

mihope Carer's Guide



mihope aims to build hope for carers of someone with a mental health condition through the provision of practical support, advice and resources, with empathy.

mihope was created by people with lived experience with mental illness and as carers of someone with a mental health condition.

It is one thing to be aware of mental illness, however it is another thing to understand it and the consequences it has for individuals, their family and the community at large. It is also another thing to know how to deal with it, either as a patient or a carer.

It's confusing, overwhelming and just plain scary for carers and you want to know where to turn to and who to turn to. mihope is here to help.

This guide has been compiled from a number of different reputable online sources to consolidate the most useful information in one place.

It can be very confusing and overwhelming to be the carer of someone with a mental health condition. We know what it's like from experience and know it sometimes helps to have someone to talk to who gets it.

Accordingly, we would like to offer an informal coffee catch up to any carer of someone with a mental health issue who wants a one on one chat. It's like a mini support group but without all the people. We are in Brisbane but can always Zoom out of Brisbane if needed. Email us at mihopecarers@gmail.com to request a catch up.

If you are concerned about your safety, or another's safety, you should contact one of the following or visit the emergency centre of a hospital:

Emergency services – 000

Lifeline – 13 11 14

SANE – 1800 167 263

You should be aware that this guide provides general information only and does not replace the help and advice required from a qualified professional. mihope is not responsible for any actions taken or not taken as a result of information or opinions given.

ABOUT MENTAL ILLNESS

Mental illness can affect people of all ages, sexes, ethnicity and socioeconomic circumstances. According to Beyond Blue up to three million Australians are living with anxiety or depression. It can also be life changing. Hopefully with treatment and care it's temporary but in some cases it means making long term lifestyle changes.

It is important to note that your loved one can't simply "snap out of it". Often treatment and care is needed to help them get better. Consider a mental illness as you would a physical illness – if someone has a broken leg you can't just tell them to get up and walk. So it is with mental illness – you can't just tell someone to get on with it and stop feeling sorry for themselves.

It is important to know that it is possible to live a full and meaningful life even if you are diagnosed with a mental illness.

The first step in caring for someone is to understand what they are facing, what they are really going through and feeling, and then care can follow from there. There are many different possible diagnoses of mental illness. The following information gives you an insight into how each type of mental illness impacts someone. It's a starting point.

TYPES OF MENTAL ILLNESS

The following is an introduction to the more common types of mental health conditions. More information is available online and SANE in particular have some detailed guides on these conditions at sane.org in the information and resources section.

Anxiety

We all experience anxiety from time to time. Anxiety is simply our body's way of reacting to a real or perceived threat. However when the anxiety becomes overwhelming it can have a significant impact on the sufferer's life.

Symptoms of anxiety include:

- Worry: fearing or assuming the worst will happen or things will go wrong. Particularly where someone has difficulty managing the thoughts and is overwhelmed by them.
- Avoidance: Avoiding certain situations, people or places that cause anxiety.
- Over preparing to prevent a perceived threat.
- Panic attacks which may last several minutes.
- Physical symptoms: these may include increased pulse rate, breathing difficulties, stomach issues, tension, feeling faint or having insomnia.

Think anxiety might be relevant to your loved one? Have them take the Black Dog Institute anxiety self-test at blackdoginstitute.org.au.

Depression

Depression is more than just feeling low, it is a mental illness that causes an ongoing low mood or sadness often with loss of pleasure in things that someone would usually enjoy. Specifically to be

diagnosed with major depressive disorder five of the following symptoms need to be present over a period of at least two weeks:

- Feeling extremely sad, empty, hopeless or tearful
- Losing interest or pleasure in things
- Significant weight changes or changes to appetite
- Insomnia or oversleeping
- Feeling physically agitated or jittery or slowed down
- Fatigue or loss of energy
- Negative thinking such as worthlessness
- Difficulty with concentration, decision making and memory
- Thoughts of death or suicide

Sufferers of depression have also reported chronic physical pain that runs through their entire body.

