

# family & carer support kit



Being informed helps to make better treatment choices.

early intervention services

## Introduction

The family is often the main source of ongoing support for people experiencing a **psychotic episode**. For both the young person & their family, the experience of this emerging illness may accentuate what is already a period of great change and uncertainty. What also is important, is the potential impact on the family unit and its day to day life.



Families and friends play important roles in supporting people with serious mental illness. Their participation also assists mental health services to improve

the health and well-being of the people for whom they care.

We know that having a mental illness affects not only the individual but also their family & friends. The impact on others will vary according to the severity, course and outcomes of the illness, as well as the life circumstances of the young person and their families and friends.

You may be a family member or friend providing support and assistance to this person, or you may just be concerned about their welfare and interested in finding out more about what help is available.

## Who Is a Carer?

Governments and many services use the word **'carer'** to identify the family members and friends of someone with a mental illness who help to look after (care for) this person.

Many carers don't think of themselves as a carer. They may be a parent of someone with a mental illness or an adult caring for a partner, parent or friend with a serious mental illness. A child who helps to care for another family member with a mental illness can also be a carer.

Many people become carers because they see it as their responsibility as the family member or friend of the person who is ill. Carers may not necessarily live with the person for whom they care. It is also important to realise that the role of carer may change over time.

Finding the right services and supports for young people with a mental illness can be difficult, and we hope you find this information helpful.

This family & carer information is intended to form one part of an overall package that includes an evening education & support program, opportunity for ongoing individual and group support, and involvement in the health care of the young person. It is intended for families of young people with emerging or newly diagnosed mental disorders.

## Family & Carer Information and support evenings



Throughout the year, Sydney South West Area Health and the Brain & Mind Research Institute will be offering these evening opportunities for families & carers.

Family group education is a powerful and viable resource for carers. It aims to increase

problem - solving abilities and reduce stress and anxiety, as well as promoting more enduring mutual support.

Family information and support evenings are offered to families and are facilitated by clinicians from the BMRI and SSWAH. The evenings are for families of young people with emerging or newly diagnosed mental disorders and provide the opportunity to meet, support and interact with other family members.

The program aims to reduce the level of distress and burden for the family, provide opportunities to ventilate concerns, promote constructive discussion and encourage enquiry and learning within a safe and confidential environment.

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## What is psychosis?

The word psychosis is used to describe conditions that affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode.



Psychosis is more likely to occur in young adults and is quite common. Around three out of every 100 young people will experience a psychotic episode - making psychosis more common than diabetes in young people. Psychosis can be treated and most people make a full recovery.

Psychosis can lead to changes in mood and thinking. A person may express ideas that seem strange or bizarre, making it hard to understand how the person feels and behaves. Often the person who experiences a psychosis for the first time may also not understand what is happening.

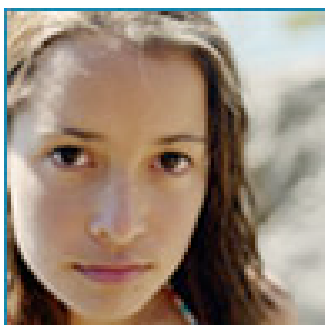
Many of the symptoms of psychosis can be very disturbing, leaving the person distressed, preoccupied and alienated from those around them. The symptoms of a psychotic episode can include:

- ❑ confused thinking - this may include difficulty with concentration and memory, conversations may not make sense or become illogical, thoughts become faster or slower
- ❑ changed feelings - this may change without any clear reason, they may feel separated from the world or their family, feel high (euphoric) or depressed
- ❑ changed behaviour - they may become more or less active, behave in a way that is different to how they describe their mood, behave in a different way than usual because of their ideas (e.g. not eating because the food has been poisoned, not leaving the home for fear of being followed, or argue with strangers because they think they are talking about them), laugh or be angry at the wrong times
- ❑ hallucinations - a person may see, hear, feel, taste, or smell things that are not there
- ❑ false beliefs - or delusions are very common for a person having a psychotic episode (e.g. secret plans others have about them, special meanings to ordinary events, having special powers, grandiosity, being persecuted, and paranoia)

*For more information & free fact sheets, visit; <http://www.eppic.org.au>*

❑ This section on Psychosis was compiled using information from EPPIC Youth Health Vic, Management of Mental Disorders – WHO 2nd ed., and Mental Health Association NSW Inc.

