

TOWARDS IMPROVED MENTAL HEALTH

An information kit produced and edited by Mental Illness Fellowship of Queensland to assist persons diagnosed with mental illness and their family members to develop an improved understanding of the illness, to cope better with the difficulties caused by illness, and to suggest ways in which their quality of life may be enhanced.

The Fellowship acknowledges the valuable contribution of related mental health organisations in Australia and overseas for the use of their information, research and text derived from various of their publications.

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Contents

| | |
|--|-----------|
| Mental Illness Fellowship | 3 |
| Mental illnesses | 5 |
| Schizophrenia | 5 |
| Bipolar disorder | 6 |
| Schizoaffective disorder | 7 |
| Anxiety disorder | 7 |
| Depressive disorder | 8 |
| Borderline Personality disorder | 9 |
| Warning signs and getting help early | 10 |
| Treatment and care | 11 |
| Working with treatment services | 11 |
| Medication | 12 |
| Hospitalisation | 12 |
| Counselling | 13 |
| Support services | 13 |
| Helping yourself | 15 |
| Impact on Family | 18 |
| Initial Response | 18 |
| Taking control | 18 |
| Working with mental health professionals | 19 |
| Special concerns of siblings and children | 22 |
| Difficult behaviour | 23 |
| Keeping a treatment record | 25 |
| Stabilizing measures | 25 |
| Involuntary protection | 26 |
| Dual diagnosis – Mental illness and substance use | 28 |
| Further Help | 32 |
| Further reading | 32 |
| Websites | 32 |

Mental Illness Fellowship of Queensland

What is the Fellowship?

The Mental Illness Fellowship of Qld, previously the Schizophrenia Fellowship of Queensland Inc, is a legally incorporated, not for profit organization established to benefit those with schizophrenia and other serious mental illness and those who care for them, through the promotion, support and raising of funds for the objectives outlined below –

Spreading a greater understanding of the special problems arising

Offering support, education and social opportunity

Actively promoting the improvement of community care facilities of all kinds, including accommodation

Encouraging research into causes and treatment

Promoting the welfare of sufferers and carers, through coordinating the efforts of volunteers and professionals

Seeking the co-operation of employers willing to provide a chance of employment

Safeguarding civil and legal rights

Advocating for the needs and rights of sufferers and carers at all levels of government and in the community

Facilitating the achievement of comprehensive and accessible systems of ongoing care

Encouraging, implementing and supporting activities aimed at rehabilitation.

What does the Fellowship do?

The various Fellowships are represented throughout Australia and New Zealand and actively pursue a number of important common functions, including –

- Assisting people with schizophrenia and their families and friends by giving advice and assistance so that they can cope more effectively
- Promoting the development of community care facilities, such as club-houses, day centres, housing schemes and rehabilitation programs, in order to provide quality living conditions in the community for people with schizophrenia
- Advancing understanding of the nature of schizophrenia and its associated problems, so that the government and the public will recognise the need for provision of better conditions and services for people with a mental illness
- Liaising with each Fellowship throughout Australia and overseas, and with other organizations, to keep abreast of up to date information in the treatment of schizophrenia and in the prevention and alleviation of suffering.

Mental illnesses

There are different forms of mental illness. Diagnosis may be difficult due to overlapping symptoms, and there is evidence to suggest that a person is able to have more than one condition simultaneously, for example schizophrenia and depression.

The exact cause of mental illness is unknown although there are many theories. Scientists generally believe there is more than one cause. They have shown there are chemical and structural changes in the brain and that often the illness runs in families but this is not always the case.

Mental illnesses are extremely complex. Much more research needs to be done to establish precise causes, which may lead to more effective treatments or to cures.

Schizophrenia

Schizophrenia is a major mental illness affecting the normal functioning of the brain. It is characterised by disturbances in a person's thoughts, perceptions, emotions and behaviour. First onset is usually in adolescence or early adulthood. It can develop in older people, but this is not nearly as common. Some people may experience only one or more brief episodes in their lives. For others, it may remain a recurrent or life-long condition.

Schizophrenia has **acute** (intense and short lived) and **chronic** (long-lasting) phases. In the acute or active phase, positive symptoms such as hallucinations, delusions and thought disorder are most obvious. They make the person feel confused, frightened and in a state of emotional turmoil and inner chaos.

Positive Symptoms reflect an excess or distortion of normal functions

- Hallucinations - distortions of the senses that are very real to the person. The brain hears, sees, smells, tastes or feels things that are not there in the external world, eg hearing voices, food tasting strange, seeing things that are not real. The most common hallucinations are auditory, when a person hears things, such as voices in his or her head.
- Delusions - fixed and false beliefs of persecution, guilt or grandeur or being under outside control. People with schizophrenia may describe plots against them or think they have special powers and gifts.
- Disorganised thinking and speech - where the speech may be difficult to

follow, eg jumping from one subject to another with no logical connection. Thoughts and speech may be jumbled and disjointed.

- Disorganised behaviour - eg dressing in an unusual manner.

In the chronic or inactive phase, which may lead up to the acute episode and often follows it, the person has more negative symptoms. The person seems to be in shut-down mode and withdraws from family and friends, losing energy and interest.

