Mental Health
Family and Carer
Information Guide
“Other people marvel at how our family has coped with our daughter having a mental illness. We don’t see it that way; it is just something you do when you love someone. It can be very lonely and stressful but we have learnt to ride the rollercoaster.

Getting the right information and knowing where to get the best help has meant that we as a family have been able to share our daughter’s life. Being able to be active in her recovery makes it all worthwhile”.

- Carer
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**Introduction**

Living with mental health challenges can have a profound impact, both on the person experiencing it, and on family and friends who are caring for them. If someone you care for is living with mental health issues, especially if this is new for you, it is likely that you’re already feeling worried, overwhelmed or perhaps wondering what lies ahead.

In Australia, around 1 in 5 people will be affected by mental illness each year, with around 240,000 Australians caring for an adult living with a mental health issue. While each person’s experience of mental distress is different, it is important to remember that treatment options are available, and many people recover fully or find that the symptoms can be well managed.

Family and friends play a vital role in supporting someone with a lived experience, and with good information, support and assistance, your caregiver contribution can be a positive and life enhancing one for everyone.

If you are reading this for the first time, you might like to know that there is also another similar introductory guide written for the person in hospital who is experiencing mental health issues. Ask your mental health clinician for a copy if you or your relative or friend would like one. This guide is called Welcome to the Ward.

There are a number of positive things that you can do as a family member or carer, to help your relative or friend, which can also help in making the situation feel less stressful:

- Find out as much as you can about the illness, medication and other treatments
- Get to know the Mental Health Service clinicians working with you and the support services available in your area
- Learn about what you can do to assist your loved one to recover
- Get emotional support for yourself or talk with other people who share a similar experience
- Get practical support when you need it
- Make sure you’re looking after yourself by getting enough sleep, eating healthy meals, taking breaks and exercising regularly

This guide has been prepared by the mental health service, in consultation with carers, families and friends of people with a lived experience and the support organisations that we work with. We use the word ‘carer’ in this guide, as short hand to mean a family member, support person or friend who provides care and support to someone who is living with a mental health issue.

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mental health issue. People often fall into the role of a carer because it becomes a natural extension of their relationship with the person. While they may be that person’s parent, partner, sibling or child, they may not think of themselves as a carer; they do what they do, because they care about that person and what happens to them. So in this guide, when we use the word carer, we mean the broader definition of this role.

Common emotional reactions you may feel

**Guilt**

Many people struggle to find a reason for the illness and wonder if they are in some way responsible. It is natural to ask ‘why?’ but remember, mental illness can happen to anyone and no one is to blame. You may also feel you do not want to be a carer, or think you are not up to the task.

**Shame**

Mental illness is highly stigmatised so you may feel embarrassed and anxious about what other people may think.

**Fear**

You are likely to worry about what will happen to the person if you can’t cope or when you are not available to help. Fears about future or current risks are normal.

**Anger and frustration**

You may feel frustrated or angry that this has happened; that the illness dominates your life; that others don’t do more; and you sometimes feel unappreciated or taken for granted.

**Grief and sadness**

You may grieve for the loss of the relationship as it was and the life you had. You may feel sad that opportunities and plans for both yourself and your friend, partner or relative have now changed. Your world has shifted and it can be hard to adjust.

**Love**

Many carers say that their love for their friend, partner or relative deepens and they develop a closer bond over time.

**Fulfilment**

The new relationship you form with your loved one can bring growth and learning for you both. Sometimes the illness pushes and motivates you to find parts of yourselves you had not yet tapped into and this can be a valuable experience for self growth.

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2 Lifeline Information Service, November 2010 ‘Tool Kit: Carers of People with Mental Illness’
Mental Health

Your feelings and motivations will fluctuate over time. Along with the joy and relief that comes with supporting recovery and successful management of the illness, there can be cycles of despair and exhaustion. You may experience impacts on your own health and wellbeing or there may be financial and lifestyle implications. Being a carer is a complex and demanding role that is focused on enabling the person you love to be as independent and fulfilled as possible whilst not losing sight of your own independence and fulfilment. It is a hugely valuable and important role and you cannot do it alone.

Mental Health

Mental health issues are common. Almost one in five adult Australians are affected by some form of mental illness. A mental illness or disorder is a diagnosable illness that can affect a person’s thoughts, feelings and behaviour and it can significantly impact on a person’s ability to take part in everyday activities, such as work, maintaining relationships and and looking after yourself.

Most people with a lived experience recover well with appropriate ongoing treatment and support. There are many different types of mental health issues and it is important to remember that this can affect people in different ways. Sometimes people with a lived experience can behave in ways that are confronting, confusing or even frightening. Very often, this behavior is misunderstood. Knowing how mental health challenges affect your relative or friend is perhaps one of the most important aspects of a caring role, and a valuable tool in supporting their recovery journey.