Think depression might be relevant to you or your loved one? Take the Black Dog Institute depression self-test at blackdoginstitute.org.au.

Bipolar Disorder

Bipolar disorder causes people to experience extreme mood changes from periods of depression to the highs of mania or hypomania where their behaviour and thoughts can be beyond their own control.

Depressive symptoms are similar to those in depression (above).

Bipolar 1 disorder involves at least one episode of mania while Bipolar II involves at least one episode of hypomania. Hypomania is a milder form of mania but still involves an unusually elevated mood for at least four days. Mania is generally more disruptive to someone's life but both mania and hypomania can cause life altering decisions to be made. It is important to remember someone suffering mania or hypomania is simply not themselves and is not "acting out".

Mania generally includes three of the following symptoms lasting a week:

- Needing much less sleep (often the first sign of an episode coming on)
- Very high self-esteem, confidence or sense of importance
- Rapid thoughts
- Being very talkative
- Easily distracted
- Increased goal directed activity or agitation
- Risky or reckless behaviour including spending money

Other characteristics include:

- reading extra symbolism into words, events, patterns
- irritability
- increased 'driven' activity without stopping to eat, drink or sleep
- increased interest in religious/spiritual ideas or themes
- increasing incidence of paranoid thoughts

Think bipolar might be relevant to you or your loved one? Take the Black Dog Institute bipolar self-test at blackdoginstitute.org.au.

Borderline Personality Disorder (BPD)

BPD sufferers have difficulties managing their emotions and impulses and the illness often manifests itself in late adolescence or early adulthood. Often those with BPD have been through something traumatic in their lives. Five of the following symptoms need to be present for a BPD diagnosis.

- Feeling empty or having low self-esteem
- Paranoia or emotional detachment
- Anxiety with relationships and feelings of abandonment
- Impulsive or risky behaviour
- Self-harm or suicidal thoughts or attempts
- Anger, moodiness or irritability
- A pattern of intense and challenging personal relationships
- Difficulties with self-image, identity or sense of self
- Moods that feel unstable and reactive

People with BPD may also appear manipulative or seek attention but remember this is the illness not the person.

Schizophrenia

Schizophrenia is not a split personality that we are often led to believe. However a key symptom is psychosis which can involve periods of false belief and hallucinations and impacts a person's thoughts, perceptions, emotions and behaviour.

Specifically to diagnose schizophrenia a person must experience two or more of the following over at least a month:

- Delusions – false beliefs that can't be changed even by evidence
- Hallucinations – either visual or auditory
- Disorganised thinking – unusual or disrupted thoughts or speech
- Disorganised behaviour -unusual, inappropriate or extreme actions
- Symptoms such as low motivation, fewer expressed emotions, feeling less pleasure in everyday life or difficulties with attention or memory

Post Traumatic Stress Disorder (PTSD)

PTSD develops in response to traumatic events. PTSD can be extremely distressing and can interfere greatly in a person's everyday life. For diagnosis of PTSD the following must be present for at least a month:

- Intrusive reminders of the event which may be involuntary and include dreams or flashbacks to the traumatic event
- Avoiding reminders of the event
- Mood and thought changes including negative beliefs and feelings of guilt, fear or shame
- Physical and behavioural changes such as sleep difficulties, feeling irritable, acting recklessly and difficulty with concentration

Eating Disorders

Eating disorders are complex mental health issues involving disturbed eating patterns, distorted beliefs and extreme concerns about food, eating and body size. The disorder involves unhealthy eating patterns which can have very serious long term physical effects on the body. It is important to note that an eating disorder is not a lifestyle choice and is often associated with low self-esteem.

Eating disorders often coexist with other mental illnesses such as depression, anxiety or other mental health conditions.

Obsessive Compulsive Disorder (OCD)

Obsessive-compulsive disorder (OCD) involves intrusive thoughts, images, or impulses (obsessions) and repetitive actions or rituals (compulsions). The illness can be both time consuming and exhausting for the sufferer but also for carers.