Negative Symptoms reflect a diminution or loss of normal functions

- Blunted expression of emotions – where the ability to express emotions is greatly reduced and is often accompanied by a lack of response or an inappropriate response to external events such as happy or sad occasions
- Thinking difficulties - a person's concentration, memory, and ability to plan and organise may be affected, making it difficult to reason, communicate and complete daily tasks
- Loss of drive – where often the ability to engage in everyday activities such as washing and cooking is lost
- Social withdrawal – avoiding other people and spending a lot of time alone.

People with schizophrenia may experience some or many of these symptoms. They may vary in severity and fluctuate over time. Each person with schizophrenia is unique, with different symptoms, experiences and needs.

Bipolar disorder (Manic depression)

Bipolar disorder affects the normal functioning of the brain so that the person experiences extreme moods from the lows of severe depression to the highs of a manic episode. People may also experience psychosis during an episode of bipolar. The common symptoms of a manic episode or high are:

- Elevated mood
- Increased energy and overactivity
- Reduced sleep
- Irritability
- Lack of inhibitions and over friendliness
- Overspending
- Reckless behaviour including driving, gambling, sexual behaviour
- Grandiose beliefs and plans
- Lack of insight. People often fail to understand that their ideas and actions seem inappropriate, reckless or irrational to others.

The symptoms of depression are:

- Loss of interest and pleasure in usual activities

- Stop seeing friends
- Be unable to cope with daily responsibilities or simple tasks such as shopping and showering
- Sleep disturbance, waking early
- Overwhelming feeling of sadness
- Loss of appetite
- Poor concentration.

These changes affect a person's ability to function, concentrate and participate in everyday life. It may impair the person's ability to carry out responsibilities at work, resulting in unemployment and economic hardship. Mania will usually develop from being quite pleasurable so that people will be reluctant to give it up, into a state that is out of control and frightening.

Schizoaffective disorder

Schizoaffective disorder is a disorder in which mood swings similar to those found in bipolar are present together with symptoms of schizophrenia (delusions, hallucinations, disorganised speech, disorganised behaviour and negative symptoms). To be diagnosed with schizoaffective disorder, there must also have been a period of at least two weeks of delusions or hallucinations without prominent mood symptoms.

Anxiety disorder

Anxiety is normal. It is a life saving response to our environment, particularly when we feel threatened or in danger. A certain amount of anxiety serves to improve performance. Clinical anxiety differs from everyday anxiety in its intensity and the degree to which it interferes with people's lives. Anxiety is often associated with depression. Onset is usually in adolescence.

Anxiety symptoms may include physical symptoms such as perspiration, palpitations, pallor, nausea, tightness or pain in the chest, shortness of breath, diarrhoea and frequent urination, headache, muscle pain, insomnia, lack of appetite, loss of libido, impotence and psychological symptoms such as irritability, anger, lack of concentration, inability to remember, fear of impending death, feelings of being outside oneself (depersonalisation) and feelings of being cut off from reality (derealization).

Some of the main types of anxiety disorders are:

Generalised Anxiety Disorder (GAD) - marked by unrealistic and excessive worry accompanied by constant and often unnecessary concern about anything or everything.

Phobias –including Social Phobia – fear of being judged negatively by other people; Agoraphobia – fear of certain objects or places; Specific Phobia – intense fear of particular objects or situations.

Panic Disorder - extreme panic attacks including all of the physical

symptoms of panic along with a fear that the panic attack itself will lead to a total loss of control or even death.

Obsessive Compulsive Disorder (OCD) - Persistent and unwanted thoughts which constantly invade and disrupt a person's life. People may end up performing the same action or processes over and over in an attempt to ease their anxiety about these thoughts.

Post Traumatic Stress Disorder (PTSD) – feelings of uncontrollable fear or flashbacks after a traumatic experience resulting in a person feeling unable to function in their daily life.

Depressive disorder

The term clinical depression describes a group of illnesses characterised by excessive or long-term depressed mood, which negatively impacts on a person's life. Clinical depression is often accompanied by feelings of anxiety.

A significant proportion of persons with depression have a family history of the illness. It is more common in women than in men, and affects a significant number of middle aged and older people.

Broadly speaking, there are two categories of depression, reactive depression and a major depressive episode. Reactive depression is when people are reacting to distressing situations in their lives but to a greater degree than is usual. The symptoms often include anxiety, poor sleep and loss of appetite.

A depressive episode is in general a more severe form of depression. It can come on without apparent cause, although in some cases a distressing event might trigger it. People become low-spirited, lose their enjoyment of life and suffer disturbed sleep patterns. They lose their appetite, lack concentration and energy and may lose weight. Sometimes their feelings of hopelessness and despair can lead to thoughts of suicide.

The illness may also appear in its psychotic form and involve a loss of contact with reality. The person may stop eating and drinking and may hear voices saying they are wicked or worthless.

The major symptoms common to all types of depression are alteration in mood, feelings of hopelessness, worthlessness, intense sadness, appetite changes, diminished power of concentration, loss of drive and sleep

disturbance.

Borderline personality disorder

Borderline Personality Disorder is diagnosed as a cluster of long standing problems with relationships, identity or sense of self, and the control of emotions and behaviour. Recurring suicidal impulses and self-harm are generally seen as the main problem areas.

Persons diagnosed with borderline personality disorder frequently experience problems with emotions and moods. Some persons have learned to cope with this situation by suppressing most emotions, but this can be a problem when emotions break through. Suppression of emotions can also result in feelings of deadness, unreality or boredom. Problems with anger are common and may include feeling angry a lot of the time, violent or aggressive behaviour when angry, or alternatively blocking most awareness of anger. Problems with moods often include depression.