Families and carers should feel able to ask mental health professionals about the diagnosis of their relative or friend, and should be aware that this diagnosis may change over time. Remember that the most important thing is that your relative or friend is receiving the correct treatment for their current problems. Even where the diagnosis is not yet clear, mental health workers should be able to explain to you how they see the problems and what treatment they recommend.

If you know the diagnosis, a mental health clinician can assist you by providing some general information, for instance a fact sheet about schizophrenia or depression.

There are many other places to find mental health information. See the chapter “Where to Find Help” later in this book for some helpful suggestions.
Treatment

Most mental health issues can be treated effectively. The majority of people who receive and participate in treatment are likely to recover well. Mental health issues are like many physical illnesses which require ongoing treatment but can be managed so that the individual can participate in everyday life.

Sometimes a mental health issue can come and go in a person’s life. Some people have only one episode and recover completely. For others, mental health challenges can recur throughout life and/or require ongoing treatment.

Mental health issues are not anyone’s fault and there is no-one to blame. A person with a lived experience cannot simply make their symptoms go away by themselves. Once you recognise signs of mental distress it is important to get treatment early.

There are many different treatments available to help people with a lived experience, which are designed to assist recovery and help people to function better.

Treatments include:

» Medication
» Psychological therapies such as Cognitive Behaviour Therapy
» Medical treatments
» Social supports and connecting with family and friends
» Health and lifestyle changes such as exercise, sleep, dietary habits and managing stress
» Participating in pleasant and meaningful activities
» Counselling
» Skills training
» Peer support groups
» Self-help books
» Mental health education

Treatment needs to be tailored to the individual and sometimes it is a complex process to gauge the right combination of medication and/or other treatment options. Often treatment is not based strictly on diagnosis. People with the same diagnosis may have very different experiences, such as differing amounts of confusion, anxiety, depression or abnormal perceptions. The choice of treatment is often guided by the frequency or degree of these experiences rather than by diagnosis alone. Treatment choices are also influenced by the personal preferences of the people involved.
Recovery is “being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues”

Families and carers are perfectly placed to support and influence the recovery of loved ones experiencing mental distress, as they are often most familiar with the person they are supporting, and they are a valuable source of information about a consumer’s life and what is important to them, beyond mental health issues. A sense of hope is important for all of us, and one of the most important ways a carer can help someone is by instilling hope for a more positive future. Often, the person experiencing mental distress may find it difficult to believe there can be “better days ahead”. Helping them to have a more positive outlook, and holding onto hope, can demonstrate your support.

Holding onto hope for families can mean balancing the uncertainty of illness with the possibility of improvement and a cautious optimism about the future.

The support you provide around mental health issues is only one part of your connection with your loved one, and it is important to view your caregiving as just one aspect, rather than the whole of your relationship. Whilst recovery must essentially be driven by the person with the lived experience of mental distress, families and carers can play a significant role in supporting the recovery process. By offering their recovery oriented support, at best described as not ‘doing for’ but ‘doing with’ or journeying alongside someone, families can provide an extra boost of support. It may mean finding a new acceptance of the challenges that mental health issues may bring, and at the same time, developing new meaning and discovering new gifts and talents along the way.

Many families and carers may find that without further knowledge and information, they may have unrealistic expectations of recovery which can lead to feelings of frustration and resentment for everyone. Carers often feel that recovery means the person should be able to function as they were before the onset of the illness. While this may be true for some, it may also place undue pressure on the person with mental distress or appear disconnected with their new reality, meaning and purpose.

Make sure that you get good professional help for yourself as well as your loved one; you might like to ask your mental health clinician for further information or referral to a specific carer support service that can help you.

It is important to encourage opportunities for making choices and maintaining a sense of control in everyday life, building on strengths and celebrating success. Supporting new community connections and helping to strengthen networks can also be a significant way to promote recovery.
In Times of Crisis

Signs for referral to the Mental Health Service

It is important to be prepared and know where to get help if you need it quickly or in a crisis. Sometimes the health of the person you are caring for can deteriorate, or perhaps their unusual behaviour means they have become a risk to themselves or others. If the person agrees, you can go together to the Emergency Department of your local hospital. You can also call the Acute Team of your local Mental Health Service and they will work with you to find the right support and treatment from there.

Warning signs that someone is becoming unwell can be different for each person, but the following signs can be used as a guide, and an indicator for referral to mental health services.

Suicidal thoughts
Take all thoughts and talk about suicide seriously. It can be confronting to know that someone you love is contemplating suicide, but talking openly about it together and encouraging them to seek professional help can prevent suicide and provide the appropriate supports that the person needs.

Marked changes of mood
You may notice unexplained elevated mood, irritability, sullenness, anger, depression or marked lethargy.

Hallucinations
Hallucinations may involve any of the five senses, such as experiencing clear sensory impressions that are not real. They may include, hearing voices or smelling odours, which are not there. The person may be seen to smile, laugh or talk to themselves.

Hearing voices
Hearing voices can be a warning sign, however it is especially concerning if the voices are telling the person to harm themselves or engage in risky behaviour.

