

### A GUIDE FOR

# Caregivers of people with mental illness



**Mental illness can affect not only the life of the person with the illness, but also their close family, partners and friends. Significant people in a person's life are often a source of support with the illness.**

**However, family, partners and friends may be faced with a loved one's mental illness without much information on ways to deal with it and its impact on their life.**

If you are a family member, partner or friend who is 18 years or over and a primary source of support for a person with mental illness, this guide was designed for you. It involves information and suggestions about how you can help a person with mental illness who is 18 years or over (there are additional considerations when caring for children and adolescents) and ways to cope with the personal impact of the illness and to take care of yourself. The information in this guide is most suitable for people who are caring for someone who has a mental illness which is severe, chronic, treatment resistant or very recurrent.

The information and suggestions in this guide resulted from a study that combined the latest research with the opinions and consensus of international panels of caregivers, people with bipolar disorder, clinicians and researchers, all with experience and expertise in dealing with bipolar disorder. (Berk L, et al. Development of guidelines for caregivers of people with bipolar disorder: a Delphi expert consensus study. *Bipolar Disorders* 2011; 13: 556 - 70). The guidelines resulting from this study were analysed and the most general advice was used to create this general guide. If you are supporting a person with bipolar

disorder, the more specific guidelines may be more appropriate for you. [www.bipolarcaregivers.org](http://www.bipolarcaregivers.org)

Not all of the information or suggestions may be relevant to you. Mental illness comes in many different forms. Caregiving experiences differ as well. Finding what works for you to deal with your situation can be a trial and error process.

This guide is NOT a replacement for medical advice and we strongly recommend that you or the person you care for discuss issues related to treatment with a clinician. Although this guide is copyright, you can freely reproduce it for non-profit purposes provided the text remains intact and the source is acknowledged. Enquiries should be sent to Claire Kelly at [mhfa@mhfa.com.au](mailto:mhfa@mhfa.com.au)

## 1: Know the illness

In order to be an effective caregiver for a person with a mental illness it helps to be properly informed about the person's mental illness. This includes knowledge about the symptoms, prevalence, risk factors and treatment options.

Sources of information can include talking to the clinician, reading good-quality, reputable websites and books. You can also learn a lot from memoirs written by people with mental illness and their caregivers, but it's important to remember that those stories are very personal and individual, and may not reflect your experience with caregiving.

These guidelines can't give you all the information you need about mental illnesses, but we recommend the following websites.

Depression:

[www.beyondblue.com.au](http://www.beyondblue.com.au)  
[www.bluepages.anu.edu.au/](http://www.bluepages.anu.edu.au/)

Anxiety disorders:

[www.crufad.com](http://www.crufad.com)  
[www.ecentreclinic.org](http://www.ecentreclinic.org)

Schizophrenia:

[www.sane.org](http://www.sane.org)

Bipolar disorder:

[www.blackdoginstitute.org.au](http://www.blackdoginstitute.org.au)

Eating disorders:

[www.thebutterflyfoundation.org.au](http://www.thebutterflyfoundation.org.au)

Substance use disorders:

[www.adf.org.au](http://www.adf.org.au)

For additional information about these mental disorders, and many other, see the National Institutes on Mental Health website: [www.nimh.nih.gov](http://www.nimh.nih.gov)

## 2: Treatment and management

### 2.1. Medication

Not everyone with a mental illness requires medication, but for some, it will become an important part of keeping well. Taking ongoing medication (even when the person is well) can help to prevent relapse, reduce hospitalisations and suicide risk if the illness is episodic and severe. Specific psychological treatments, illness self-management strategies and good support from caregivers and clinicians can also help people to keep well and enjoy life.

It is useful to learn what you can about medications. For example, while some medications begin to work quickly, others take days or weeks to be effective. Medications can have side effects. Some of these go away when the person gets used to taking the medication, or respond to a change in dose, but others are more serious and the person may need to change medications with the advice of their clinician if this happens.

For more information about medications, and what may happen if the person tries to stop taking medication without advice, see section 4.1.

### 2.2. Psychological treatment

Psychological treatments can be effective alone in managing mild to moderate mental illnesses, but are generally not sufficient to treat a severe or complex condition. This is particularly true in the case of psychotic disorders, where medication is required to treat the positive symptoms.

The main psychological treatments that have shown benefit are cognitive behaviour therapy, interpersonal therapy and family therapies. Many other psychological treatments are available and may be of benefit depending on the individual concerned and the needs of the family and other caregivers.

### 2.3. Complementary and alternative therapies and self-help strategies

There are a small number of complementary, alternative and self-help strategies which have demonstrated effectiveness in treating mental illnesses. Different therapies have been shown to be effective for different illnesses. Consult reputable sources for information, such as the beyondblue "What Works" books (see link in chapter 1).

Most therapies, such as self-help books based on cognitive behaviour therapy, have been shown to be most effective when guided by a clinician. Others, such as exercise and massage therapy, may enhance a person's response to treatment and improve mood symptoms.

Many herbal supplements, naturopathic and homeopathic therapies exist which have never been evaluated for safety or effectiveness. These should not be used without consulting with a clinician and should never be used to replace effective medications. If you are not sure whether a complementary or alternative treatment is safe or effective, seek and follow the advice of your clinician.

### 2.4. Reducing triggers of illness and making lifestyle adjustments

'Triggers' are 'stressors' that increase the risk that the person will develop symptoms. Recognising a trigger provides the opportunity for the person to put supports in place to avoid illness.

Common triggers include stressful life events, both positive (e.g. the birth of a baby or a work promotion) and negative ones (such as ending a relationship or losing a job), conflicts and interpersonal stress, and the use of alcohol and other drugs.

To keep well the person may need to make some adjustments to their lifestyle and goals. The extent of this adjustment can differ from person to person. It usually takes time for the person to make these changes and work out how to live well with the illness.