Other difficulties include abuse of drugs or alcohol, binge eating and problem gambling in response to these emotional problems and as ways of attempting to cope.

Other symptoms include strong and changeable feelings of love and hate and great sensitivity to signs of rejection or criticism. There is a tendency to not see or not trust the positive aspects of a relationship.

Warning signs and getting help early

If mental illness is diagnosed early enough, there is a good chance it can be controlled with low doses of medication and hospitalisation may not be needed. There is also a better chance that relationships with family and friends will be preserved. Early treatment also reduces stress for families and friends because symptoms are more likely to be controlled before they get too severe.

It is important that families not wait until their relative's symptoms are so severe that hospitalisation is the only option. Families need to be able to tell the difference between normal behaviour and danger signs. But sometimes it is hard to tell what is normal and what is not, especially when dealing with a teenager or an older person. In some cases, diagnoses may be delayed because of confusion with teenage rebellion and mood swings or in the case of older people it may be put down to the aging process.

One important danger sign is withdrawal from family and friends. While it is normal for teenagers to withdraw from their family, it is not normal for them to also retreat from their friends.

Other danger signals include:

- Fear of leaving the house (particularly in daylight hours)
- Changes in sleeping and eating patterns – pacing at night
- Uncharacteristic neglect of personal appearance or hygiene
- Believe, without reason, that someone is plotting against them
- Difficulty in concentration and deterioration in work or school performance
- Extreme preoccupation with a particular theme
- Marked changes in mood – from extreme excitement or anxiety to quietness or sadness.

These behaviours are a sign that something needs to be checked out, particularly if they have been present for some weeks. There may only be a minor disturbance but a mental illness may be developing so seek a medical assessment as soon as possible. General practitioners are a good starting point, they can refer to a psychiatrist for a diagnosis.

For more information on danger signs and approaching your doctor, contact the Mental Illness Fellowship for the pamphlet *Something is not right: getting help early for mental illness*.

Treatment and care

Mental illness can be treated and managed. The most effective treatment usually includes a combination of medication and psychological counselling. A good understanding of the illness and its treatment is important in living well with a mental illness.

Working with treatment services

The first step in obtaining the treatment to which you are entitled is making contact with the public health system. A general practitioner (GP) can give you a referral to a psychiatrist if appropriate. Psychiatrists can work in the public system, at Community Mental Health Services, where there is no charge, or in private practice where there may be a charge, mostly claimable under Medicare.

It is really important to find a psychiatrist you can trust and work well with. If you can afford to see a private psychiatrist then shop around and find one that suits you. If you are in the public system there may not be as much choice but you still have the right to the best service you can get.

After an initial assessment is made, the psychiatrist may recommend that you spend a while in hospital until symptoms are under control. Alternatively, it may be decided that you do not need to go to hospital, but can be treated from the start in the community. The treatment prescribed will usually include a combination of medication and rehabilitation.

If you are referred to a Community Mental Health Service, while the psychiatrist is responsible overall for your treatment, you are likely to be given a case manager who will be responsible for coordinating your treatment, providing information and support to you and your family as well as referral to relevant community agencies.

To make it easier for your family to support you during this difficult time, it might be helpful to sign a document indicating that you give permission for the Community Mental Health Service to release information to your friends or family about your treatment, diagnosis and prognosis.

Getting the best from your psychiatrist

- Shop around and find a psychiatrist who suits you. It may be useful to discuss this with your GP or others who have a mental illness.
- Remember, your psychiatrist is there to help you as a professional.
- Be clear and assertive about what you want
- Direct the conversation into areas that are important to you
- Use your time with the psychiatrist wisely and efficiently. For example, take a list of issues you wish to discuss
- Give clear information about how you are feeling and what is happening to you. It may be useful to keep a diary and record what has happened
- Be as honest as you can because the information is confidential
- If you are feeling stressed during appointments ask your psychiatrist to write down important information for you

Medication

The development of mental health medications has revolutionised the treatment of mental illness. Now, most people with a mental illness can live in the community. These medications are not addictive and work by correcting the chemical imbalance associated with the disorder.

Mental health medications are powerful drugs, which can cause side-effects. They should always be used with care, under a doctor's supervision. Because each person responds differently to medication, trial and error is needed to work out which drug and dose is best. This period of trial and error can be extremely trying for everyone involved but as medication is often taken long-term, doctors have a duty to prescribe the most effective medication and ensure any side effects are kept to a minimum. You can help by providing as much information as possible about your symptoms, side-effects and other problems.

You should be given written information on the drugs prescribed for your treatment including any side-effects which may occur. Ask your doctor if you have any questions.

Medication is only part of the treatment. It does, however, provide a base for recovery and enables people with a mental illness to benefit from other forms of help available.

Hospitalisation

Hospitalisation is often needed for people who have suffered their first episode of a mental illness. It may also be necessary when a person has a serious relapse. People need to go to hospital to protect their own well-being and safety. Hospitalisation also allows doctors to control an episode more easily. They can work out the best type of medication and control side effects in the controlled situation of a hospital.

Most people who voluntarily go into hospital stay for a few weeks on average on the first occasion. It takes a few weeks for medication to start to have an effect on symptoms.

The hospital services include nursing care, counselling, a rehabilitation program and discharge planning. A case manager may be appointed to look after the person and coordinate ongoing care when he or she leaves hospital.