Fixed false beliefs about themselves, other people or environmental cues
For example, the person may wrongly believe they are being tricked, followed, or that their thoughts are being controlled by outside forces such as TV or radio.

Alterations in speech and communication patterns
The person may unexpectedly change the topic of conversation or their answers may be unrelated to questions asked. Conversation may be brief and shallow or speech may be loud, pressured and difficult to interrupt.
Disorganised behaviour
There may be difficulties in organising daily routine tasks such as maintaining hygiene, or the person may be dressing in an unusual manner such as wearing heavy coats in summer or applying makeup inappropriately.

Decreased ability to initiate and continue with previously enjoyed activities
The person may sit, apparently preoccupied, for long periods or remain in bed throughout the day and show little interest in participating in work or social activities.

Threats to others or thinking about killing or seriously injuring others
This may include vague thoughts of revenge through to well formulated plans, without the act itself.

Self-destructive or high risk behaviour
This may include taking illicit drugs, self-harm or self-mutilation or engaging in persistent and unsafe sex.

Poor concentration and distractibility
The person may have trouble concentrating when reading or following another person’s conversation, or may start tasks and not finish them.

Confusion and disorientation
The person may forget who or where they are.

Marked sleep changes
The person may sleep excessively, have difficulty falling asleep, or wake much earlier than usual. Some people may have prolonged wakeful periods and stay up all night.

Persistent and intense anxiety
This may occur only in specific situations or may be general and unrelated to specific events or situations.

Significant changes in social, work related or interpersonal functioning
For example the person may spend money excessively, or they might clean or tidy up to an extraordinary degree. Activity or inactivity can be to extremes.
Who to contact

If you feel your relative or friend is becoming unwell, or possibly heading for a crisis, it is important to discuss what is happening with them and encourage them to seek help.

If your relative or friend is already working with a health professional or psychiatrist from the Mental Health Service, you may wish to contact them or another staff member from the community mental health team to seek some additional help.

Alternatively you may contact the persons GP or the Mental Health Line on 1800 011 511

Planning ahead

When a crisis situation has settled, or before it occurs, it helps to write down a plan of how to access immediate help when you need it. Remember to keep the mental health service and your mental health clinician numbers handy. You may also want to think about which other family member or friend could look after the children, or pets, at short notice if you had to go with your loved one to hospital.

It can be helpful to have a conversation with your loved one about what they would like to do if they become unwell and who they might like to support them. A Mental Health Consumer Wellness Plan is a form that you can use to write down helpful information ahead of time (you can ask your mental health professional for a copy of this).

If the situation is life threatening or you need to keep yourself and others safe:

» Seek help immediately – call 000 (Triple Zero) and request ambulance, police or both.
» Provide a calm, safe environment.
» Minimise noise and activity.
» Remove items that might be a danger
» Reassure your relative or friend that help is coming

Other supports in a crisis:

Emergency: police & ambulance........................................ 000 (24 Hrs)
Lifeline telephone counselling........................................... 13 11 14 (24 Hrs)
Suicide Call Back Service.................................................. 1300 659 467 (24 Hrs)
Kids Helpline...................................................................... 1800 55 1800 (24 Hrs)
Visiting a Mental Health Inpatient Unit

Visitors are welcome in our mental health units. Friends and family are important in supporting recovery. It can be helpful for visitors to know about some of the differences between mental health units and other hospital units:

Mental Health inpatient units generally have secure entry. Staff will escort you into the unit to visit your friend or relative, and then escort you out when you’re ready to leave.

Certain things aren’t allowed in the unit, in order to help keep everyone safe. These things are referred to as contraband, and include things like cigarette lighters and weapons. You should check with the unit to find out about contraband. Visitor’s belongings may be searched prior to entry to the unit. You won’t be able to take things like handbags, backpacks or mobile phones into the unit; we will provide a secure space where you can store these.

There are times when the units aren’t open to visitors, such as during treatment times. It is always a good idea to phone the unit in advance of your visit to ensure it will be a good time for you to come.

Children are welcome to visit friends and relatives in the mental health unit. All units have a procedure and specific space allocated to support visits from children. It is very important to phone the mental health unit before bringing a child to visit someone in the unit, to ensure things are in place to support a positive and stress free visit.

Cards and gifts are lovely to receive while in hospital, however in the mental health unit there may be some limitations about what can be brought in. Please check with hospital staff in advance as to what gifts would be appropriate. Many people often appreciate useful things, like nice soap or shampoo; new socks; or a photo of special people, places or pets. Unfortunately, pets can’t come and visit, however many of our units have a pet therapy program in place.

If you aren’t sure, please ring the unit and ask.
Urgent Second Opinion

Family members and carers often know the consumer best. During an inpatient mental health hospital admission, it is important to let staff know if you notice that ‘something is just not right’ about your relative or friend or if you notice any worrying changes in their health. Speak immediately with your relatives treating team if you feel that the health care concerns raised have not yet been addressed or acted upon by staff.