## 2.5. Developing a good support system

Many people with mental illness recommend developing good support networks. These networks usually include family members and friends for companionship and to help with the illness when necessary. A clinician with whom the person has a good relationship is essential. The support system may also include more distant acquaintances such as a neighbour (for example to pick children up from school or collect mail when the person is in hospital) or work colleagues who are supportive. Peer support or mutual support groups can provide opportunities to communicate with like-minded people.

Recognising a trigger provides the opportunity for the person to put supports in place to avoid illness.

## 3: Supporting the person when they are ill

Caregivers differ in how much and what type of support they provide (e.g. some help only when there is an emergency, while others also assist the person to try to prevent relapse). The type and severity of the illness will influence what support the person needs. There are lots of things you can do to help, but you need to work out what suits you, the person and your caregiving situation (see 'Considering how involved to be in helping the person with their illness' section 7.1). Below are suggestions for supporting the person in the different phases and severities of illness. The next chapter focuses on ways to help the person prevent relapse and enjoy life.

### 3.1. Helping when an episode occurs

There are helpful ways to communicate with the person and support them when an episode occurs.

#### *Communicating calmly*

When the person is ill, it is best not to communicate with them in emotional or loud ways (e.g. by shouting or very emotional expressions of concern). Keep in mind that the person is ill and try not to react impulsively to what the person says or does (e.g. if the person is irritable try not to respond in the same way).

Being supportive does not mean you have to agree with what the person says when they are ill. You can acknowledge that what they say is very real to them (e.g. "I know you are convinced that you should quit your job, but I am not so sure"). Validating the feeling behind what they say can be supportive (e.g. "I can see you are feeling fed up with your job right now, but maybe you need to wait until you are a bit less upset about things before making a decision to quit").

#### *Supporting the person to access treatment*

Encourage the person to contact their clinician or mental health team if they have not already done so. You can offer to assist them to access treatment. If the

person is severely ill or there is a risk to their wellbeing or that of others, they need emergency assistance (see 'Dealing with a crisis' section 3.2). Encourage the person to focus on getting well as their primary goal.

#### *Helping to monitor the illness*

Keep in contact with the person and observe, listen and tactfully enquire about how they are. In this way you can assist with monitoring the symptoms to see if they are becoming worse.

#### *Helping if the person needs to go to hospital*

Some episodes are more severe than others. While many people can be treated at home, sometimes people with severe mental illness need to be treated in hospital for a short time.

Hospitalisation may be recommended if:

- There is a crisis, such as the person is severely ill and their functioning is very impaired or they are in danger of doing something with damaging or life threatening consequences (see 'Dealing with a crisis' section 3.3).
- Treatment and support does not seem to help their symptoms.
- Changes to their treatment require close supervision of medical staff.
- They need to address alcohol or drug problems.
- The person has symptoms that have a disruptive effect on their life, and they need time out to focus on getting well.

If the person has severe symptoms and is finding it hard to function, encourage them to talk to their clinician or mental health team about whether hospitalisation may be helpful. In some countries there are halfway houses, which offer a peaceful and contained environment for people who are not too severely ill. This may also be an option for the person to discuss with their clinician.

If the person's clinician recommends hospitalisation, encourage the person to seek voluntary admission to hospital rather than to be admitted against their will. Discuss with the person that going

to hospital may be an opportunity to take time off to get well, away from stressful demands. In extreme situations involuntary hospitalisation may sometimes be recommended (see 'Planning for times when the person is severely ill' section 3.4).

If the person is admitted to hospital, you can:

- If necessary, provide information to assist with treatment (e.g. about the person's recent symptoms or medications).
- Tailor your contact with them to what the person is comfortable with, as the person may feel vulnerable about social contact.
- Take time to rest while the person is being cared for in hospital.

### 3.2. Dealing with a crisis

- If the person is suicidal, see "Mental Health First Aid Guidelines for suicidal thoughts and behaviours."
- If the person is engaging in non-suicidal self-injury, see "Mental Health First Aid Guidelines for non-suicidal self-injury."
- If the person is experiencing severe psychosis, or is psychotic and becoming aggressive, see "Mental Health First Aid Guidelines for severe psychosis."
- If the person is using alcohol or other drugs and becomes aggressive, see "Mental Health First Aid Guidelines for developing problem alcohol use" or "Mental Health First Aid Guidelines for developing problem drug use".

### Get help

If you think that things may be reaching a crisis point, call the person's clinician or mental health team and express your concerns (if the person does not call them). Do not hesitate to call the mental health crisis team, clinician or an ambulance if a crisis occurs. If the person urgently needs to be restrained to stop them from harming themselves or others, you might need to call the police. If you are in danger, consider your own safety first and then get medical help for the person.

If you do not get the help you expect from these emergency services, be persistent and contact another clinician or take the person to a hospital emergency department. Sometimes caregivers find that emergency health services are not available or able to assist them in a crisis, and they need to care for the severely ill person at home. If you are caring for a seriously ill person at home, make sure you have the necessary support (e.g. from clinicians, appropriate family and friends). In a crisis don't be afraid to ask for assistance to prevent negative consequences.

It might be worth finding out about helplines in your area that assist people or their family or friends in a crisis, as these helplines can be a valuable source of support. Counsellors are usually trained to listen and assist people to deal with crises and they may offer referral to appropriate services. Your local telephone directory will have numbers of helplines in your area.

### Communicate clearly and calmly

In a crisis communicate with the person clearly and calmly. It is also not a good idea to give the person lots of instructions. Don't argue, criticise or behave in a threatening way towards them. If appropriate, give the person choices to reassure them that they have some control over the situation (e.g. If you are trying to distract them from risky behaviour, you could ask "Should we go for a walk or would you prefer to watch a movie?").

### 3.3. Planning for times when the person is severely ill

When the person is relatively well, you can make plans with them about what to do if they become severely ill. Making plans in advance can help you to feel more prepared. You can help the person to be treated in ways they would prefer to be treated when they are severely ill by planning things in advance. This is a type of advance directive. When the person is relatively well consider discussing:

#### Who to contact in a crisis

Find out who the person would prefer you to contact if they become severely ill and you need to access treatment on their behalf. There may be local service options to assist the person in a crisis (e.g. mental health crisis team, ambulance). You might also need to enquire if certain emergency services will assist a person who is very ill, but not in immediate danger of harming themselves or others. If you live in a remote area where there are no local emergency services, find out where you can get help if you need it urgently. If the person has established a good relationship with a particular clinician over time, this clinician may be helpful in a crisis.