Counselling

While medication is very important in the treatment of mental illness, most people also need counselling or psychotherapy if they are to learn to cope with their illness

One aspect of counselling is education about the illness, looking at symptoms, medication, early signs of relapse and strategies for coping with symptoms that medication doesn't help. Counselling will also address personal issues and is tailored to each individual's needs.

Support services

Everyone needs their own support network. People with a mental illness may need support from a wide range of different services. It can be difficult to get the support you need but you are entitled to a range of support in line with your needs.

- Talk to others about the services that would be useful for you (your case manager or other people with a mental illness)
- Ring the health department and ask for information about services
- Be polite but assertive about your needs. Making a list of what you want to say beforehand can be helpful
- Use an advocate: an advocate is simply another person whom you choose to help represent you. They can be a friend or relative, or someone from another agency or community organisation.
- Contact the Mental Illness Fellowship for information

Income

Many people with mental illness receive Social Security benefits. Make an appointment to see the Disability Support Worker at your local Centrelink office and they can assist you to establish your entitlements. If you have a case manager, then they can help you work out your entitlements too.

Accommodation

It is important to have a good place to live, somewhere where you feel safe. It can be helpful to talk over the options with someone you trust such as your case manager or a friend or relative. The deciding factor as to whether you live at home with your family or somewhere else may be whether there is anywhere else to go, as there is a lack of appropriate accommodation in the community for people with a mental illness in Australia.

The options include:

Transitional Accommodation: Some mental health services operate transitional accommodation programs. These provide a place to live and living skills training for up to a few months.

Long term supported accommodation: Generally means a property shared with other people who've also experienced a mental illness. The property, often called a group home, is typically operated by a community organisation which ensures rent and bills are paid, and provides various levels of support. People may find this a useful option, combining a degree of independence and security, but there are long waiting lists.

Independent accommodation can mean anything from a public housing unit to owning your own home. Public housing waiting lists are very long so register interest as soon as possible. Some community organisations provide outreach support to people living in their own accommodation.

Boarding houses vary widely in quality and cost and need to be assessed individually.

Rehabilitation programs

Rehabilitation means help to recover from the effects of mental illness, to get used to living an ordinary life in the community again. There is a great variety in the type and availability of rehabilitation programs. Larger cities generally have more to offer, but ultimately your choice depends on which programs are accessible and appropriate to your needs. Enquire at your mental health service or the Mental Illness Fellowship about programs available locally, and ask around about those that others would recommend.

If you are keen to return to work there are employment agencies that specialise in finding work for people with a psychiatric disability. Many people who have experienced a serious mental illness prefer to do a voluntary or part-time job, and only consider full-time work if and when they feel ready to do so.

Helping yourself

As well as clinical treatment and support programs, there is a lot people can do themselves to deal positively with the effects of mental illness.

Some things which people have found helpful are:

- Sleep, get eight or nine hours sleep during the night
- Being sociable, try to get out of the house at least once a day and do something once or twice a week where you mix with people
- Identify triggers and warning signs
- Avoid recreational drugs
- Avoid stress

Stress

Moderate stress is actually useful because it helps you to get going and to do things. Too much stress however is uncomfortable causing tension, anxiety and fatigue. It results from a sense of being unable to cope with the current demands that life makes. If you are having these feelings you should discuss them with your doctor or case manager so they can help to reduce the stress, by adjusting medication or suggesting other ways in which you can get support.

Too much stress can contribute to a return of symptoms. Learning how to manage stress positively can enhance your lifestyle and help you keep well.

Try to:

- Make time for relaxing and doing things you enjoy
- Talk problems out regularly with a friend, relative or mental health professional
- Deal with one thing at a time to avoid feeling overwhelmed
- Work out which situations make you feel stressed and try to avoid them; eg if you tend to feel lonely and stressed on the weekend plan to do something sociable on these days.

Identify triggers

Some people can identify situations or events that can be triggers to their becoming unwell. Learning about your triggers can help you avoid those situations or take action to prevent yourself becoming unwell. Notice any patterns in when your illness gets better or worst. For example:

- Do you become unwell when you are going away?
- Are particular times related to your illness, for example Christmas, or anniversaries?
- Do stressful situations cause you to feel unwell?
- Is your illness related to drugs or alcohol?
- Do weather patterns or seasons affect how you feel?

Responding to triggers

- Take particular care of yourself at times that you are vulnerable, by
 - spending time relaxing
 - getting enough sleep
 - talking to a friend about how you are feeling
- Avoid the situations that trigger you, although it is important not to avoid everything
- Talk to your doctor about increasing your medication during stressful times.

Early warning signs

Some people have signs that tell them when they are becoming unwell. For example, they may:

- have difficulty sleeping
- begin to feel agitated or afraid
- find they do not want to do activities they normally enjoy
- feel irritated about things that don't normally bother them
- experience other symptoms of the illness.

It is useful to learn about your early warning signs. If you seek help and take action when you first notice them, this may prevent you from becoming unwell.

Recognising early warning signs

- Think back on what happens to you when you first become unwell
- Ask friends and family what they think seems to happen when you first become unwell
- Make a list of the things you notice that may be early warning signs and talk to your psychiatrist, health worker and family about them

Responding to early warning signs

- **If you are experiencing early warning signs some of these ideas may help:**
 - slow down your activities
 - have a rest day
 - restrict social activities to less stressful ones
 - get plenty of sleep at night
 - do relaxing activities
 - stay with a calm, supportive friend or relative
 - talk to your case manager

- Learn whom you can trust and listen to them when they tell you that you may be becoming unwell
- Talk with close friends and family and work out what you want them to do if they notice you are becoming unwell.