In mental health inpatient units, family members and carers can escalate their care deterioration concerns through the R.E.A.C.H communication process. REACH stands for Recognise, Engage, Act, Call and Help is on its way. Look out for the REACH contact number displayed in the brochures and posters with this information.

Looking After Yourself

When you care for someone with a lived experience, it is more important than ever to make sure you are looking after yourself. Care giving can be emotionally and physically demanding. Many carers find it difficult to focus on their own needs, and at best, put them at a distant second.

When you spend extra time with your loved one to meet their needs, it is easy to become overwhelmed and neglect your own needs. Things like meeting up with your friends, exercising and eating regular healthy meals can go by the wayside. Finding a manageable balance between work and leisure time may be tricky with extra demands on your time, and you may even have given up paid work or cut short your plans for further education in order to manage the extra challenges that caring brings. Finding at least 15 minutes a day for yourself will help you to feel more energised and able to cope with the tasks ahead. Remember to focus on doing activities that you love and be gentle with yourself along the way.

Some examples of things you can do to look after yourself:

- Practice meditation and mindfulness
- Keep physically active or go for a walk
- Eat regular healthy meals
- Try to focus on at least one positive aspect of your day
- Get adequate rest and sleep
- Talk to a friend
- Spend time outdoors
- Listen to uplifting music
Talking it over

Many carers find that talking about their concerns with counsellors and trained professionals who understand the caring role is helpful. Others find that talking with other carers who understand what you’re going through and share similar experiences can help relieve the feelings of isolation. Seeking help amongst others whether it is from professionals or other carers is a positive sign of strength and helps you to understand that your feelings are a normal reaction to a stressful situation. This is important and helps you to take care of both yourself and your loved one. Many carers find that local carer support groups are an invaluable source of support and encouragement.

Family relationships

Changes in one family member’s mental health or behaviour can easily impact on others in the family in a ripple effect. Similarly an experience of trauma or other challenging life experience that affects one person can also be felt in different ways by others in the family and can have deep and lasting effects. Relationships within families can change and shift as a result and it is important to focus on the wellbeing and safety of everyone. With sensitive support and care, family relationships can heal and flourish. Mental Health Service clinicians and carer support services in your local area can be a wealth of information and support, and are best equipped to advise you of the services and programs that are available to you.

Taking a break

Sometimes being able to make time for yourself and take a break from caregiving requires some practical help and support to make it happen. Respite services allow you to take regular breaks when you need them, which is essential to managing your role as a caregiver. You will feel more calm and effective as a carer if you can build in some planned respite into your routine. Respite can involve short breaks while you take part in a particular activity such as an exercise class, or for longer periods to go on holiday or just have a break. Some respite services also offer emergency options for instance if you need to be urgently admitted into hospital.

Respite options might include offering a meaningful activity for your loved one to participate in, so that you have the opportunity for a break, or it may include a retreat for carers, a pleasant activity such as bushwalking or attending a course. Other options may include a holiday away in specifically funded respite accommodation.

Contact your local Commonwealth and Respite Carelink Centre for further information about respite service options.
Working Together

Families and carers play a crucial role in supporting people with a lived experience, and this support is at its most helpful when clinicians and the treating team work together in partnership with the consumer and the family. As a carer, you have a unique and valuable understanding of your loved one’s daily experience of their illness and you can advocate for their needs and preferences as well as contribute to the overall treatment plan.

There are three important aspects to this partnership with families and carers, which is encouraged and supported by the Mental Health Service:

» To connect with families to receive or share important information and background about their loved one

» To provide advice, information and education to families and carers on how best to help the person living with mental health issues

» To offer emotional support and referral to carer support services, so families and carers can make sure their own health and wellbeing needs are looked after

The Mental Health Service highly values the support and assistance that people with a lived experience receive from families and carers and often you may be the only constant support in your loved one’s life. Carers have the right to be involved and participate in planning and decision making processes for themselves and the person for whom they care, whilst respecting the rights of the person receiving health care. Due to privacy, confidentiality laws and some requirements of the Mental Health Act, clinicians involved in treating your loved one, may not be able to answer all of your questions without his/her consent to share information with you. However this does not mean that clinicians can’t answer general questions that will help you understand what your relative is going through, or provide information about the illness, medication and side effects, without the need to discuss personal details.

Further information and fact sheets are available about mental health issues, the Mental Health Act and about caring for someone with mental health challenges. Please ask your mental health clinician for help with accessing more details, including referral to recommended services for families and carers.

Privacy and confidentiality

Mental health clinicians are keen to work with family members and carers and understand that families and carers need information about their relative or friends treatment plan. Clinicians also understand that families and carers play a vital role in supporting the recovery of their loved one, especially if they receive the appropriate information and support.
Sometimes, because of privacy, mental health clinicians may not be able to discuss some of the issues affecting your relative or friend. This will occur if your relative or friend does not give consent for release of their information to you. This situation changes in the event that your relative or friend is receiving services under the Mental Health Act, and you are either a Designated Carer or Principal Care Provider under the Act. See the Mental Health Act section for further information.