Common obsessions may include:

- Fear of contamination from germs, dirt, toxins, and other substances
- Fears of harm to oneself, or to others
- Intrusive sexual or violent thoughts
- Concerns with symmetry, order, and routine
- Concerns about spirituality or religious issues

Common compulsions may include:

- Excessive handwashing or cleaning
- Repeated counting and ordering of objects
- Excessive checking of locks, electrical appliances, and other things associated with safety
- Touching, tapping, counting, or moving in a certain way or a certain number of times
- Mentally repeating words or numbers a certain number of times

HELP

ACKNOWLEDGING THE PROBLEM

Half the battle with treating a mental illness is identifying the problem and acknowledging there is something wrong. Once the issue is acknowledged then treatment and care can begin.

Using the specific symptoms outlined in About Mental Illness is a useful starting point.

According to SANE the following are characteristics to look out for in someone that show they may be at risk of developing mental health issues.

- be unusually sad or worried for more than two weeks
- lose interest in doing things, especially activities they usually enjoy
- change their sleeping patterns; be constantly tired, lack energy, or have troubled sleep or insomnia
- withdraw from their social life; spend less time with friends and family
- become over-sensitive to criticism or authority
- have a change in appetite; start to eat very little, or eat much more than previously; lose weight; vomit frequently
- experience frequent health complaints such as head or stomach aches, general aches and pains
- become persistently irritable
- have trouble concentrating or making simple decisions
- think they are worthless and have low self-esteem
- make comments about suicide, talk about feeling hopeless, or say life is not worth living
- become so anxious they have difficulty breathing, start to sweat or choke, or feel faint and shaky
- blame themselves unreasonably for things not going right
- behave aggressively and provoke fights
- abuse drugs or alcohol

WHAT TO SAY

If you have identified there is a possible issue then the next step is to reach out and initiate a conversation. You may be uncertain about what to say but Black Dog Institute suggest you choose a time and place where you are both relaxed and start with mentioning the change in behaviour and add something positive. For example “I’ve noticed that you’ve been.... You’re usually so....”. The important thing is to listen and show the person you are there to support them. Beyond Blue have also provided the following statements as ways to keep the conversation moving:

“I’m here for you”

“I can see this is a really hard time for you”

“I’m not sure what to do, but I’m sure we can figure it out together”

“What can I do to help? Just tell me how”

“I know it doesn’t feel like it now but there is hope things can get better”

“Don’t think you have to deal with this on your own. I’m here for you”

“I know it can be hard to talk about this – thanks for trusting me with it”

If the person is not yet ready to talk there is no point forcing the issue. Letting them know it's OK and you are there to talk when they are ready is the best approach. Check back in with them on a regular basis and they may be more open to talking in time.

SUICIDAL THOUGHTS

If someone is seriously injured or at risk of harming themselves right now, call 000 for an ambulance. For free, confidential 24/7 counselling call Lifeline on 13 11 14 or Suicide Call Back Service on 1300 559 467. No problem is too big or small.

Warning Signs

Usually, but not always, there are warning signs that someone is suicidal. Beyond Blue suggest the following are signs to watch out for.

Changes in relationships

- Withdrawing from other people
- Feeling like they don't belong or won't be accepted
- Feeling like they're a burden to other people
- Feeling like a failure or a disappointment
- Feeling isolated or lonely
- Finding it hard to talk to people
- Fighting with people

Emotional changes

Feeling:

- depressed or hopeless
- anxious or stressed
- trapped
- angry
- overwhelmed
- numb
- like there's no future
- worthless or alone.

Routine changes

- Struggling to maintain a routine
- Struggling to maintain hygiene or appearance
- Poor or disrupted sleep
- Changes to eating patterns or rapid weight changes

Changes to thinking

- Getting stuck on negative thoughts about themselves and the future
- Intrusive thoughts
- Trauma flashbacks
- Finding it hard to focus or concentrate
- Being distracted

Behaviour changes

- Self-harming
- Increased alcohol, drug or other substance use
- Recklessness and aggression
- Giving away sentimental or expensive possessions

Raising Suicide

The experts say you can't make things worse by raising suicide – in other words talking about suicide won't increase the chance of someone attempting to take their own life.