Managing symptoms

Taking medication may be the most useful thing you can do to reduce or even eliminate the symptoms of mental illness, but if you still get them sometimes there are other methods you can use to complement the medication, asserting a degree of personal control over the symptoms. It makes sense, obviously, not to do things which experience tells you will bring them on or make them worse.

- Keep a diary or a plan of activities
 - Spread out tasks and activities over the week
 - Set yourself goals to achieve and set deadlines to complete difficult tasks
 - Arrange appointments for earlier in the day
 - Do things with others
 - Keep in a good day/night pattern
 - Set realistic expectations
 - Plan enjoyable and relaxing activities
 - Reward yourself for your efforts
 - Be physically active
 - Eat well.

Suicidal thoughts

It is important to be aware that suicide is one of the main causes of death for people with mental illness. Suicidal thinking is temporary, but it is dangerous to try to cope with these symptoms on your own. The key steps to surviving suicidal thoughts are:

- Tell someone—your doctor, case manager, relatives, friends
- Seek help—your doctor or case manager can help you manage your low feelings
- Don't be alone—keep company around you and perform some positive activity.

Impact on family

The majority of mentally ill people now live in the community and many of them are living with and being cared for by their families. With knowledge and understanding, carers can play a constructive part in assisting the ill person to survive and cope with the experience of mental illness. Carers should regard themselves and be accepted as members of a caring team – a ‘therapeutic alliance’ between the ill person, the carers and the health professionals.

Initial response

For families who have been living with a mentally ill person for a while the diagnosis may come as a relief. At last they know what is wrong but the stigma surrounding mental illness and the lack of knowledge about the illness make it hard to cope with. The initial response when a family first learns that a loved one has a mental illness is likely to be:

- Grief at the loss of the person as they were
- Anger and frustration at being unable to do anything or get any real help
- Guilt at the mistaken belief that they caused it

In the early months after diagnosis, families live in turmoil. They need support and information about mental illness and services.

Taking control

Education is crucial. Mental illness can be confusing and complicated and the mental health system is complex. Without a good working knowledge of both the illness and the system, life can be overwhelming and frustrating for the family.

Family education and support programs help families to come to terms with the emotional impact of having a relative with a mental illness. On a practical level, counselling helps families develop ways to deal with their unwell relative. It looks at communication, emergency situations, and setting reasonable goals and limits. For more information on family education speak to the community mental health centre or contact the Mental Illness Fellowship.

Sometimes it seems impossible, in the midst of the day-to-day trauma of dealing with a relative with a serious mental illness, to have any real life of your own. However, it is vital that you do so. The following are some suggestions to help you to deal with the difficult situation you find yourself in.

- Participate in activities that are yours alone, for example working, going to the cinema, talking with friends, going on vacation
- Remember that your inner resources are greater than you generally imagine
- Accept the limits of what you can do and what you can give to your relative
- Accept the reality of your relative's illness and limitations without blaming yourself or others
- Learn to accept the unpredictable and unexpected
- Continue to educate yourself and others and seek support – join a local support group
- Strive for good physical health by means of a good diet and sufficient exercise. Do things to reduce your stress level
- Make efforts to maintain social contacts

Working with mental health professionals and facilities

For relatives or other carers, the relationships established with mental health professionals and case managers involved is very important. Giving some thought regarding how to deal with them can have a significant impact on the way in which they respond to your needs. By viewing them as allies, your exchanges with them will be much more positive and satisfying.

To enhance your relationships with professionals and service providers –

- Be courteous – courtesy is to your advantage as a service user and as an advocate for your relative
- Provide relevant information
- Be respectful of their time
- Ask how you can be involved in a supportive way
- Request meetings, with or without your relative present, when you feel the need. In addition, you may ask for diagnosis, treatment plan, medication information and prognosis, although your relative's consent may be required
- Expect to be treated respectfully and with consideration.
- Keep in mind the frustrations and constraints mental health professionals face

Carers questions for discussions with mental health staff

Questions to ask about diagnosis

- What illness does my relative have?
- If a diagnosis hasn't been made, what are the possibilities?
- What has led to this diagnosis?
- What signs and symptoms suggest this?
- What is the likely cause?
- Where can I get information about this illness?

Questions to ask about assessment

- What tests have been done and what further tests may be done?
- Are there any physical problems that have been discovered?

Questions to ask about the patient's care and treatment

- What are the aims of care and treatment?
- What is the plan for treatment?
- Who is involved in the treatment?
- What happens if my relative refuses treatment?
- What are the advantages or disadvantages of hospital treatment?
- If they go to hospital how long are they likely to stay?
- If they go to hospital, what arrangements will be made for the care of my relative, after they leave?
- Will our family be routinely involved in discussions about our relative's treatment?

Questions to ask about medication

- What medication is to be used?
- Why was this medication chosen?
- What are the possible side effects?
- What signs do we look for that might mean the dosage needs changing or the side effects are too much?
- What will happen if my relative stops taking medication?
- Do you have any written information regarding the medication?

Questions to ask about getting help

- Who is our key contact in the treating team?
- How can we get in touch with the psychiatrist?
- Who do we contact if we are worried?
- What do we do in an emergency?
- How can we get a second opinion?
- Are there any local self-help and/or family support groups?