As a relative or friend, you can still:

» Let the mental health clinician know about your concerns and the clinician can listen to your concerns without breaching confidentiality
» Provide valuable information and insights that could help the mental health clinicians to better care for your loved one
» Seek general information about ways to support your loved one

Complaints, Compliments and Feedback

The Mental Health Service welcomes feedback including complaints and compliments. Carers are encouraged to identify and report when things are not quite right and staff are encouraged to talk openly to the consumer and/or carer about a matter towards making continuous service improvements.

If you wish to contact the service to provide feedback, follow the steps below, with options for further assistance if the issue is not resolved initially, to ensure that an issue can be addressed quickly and the service can work together with you to find a solution.

» Let the mental health professional know that you have a concern
» Contact the local Service Director of the Mental Health Service
» Contact the Complaints, Compliments, Issues & Legal Manager at Mental Health Drug and Alcohol, or the Director of Mental Health Drug and Alcohol
» Contact the Chief Executive of the NSLHD
» Contact Health Care Complaints Commission
Official Visitors

Official Visitors are appointed by the NSW Minister for Health to visit mental health facilities in NSW. They are independent of the health system and come from the community from a range of cultural, professional and personal backgrounds. They aim to safeguard standards of treatment and care, and advocate for the rights and dignity of people being treated under the NSW Mental Health Act 2007.

The Official Visitors make regular visits to all inpatient mental health facilities across NSW; they talk to patients, inspect records and registers, and report on the standard of facilities and services. They liaise with staff about issues or concerns and report any problems to the Principal Official Visitor and/or Minister for Health.

Consumers, carers, family members and staff can contact the Official Visitors and they will listen to your concerns and help you resolve them. See the ‘where to find help’ section for contact details.
Mental Health Act

About the Mental Health Act

Under the Act, a person who is mentally ill or mentally disordered may be detained to enable appropriate care and treatment to be provided, subject to certain conditions.

Who is a mentally ill person under the Act?

A mentally ill person is someone who has a mental illness and, because of that illness, there are reasonable grounds for believing the person requires care and treatment in a mental health facility in order to protect them and/or others from serious harm.

Who is a mentally disordered person under the Act?

A mentally disordered person is someone whose behaviour is so irrational there are reasonable grounds for believing the person requires care and treatment in a mental health facility to protect them and/or others from serious physical harm.

Who is a mental health consumer?

A mental health consumer is a person who has a lived experience of a mental health illness or mental health disorder, and/or a person who is receiving treatment from a mental health service (either voluntarily or involuntarily).

Designated carers

Designated carers are nominated by the consumer in most cases or identified by treating clinicians according to a hierarchy in the Act. Consumers can now nominate up to two designated carers.

Principal care provider

The principal care provider is the individual who is primarily responsible for providing support and/or care to a consumer (other than wholly or substantially on a commercial basis). A person in receipt of a Carer’s Pension is not seen as providing care on a commercial basis and can therefore be considered as a principal care provider.

The principal care provider may also be a designated carer of the person and has similar rights to information about a consumer as a designated carer.

An Authorised Medical Officer or the Director of Community Treatment may determine who the principal care provider of a consumer is. A person cannot be the principal care provider if they have been excluded by the consumer from being given notice or information.

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3 The New South Wales Institute of Psychiatry on behalf of NSW Health, Fact Sheet: Carers and Families, Amendments to the NSW Mental Health Act (2007)
However, treating clinicians are not required to give notice or information to the principal care provider, or to appoint a person as the principal care provider if they reasonably believe that to do so may put the consumer or the principal care provider at risk of serious harm.

**Notification to carers of certain events**

Designated carers and the principal care provider are to be notified by the treating clinicians of events affecting the consumer, such as when the consumer is:

- detained in a mental health facility;
- absent from the facility without permission, or fails to return at the end of a period of leave;
- to be discharged;
- reclassified or admitted as a voluntary patient;
- considered for a community treatment order (CTO) and an application is being made to the Mental Health Review Tribunal;
- under a CTO which is being varied or revoked;
- considered for Electroconvulsive Therapy (ECT) and an application is being made to the Mental Health Review Tribunal;
- believed to require a surgical procedure or special medical treatment and consent is being sought from the Tribunal or the Ministry of Health;
- to be transferred, or has been transferred, between mental health facilities.

Designated carer(s) and the principal care provider can make a request to:

- have the consumer they are caring for admitted to a mental health facility;
- be provided with information about the types and dosages of medication being administered to the consumer;
- have an Official Visitor visit;
- have the consumer they are caring for discharged from a mental health facility, and appeal to the Tribunal against a refusal to discharge the consumer.
Mental Health Review Tribunal

If your relative has been admitted as an involuntary inpatient under the NSW Mental Health Act, they will be reviewed under this system by the Mental Health Review Tribunal. This is an independent body consisting of a community member, a psychiatrist and a lawyer who will assess the person’s mental state and care in hospital, and make decisions about the maximum amount of time the person can be held as an involuntary patient in hospital. The tribunal does not make decisions about day to day care that the person requires e.g. medication; this is the decision of the treating psychiatrist.