#### When and how to act on their behalf

You might need to discuss when to intervene on the person's behalf (e.g. when certain specific symptoms or behaviour is present). If necessary, discuss Power of Attorney agreements to arrange for yourself or others to make urgent decisions on the person's behalf, temporarily and in specific situations.

#### What information to provide

Based on their previous experience the person may prefer certain treatments over others. Ask the person about information that you may need to provide to clinicians or hospitals (e.g. information about the history of their illness and treatment, and about their health fund and social security). Reassure the person that you recognise the sensitivity and confidentiality of this information.

What hospital or treatment centre the person can go to

You might need to discuss what hospitals will admit the person, as in certain places hospitals might only accept people with specific medical insurance or who have been referred by affiliated doctors. If there is a choice, the person may prefer a particular hospital or treatment. Make sure you have directions to the hospital in case you need them.

#### Involuntary hospitalisation

If the person has been severely ill in the past, you may need to discuss with them under what conditions to consider involuntary hospitalisation. It might be an idea to find out about involuntary hospitalisation procedures in case you need to use them. Confirm with the person that actions that you have both agreed upon about obtaining involuntary hospital admission are acceptable to them and will not damage your long-term relationship.

#### Who does what?

If the person is usually temporarily unable to complete certain tasks when very ill, it may also be helpful to establish who does what to share some of the tasks. The person may be relieved to know there is a plan in place to take care of urgent responsibilities.

### 3.4. Supporting the person after an episode

What people need after an episode of illness varies from person to person and even between episodes. The person may need time to get better, to get over the impact the episode had on their lives, and to resume their usual activities. You may need to adjust your expectations of the person.

There are a number of ways to support the person after an episode of illness. Consider the following suggestions:

- The person may need rest, routine, something to do, something to look forward to and love and friendship. If you don't know what they want or need, ask, without being domineering or overindulgent.
- Do things with the person rather than for them, to help to rebuild their confidence.
- Focus on wellness and positive behaviour, rather than illness and problem behaviour.
- Encourage the person not to try to get everything done at once, to prioritise essential tasks and do less stressful activities. If the person finds it hard to make a start on things, encourage them to set a small manageable goal.
- Offer assistance if the person has difficulties with remembering things or concentrating (e.g. assist the person to remember appointments by writing them down).

### 3.5. Supporting the person with mild ongoing symptoms or difficulty functioning

Some people do not need or want support with their illness between episodes. However, if the person has mild ongoing symptoms or difficulty functioning they may welcome a little appropriate support.

Ask the person if they have consulted their clinician about ways to manage these symptoms or difficulties, or what has worked in the past. Encourage the person to keep to a basic routine that includes regular sleep patterns and time for relaxation.

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## 4: Helping the person to keep well and enjoy life

### 4.1. Supporting the person's medical treatment

The extent to which you are involved with the person's treatment is a personal decision which will be influenced by the preferences of the person you are caring for, their clinician, and yourself, and will also be affected by the severity of the illness. Although you may need to take a more active role when the person is ill, you shouldn't take over from the person in managing their medication for them. This can make you exhausted and undermine the person's confidence.

You can also assist the person to monitor the effectiveness of the treatment or provide support if side effects occur. Telling the person if you see improvement in their symptoms since starting treatment can be useful feedback for them. Encourage the person to take an active role in making treatment decisions with their clinician and to have regular appointments with their clinician to help monitor their progress. If treatments are slow to work, or the person needs to try new treatments, encourage them to persevere and not give up hope.

#### What if the person decides to stop or reduce their medication?

Sometimes, people stop taking their medication, or do not take it regularly or at the required dose. This may have been a joint decision by the person and their doctor, in response to side effects or because the medicine is not effective.

However, there are other reasons why people stop or reduce their medications. Some of these can indicate a problem. For example, someone who is developing an episode of psychosis may have lost insight and see no need for medication, or someone who denies they have a mental illness may be refusing more generally to take steps to manage it. Sometimes people refuse to take medication because they are afraid of the stigma of mental illness and its treatment, or concerns about side

effects. Discussing these concerns may help to overcome them.

The person may also be forgetting to take medication. If this is the case, suggest strategies that might help (e.g. using a pill organiser or taking medication at the same time as doing another routine activity).

If you are concerned that the person has made a decision to stop or reduce a medication without discussing this with their doctor, you need to address these concerns with the person. Ask them why they have stopped their medications. Listen to their reasons and try to understand their point of view. If needed, offer the person a different perspective. For example, if the person is concerned about stigma, reassure them that taking charge and using medication to treat an illness is nothing to be ashamed of. Taking medication is an active coping strategy not a sign of weakness.

Encourage the person to talk openly about their medication with their clinician.

The clinician will be able to help to address any incorrect beliefs the person has about medication. If the problem is unpleasant side effects, the clinician may help the person to try a different medication or look at ways to reduce or eliminate those side effects.

To make an informed choice, the person may need to know that certain medications do not work as well when they are stopped and then started again. Also, certain medications should be stopped gradually. If the person does want to stop their medication, they may also need to discuss how to stop with their doctor.

**If the person is well**, ask them to consider the pros and cons of taking medication, and what is at stake if they relapse. Negotiate an agreement with them to resume medication if signs of relapse appear.

**If the person is currently unwell**, suggest that they wait until they are well to make such important treatment decisions. Remind them that their

medication may relieve symptoms that the person finds particularly unpleasant (e.g. agitation or racing thoughts). In this case you may also need to call the person's clinician or mental health team and express your concerns.