The best way to raise the subject is to be direct – simply ask “are you having thoughts about suicide?”.

It can be daunting to bring this up directly but research shows that asking about it won't put the idea in their head. Instead they'll likely feel relieved someone is there to listen and support them.

The conversation might be a long one so make sure the time is right – when you are both relaxed and have time to devote to the discussion. Again listening and asking open questions is important. These questions might include:

“How long have you felt like this?”

“Have you felt this way before?”

“Do you have any specific plans?” – research has shown suicide is more likely to be attempted if there is a specific plan in place.

Options available include calling Lifeline or the Suicide Call Back Service or follow the ideas in Getting to Help.

GETTING TO HELP

Once the issue has been identified and acknowledged the next step is to seek help.

Often the first step is to see your GP. The GP can assess the situation in a non-judgmental way and provide some ideas for managing the issue which may include medication or referral to a psychiatrist or psychologist.

It's a good idea to book a longer appointment with the GP and take specific examples of what's going on rather than general statements of not feeling good. Writing them down is a good idea.

You can gently suggest that you could go along to the appointment if the person you care for is open to the idea. Your perspective is invaluable especially if your caring for a young child, the person is so unwell they are unable to communicate what is going on with them or they diminish their condition.

Other options include contacting an online counselling service or going straight to a psychologist (although in Australia if you are referred by a GP it is possible to access medicare rebates for up to

10 appointments – otherwise you have to pay the full fee less any private health care rebate you may be entitled to).

There are several online counselling services specifically for children including [Kids Help Line](#) and [Headspace](#) who provide counselling over the phone or via online chat.

TYPES OF TREATMENT

There are numerous possibilities when it comes to treatment for a mental health condition. It is useful to know what the possibilities are in order to have a meaningful conversation about treatment for your loved one. You will have a role to play.

Lifestyle

There are many things we can adjust in our everyday living which have a positive effect on mental health without having to spend any extra money.

Sleep

Getting enough regular sleep is critical to mental health. Often one of the first signs that something is going astray with mental health is sleep patterns become disrupted. Encourage your loved one to aim for at least eight hours sleep a night with no disruptions which means no access to social media.

Spending too much time in bed can also affect mental health. Where possible establishing a routine where the person you care for goes to bed and gets up at the same time each day is useful.

Exercise

Exercise is critical in managing mental health, even small amounts of activity can have a significant benefit for mental health. Exercise helps increase mood through improved fitness and the release of natural chemicals in the brain.

When someone is feeling anxious or depressed it can be hard to get them started and maintain a regular exercise routine. Beyond Blue suggests the following tips to help get started:

1. Start simple

Increase your activity levels gradually to improve self-confidence and build motivation for more energetic activities. Start with simple activities such as walking a short distance to work or school.

2. Do what is enjoyable

People with anxiety and/or depression often lose interest and pleasure in doing things they once enjoyed. Plan activities with friends or family that are normally enjoyable, interesting, relaxing or satisfying – with time these activities will become enjoyable again.

3. Include other people

People with anxiety and/or depression often withdraw from others, but continuing to socialise is an important part of recovery. Staying connected with friends and family helps increase wellbeing, confidence and provides opportunities to socialise.

4. Make a plan

Planning a routine can help the person you are caring for become more active – make sure some form of exercise is included each day. Try to stick to the plan as closely as possible, but be flexible.

Diet

A healthy diet means the brain will have all the nutrition it needs to function at its best. It also means someone will be generally healthy and sleep better. To help stay mentally healthy they should eat a well balanced, nutritious diet.

The task of helping prepare healthy meals is also good for those with depression where they are able to. You should encourage your loved one with depression or anxiety to help in the preparation of meals even if only in small way.