The Tribunal hearings are sometimes held in person or they may be by video conference. The consumer has an opportunity to give their perspective and the carer or other family member also have the opportunity to tell the Tribunal how they feel about the proposed order.

Mental Health Advocacy Service

The Mental Health Advocacy Service can represent people in hearings that relate to their detention and treatment in hospitals and the community, and can provide free legal advice and assistance about mental health law. Family members and carers are welcome to call them for advice.

Consumer Wellness Plan

A Mental Health Consumer Wellness Plan is designed to facilitate consumer involvement in their own care, particularly in terms of symptom management, relapse prevention and crisis planning. It serves as a recovery aid and a prompt or reminder about what to do to support someone’s recovery. It includes a component of the form where consumers can nominate what they would like to happen (or not happen) if they become unwell, such as who might look after the children, who to contact and who would be preferred to be involved in care and treatment planning. It also includes an opportunity to document the type of supports and treatments or medications that keep the person well, and those that are unhelpful.
Advanced Care Planning

Advance Care Planning is thinking ahead about a person’s preferences for health care treatment should they be seriously ill or injured. Having discussions about preferences for care with family members, friends, GP and health care professionals ensures a person’s wishes are known if there comes a time when they are unable to make or communicate decisions for themselves.

An Advance Care Directive is a formal written record of a person’s wishes, preferences and instructions about future medical treatment. It can play a critical role in reducing stress for the person and/or family when the person is no longer able to make decisions. For this reason an Advance Care Directive is sometimes referred to as a “living will”. An Advance Care Directive contains the person’s instruction about consenting to, or refusing specific treatments in the future. It may also include statements about the person’s values, beliefs and goals for medical treatment and record preferences relating to care if the person has a serious, life limiting (or threatening) illness. If there is an Advance Care Directive it is important that this information is given clearly to hospital staff.

Financial Support

Some carers may be eligible for financial support from Centrelink depending on circumstances.

Carer payment

The Carer Payment is an asset tested benefit, to provide financial support to people who are unable to work in substantial paid employment because they provide full time daily care to someone with severe disability or medical condition, or to someone who is frail aged.

Carer allowance

The Carer Allowance is not asset tested and is a fortnightly income supplement for parents or carers providing additional daily care and attention to an adult or dependent child with disability or a medical condition, or to someone who is frail aged. Carer Allowance can be paid in addition to a carers wages. Contact Centrelink for more information.
Useful Questions to Ask your Health Professional

The questions outlined below are frequently asked by carers and family members, and may help you to decide what you need to know. Mental health professionals are an important source of information and support. Family members and carers are encouraged to ask questions of health professionals and if there is anything that you don’t understand, ask them to repeat the information or write it down for you.

» Where can I find more information about the illness?
» What behaviours might I expect and how should I manage them?
» What is the medication and what is it supposed to do?
» What are the side effects of the medication?
» What should be done if a dose of medication is missed?
» What other treatments are available?
» What are the aims of the care / recovery plan?
» How can I get a second opinion?
» What can I do to help?
» What are the early warning signs for becoming unwell again?
» Are there any local carer support services that can help me?
» What are my rights and responsibilities?
» Are there any restrictions on sharing information about my relative?
» Will I be included in meetings concerning their care and treatment?
» Is there a copy of a discharge plan that I can have?
» Who do I contact if I have a concern?
» Who do I contact in an emergency?
» Is there a follow up appointment?
When Children are Involved

When someone in your family experiences mental distress, the impact of this can unintentionally affect the whole family including children and young people. This can be a stressful time for everyone, as families are trying to cope and come to terms with the situation and sometimes the particular needs of children can be hard to recognise or meet in these times of stress.

It can take time to understand what is happening when someone first experiences mental health issues or during times of crisis, and children and young people may need some extra support to make sense of it all. When a parent has mental health challenges, it is particularly helpful to explain the situation to children, using age appropriate language, and reassure them that they are loved and they are not to blame. Listen to what children say and take time to acknowledge and validate their feelings. Children often need to be reassured that the illness is not their fault as they may imagine that they have somehow caused the illness.

Sometimes ordinary life can be disrupted, so it is important to explain the situation and any changes to children, for example if someone else will be helping to look after them. Try to have a consistent carer where possible and to maintain normal activities and routines, including regular meals and bedtimes. Sometimes children and young people take on extra caring responsibilities at these times, and in this situation it is especially important to ensure that these responsibilities are not too much for the child to cope with. This will depend on their age, personal coping style and other demands on their time.

If your loved one has been hospitalised in a mental health inpatient unit, children and young people are welcome to visit them. Most inpatient units have a family friendly room designed to be a safe and comfortable place for family and children to visit on the ward. It is advisable to contact the unit in advance to let them know and to prepare for young visitors so that a member of staff can be available to support the visit and answer any questions you or your children may have. The Mental Health Service has specially trained mental health clinicians (COPMI Clinicians) who work to support children and families and can help you in thinking about the needs of children when a family member is unwell or in hospital. They can be contacted through the Child and Youth Mental Health Service in your area or by discussing this with the mental health clinician involved in your care.