## What is Early Intervention?



Early intervention aims to give the right specialist treatment as early as possible. Early intervention aims to minimise the effect of an 'emerging' mental health problem by providing age appropriate help at the right time which suits the individual, their circumstances and the stage of the disorder. Most people with a mental illness do not first get sick overnight. The illness slowly gets worse over a period of time, sometimes weeks, months or years. This is what 'emerging' means. Treatment can be given before an acute psychotic episode begins.

The onset (or first episode) of a mental disorder mainly occurs in young people (twelve to 25 years) and generally affects both males and females equally. By far, mental disorders are the most significant health problem young people will face.

Often the biggest barrier to getting treatment is recognising the prodromal signs of psychosis before things get worse. The prodromal signs are the earliest signs of a psychotic episode. This time is often described as *'something is not quite right'*. It is the time between the first change from normal thinking, feeling or behaviour and the onset of psychosis. In Australia, it is thought that most young people will start to feel the effects of this prodrome for between two and a half and three years before getting specialised mental health treatment, after the psychotic episode has begun

Intervention as early as possible, when prodromal signs are first noticed, is very important. It decreases the disruption caused by the illness to the life's of the young person, their family and friends. Without early intervention, the illness can delay the young person's development to a mature adult, cause family and social problems and delay or stop them from studying or getting job. Other problems such as using drugs and alcohol (substance abuse), unemployment and behavioral problems may develop or get worse and the illness may also become worse. The earlier psychosis is recognised and treatment starts, the better the result in the future.

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## Who is a case-manager?

When young people are offered treatment they are allocated a Case Manager and often a doctor. The case manager is the main point of contact during a young person's involvement with the health service.



The case manager will:

- provide information about the mental health problems
- provide individual treatment that will help recovery
- introduce other services within and outside the health service that may be able to help – for example, with education, money matters, accommodation, or employment.

Case managers come from a range of backgrounds and qualifications. The case manager will be a qualified clinical psychologist, social worker, occupational therapist or registered nurse.

Doctors work as part of a team to help work out the difficulties being experienced, and the best way of treating them. The doctors will be psychiatrists (doctors who are specially qualified in treating mental illness) or registrars (doctors training to be psychiatrists).

Doctors have an important role in:

- diagnosing the mental health issue that a young person is experiencing
- making sure that the mental health issue isn't caused by any physical illness
- developing plans for treatment, including the use of medication
- monitoring your recovery.

*(information used courtesy of ORYGEN Youth Health)*



## Access to information



Mental Health Services should work closely with consumers and carers to meet their information and education needs. Depending on the type of service, this means working together about treatment and case management options, how to deal with difficult behaviours, how to find practical help and generally assist family members in dealing with the illness. How much information is provided may depend on how much the consumer wants you to be involved. This can be difficult. Mental health workers have a responsibility to talk as early as possible with the person with a mental illness about what information they want shared with the families and carers. If possible, carers may also want to sort out with the person with a mental illness and their mental health case

manager what they will be told or will then do if the person becomes unwell. Within the confines of the legislation, mental health services should aim to meet the needs of the person with a mental illness, their family members and other carers.

## Legislation (The law)

All public mental health services are governed by the Mental Health Act, and other laws. In general, information about the person with a mental illness cannot be given to anyone unless he or she gives consent.

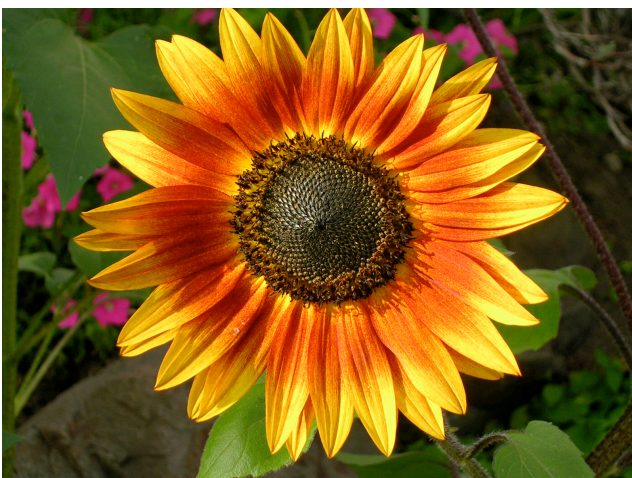
However, there are times (usually when the person is very unwell) when the Mental Health Act allows information to be shared by the mental health service without the person's consent.