Routine

A well established routine has shown to be beneficial for those with mental health issues. Sleep, activity and diet should all be part of this routine. A routine provides a sense of structure, security and control and helps reduce stress. It does this by reducing the cognitive load – you don't have to stress over making decisions about simple things, they are just part of the routine.

Of course a routine needs to have some flexibility and may need to change from time to time but a daily structure that is followed most days is beneficial.

Social Interaction

Connecting with others is an important part of recovery from mental illness. It may seem a huge effort and not something your loved one wants to do but making the effort can have a beneficial effect. Connecting need not be face to face and it can be with family or friends or as simple as greeting the workmates or the teacher or friends at school.

Psychiatrist

A psychiatrist is a medically qualified specialist doctor who assesses and diagnoses mental health conditions and prescribes treatment which may include medication or psychological interventions. You will need a referral from a GP to see a psychiatrist.

Unfortunately it can take some time before you get an appointment with a psychiatrist. It is worth ringing around to try and find availability.

Where it is a child you are caring for parents can expect to be involved in the psychiatry sessions as the psychiatrist may want to speak to parents alone and/or with the child present as well as spending time with the child by themselves.

It can also be useful to attend psychiatric appointments where you are caring for an adult as you can provide your perspective as to how the patient is going.

Medication

Medication is often a first line of treatment for mental health conditions. Often there is some trial and error in working out the optimal medication as what works for one person may not work for the next.

This can give rise to some frustration as it takes time to gradually introduce a particular medication and if it is not effective you need to wean off the drug before starting the next one.

One of the downsides of medication are the possible side effects which vary depending on the medication. You should check with your doctor when they are prescribing the medication. A common side effect is sedation which can be hard to handle for some.

Psychologist

A psychologist provides help with mental health through talk based therapy. This often complements the medication prescribed by the psychiatrist.

It can take several sessions with a psychologist before you see a benefit but some people receive a benefit from the first session.

It can also take some time before an appointment with a psychologist becomes available.

As for the psychiatrist you may be involved as the carer in psychology sessions although this is particularly so with younger children.

One of the main types of therapy used by a psychologist is Cognitive Behaviour Therapy (CBT) which helps people discover how their feelings, thoughts and behaviour can get stuck in unhelpful patterns.

For other information on psychotherapy see the SANE Guide at sane.org.au in Information and resources.

For a short video on what to expect from a child psychologist or for families see emergingminds.com.au in the Resources tab.

If you see a psychologist in public practice you are entitled to a Medicare rebate for 10 sessions per year if you obtain a referral known as a mental health care plan from your GP.

School Counsellor

If you are caring for a child your child's school may have a dedicated school counsellor who is also able to provide support with your child's mental health and well being. It is a good idea to communicate what is going on for your child with their school and the school counsellor may be your point of contact.

Mindfulness

Mindfulness is the process of bringing your attention to the present moment without making judgement. It takes practice to become good at mindfulness and but is worth exploring. In mindfulness we use our five senses to connect with the outside world rather than becoming caught up in our thoughts. We let our judgements and hang ups come and go and focus in on the present moment. An example might be mindful eating, totally engaging in the taste, smell and texture of the

food rather than going through the motions of eating and barely noticing we've eaten when we finish.

The benefits of mindfulness are many and include:

- Reduction of stress and anxiety – by being more aware of our negative thoughts we can take action to head them off before they become worse
- Help avoid unpleasant thoughts and feelings – the aim of mindfulness is to let these thoughts and feelings come and go without having an impact
- Improve sleep – mindfulness can help you get off to sleep more easily as well as sleep more deeply
- Highlight positive things – by being aware of the present moment we can capture when things are going well more readily
- Create healthy habits – being mindful can help you catch when you are drifting
- Improve concentration – being present in the moment helps you catch when you are becoming distracted. You can then act according to your wishes eg take a break, refocus etc.
- Notice warning signs earlier – it is easier to notice if things are going astray if you are in the moment
- Research has show that mindfulness can help rewire the brain to a more functional state