This set of questions is adapted from those developed by the Royal College of Psychiatrists (UK) for families or carers to use in discussion with mental health professionals. It is useful to:

- Have these questions prepared before the interview and record the answers
- Keep an ongoing diary record of observations you have made about your relative – to take to the meeting
- Explain to MH staff if you want, what you say to them, to be confidential and not repeated back to your relative
- Have an arrangement with your relative that it is OK for you to be kept informed

Confidentiality

The issue of confidentiality is often a difficult one between families and professionals. It might be helpful to have your relative sign a document indicating that he or she gives permission for a particular person or facility to release information to you about his or her treatment, diagnosis and prognosis. Try to obtain a consent when you and your relative are calm and on good terms.

Of course, your relative may not be willing to cooperate. In such a case, mental health professionals are required to maintain confidentiality. There are, however, ways the professionals involved can still give you information, such as by speaking in generalities.

On the other hand, the relationship between the caseworker and the patient must also be respected. If a person is paranoid or mistrustful, learning that his or her caseworker has been talking to family members can cause friction in this relationship.

There is also nothing wrong with calling a hospital and asking for a general progress report. Again, it helps if you can tell the hospital that you have a written release of information letter from your relative. Do not be hesitant to call the hospital if they have not called you. It may be a busy facility whose staff may not yet have had a chance to call you. They also may have no way of knowing that you exist.

You do not want to disrupt the activities of health professionals, but you do want the staff to know that you are concerned and want to be updated periodically, so that you can be available to assist with the treatment or care plan.

Special concerns of siblings and children

Having a relative with a mental illness can seriously affect everyone in a family, and each member's reactions will differ somewhat. Often siblings or children of a person with a mental illness may try to distance themselves from the situation as soon as they can, and may act as if it is not their concern.

Nonetheless, the family member's illness is usually a traumatic part of their childhood. In their young adulthood, they often fear becoming ill themselves. As they grow older and have families of their own, they worry about their own children becoming ill. Many siblings back away from the entire issue and let their parents handle all the problems with their mentally ill brother or sister. However, they know that when their parents are no longer alive they may then feel compelled to handle the problems.

Having a parent or sibling who has a mental illness can interfere with the normal developmental process. Special support or therapy may be necessary later in life to assist in the processing of the experience, if the necessary education and understanding are not available while the family is in the midst of the experience.

People's limits and tolerance for being with someone who is ill or disabled vary greatly. It is best if everyone can respect these differences. It takes different amounts of time and a degree of maturity before someone is ready to involve himself or herself with a mentally ill relative.

Growing up with a relative who has a mental illness

Siblings and children of people with a mental illness may experience a range of emotions including denial, confusion, shame, sadness, guilt, fear, frustration, anger and resentment.

Having a parent or sibling with a mental illness often interferes with, or significantly affects –

- Social relationships
- One's image of one's family
- Relationships with one's parents
- One's choice of activities and responsibilities
- One's emotional wellbeing.

Things that help include –

- A family that is open to discussing the illness and its effects on everyone
- Supportive relationships with people to whom one can talk about the situation
- Learning about the illness, especially about how likely it is that one or one's children will become ill
- Focusing on one's own activities and relationships.

Difficult behaviour

What are the reasons for it?

People with a mental illness sometimes behave in ways that create difficulties at home. They may become demanding or abusive or depressed.

There could be many reasons for this difficult behaviour. They may feel frustrated by the effects of the illness upon their lives, they may feel depressed at not having a job, friends or a loving relationship. Their medication may be causing uncomfortable side effects or they may be becoming unwell. A change of dosage, or even a change of medication may take the edge off things.

Suggest an assessment if it is felt this may help.

How should you respond?

Try to make allowances where it is sensible to do so. Do not make an issue out of something that really does not matter too much. On the other hand, do not automatically excuse someone every time they say or do something that really is unpleasant.

Explain the ground rules for living at home, but remember that someone with a mental illness finds it difficult to concentrate on a lot of issues. So, limit the rules and keep them simple. As a relative, it is necessary to be a reliable and stable reference point as the person's world shifts in a frightening manner. Having set limits on what is acceptable behaviour, be firm and stick to those limits.

So long as a person is reasonably well, a level of self-control is usually possible. It is wrong and actively harmful to assume that the person cannot take any responsibility for his or her actions. A flare-up of acute symptoms will however interfere with the person's usual behaviour and control.

Violent behaviour

It is unfortunate that the general public still associates mental illness with violent behaviour. This attitude seems to be reinforced by the way in which the media report and emphasise such incidents.

Only a small percentage of violent crimes are committed by people with a mental illness. When they do commit an act of violence, it is usually because they are unwell. This may be due to their ceasing to take medication or because services in the community do not provide sufficient support and care to sustain them. This needs to be remembered, and the community constantly reminded of the need for such services. However, the fact that violence can and does sometimes happen needs to be acknowledged.

Verbal violence

Not all violence is physically dangerous. The family is generally the focus of verbal attacks, often being blamed for everything that has gone wrong. Accusations may be wildly divorced from the facts, but the nature and fervour of the attack can leave a parent or spouse feeling confused about what to think, let alone what to do.

The first rule is never to argue back. When a person has calmed right down, it may be possible to clarify some of the issues. It is vital to acknowledge any valid points that he or she has made. It is not helpful to accept blame for the sake of peace.