### 4.2. Helping to reduce triggers

Although it is not possible to protect the person from all stress, you and the person you care for need to find ways to manage stress, reduce triggers and maintain a lifestyle that helps them to keep well.

#### Identifying triggers

The first step is to get to know some of the triggers that may affect the person. It may help to have an idea of what commonly triggers symptoms (see 'Common triggers of symptoms' section 2.4). Some triggers will be unique to the person, so ask them what they think triggers symptoms or makes them worse. Also think back to the person's previous episodes, and work out if there were particular stressors that occurred just before they became ill.

#### Lifestyle factors to encourage

You can support certain strategies the person uses to reduce triggers and keep well. These might include regular sleep patterns, a sensible daily routine, a healthy diet and regular exercise. The person should reduce or avoid the use of alcohol or other drugs and find healthy ways to relax and unwind.

#### Practical help

There might also be practical things you can do to help reduce triggers such as cutting down the number of responsibilities the person has at home when they are struggling with mild symptoms. The person may also benefit from practical assistance if a stressful event occurs. Offer to listen if the person needs to talk and they want to, discuss options for solving any problems that are causing stress.

#### Reducing conflict

Some people with mental illness are very sensitive to stressful interactions (e.g. conflict or distressing criticism), and this can contribute to relapse. Mental

illness can put a strain on relationships. If there is conflict in your relationship with the person, it may help to find out about good communication skills (see 'Maintaining or rebuilding your relationship' section 5.4), and ways to express grievances that are not hostile and can bring about positive change. In relationships it is also important to communicate about positive things; not only about problems. However, do not blame yourself for the occasional emotional outburst.

### 4.3. Helping to prevent relapse by recognising warning signs of illness

Some people who experience recurrent episodes of mental illness show consistent early warning signs over time. However, they may not always be aware of these changes. If you know the person's warning signs, you may be able to help them to recognise when they occur and to take steps to prevent relapse. If the person does not want assistance with their warning signs, noticing when the signs occur can make it easier for you to understand the person's behaviour and plan how to respond to it.

Research studies suggest that learning ways to recognise and respond to warning signs may help reduce relapse. There is some introductory information below and community and health services in your area may be able to provide additional training.

#### Knowing the person's warning signs

To get to know the person's typical warning signs, first find out about warning signs that are common for a lot of people, such as changes in sleep and appetite. Ask the person if they are aware of any warning signs themselves. Think about the last time the person was ill – what did you notice in the days and weeks leading up to the episode? It might help to write a list of warning signs so you can refer back to them.

#### Identifying the person's warning signs when they occur

Be alert to changes in the person's usual behaviour and thinking. Remember, though, that some variation in mood is

normal and need to be distinguished from mood symptoms. Emotions that depend more on good or bad things occurring in the environment usually resolve quickly, causing minimal disruption to daily life.

It is important to keep an eye on mild ongoing symptoms between episodes, as they increase the person's risk of relapse. But be careful not to constantly question everything the person says and does for signs of illness, or it may be difficult for them to enjoy the times when they are well. Being very familiar with the person's pattern of illness may assist you to distinguish if something is a warning sign or not.

#### Communicating with the person about their warning signs

Talk to the person when they are well about how they would prefer you to communicate when you have noticed warning signs of illness so you are able to handle this as tactfully as possible. Express your concerns in a way that is non-judgmental and unthreatening (e.g. "I have noticed that you have been a bit down lately").

Let them know what warning signs you have noticed as soon as possible. Ask the person if they have also noticed these, and if they could be warning signs of illness. If the behaviour you have noticed occurred in a previous episode, remind the person about this, and explain that this is the reason for your current concern. If you are unsure whether something is a warning sign, discuss this with them. If the person is anxious about becoming ill, reassure them that they can deal with the illness and that you are available to support them.

Some people who experience recurrent episodes of mental illness show consistent early warning signs over time.

#### 4.4. Helping the person to gain confidence and live well

Besides assisting the person with their illness, you can support their efforts to regain their confidence and make a good life for themselves.

##### Supporting the person to live well with their illness

People may go through a natural grief process when coming to terms with their mental illness. They may deny the illness or experience a number of different emotions such as sadness, anger or shame. It can take time for people to adjust to the illness. 'Recovery' is a term used to describe "a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness". Rather than being an end point that the person achieves, 'recovery' may be an ongoing and very personal process of finding ways to manage the illness and live well.

When the person is well, encourage them to do things they enjoy and that are not too stressful. Adjusting to the illness may be easier for the person if they set small manageable goals that involve their interests, talents, skills and values. If the person needs to make changes to their job or study plans in order to keep well, take time to listen and discuss alternatives, as this can be a challenging time for the person.

##### Rebuilding confidence

Sometimes the illness can dominate the person's life so that they forget their strengths, and abilities. You can help to rebuild confidence by encouraging the person to do manageable things, especially things that involve their strengths and interests. When appropriate, mention things you appreciate about them. However, be careful that this does not come across as condescending or patronising.

When people manage to do things for themselves they develop confidence and independence. What the person can manage to do may depend on how ill or well they are. Even when the person is ill, they may still be able to do things for themselves depending on the severity of the illness.

##### Avoid focusing on the illness all the time

Whenever possible, do things together that have nothing to do with the illness and let them know that they are important to you. Try not to make the illness the central topic of conversation between you. Rather, relate to the person as the friend, partner or close relative they are. It can also be good for family relationships if the focus in the family is not constantly on the person and their illness.

#### 4.5. Helping the person adjust to wellness

Being well can free the person to enjoy life, however, some people find it hard to adjust to wellness. They may struggle to take on new opportunities that become available when they are well, or be reluctant to engage in social activities. If the person seems well but still needs a lot of help, be cautious about automatically assuming that they are finding it difficult to adjust to being well. They may have mild ongoing symptoms or ongoing difficulties in daily functioning and find it difficult to carry out their usual tasks (see section 3.5). However, if the person is symptom free and able to do things, but finds it hard to step out of the 'sick role' consider:

- Stepping back and encouraging the person to do more for themselves.
- Encouraging them to do things they enjoy (e.g. visit friends or pursue a hobby), both on their own and with you.
- Reminding the person that although they may have a lot to do, they don't have to do everything at once.
- Asking the person when appropriate for help or a favour, so they can experience how good it is to be the person who is doing the giving.
- Discuss with the person how they feel about the changes and demands involved in being well.