Mental Health Services in NSW aim to provide the least restrictive care available. Most people with a mental illness get treatment without the need of legislative involvement. Sometimes the rights and wishes of the person will not be the same as the family or carer, particularly if the person with a mental illness does not want his/her family member involved. This may cause problems and frustration for everyone, especially the family or carers.

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## Carer Assist [Schizophrenia Fellowship]



Jan Doyle is the Carer Advocate for the inner west. She helps the family / carers of people with any mental illness / disorder with information, education, advocacy and support. This is provided in a number of ways:

- \* Helps you find your way around the mental health system
- \* Providing information on mental illness
- \* helping you care with the grief and other problems that mental illness can cause
- \* Finding support for yourself
- \* Providing access to information and services that you may need
- \* providing advocacy if you need it

Jan is normally in the office on Mondays, Tuesdays & Wednesdays and is happy to help carers in any way that she can. Tel: 9879 2600 Mob: 0423 767 012 Email: [jan@sfnsw.org.au](mailto:jan@sfnsw.org.au) Web: [www.sfnsw.org.au](http://www.sfnsw.org.au)

# Service contact lists

This kit aims to provide you with information about the types of services that may help your family. As phone numbers, the names of services and service locations change from time to time, not all contact details are listed. The mental health service you contact should have a more detailed list. You can also get phone numbers of community mental health services and hospitals from the front of the White Pages. The Rozelle Hospital can also give you after hours urgent information. The case manager or duty worker at the community mental health service should also have contact numbers.

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## What do I do in a [mental health] emergency?



Not all people with a mental illness end up in a crisis. However some people and their families do have very difficult and stressful times. In a crisis you may not know who and when to contact for help. The following information is provided to help you with any questions or concerns you may have, especially in a crisis or emergency.

### *What can I do to prevent a crisis?*

If you are concerned that the person in your family who has a mental illness is in a crisis, it is important that you talk to their Case Manager, GP or another person on the Community Mental Health Team. You can discuss with them what may be warning signs that show the person is becoming ill.

Telling these people your concerns may help to avoid a crisis. It is also a way of helping to plan what to do in a crisis to minimise the effect on the person and the family and assist with a speedy recovery.

### *Who should I call first?*

If you feel there is a crisis, then you should seek help, especially if you feel worried about your safety or the safety of your family member. Who you should call first will depend on the type of crisis or emergency and when it happens. If you do not know, you can ask your Community Mental Health Team.

### *During business hours*

The best person to speak to is your family member's Case Manager at their local mental health service. They will be the person who knows your situation, They will be able to support you and your family member to decide what to do next. If your family member's Case Manager is not available, another worker should be available through the Community Health Service.

Depending on where you live, the contact telephone numbers are:

For Adolescent Mental Health Services (under 18 years - Area wide services)

- Adolescent Mental Health Services: 9515 9000 (ask for Adolescent Team)

## For Adult Mental Health Services (18 years +)

- Camperdown Community Health Centre: 9515 9000
- Marrickville Community Health Centre: 9560 4500
- Redfern Community Health Centre: 9395 0444
- Croydon Community Health Centre: 9378 1100
- Canterbury Community Health Centre: 9787 0600

The Area Health Service also has a 24 hour toll-free Mental Health Access Line. This phone number will help you to find the information and service you may need. The number is 1800 626 825.

### ***If you, a family member or someone else is in danger***

If you or another person is in immediate danger then contact the police. After you have done this, you may also contact the Mental Health Service.

Police: 000

### ***If the physical health of your family member or another person is at immediate risk***

If someone needs emergency medical help then contact the Ambulance Service. This includes times when the person has caused serious physical harm to themselves, or has overdosed.

Ambulance: 000

### ***After hours and on weekends***

After hours and on weekends, contact the Acute Care Service (ACS) at your local community health centre, whose contact phone numbers are above. If you are unsure whether it is a mental health crisis or an emergency, you can call the ACS to talk about this over the phone and they will help you to decide what to do next. They may talk to your relative over the phone, arrange a home visit to assess them or ask your relative go to The Rozelle Hospital or The Missenden Unit for more help.