If a verbal attack has been triggered by alcohol or any other addiction, explain that the added complication is too much for the family to cope with. To live somewhere else may be the only solution if excessive use of alcohol or use of illicit drugs persists.

Violence to property

Damage to property and possessions may be the result of extreme frustration. For example, broken windows may be a reaction to overwhelming tension as well as a clear signal for help.

Violence to property may also result from paranoid misconceptions. Whatever the reason for it, it signals an escalation of tension or symptoms. Medical help and advice should be sought if you are unsure about how to cope with it.

Serious violence to self

Suicide is more common amongst people with a mental illness than among the general population. People who have talked of taking their lives or have attempted to do so in the past may continue to be at risk from time to time.

Families may pick up danger signals, the important thing is to act on the signal even if you feel unsure about it. Share the anxiety with someone who will know how to intervene – preferably a doctor or another health worker who knows the person and his/her clinical history. The common belief that someone who talks about suicide will not do it is completely wrong.

Keeping a treatment record

A crucial function for families is to keep a treatment record. Of course, you may not be privy to everything. But if you keep the best record you can, and make it available each time your relative is admitted to a new program, or starts working with a new case worker or other mental health professional, you will be offering invaluable information

The record need not be extremely detailed – what you want to offer is an overview. Such a record can also be helpful in justifying the need for treatment, voluntary or involuntary admission, or supported accommodation.

Include the following information in your record –

Level of functioning prior to becoming ill – highest level of school completed, work experience, level of basic life skills (cooking, cleaning, money management, independent living experience), social skills, relationships with peers, significant achievements.

Symptoms – When they began, what they are, most effective ways of dealing with them, dates of more severe episodes.

Treatment – Dates of the first psychiatric hospitalisation or treatment, how long it lasted, the diagnosis, how much improvement there was afterwards, what psychiatric medication has been tried, when, how effective it was, and how serious the side effects were. Similar information should be included for any subsequent hospitalisations or involvement with treatment programs.

Level of functioning between hospitalisations or involvement in treatment programs.

Names, addresses and phone numbers of all doctors, other mental health professionals, service providers and other significant persons involved with your relative's past or present treatment.

Stabilising measures

Regular medication

Most psychiatrists are of the opinion medication is necessary over a long period. It should be taken regularly as prescribed, even when the person is feeling well. Fine-tuning of medication is often necessary to keep pace with the effects of the illness and normal life events. New medications, which may have fewer side effects, should be made available if the person is distressed by medication induced symptoms.

Ongoing support

The right level of ongoing, caring support from family, friends and mental health professionals helps a person to maintain stability and manage his or her life.

Calm atmosphere

Those around the person need to maintain a calm, non-critical position. Because this is not always easy, a person should be away from the family or others with whom they are living, for part of each day.

Suitable accommodation

The place where a person lives needs to be right. The illness can have a very unsettling effect, so it is important that the person feels physically and emotionally comfortable in his or her accommodation.

Occupation

Everyone needs something to do which gives them a sense of purpose, and this applies equally to someone with a mental illness. Gainful employment or voluntary work, if only on a part time basis or of limited complexity, needs to be encouraged wherever possible.

Making adjustments

The person with a mental illness is vulnerable to all kinds of stressful events, both pleasant and unpleasant. For example, if there are to be big changes in the person's life, the surrounding three to four weeks may be a particularly vulnerable time. Try to give more support and make fewer demands at stressful times. Changes in medication may also be needed.

Other useful suggestions

There are real advantages in maintaining a healthy diet, taking regular exercise and avoiding cigarettes, alcohol or illicit drugs. Anything that improves or maintains physical wellness will benefit the person with a mental illness. Particularly try to establish good sleep patterns – that is, awake during the day and sleeping at night. Try to keep up family relationships, social contacts and friends, interests and hobbies.

It is also important to ensure that the physical, as well as the mental health of the person is properly monitored by health professionals on a regular basis.

Involuntary protection

There are occasions when it may be necessary to seek involuntary treatment for a person who is refusing to accept it voluntarily. Remember, a person's rights as a citizen extend beyond personal liberty and the freedom of self expression – they extend to the guaranteed right of physical safety during the occasions when the person is not able to protect himself or herself from the consequences of life threatening behaviour.

In such instances, decisive action may need to be taken to protect the person from harming himself or herself, or others. At such times it may be necessary to involve police officers to ensure a person is conveyed to an appropriate place of safety, where professional clinical care and treatment is made immediately available.

Care and effective treatment is only possible if the person is alive to receive it, and carers should not hesitate to invoke emergency intervention by police to maintain the physical safety of all concerned.

Dual diagnosis– Mental illness and substance abuse

Dual diagnosis is when a person is affected by both mental illness and substance use (specifically the use of alcohol and/or drugs). Mental illness and substance use interact to make each diagnosis worse, and to have serious adverse effects on many areas of functioning (including work, relationships, health and safety). Recovery from mental illness is made much more challenging for people with a dual diagnosis, and the issues faced by families of people with dual diagnosis can be even more devastating and confusing than with mental illness alone.

Why do people with mental illness use drugs and alcohol?

Research has determined that people with a mental illness use drugs and alcohol for the same reasons as other people – to feel better or different, relax, have fun and be part of a group. People use drugs generally for their perceived benefits. Other reasons for drug use include curiosity or experimentation, to relieve stress, cope with problems, or overcome boredom.