#### 4.6. Stepping back to let the person do more for themselves

People can become used to caregiving relationships. Some caregivers find it hard to step back and adjust to the person's independence, even though they are happy that the person is well. This ongoing caregiving can be exhausting for you and make it difficult for the person to develop confidence in their own abilities.

If you think this may be occurring in your situation, look at the benefits of being less involved in caregiving than you were before. Take time to relax and focus on other aspects of your life, relationships, hobbies or work.

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## 5: Taking care of yourself

Caregivers are at increased risk of becoming depressed and having other health problems. As a caregiver, you need to take care of yourself as well as the person, or you might end up feeling overwhelmed and burnt out. Although some caregivers report positive aspects of caregiving, this role can be very stressful at times.

You might find that all your energy goes into helping the person. However, if you neglect your own health and wellbeing, you may develop health problems. Also, you can't provide optimal support if your own health is compromised. There are some suggestions below about ways to take care of yourself.

Caregivers may also benefit from counselling to assist with the changes and problems that sometimes arise from caring for a person with mental illness. Group information sessions or 'psychoeducation' for caregivers run by trained health professionals can be useful and help to reduce some of the stress involved in caregiving.

### 5.1. Helpful coping strategies

Certain ways of coping are more helpful in reducing stress than others. Ways of coping that may be helpful include:

**Getting organised.** Although it might take a little time, getting organised will probably save you time in the long run. Prioritise what is essential to do and postpone or cancel other tasks. Arrange to share or delegate certain caregiving tasks and other demands.

**Restore your energy.** Making even a little time to do things that you find relaxing, or enjoyable may help to restore your energy. If the person is severely ill and cannot be left alone, arrange for someone else to be with them or for respite care while you have a break.

**Get rid of unrealistic expectations.** Dealing with a loved one who has a mental illness can be stressful. If you try to live up to unrealistic expectations of what you 'should' do as a caregiver you might increase your stress levels and become exhausted and resentful. Also, having unrealistic expectations of what the person and their clinician can do

to control the illness can also lead to frustration and disappointment.

**Maintaining boundaries and setting limits.** Learn to say "no" to demands that are unreasonable or unmanageable. Keep in mind that although you can help, the person needs to find ways to deal with their own illness.

**Acknowledge that you have needs too.** Use the time when the person is well to focus on things that are important to you, besides the illness. Devote some time to doing things that you enjoy, and maintain contact with friends and family.

**Developing your own support system.** There may be caregiver support organisations in your community or online. Having someone to talk to whom you can trust can make it easier to cope.

**Taking steps to sort out problems.** A problem solving approach can be very useful to deal with difficulties. See box for an example of a problem-solving strategy.

### Problem solving steps

## The 4 problem solving steps are:

### 1. Clearly define what the problem is

To come to a clear understanding of the problem, without blaming yourself or others consider how it developed, when it occurs and why it is a problem.

### 2. Work out what solution or solutions to try by:

- 1) **Making a list of different ways to try to solve the problem:** Use your imagination. Ask others if you like. It doesn't matter how unrealistic the solutions are at this stage.
- 2) **Evaluating each solution**
  - How practical or realistic is this solution in your circumstances?
  - What are the possible risks and negative consequences that may occur if you choose this solution?  
Are there ways to prevent or deal with these consequences if they occur?
  - What are the possible benefits if you choose this solution?
- 3) **Deciding which solution (or few solutions) you would like to try.**

### 3. Develop a plan of action and follow the plan

Decide what you need to do first to implement the solution you want to try and work out a step-by-step plan. Then put your plan into action.

### 4. Review how the solution worked

Acknowledge the effort you have put into trying to manage the problem and congratulate yourself if the solution worked. Many problems require that you try different solutions before solving them. If the solution was not helpful or there are still parts of the problem that need to be solved, return to earlier steps to try other solutions. Sometimes people learn from trying to solve a problem that there is another underlying problem that needs attention first.

Some problems are more difficult to solve than others. Difficult situations can take time to change or may not even be able to be changed. If this is the case, find ways to make things a little easier and enjoyable for yourself, despite the situation.

## 5.2. Caring about your health

Sometimes caregivers find that they don't have time to consider their own wellbeing. However, even small changes are important when trying to develop a healthier lifestyle. Rather than aiming to lead the perfect lifestyle, try to incorporate small improvements such as a little regular exercise, healthy balanced meals and regular sleep.

Don't try to save time when you are busy by neglecting your own hygiene or health. Avoid negative coping strategies such as drinking too much alcohol, smoking or overeating.

### Reducing your own stress or depression

Picking up signs that your emotional health is deteriorating gives you the opportunity to take timely action to keep well. If you notice signs of stress or depression, develop a plan for coping (e.g. delegate more of your duties and take time off).

Signs of depression include flat or sad mood or loss of interest in things. Other symptoms include a lack of energy and feeling tired, sleep difficulties, appetite changes, feelings of worthlessness and excessive guilt, and thoughts of death or suicide. People who are depressed may withdraw from social contact or be very irritable in company. They can find it much harder to function at work or to complete daily tasks. If these symptoms persist for at least two weeks, don't ignore them. Contact your doctor for an assessment and to discuss treatment options.

Some of the signs of stress include being more irritable, short-tempered tense or anxious than usual, having minor aches and pains or feeling run down and becoming ill often.

## 5.3. Adapting to caregiving

Caregivers can experience a range of understandable reactions when trying to come to terms with the person's illness and its consequences. There are things that can make adjusting to the changes a little easier.

### Coming to terms with the illness

After the person's first episode of mental illness, caregivers may go through a number of stages that are part of a natural grief process. These stages range from initial shock, disbelief and emotional turmoil, to gradual understanding, acceptance, and hope. The grief may return in times of difficulty.