Telephone numbers you may find useful in an emergency

Police - 000

Ambulance - 000

Mental Health Access Line - 1800 636 825

Alcohol and Drug Information Service - 1800 422 599

Rozelle Hospital - 9556 9100

Lifeline - 13 11 14

ARAFMI - 1800 655 198 [Carers 24 hr support line]

# Where can I access reliable internet information?

(not listed in any particular order)

## Australian websites

### ***Reach Out!***

This is an interactive internet site for young people. There is information about the who young people can talk to about their problems and how to get in touch with services in their local area throughout Australia. [www.reachout.com.au](http://www.reachout.com.au)



### ***Somazone***

This is an interactive internet site for young people that is about general health and well-being. It has personal stories, a question & answer section and where to find support services in your area. [www.somazone.com.au](http://www.somazone.com.au)

### ***Headroom***

This website is designed by young people. It promotes mental and emotional well-being. It is for adolescents, children, families and friends, professionals and service providers. [www.headroom.net.au](http://www.headroom.net.au)

### ***Australian Drug Foundation***

The Australian Drug Foundation (ADF) works to prevent and reduce alcohol and drug problems in the Australian community. Click on 'DRUGHit', a site designed for young people that has information on different drugs, their effects, statistics and frequently asked questions. [www.adf.org.au](http://www.adf.org.au)

### ***beyondblue***

This national website strives to provide the best, most reliable and useful information. It also provides ways for people whose lives have been affected by depression to tell others about their experiences and concerns. The website explains the common symptoms of depression; provides information about the causes and treatments of depression; gives examples of people's treatment experiences; provides feedback to professionals about what consumers find most useful; provides links to other information services and support groups; gives hope and stories of recovery. [www.beyondblue.org.au](http://www.beyondblue.org.au)

### ***SANE Australia***

SANE is committed to improving the well being of Australians seriously affected by mental illness. This site offers information about mental illness for carers, family and friends. It has a bookshop, fact sheets, more links and an online helpline where you can ask questions about mental illness and other related topics. [www.sane.org](http://www.sane.org)

### ***Commonwealth of Australia Department of Health and Aged Care***

The Australian Government Department of Health and Aging aims to improve mental health outcomes in Australia by providing a national policy for mental health. Click on 'publications & resources' for mental health information for young people and parents. [www.health.gov.au](http://www.health.gov.au)

### ***Better Health***

This is the site of the Victorian Department of Human Services. It provides information on many health topics. [www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)

### ***Early Psychosis Prevention and Intervention Centre (EPPIC)***

EPPIC is a comprehensive service aimed at addressing the needs of young people aged 15-30 years who are experiencing, or who have experienced, their first episode of psychosis. [www.eppic.org.au](http://www.eppic.org.au)



### ***The Black Dog Institute***

The Black Dog Institute is an educational, research and clinical facility offering specialist expertise in mood disorders - a range of disorders that include depression and Bipolar Disorder. The Institute is attached to the Prince of Wales Hospital and affiliated with the University of New South Wales. [www.blackdoginstitute.org.au](http://www.blackdoginstitute.org.au)

### ***InfoXchange***

This site provides a lot of up-to-date information on services and other topics for young people, including health, employment and the community. [www.infoxchange.net.au](http://www.infoxchange.net.au)



### **International**

### ***American Academy of Child and Adolescent Psychiatry***

This site aims to help parents and families to understand developmental, behavioral, emotional and mental disorders affecting children and young people. [www.aacap.org](http://www.aacap.org)

### ***The Royal College of Psychiatrists UK***

Click on 'mental health information' for a list of comprehensive resources on mental health problems. [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

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## **What services are available?**



The Area Health Service - Eastern Zone, provides specialist mental health treatment to people living in Canterbury and the inner west areas of Sydney. Community Health teams can provide assessment, case management, youth group programs, family support, help with admissions to hospital, liaison, advocacy and referral to other specialist services.

Mental health services are provided throughout the community in a variety of places/services clinical streams. Young people and adults can get the right help for their age and the stage of their illness from adolescent and adult community mental health teams.