The COPMI (Children of Parents with a Mental Illness) website has information and resources for parents, family and friends supporting a child who has a close family member affected by mental health issues. The website also has age appropriate information and helpful videos for children and young people.

In addition, the Young Carers Program, Carers NSW, is a free service for carers aged 25 years and under, with information, support and events for young carers.
When mental health issues affect you in pregnancy or with a young baby

Depression and anxiety are common during pregnancy and in the first year after a baby is born. Other mental health issues can also be brought on or symptoms may increase following the birth of a baby. Bringing a new baby into the family is often a time of great adjustment and stress for parents. Adjusting to this major life change, as well as coping with the day-to-day demands of parenthood, can make some people more likely to experience mental distress. Talking with a member of the treating team can be a helpful step in identifying supports and discussing a referral to services, which may be able to help you and your family.

The Mental Health Service has specially trained Perinatal and Infant Mental Health (PIMH) clinicians who work with families where a parent who is pregnant or parenting a new baby requires the ongoing support of the Mental Health Service. Referrals for these clinicians can be made by the mental health clinician involved in your care when needed and with your agreement.

Other helpful local services during the perinatal period:

» Maternity services - during pregnancy
» Your local Child and Family Health Nurse (Early Childhood Centres) after the birth
» Your local doctor or GP
» For people with a lived experience, contact your mental health worker.
Family & Carer Mental Health Program

The NSW Family and Carer Mental Health Program focuses on improving the wellbeing of families and carers of people living with mental health challenges, as well as promoting the recovery of the people they support. Families and carers play a critical role in promoting positive mental health and recovery, together with consumers, clinicians and relevant professionals.

Carers need support, information and education to help sustain them in this role.

The Program focuses on:

» Family inclusive mental health services – through expert advice and consultation by specialist staff to embed best practice culture in service delivery;

» Engaging and including families and carers in the service system and being responsive to their unique needs;

» Providing education, training, individual support and advocacy services for families and carers;

» Working in partnership with families and carers to improve awareness of and access to a diversity of services relevant to their needs.

In NSW, the program provides comprehensive support for families and carers through the public mental health system and the community managed service sector, and links with existing local programs to provide a balanced and effective system of support.

In Northern Sydney Local Health District, **Uniting Recovery** provides specialist mental health family and carer services, including education, training, individual support and advocacy services.

**Uniting Recovery can be contacted at 8599 4855 or email familycarerNSCC@unitingrecovery.org.au**
## Family and Carer Support

<table>
<thead>
<tr>
<th>Organization</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uniting Recovery</td>
<td>Tel: 8599 4855 \nEmail: <a href="mailto:familycarerNSCC@unitingrecovery.org.au">familycarerNSCC@unitingrecovery.org.au</a></td>
</tr>
<tr>
<td>(mental health specific emotional</td>
<td>support, information, advocacy and education for families and carers)</td>
</tr>
<tr>
<td>Carers NSW</td>
<td>Tel: 1800 242 636 \n<a href="http://www.carersnsw.org.au">www.carersnsw.org.au</a></td>
</tr>
<tr>
<td>Carer information, support and</td>
<td></td>
</tr>
<tr>
<td>counselling</td>
<td></td>
</tr>
<tr>
<td>Mental Health Carers NSW</td>
<td>Tel: 1300 554 660 \n<a href="http://www.arafmi.org">www.arafmi.org</a></td>
</tr>
<tr>
<td>Northern Sydney Local Health District</td>
<td>Local education, support and activities</td>
</tr>
<tr>
<td>Respite Services</td>
<td>Commonwealth Respite and Carelink Centre \nTel: 1800 052 222</td>
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</tbody>
</table>