If you experience emotions linked to this natural grief process, allow yourself to grieve. Remember that while the changes and losses connected to the illness are real, people with the illness and caregivers often find new meaning and ways to enjoy life despite the illness.

### Acknowledging your natural reactions and deciding how to deal with the situation

You may experience a range of intense emotions in response to the person and their illness. Some of these feelings may be part of the process of coming to terms with the illness. Others may be reactions to your situation. Acknowledging these natural reactions and deciding how to deal with them can make it easier to cope.

If you are feeling angry, try to find a constructive release for your anger (e.g. go for a walk, play sport, paint, write in a journal, or talk things through with someone you trust). If you are angry about something the person has done, wait until you have calmed down to discuss the person's behaviour with them. Delay discussing your angry feelings until the person is well and more able to deal with these issues (see 'Using good communication skills' in section 5.4).

If you are feeling rejected, try to not to take hurtful talk and behaviour personally. Do something you enjoy to distract yourself from feeling sad or rejected. If you are sad about the way your relationship with the person has

changed try to rebuild the relationship (see 'Maintaining or rebuilding your relationship' section 5.4).

At times you may feel like you want to withdraw from the person or leave them. If this happens, don't be critical of yourself. It may be a feeling that passes. You may be exhausted and need to take some time out for yourself.

On the other hand, if you decide that you cannot continue in your current situation and would like to leave or withdraw from your relationship with the person, you should first discuss what you are going through with the person. You may be able to find ways to resolve some of the difficulties together. Speaking to a counsellor or relationship or family therapist can help.

## 5.4. Maintaining or rebuilding your relationship

Mental illness can challenge relationships and sometimes it takes a bit of time, patience and effort to maintain or rebuild them. Once the person is more well, it may be possible to slowly regain some of the closeness you had previously.

To do this, start by sharing activities you both enjoy. Begin to encourage giving and taking in your relationship. For example, providing ask the person to start helping more and accept their support when it is offered. Relationships that involve more give and take can be less stressful and more rewarding for both people. It is also important to communicate our appreciation when the person does something we appreciate. People are also more likely to continue doing the things that give them positive feedback.

If the person is your partner and they have lost interest in sex due to symptoms of illness, offer companionship and allow yourselves time to rebuild your intimate relationship.

### Using good communication skills

There are ways of communicating with each other about grievances that are constructive and are less likely to come across as hostile or critical. These skills take practice and time to learn.

*Practise active listening.* People seldom

take time to really listen to each other's point of view. Difficulties and conflict are much easier to sort out once people understand where the other person is coming from. To actively listen you need to look at the person when they talk and focus your attention on what they are saying. Acknowledge what you hear by nodding, verbally indicating that you have heard or asking them to continue and ask for clarification to check that you have understood their viewpoint. Summarise what you have heard to check with the person if your understanding of their viewpoint is correct, without adding personal opinions or judgments.

*Using a positive request for change* can be useful if there is a specific behaviour that you would like to see the person change. This differs from criticism as it is not about what the other person has done wrong. Instead, it is about what you would like to see change. When doing this, use 'I' statements. For example "I would like your help with ..." "It would mean a lot to me if you would do..." Be specific without making too many demands at once. Tell them how you think this could benefit yourself and where possible, the other person.

*Calmly express your feelings about the person's behaviour.* When doing this, address the specific behaviour that is bothering you rather than globally blaming the person. Use 'I' statements and suggest what the person can do in the future to prevent this from happening again. If the person starts arguing, try not to engage in the argument. If necessary, simply restate your opinion and leave it at that.

*Work together to reach a compromise.* Sometimes conflict can develop into a struggle to 'win' the argument, leaving people feeling unheard and angry. Avoid this by working on resolving the conflict together. There are several ways you can do this. Spend some time separately listing ways to sort out the problem that suit you. Discuss these options together and aim to find something that is reasonably fair to both of you. If it is hard to find a solution that is acceptable to both of you, suggest a way to try out

different solutions. Perhaps you could do things their way this time if they agree to do things your way next time. If compromise is not possible you may need to agree to differ. Even people in a good relationship sometimes need to agree to differ about certain issues.

### **5.5. Recognising the positives**

Some caregivers find positive things about caregiving, about the person and about themselves that make it a bit easier to cope with the person's symptoms. For example, caregivers sometimes report that they have learnt from caregiving to be more tolerant and empathic and gained confidence in their ability to cope.

Caregivers may also gain a new appreciation of the person's positive attributes, such as their creativity, their abilities or talents, or their courage in battling the illness. Some caregivers report that acknowledging the person's positive qualities helps them to deal with the mental illness.

Finally, remember that caregivers often do not receive the recognition they deserve. Acknowledge what you do and the efforts you make, and be kind to yourself.

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## 6: Taking care of yourself in specific challenging situations

Caregivers may find that it is helpful to think in advance about how they might deal with specific challenges, such as a pattern of more frequent relapse or crisis situations.

### 6.1. If the person is ill a lot of the time

Some people have patterns of illness that are more severe. They may relapse more frequently or their illness may be more resistant to treatment. This can be very challenging. Don't give up hope as getting well can be a slow process. Patterns of illness can change and there are things that may help to make it a little easier to cope.

If the person you are caring for is ill a lot, find out what resources are available to support yourself, the person and the family. Try to keep to your usual routines as much as you can and avoid isolating yourself socially. If you are feeling stressed, go easy on yourself – find ways to give yourself a break, such as talking to someone you trust, watching a funny movie, or going for a walk.

It might help to make some lifestyle changes to cope with the person's persistent or recurring illness (e.g. rethinking the household budget, adjusting your work hours or arranging for others to take over more tasks). Suggest that the person gets a second opinion from an expert clinician on other ways to manage the illness. Ultimately, if you can't change the situation, focus on things that you can control.

### 6.2. Reducing stress if a crisis occurs

Caregivers can feel exhausted and overwhelmed when going through an illness-related crisis. Stress can be reduced if you prepare in advance for times of crisis (see also 'Dealing with a crisis' section 3.3).

