staff working with clients and their families and carers

At Mind, we respect the role and expertise of family members and other carers in a person's recovery from mental ill-health. We will listen to carers and invite them to be involved in their loved one's care.

Diagram: How carers are involved in their loved one's care



Information needs to be available routinely, frequently and in different ways.

The relationship with Mind staff will be encouraged in the form that is most appropriate for each individual and their carers.

Service delivery staff and carers may share ideas, experiences and suggestions about how to respond to a specific client.

Identify if the carer requires additional support. For example, offer, complete and regularly review carer brief assessments.

Carers receive targeted referral to appropriate services that are relevant to their caring role (through the warm line, carer peer workers or Mind staff). 1. Identify and welcome carer/family members who form part of a consumer's informal care support system

2. Disseminate general information about services to families and carers

> 3. Build and maintain communication relationships with family members and carers

4. Involve family members in service delivery and review

> 5. Support carers and family members and carers in their caring role

Families and carers and the essential role they play are identified at first contact or as soon as possible thereafter.

The carer's views and knowledge needs to be recorded and shared with the team.

There is a lot of information which staff can provide. For example Mind's purpose, structure and services, challenges, resources and general suggestions.

Carers need to know when and how to communicate with staff.

Including:

- individual goal setting
- individual's recovery plan
- exit planning
- advanced statements and being nominated persons.

Proactively disseminate information to family members.

Implementation

Carer welcome and identification

Mind staff identify and welcome families and carers at first contact or as soon as possible thereafter.

Some useful tools for staff to identify and welcome carers include:

- training on family inclusive practice
- the *carer welcome letter* template
- Mindlink training for accurate family and carer record keeping.

Who do you see every day or every week? Who do you rely on the most? Who would you go to for help if you were in trouble?

Who supports

you when you

need it?

Conversation starters -How to identify carers - from Mind's family inclusive practice training.

> Who are the people you worry about or worry about you?

Who are the most important people in your life?

Do you have children?

Who do you hang out with on weekends; on weekdays?

Definition of carer aware

The definition of carer aware is to be aware of and welcome the valuable contribution families and carers can make, and to be mindful of carers' and other family members' own needs as well as the needs of people with mental ill-health. Staff need knowledge, training and support to become carer and mental health aware (Carers Trust, 2013).

How our staff will be carer aware

In order to establish sound relationships with family members and carers, each staff member at service level aspires to the following:

1. Be an effective communicator

A staff member who is an effective communicator will:

- be friendly
- listen
- be clear
- be honest
- provide and coordinate information.

2. Be professionally competent

A staff member who is competent will know how to:

- support each person's recovery
- recognise each person's strengths and foster hope and possibilities for the future
- engage with family members and carers

- recognise when information and resources will be of assistance to family members
- continue professional development and learning.

3.Be genuinely respectful of diversity

A staff member who is respectful of family members and carers will:

- welcome each family member
- honour cultural and social diversity
- understand how the lifecycle affects different family relationships (such as older and younger parents or partners)
- affirm strengths of each family member
- treat each person with mental health challenges and each family member with dignity.
- 4.Demonstrate commitment and compassion

Commitment is more than obligation or duty. A staff member who is committed and compassionate will:

- be sensitive to the emotional needs of family members, carers and clients
- understand what each person is going through
- be available and accessible

 go beyond responses which are 'just a job' where a person is 'only another case'.

5. Strive for equality and partnership

A staff member who strives for equality and partnership with family members will:

- share power with the individual with mental health challenges and with family members
- foster empowerment
- provide options
- look for ways to share decision making.

6.Build trust

Trust means having confidence in someone else's reliability, judgement, word and action. A staff member, and therefore Mind, will be trusted as a consequence of:

- being reliable
- using sound judgement
- maintaining confidentiality
- having the confidence and skill to act in the best interests of people who trust them and make good efforts to follow through on what was agreed (Fyffe, 2011).

"Carers are part of the consumer's recovery plan and a lot of times having them on board helps in keeping things smoother and everyone on the same page. The consumer feels supported as the carer is supported by us in the care coordination of the consumer's recovery plan." How Mind supports our staff to be carer aware

We provide an induction to new staff on our approach to working with families and carers.

We employ carers with a lived experience of caring.

We have an internal newsletter that keeps staff updated on relevant carer issues. There is a lot of information on the staff intranet about carers. This including links to external resources and a database on carer support groups.