Adolescent and adult community mental health teams, child and family services, drug health services, GP's, non-government organisations and multicultural agencies, work together to provide the best treatment they can for young people and adults. This flexible approach to providing services is important to make sure that you get the help needed to lessen or even prevent the effects of the illness.

It is important for the young person, their family and close friends to understand as much as possible about the treatment of psychosis. Information helps everyone to recognise any symptoms, understand their relationship to stress, and helps the person to work towards recovery.

## Finding information on medications



Written information is available for all prescribed medications. This is called the Consumer Product Information (CPI). It is available from your chemist and should be included when the script is dispensed. The Acute Care Team, the Case Manager, treating Psychiatrist, General Practitioner or Consumer Consultants, may also provide copies to you. The CPI is a leaflet produced by the Pharmaceutical Company by Government regulations. It describes the symptoms and

disorders for which the drug can be prescribed, the side effects and any precautions or interactions with other medications. These information leaflets should not replace the discussions normally held with the prescribing Doctor. Any questions you may have after reading this information should be directed to the prescribing Doctor or your General Practitioner.

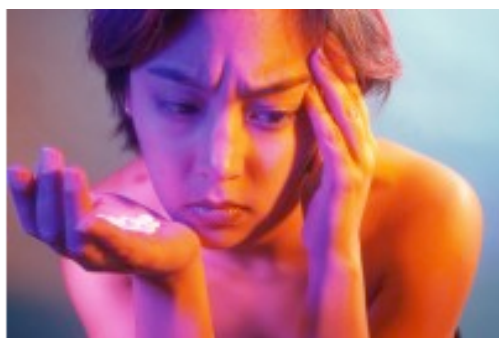
A list of all medications, current and past, including dosages should be kept along with any noted side effects, complications and benefits. The local General Practitioner should be seen regularly and informed of all current medications as well as any changes to doses and general physical health.

Some companies write an internet web address on the medication package for further information. These web sites will often have information on a wide variety of topics and include links to other specialist agencies. Some of these sites are listed in this family & Carer information package.

There are many books, internet sites, support lines and brochures that offer information on medications. Where as some of these may provide you with invaluable information, care should be taken to check the source, author's interest, the country and year of publication.

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## The impact of drugs and alcohol on mental health



### *Why do people use drugs?*

The reasons why individuals with a mental illness use substances vary. Those who do often say they get some kind of relief from distressing symptoms and to escape their worries. Substances are also chosen to relieve depression, to feel more normal, or to decrease the side effects of antipsychotic medication (Addington & Duchak, 1997). Other common reasons given for the use of alcohol and other drugs are to 'get high', to feel relaxed, to feel energetic, to give them confidence, because their friends do, or because they are

bored (Dixon et al., 1991; Noordsy et al., 1991). These are understandable reasons for drug use. However, if drug use continues, problems are likely to occur.

## Dual diagnosis:

The term dual diagnosis refers to the presence of both a substance misuse disorder and a separate mental illness.

### *Is dual diagnosis common?*

The combination of mental illness and substance abuse is so common that many health professionals now expect to find it. In the past, health services did not always recognise this problem. Now there is an increasing number of programs trying to address the treatment needs of people with both problems. It is now generally agreed that as many as 50 per cent of people with mental illness also have a substance misuse problem. The drug most commonly used is alcohol, followed by marijuana. Misuse of prescription drugs such as tranquilisers and sleeping pills is also common.

### *Will everyone have the same reaction to drugs?*

No, many factors will effect the type of reaction experienced. These factors include the individual characteristics of the person, their mood at the time of drug use, their environment, the amount of the drug used and the combination of drugs used. Drugs have the potential to trigger mental health problems or make symptoms in people already experiencing a mental illness worse.

### *Can using alcohol and other drugs cause mental illness?*

Many people are able to use substances without experiencing mental health problem as a result. Substance misuse may precede the onset of a mental illness and thus may be considered a trigger or cause. Although it is as yet unclear how this may happen, it has been suggested that repeated substance misuse may alter certain chemicals in the brain (Meuser et al., 1992). Substance misuse may also follow the onset of the illness and may be seen as an attempt to alleviate certain symptoms (Addington & Duchak, 1997; Dixon et al., 1991).