Ways to reduce stress in an illness related crisis:

- Reassure yourself that the crisis will pass.

- If you are feeling very stressed during and after a crisis, talk to someone you trust or contact a helpline.
- Schedule a bit of time to relax and unwind after the crisis, even if you are very busy.

Sometimes the effect of the crisis can linger after it is over. Try to restore your usual routine as soon as possible. If some time after the crisis you can't stop thinking about what happened, you feel distressed and unable to focus on everyday tasks, consider getting professional counselling.

### 6.3. If there is a lot of conflict between you and the person

Mental illness can put a strain on relationships. However, not all problems are caused by the illness. Stressful interactions and conflict may be distressing for both you and the person. There are ways to try to improve communication and rebuild your relationship with the person (see 'Using good communication skills' in section 5.4). When trying to sort out problems in relationships it can be useful to consult a health professional who knows a lot about the illness and counselling for relationships.

### 6.4. If the person is ill, irritable and very critical of you

It can be hard to maintain perspective if the person who is ill is also very irritable and criticises you a lot. Finding ways to detach and set boundaries without being drawn into arguments can be helpful.

It may help to detach from the situation a little by reminding yourself that the person is ill. Don't try to defend yourself by arguing logically with the person. Address the specific comments or behaviour (e.g. shouting) that are unacceptable or concerning, without criticising or blaming the person as an individual. Say something like "I understand you're upset but I'm not going to tolerate being spoken to in this way," and walk away. Don't be drawn into reacting to their irritability or believing the criticism.

## 7: Working with the person to deal with the illness

People with mental illness differ in what help they need and want from caregivers, and caregivers differ in what support they are willing and able to give. Caregivers also need to take into account what support is realistic for them to provide (e.g. to consider their other commitments and their own health). Some caregivers are unsure how involved they should be in supporting the person. It can take time and a process of trial and error to find ways to help the person that suit both of you.

Making agreements and plans together and working as a team with the person and their clinician may help to reduce the impact of the illness on both of you. Talking with the person about the illness, its management and how you can help may assist both of you to deal with it.

People generally need more support when they are more severely ill or in crisis. At these times caregivers might need to reach out to other people or community services that can step in.

If a caregiver constantly intervenes in the person's life, the person might experience this as intrusive, and refuse to ask for help when they really need it. Repeatedly telling the person what they should be doing to manage their illness might come across as nagging. Tell the person that you would like to help them to manage the illness, but do not want to be intrusive or get in the way. When the person is well, ask them if the support you have been providing is appropriate.

It is not always necessary to mention the illness when encouraging illness management strategies (e.g. invite the person to go for a walk with you because the dog needs walking, not because it might help the person's depression). Also, keep in mind that not all support has to be described as such; sometimes just sitting with the person can be supportive or you can provide practical help or affection without discussing this in advance.



### 7.1. Negotiating caregiver involvement

It is best to discuss your involvement when the person is relatively well. If the person *has only recently received a diagnosis they may not be ready to accept the illness or discuss its management*. Invite the person to share their views on what helps people to manage mental illness. Don't feel obliged to use psychiatric jargon. Many families have their own ways of talking about the illness (e.g. feeling really down or very high).

You could ask the person what you can do to help in specific circumstances (e.g. what you can do to help when the person struggles to get up in the morning when they are becoming depressed, or how to assist them with their plans to prevent relapse). There is a possibility that the person may not know what help they need. If you have some ideas about how you could help, discuss these options tactfully with the person.

Through discussion with the person, you need to come to some agreement about the nature and extent of your involvement. For example, you might agree that you will provide specific support when it is needed, and the person will try to let you know if they notice any of their warning signs or need help. Consider formalising the way you help into a plan.

#### When creating a plan:

- Keep your plans simple so they are easy to follow.
- Consider writing your plans down and keeping them in an easily accessible place.
- Review your plans as circumstances change or you acquire new information.

When making your plans, you need to commit only to actions you feel you can be reasonably consistent in taking. For example, don't commit to being available for phone support at all times of the day and night if you have to look after small children or can't be contacted when you're working. You might instead agree that overnight or during business hours

the person needs additional supportive contacts. You can't always be perfectly consistent either - unpredictable demands and circumstances do occur. If you cannot provide the usual support, try to arrange with the person for a back-up support person or organisation to step in.

It is not always possible to implement exactly what is specified in a plan, but it can provide direction and a basis from which to work. You can have plans for dealing with different aspects of the illness (e.g. a plan for dealing with suicide risk and another for what to do when the person becomes depressed).

Sometimes people do not want to discuss their illness or to make plans. Even if the person does not want to discuss illness management, having your own plans can help you to be prepared.

### 7.2. Working with the person and their doctor

Some people with mental illness prefer to manage their treatment with their clinician as independently as possible. Others welcome the opportunity to form a team with their clinician and caregiver to deal with certain aspects of treatment. If you would like to play an active role in assisting the person with aspects of their treatment, here are some suggestions:

- Discuss with the person the possibility of working with them and their clinician. If you would like to accompany the person to an appointment, offer to do so.
- Ask the person to let their clinician know that you are the primary caregiver and your contact details in case there is an emergency and the clinician needs to contact you.
- Find out about confidentiality laws that may restrict clinicians from being able to provide information and discuss their patient's treatment with you.
- Keep in mind that you do have the option of contacting the clinician if you are concerned about the

person's wellbeing. Even if they can't talk to you about the person, you can still share important information with them.

- In order to overcome restrictions on confidentiality, discuss with the person what information they would like the clinician to share with you and under what circumstances (e.g. if the person becomes very ill, or information to assist in the person's ongoing care after discharge from hospital). Ask the person to let their clinician know what you have agreed upon.
- Consider developing 'power of attorney' agreements or advanced directives to arrange what you can do to help with urgent treatment or other decisions when the person is severely ill (see 'Planning for times when the person is severely ill' section 3.4).
- While the person is severely ill, try to keep in contact with their treatment team.
- When communicating with the person's clinician, don't be afraid to ask questions, or to ask for clarification if the information provided is confusing.