Mind provides training on confidentiality and consent and working with families and carers.

> Staff can call the Carer Helpline to get advice on carer issues and find out about services in their local region.

Confidentiality and sharing information

Enabling family conversations in an environment of confidentiality and consent

Sharing information with families and carers is best practice.

However, we also recognise privacy and information sharing is a balancing act between clients' rights, best care, risks and carers' information needs.

When working with clients, our staff will:

- discuss with clients the boundaries of confidentiality and required consent to share personal information
- provide an explanation of the difference between information that you cannot share without consent (personal and sensitive) and information that can be shared (general)
- support clients to identify information they do feel comfortable sharing and possible ways that carers can be included
- support clients to identify other people they may like to share personal information with or include
- regularly check in with clients around including carers, and explore benefits and barriers
- explore with clients what information a carer requires to be able to provide appropriate support
- encourage and support the use of advanced statements to allow clients to plan their support when they are well, including how family can support (Patient Information Centre, 2010; Slade et al., 2007).

When communicating with carers our staff will:

- discuss with carers the boundaries of confidentiality and required consent to share personal information
- provide an explanation of the difference between information that you cannot share without consent (personal and sensitive) and information that can be shared (general)
- provide carers with general information about Mind services, the *Mind's approach to recovery oriented practice* model, and the tools used in recovery planning such as strengths based assessments, individual recovery plans and safety plans
- provide carers with information about carer support services and make a referral if required
- support carers to obtain information about the broad nature of an illness, common treatment medication issues and common behaviours (see Mind's intranet for resources)
- support carers to obtain information about mental health care and how to develop skills for the caring role in mental health
- invite carers to ask questions and make time to listen, acknowledge and encourage
- invite carers to share their perception of wellness, risk, current problems and needs while keeping the client informed of your conversation (Patient Information Centre, 2010; Slade et al., 2007).

Carer champions

4.

Mind has carer consultants and carer teams. We also support the development of carer champions in each geographic division to promote family and carer engagement and participation.

To be a champion means to:

- speak up and promote families, carers and clients
- take initiative, and be a resource on behalf of other staff
- help other staff with problem solving to seek win-win solutions (Fyffe, 2011)
- support carer involvement and promote a carer aware culture.

l'm a carer champion

5. Information and engagement

Mind recognises the benefits of involving families in care and providing a range of programs to assist and support carers to ensure their own wellbeing is maintained.

Being involved in the care team and having access to information, ensures families and carers are valued and empowered (Wilson et al, 2014).

Information

Carer education and information is a basic carer need that is essential for carers to be effective (Auditor General Victoria, 2002). Carers highly value accurate and up to date information that helps them understand mental illhealth, supports that may be available and how to provide support and care (Milne et al. 2013). A key platform of our strategy is to ensure carers and families have the right information at the right time.

All staff can assist carers with developing their knowledge and skills. Staff are able to utilise the following resources and links when information is needed:

- Carer Helpline and internal carer warmline
- print and on-line information supports including e-news and the Mind carer forum
- accessing the resource hub available on the Mind intranet.

Carers can additionally access information through:

- Mind's carer welcome letter
- an appointment with a staff member
- the Mind welcome pack
- Mind's website and carer pages
- interactions with staff during critical points in a client's care such as individual goal setting, individual's recovery plan, and exit planning.
- Carer e-newsletter Community Mind

Engagement

Encouraging carer voice in our organisation

Sometimes we find inclusion, participation and engagement are merged in policy. We believe a clearer understanding and defining of these terms will support better outcomes for families and carers.

Inclusive practice:

Inclusive practice refers to the service delivery level approaches to including families and carers as partners in care which aim to:

- support and facilitate family members' and carers' contribution to an individual's recovery. This may include identification of carers, inclusion in service planning, information sharing and discharge planning.
- assist and enable families and carers to maintain their commitment, caring and support for their family member with mental health challenges
- identify and respond to the specific support needs of family members and carers in their own right (Fyffe, 2011).

Participation:

Participation refers to activities and opportunities to give families and carers a voice within Mind.

Engagement:

Engagement refers to how families and Mind staff participate in a two way dialogue. Engagement is about how families and carers work in active partnership with Mind at various levels across the organisation-direct care, organisational design and governance, and policy making-to improve Mind's response to the impact of mental ill-health on the wellbeing of families and carers in their own right, and work with them as partners in care (WA Government, 2007; Carman et al. 2013).