The immediate effect of drugs and alcohol usually provides relief from the positive symptoms of mental illness, but withdrawal from the drug or alcohol will make these symptoms worse. People with a dual diagnosis may readily associate the reduction of the symptoms with the drug use, but less readily associate the increase in severity of the symptoms with the withdrawal.

Consequences of dual diagnosis

People with a dual diagnosis generally have difficulty following through with treatment, and hence the course of the mental illness may be more severe and of a longer duration.

Behaviours associated with dual diagnosis may be very hard for the family and society to tolerate. Dependence issues compounded with mental illness symptoms can result in overbearing behaviour, reduced concern for the consequences of behaviour, and reduced connections with society. The following areas of life are often affected –

- Physical or psychological health
- Problems with relationships (family, friends)
- Problems with stable accommodation, finances, employment or education
- Problems associated with civil or criminal law.

The family can be faced with more issues about taking care of themselves, including avoiding violence and protecting assets, than with mental illness alone.

Do drugs and alcohol cause mental illness?

Drugs and alcohol can cause a substance induced psychosis in susceptible individuals. This psychosis may subside once the drugs or alcohol are out of the system and minimal treatment is usually required. People remain more susceptible to the development of a psychosis if they re-use that drug. For susceptible individuals, this psychosis may not subside, and after six months of symptoms, may be re-diagnosed as schizophrenia or schizoaffective disorder.

Treatment and recovery issues related to dual diagnosis

Assessment is needed over an extended period to accurately determine the diagnosis. The recovery process can be prolonged for someone with a dual diagnosis and relapse is more likely. Withdrawal effects need to be taken into account when a person is admitted to a psychiatric service. The more information the clinical services have, the better.

Monitoring risk of suicide and self-harm is extremely important, as risk is higher than for people with a single diagnosis. In harm reduction, relapse is an expected part of change and can contribute to learning. The rate of relapse may be higher for someone with a dual diagnosis.

Issues for the family in relation to dual diagnosis

- Violence and intimidation are often a feature of behaviour of people with dual diagnosis.
- Families need to consider how to manage this issue and the safety first principles.
- Violence and intimidation are often associated with getting more money for drugs or alcohol.
- Families often benefit from developing strategies that support the person without supporting the drug or alcohol taking, for example buying food rather than giving the money for food.
- Agitation is often a feature of the behaviour of someone with a dual diagnosis when they are in need of drugs. Families can benefit from recognising this pattern of escalation and developing strategies to withdraw from the interaction before it has escalated.

- The impact of the dual diagnosis will often result in families being called upon financially to support the person. Rent, clothing, haircuts and transport all become less of a priority and families are put in the difficult position of making up the shortfall or having their family member suffer the consequences. This can be a difficult dilemma. One possible solution is to financially support the person in a way that does not support their drug use.
- Suicide and threat of suicide is often a feature of the behaviour of people with dual diagnosis. The family needs to have considered its response to this issue, how to recognise a real threat and seek treatment and support accordingly.
- Relapses can be discouraging for the person with the illness and the family. Consider the concept that relapses are learning opportunities rather than failures and provide positive support.
- Understand the person's perception of their problems and needs, work with what he or she wants to do about their behaviour, and respect his or her choices about lifestyle.
- Consider what behaviour is acceptable for you. Communicate this clearly and stay true to your word.
- Families experiencing the impact of dual diagnosis are subject to large amounts of stress. Taking steps to reduce it will improve everyone's wellbeing. Seek support where necessary to learn these skills and take care of yourself.

What can family and friends do to help?

In addition to the specific interventions previously mentioned, there are many things family and friends can do to help.

Always remember that dual diagnosis is a medical condition that requires medical treatment. Just as you cannot stop a person's bleeding by talking to them, you cannot stop a dual diagnosis without medical intervention. Treatment is effective.

Find out as much as you can about the condition. Knowledge is power and gives you a much better chance of developing good coping strategies.

Be patient. People experiencing dual diagnosis need to come to some insight regarding their illness. This is not always easy and takes time.

Know what to expect from the mental health system and be prepared to be assertive in seeking appropriate care. Link in with community organizations that offer support and services that complement the mental health system. They often provide educational programs, counselling and local support groups.

Remember to stay healthy yourself. Do not underestimate the impact of the illness on you. Episodes of dual diagnosis often involve trauma and grief and have an impact on whole families. Be prepared to seek support to develop strategies that keep you well.

Further help

Specific lists with phone contacts rapidly become out of date, so instead please call the Mental Illness Fellowship and we will provide a current contact number for the assistance you need.

Further reading

- Surviving Schizophrenia, A Family Manual E Fuller Torrey
- Ecstasy and Agony, Living with Mood Swings S Abraham
- Understanding and Coping with Schizophrenia Ken Alexander
- When Someone you love has a Mental Illness Rebecca Woolis
- Power over Panic Bronwyn Fox
- The Angry Heart, Overcoming Borderline And Addictive Disorders Santoro & Cohen
- Taming the Black Dog Bev Aisbett
- When Someone You Love is Depressed Rosen Epstien et al.
- Children of Parents with mental Illness Vicki Cowling
- Everything's All Right. About teenagers whose lives are affected by mental illness – their own or that of people closest to them. Crocker & Curry
- Mental Illness Fellowship Newsletter

Websites

- www.mifq.org.au
- www.schizophrenia.org.au
- www.sane.org
- www.depressionnet.com.au
- www.arafmi.org.au
- www.carersaustralia.com.au