Even with good illness management, relapse can and does occur. If this happens and the person is disappointed, support them by:

- Listening if the person wants to discuss their disappointment.
- Reassuring the person that they did their best.
- Suggesting that sometimes medications and other illness management strategies need to be adjusted.
- Encouraging the person not to give up hope, as finding what works to manage the illness is a trial and error process.



### 7.3. When the person has difficulty with their illness management strategies

It can be difficult for the person to use strategies to prevent relapse or reduce symptoms because they may need to go against what their mood tells them to do. For example, it can be very hard to get out of bed and follow their usual routine when they are feeling depressed and lacking in energy.

If the person finds it difficult to use strategies that may help them to prevent relapse you could:

- Encourage them to keep trying.
- Temporarily take a more active role in assisting the person (e.g. help them to do an activity when they are depressed by doing it together).
- Support them behind the scenes (e.g. maintain regular household routines to reinforce the person's routine).

If you have ideas about what might make illness management strategies, tactfully discuss these with them.

### 7.4. Difficulties in working with the person to deal with the illness

It is not always easy to work together to deal with the illness. Good communication skills can sometimes help to sort out disagreement and conflict (see 'Using good communication skills' in section 5.4). You may also find that the person does not always want your help or they may refuse to treat or manage their illness.

#### If the person does not want your help

You may find that the person does not always want your help. It may be that they are able to manage well without it, and this is fine. They prefer to work with someone else on their management strategies, in which case you should help them to find the right person.

However, it may be that they are depressed and irritable and pushing you away, or isolating themselves. If this is the case, try to maintain contact and ensure they can reach you if they decide they need your help. If the person is having

an episode of psychosis they may have lost insight and see no need for help, in which case you might need to seek help for them anyway.

#### If the person refuses to get their illness treated

Mental illness that is not treated and managed can have a very negative impact on the person and their family. This is especially true for severe mental illness.

Try to understand why they refuse. They may fear the stigma of mental illness, and you can talk about this. They may have concerns about treatment, particularly medication (e.g. they may believe medication is addictive or that side effects will be intolerable) and these concerns could be discussed with an expert. Assess how ill or well they are so you know how to respond to this refusal.

If the person who refuses treatment is unwell, or their symptoms are escalating, you may need to seek help for them against their wishes. Get urgent medical help in a crisis (see 'Dealing with a crisis' section 3.3). If you have developed a plan for such times, use it.

If the person who refuses treatment is relatively well, recognise that the decision to accept treatment is their own to make. Be patient and supportive, and try to negotiate with them to get treatment if they develop symptoms.

Over time, the person may come to accept the importance of accepting or seeking treatment. If they do not, you may need to try a new approach. Talk to the person about the way the illness is impacting their life, your life and the lives of others, and how treatment could improve this. Ask them to consider strategies to minimise the risk of relapse, for example, avoiding alcohol and other drugs. You may also benefit from consulting a clinician yourself, or speaking to someone else that you trust.

## 8: Dealing with stigma, discrimination and disclosure

Dealing with stigma or discrimination from others can be difficult and painful for both the person and the caregiver.

**Stigma** involves stereotyped beliefs about the negative qualities of a particular group (e.g. people with mental illness). A person that is considered to belong to this group is automatically considered to have the negative qualities connected with the group. These beliefs distort and taint the person's reputation and status. Stigma can come from external sources (e.g. the family, friends or community). Sometimes, when people experience other people's stigmatising attitudes, they start to believe them. They may see themselves as being less capable or worthy than others. This is called self-stigma.

**Discrimination** occurs when these stigmatised beliefs are acted on and the person is unfairly treated. Stigma can come from others or society in general, or be part of your own beliefs. Dealing with stigma and discrimination can be difficult and painful for both the person and the caregiver.

Caregivers who are concerned about stigma sometimes isolate themselves from social contact and become depressed. Consequently, they may miss out on valuable sources of support and enjoyment.

### 8.1. Ways to deal with stigma and discrimination

#### Become informed

Most stigma is based on a lack of information and understanding about the illness. Being well informed about the illness can help you to recognise and correct some of the misconceptions involved in stigma.

#### Mix with people who accept the illness

Many caregivers find it rewarding to attend a support group where they and the person they care for are accepted, and mental illness is understood.

### Think carefully before deciding to speak out against stigma or discrimination

Some people believe that speaking out against stigma that results in discrimination is always essential. However, whether or not to speak out against stigma or discrimination is a personal choice. What you decide might differ depending on the circumstances. When you and the person you are caring for are deciding whether to speak out or not, consider how stressful this may be, whether there may be negative repercussions, the likelihood that speaking out may change people's attitudes, and whether to disclose your own situation or just speak out against stigma generally.

It is important to let the person decide how they would like to respond to stigma and discrimination from others. Only encourage the person to take a stand against stigma and discrimination, if this is not too stressful for them.

If the person is experiencing a high level of self-stigma, encourage them to develop their abilities, interests, and a sense of purpose, as this might increase their self-confidence and resilience to stigma. Peer support groups where mental illness is accepted can provide good buffers against stigma for those affected. Remind the person that mental illness is like other recurrent health conditions.

### 8.2. Disclosing the illness or your caregiving role

The issue of disclosure can be a sensitive one for people with mental illness and their close family and friends. You and the person have a right to privacy. This means that you need to be cautious about who you tell about the person's illness or your own situation. However, keeping the person's illness a secret from close family and friends, due to concerns about stigma, can eliminate potential sources of support and lead to isolation.

It can be difficult to decide who to tell and what to say about the person's illness or your situation. Consider who needs to know, and the positive and negative implications of sharing the information. Consider as well how much information you wish to share, and how.

If friends or relatives avoid you due to stigma, develop other more supportive relationships.

It is important to let the person decide how they would like to respond to stigma and discrimination from others.