## Help and Support Lines

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td>Mental Health Telephone Line</td>
<td>Tel: 1800 011 511</td>
</tr>
<tr>
<td>Lifeline Helpline</td>
<td>Tel: 13 11 44</td>
</tr>
<tr>
<td>Suicide Call Back Service</td>
<td>Tel 1300 659 467</td>
</tr>
<tr>
<td>National Sexual Assault, Domestic and</td>
<td>Tel: 1800RESPECT – 1800 737 732</td>
</tr>
<tr>
<td>Family Violence Counselling Service</td>
<td></td>
</tr>
<tr>
<td>Family Relationships Advice Line</td>
<td>Tel: 1800 050 321</td>
</tr>
<tr>
<td>Mensline Australia</td>
<td>Tel: 1300 789 978</td>
</tr>
<tr>
<td>Parent Line NSW</td>
<td>Tel: 1300 1300 52</td>
</tr>
<tr>
<td>Post and Antenatal Depression Association</td>
<td>Tel: 1300 726 306</td>
</tr>
<tr>
<td>(PANDA) Helpline</td>
<td></td>
</tr>
<tr>
<td>Pregnancy, Birth, and Baby Helpline</td>
<td>Tel: 1800 882 436</td>
</tr>
<tr>
<td>Tresillian Parents Helpline</td>
<td>Tel: 1300 272 736</td>
</tr>
<tr>
<td>Karitane Careline</td>
<td>Tel: 1300CARING - 1300 227 464</td>
</tr>
<tr>
<td>Kids Helpline</td>
<td>Tel: 1800 55 1800</td>
</tr>
<tr>
<td><strong>Mental Health</strong></td>
<td><strong>Contact</strong></td>
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<tr>
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</tbody>
</table>
| Beyond Blue       | Tel: 1300 224 636  
  [www.beyondblue.org.au](http://www.beyondblue.org.au) |
| Black Dog Institute | [www.blackdoginstitute.org.au](http://www.blackdoginstitute.org.au) |
| Children of Parents with a Mental Illness (COPMI) | [www.copmi.net.au](http://www.copmi.net.au) |
| Dementia Behaviour Management Advisory Service (DBMAS) | Tel: 1800 699 799  
  [www.dbmas.org.au](http://www.dbmas.org.au) |
| Family Drug Support | Tel: 1300 368 186  
  [www.fds.org.au](http://www.fds.org.au) |
| Headspace | [www.headspace.org.au](http://www.headspace.org.au) |
| Mental Health Advocacy Service – Legal Aid NSW | Tel: 9745 4277 |
| Mental Health Association Directory of Mental Health Services in NSW | [www.directory.wayahead.org.au](http://www.directory.wayahead.org.au) |
| NSW Official Visitors Program | Tel: 1800 208 218 (toll free)  
| Raising Children Network | [www.raisingchildren.net.au](http://www.raisingchildren.net.au) |
| Reachout | [www.au.reachout.com](http://www.au.reachout.com) |
| Relationships Australia | [www.relationships.org.au](http://www.relationships.org.au) |
| Sane Australia | Tel: 1800 187 263  
  [www.sane.org](http://www.sane.org) |
| Siblings Australia | [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au) |
| Transcultural Mental Health Centre | Tel: 1800 648 911 |
### Services for Young Carers and Children

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>Young Carers Program (Carers NSW)</td>
<td>Tel: 1800 242 636 <a href="http://www.youngcarersnsw.asn.au">www.youngcarersnsw.asn.au</a></td>
</tr>
<tr>
<td>Young Carers (Carers Australia)</td>
<td><a href="http://www.youngcarers.net.au">www.youngcarers.net.au</a></td>
</tr>
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</table>

### Other Resources

<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact Information</th>
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</thead>
<tbody>
<tr>
<td>Centrelink (Carers)</td>
<td>Tel: 132 717</td>
</tr>
<tr>
<td>Healthdirect Australia</td>
<td>Tel: 1800 022 222 <a href="http://www.healthdirect.gov.au">www.healthdirect.gov.au</a></td>
</tr>
<tr>
<td>Housing NSW Contact Centre</td>
<td>Tel: 1800 422 322</td>
</tr>
<tr>
<td>Mother Safe Medications in Pregnancy &amp; Lactation Service</td>
<td>Tel: 9382 6539</td>
</tr>
<tr>
<td>NSW Trustee and Guardian</td>
<td>Tel: 1300 364 103</td>
</tr>
<tr>
<td>NSW Companion Card</td>
<td>Tel: 1800 893 044 <a href="http://www.nswcompanioncard.org.au">www.nswcompanioncard.org.au</a></td>
</tr>
<tr>
<td>Translating and Interpreting Service</td>
<td>Tel: 131 450</td>
</tr>
</tbody>
</table>
If you need an Interpreter

If you need an interpreter to help you contact our service telephone the Translating and Interpreting Service. The number is 131 450. Tell the Translating and Interpreting Service the language you speak and the name and telephone number of our service.

Interpreters are available in Public Hospitals and Community Health Centres. An interpreter can be booked to come to an appointment in a person’s home or in a health facility, or can be available over the phone. The service is confidential and free of charge.

It is a good idea to use an interpreter if you think it would be helpful for yourself or for a relative or friend. It is better to have an interpreter present to ensure nothing important is missed.
Acknowledgements

Thank you to everyone who contributed towards the development of this guide. In particular, we acknowledge the many families and carers who contributed their valuable time to provide suggestions to improve this resource. We also acknowledge the support from staff and local service providers who reviewed drafts and provided feedback.

If you discover an error or omission while reading through this resource, we would welcome your feedback. Please contact:

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Northern Sydney Local Health District
Tel: 9887 5657
Email: angela.hunter@health.nsw.gov.au

Disclaimer

All possible care has been taken in the preparation of the information in this resource. The producers of this resource shall not be held liable or negligent for the accuracy of information. The information provided is to be used for support and educational purposes only. It should not be used as a substitute for seeking professional care.

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