There are many books, apps and websites designed to help you become more mindful. One such book is *The Happiness Trap* by Dr Russ Harris which is highly recommended. These are a useful jumping off point on your mindfulness journey. They all have different types of mindfulness some of which are:

- Meditation – meditation is a form of mindfulness and is a great way to approach it. It is not, however, the only way.
- Breathing – mindful breathing is a great way to be mindful and be in the moment. Your focus becomes on your breathing and everything else just comes and goes.
- Walking – if we are mindful when we walk, especially in nature, we can use all of our five senses.
- Eating – as above
- Listening – focusing solely on what someone is saying and not trying to think of a smart reply or judging what they are saying in also a form of mindfulness
- Body scan – lying down or sitting allows us to slowly scan our whole body from toes to the top of the head to search out spots of stress and to ground ourselves. This can be useful when going to sleep.

Finally, mindfulness may sound like mumbo jumbo to some, and while it's not for everyone, it is definitely worth trying as the benefits can be significant.

One app for children that is recommended is Mindfulness for children app.

ONGOING CARE

For children, Kids Helpline provides phone and online support to youths with a mental health issue and also offer Parentline where parents can chat to a counsellor about issues bothering them. Other organisations that provide useful information and resources online include Emerging Minds and Headspace.

TIPS FOR BEING A CARER

- **Ask how you can help:** Asking is the best way to discover how you can help. It may even be you find out you are doing something with the best intentions but your loved one wants you to stop. If they cannot think of ways to help them you can offer suggestions. Some practical ideas are in the next section.
- **Give them time:** It can take time for someone's mental health to improve. This also applies to day to day communication – the person you are caring for may not always be in the mood for interaction, give them some time and then come back to whatever it is.
- **Be open minded and non-judgemental:** Sometimes the behavioural changes associated with a mental illness can be difficult to deal with. It is important to remember it is the illness not the person which is causing the changes.
- **Encourage sticking to the agreed plan:** The person you are caring for is likely to wander away from the agreed plan from time to time and will need some gentle encouragement to refocus.
- **You are not to blame:** You might hear some hurtful comments from your loved one and their anger and irritability can be hard to control for them. It is not your fault and you have to try and not take any comments personally (as hard as it is) as again it is the condition talking. Your efforts at support and care may also be under appreciated which can make it hard to keep backing up.
- **Try to be patient:** It can take time to get better and there will be setbacks.
- **Setting house rules can help:** Although there will likely be times when your loved one cannot live up to the rules.
- **Ask how they are:** This may seem obvious but checking in on how someone is going shows you care.
- **Avoid cliches:** It will not help to use phrases such as “cheer up” or “it could be worse” as this can further isolate the person you are caring for.
- **Do not define your loved one by their condition:** The person you are caring for is more than a mental illness and you should ensure you focus on other aspects of their life. Is their physical health alright?

- **Encourage your loved one to do things:** You need to be realistic in what you expect the person you care for to do but social contact will help with their wellbeing and should be encouraged within reason.

CARING FOR YOURSELF

According to SANE carers of people with mental health conditions often do not get the support they need and can suffer burnout. Burnout can include fatigue, cynicism, low mood and feelings of guilt or shame. In order to effectively provide care, carers need to prioritise their own well being.

Looking after your well being includes you staying physically healthy which means exercise, sleep and diet are important.

Taking time out to do activities you enjoy and to spend time with other family members and friends is also very important.

It is also important to set boundaries around your care so you do not suffer from burnout. It is ok to say no from time to time.

Carer's mental health can also suffer under the burden of caring for someone with a mental health condition and some carers find it useful to see their own psychologist for support.

Families are often impacted by someone in the family having a mental health condition whether it is a parent or a child. This can create tension or uncertainty in the family unit and mean changes in how the family lives their lives. It is important to make time for all family members which includes "date nights" for parents and doing things as a family unit as well as separately with all children in the family.

There are also organisations that can help which include:

- Mental Health Carers Australia: <https://www.mentalhealthcarersaustralia.org.au/>
- Carer Gateway: <https://www.carergateway.gov.au/>