The vulnerability model is one theory used to describe the interaction between substance use and mental illness. Many treatment approaches use this model to explain dual diagnosis to people with a mental illness. The philosophy of this model is some people have a vulnerability to psychotic disorders. The individual who is 'vulnerable' to psychosis has a 'sensitive brain'. This brain is very sensitive to stress – either chemical or environmental. One of the major stressors that needs to be avoided or eliminated is substance use.

Substances make psychosis worse because they may increase or worsen positive symptoms. A possible consequence is more damage to an already vulnerable brain. Thus, it is not necessarily about disapproving of substance misuse, but rather of having a specific illness and stopping a behaviour that may make the illness worse.

### *What is the down side of drug use?*

It is understandable that people try to find something to help them feel better. However, there are a number of consequences from using drugs. These include:

- ❑ Alcohol and other drugs can stop many medications from working properly
  - ❑ Use of alcohol and other drugs increases the risk of relapse in someone who has experienced psychosis
  - ❑ Using drugs can prolong the duration of symptoms and reduce the person's chance of recovery
  - ❑ The desirable feelings produced are short lived, while the negative consequences may last a long time
- The problems or symptoms they are trying to escape from are still there once the effect of the substance has worn off
- ❑ Alcohol and other drugs can have a damaging affect on physical health, causing damage to including the heart and respiratory systems
  - ❑ When under the influence of alcohol and other drugs people may also engage in other risk taking behaviour

While this overview of the problem of substance misuse and mental illness is not a very positive one, there are some encouraging signs that better understanding of the problem has lead to better treatments.

## *What can family and friends do to help?*

Many family members and friends of people who use substances can feel powerless and distressed by seeing their family member or friend causing harm to themselves. Families may feel angry and blame the individual for being foolish and weak-willed. They may feel hurt when their child breaks trust by lying and stealing. But it is important to realise that mental illness and also substance abuse are disorders that the individual cannot take control of without professional help. Individuals with difficult problems such as concurrent mental illness and substance abuse misuse do not respond to advice like 'just say no' or 'snap out of it'. Medication combined with appropriate self-help and other support groups help most, but individuals are still likely to relapse.

Sometimes it is a friend or family member who notices that someone may be having difficulties with alcohol and other drugs. The family member or friend may want to sit down and discuss their concerns with the person. This should be done at an appropriate time, when the person is not intoxicated and everyone is calm and able to discuss the issue.

Supporting the person to find other ways of coping without drugs can be helpful. For example, if a person feels that they are using cannabis to deal with stress, they can approach this differently by learning other skills such as relaxation, gentle exercise and problem solving skills. The person should be encouraged to seek advice and support or to speak with their doctor or other health professional.

It can take a person time to realise that the negative effects of alcohol and other drugs outweigh the short term feelings they get from using substances. Some people may refuse to seek help. This can be a frustrating period for family or friends who want the person to stay well or get better. Caring for someone who is using substances can be like being on a roller-coaster, experiencing the highs and lows and not knowing what lies around the corner. Family and friends can be left feeling stressed and it is important that they feel they have support at this time.

## *Some suggestions*

- ☐ Remind the person that the drugs are harmful, or remind them how much alcohol they can drink safely
- ☐ Encourage open discussion about drug use
- ☐ Listen to the advantages your family member or friend sees in drug use, then ask them about the disadvantages. Sometimes the advantages are immediate, while the disadvantages occur later. This does make it hard for the person to stop
- ☐ Look for possible stressors which may lead to drug or alcohol use, and discuss ways of minimising these stressors (e.g. fights with family, pressure at work, boredom)
- ☐ Discuss other ways of coping with anxiety
- ☐ Make a firm rule about drug taking and excessive drinking. Be prepared to support the rule. This may involve giving rewards / privileges if your relative keeps the rule, and taking away privileges if they break it
- ☐ Get support for yourself. Join a family support group or self-help group
- ☐ Understand that relapse is part of the recovery process and have patience. Dual recovery may take months or years





## ***Try to avoid***

- ~ Nagging or criticising as this may make things worse
- ~ Getting into arguments about your rules or decisions
- ~ Setting a poor example by drug taking or heavy drinking yourself
- ~ Letting the family encourage drug or alcohol use
- ~ Allowing yourself to be talked out of sticking to a rule – it is important to be consistent

## ***Where can families go for more information and support?***

Links between substance use and psychotic symptoms can be talked about as part of case management and through group education programs. The case manager is responsible for the ongoing assessment of substance abuse, and can offer education about the effects of drugs and alcohol and interaction of these substances with psychosis. They also provide support and counseling about reducing or stopping substance use.