"Family and carer engagement and participation requires our sustained collective effort. To be a great organisation we have to better listen to the voices of consumers and carers." - Mind Participation Team

For information and advice on consulting with carers ask our Carer Consultant: carers@mindaustralia.org.au

How carers and families are involved with Mind

I had a chat with my son's support worker about being involved in my son's care.

an sheet of

I am part of the carer reference group.

I completed the Mind satisfaction survey.

l wrote a letter expressing my concerns.

I attended a consultation.

l wrote an article for a Mind newsletter.

l spoke to a staff member and provided feedback. I participated in an in-depth interview about my experiences of Mind and my hopes and dreams.

I went to Mind's Community Conversation forums.

6. Support

At Mind, we recognise that caring for someone living with mental health issues can be stressful and that sometimes families and carers need support. We offer a range of family and carer supports. The Carer Life Course Framework informs service delivery practice.

Go to: www.mindaustralia.org.au/ forums

"Carers view needs inside their own lifelong relationship, life-course and biography. We need to understand the unique individual in order to assist."

- Mind staff member

The Carer Helpline

Our helpline is a source of specialist support for mental health carers. The helpline is also a great source of information, advice and referral for Mind staff, health professionals and other interested groups to find out about supporting families and carers in the community.

Call the Carer Helpline 1300 554 660 or email: carers.helpline@mindaustralia.org.au

Online carer forum

Accessed via Mind's website, the online carer forum is a place where mental health carers can share information, experiences and offer each other support.

"Thank you, thank you to everyone that picked up that phone and assisted. You don't know how much you helped." - Carer

Education

We know carers have a need for knowledge about mental health and how best to support their loved one. We provide carer education led by experienced carers. The focus is on helping build skills and resilience. Session details are available on the Mind website and promoted through our carer e-newsletter *Community Mind*.

Go to: www.mindaustralia.org.au/ carer-education or call the Carer Helpline 1300 554 660

Support services

Mind offers a range of additional carer and family support services, including:

- Counselling and peer support -A helpful starting point to better understanding, self-care, mapping supports and getting help. Sessions are delivered by supportive counsellors and carer peer workers and are generally delivered as a brief intervention (one-three sessions).
- Short term in-home respite Having a skilled mental health worker provide additional support to consumers can really assist carers to take time out. Carers can choose how short term

support could work for them - whether it is assistance with the everyday, community linkage or social support.

- Recreation days and events We deliver a range of activities and events for carers and for clients that are designed to increase connection, improve social and emotional wellbeing, and provide a break.
- Support groups Peer support and sharing of learned wisdom have been recognised by many families and carers as essential in their caring journey. Our varied groups aim to increase carers' social connections, learning and self-care.

Call the Carer Helpline 1300 554 660 or email: carers.helpline@mindaustralia.org.au

Note: not all services are available at all Mind locations.

Carer warm line (internal)

Our workers are encouraged to identify carers early, and provide support as part of our everyday delivery of mental health services. Workers can offer carers additional support through referral to our carer warm line for additional peer to peer support, information and education that will help them in their role.

Moving forward

Achieving the aspirations described within this document will require the commitment of the whole organisation. We thank you for your support and encouragement in creating a new approach to supporting carers. *"Mind understands the need to support carers so they in turn can continue to support the person with the mental illness."*

- Mind Family and Carer Reference Group member

Are you caring for someone living with mental ill-health?

Here are 10 tips for coping.

- 1. Look after yourself.
- It is normal to experience different emotions while caring.
- 3. Don't isolate yourself.
- 4. Don't blame yourself.
- Have a plan in case of an emergency.
- 6. Set clear boundaries.
- Contact Centrelink if you have financial problems.
- Seek help when things get really hard.
- Seek out information through workshops, support groups and online.
- 10. Finding the right help can be hard, but don't give up.

Mind Connect 1300 286 463 Carer Helpline 1300 554 660 mindaustralia.org.au





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Mind Connect 1300 286 463

Carer Helpline
1300 554 660

mindaustralia.org.au info@mindaustralia.org.au

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Mind Central Office | 86-92 Mount Street PO Box 592 | Heidelberg VIC 3084 Mind Australia Limited ABN 22 005 063 589