Drug and Alcohol teams might also support this work by offering an appointment to assess the client's substance use and by offering support, counseling, and referral to appropriate support groups. The care plan can then reflect a coordinated dual disorder approach including both services, with the mental health team continuing to provide case management.

## ***Drug and Alcohol Counseling Services***

- Central Information Lines                      Ph: 9515 6311
- Royal Prince Alfred Hospital                Ph: 9515 7611
- Concord Hospital                                Ph: 9767 8320

## ***Self-help groups***

Family Drug Support (FDS) (20 Page Avenue, Ashfield) runs an open support group each Monday night from 7 to 9pm to provide support and information for family members and friends of people affected by drugs and alcohol. The person with the problem does not have to be in treatment for family members to participate in this group. The group is open to anyone and provides opportunities to talk and listen to others in a non-judgemental, safe environment. Ph: 9818 6166 or 1300 368 186 (24 hour telephone support).

NAR-ANON is a support group for people affected by another's drug use: 9418 8728 (24 hours)

Al-Anon: Support for family members of people with problematic alcohol use: 4969 3889.

## ***Telephone numbers and websites for more information***

Alcohol and Other Drugs Information Service (ADIS) - provides a 24 hr phone service that offers information, counselling and support on drug and alcohol issues. It also provides information regarding all current Drug and Alcohol agencies across NSW. Phone: 9361 2111 (Sydney) 1800 422 599 (outside Sydney, toll free).

[www.ceida.net.au](http://www.ceida.net.au) - The Centre for Education and Information on Drugs and Alcohol (CEIDA) provides information and professional development services to the health and related fields in New South Wales. CEIDA is based in Sydney, NSW, Australia and is funded by the NSW Health Department.

[www.adf.org.au](http://www.adf.org.au) - The Australian Drug Foundation

[www.fds.org.au](http://www.fds.org.au) - Family Drug Support provides a Guide to Coping resource

[www.swsahs.nsw.gov.au/areaser/midas/default.asp](http://www.swsahs.nsw.gov.au/areaser/midas/default.asp) - MIDAS, dual diagnosis services: a reference point for information including links to programmes in Australia and overseas which are independent of SWSAHS

# We can all help. Together.



## **How should I relate to the person who is unwell?**

If you are with a person when they are psychotic and behaving strangely, you may feel frightened or frustrated. It is important to remember that they are still your son, daughter, brother, sister, wife, husband, partner or friend. It is very difficult for a person who is ill to be how they usually are. Often families and friends ask how they should behave and talk to a person who is psychotic. There are no set rules, however, some general guidelines can be helpful.

- ❑ Be yourself
- ❑ Get information and understand that the person may be behaving and talking differently due to the psychotic symptoms
- ❑ Understand that psychotic symptoms are stressful for everyone and that you may have a range of feelings – shock, fear, sadness, anger, frustration, and despair
- ❑ Talking with other people will help you to deal with these feelings
- ❑ Believe a person will recover – even if it takes time. Be patient
- ❑ Try not to take it personally if a person says hurtful words to you when they are unwell
- ❑ When a person is in an acute stage they may seem child-like. Sometimes they need to be in a safe, comforting environment and sometimes they need others to help with decisions
- ❑ When a person has acute psychotic symptoms they may be fixed in their beliefs and ideas. Don't get involved in long disagreements. Listen with interest to gain an understanding of their current reality and for future reference, to discuss when they are better

*Prescribed Medication (antipsychotics) is often effective in reducing or stopping voices, though it can sometimes take up to several weeks before they work well.*

**Managing hallucinations** - When your relative sees or hears things that you do not see or hear, or when they talk to themselves or to ‘voices’.

Try to:	Avoid:
Act calm Offer distractions Involving them in something interesting Asking them to help you with tasks around the home Engaging them in pleasant conversation Encouraging them to be with people they know well	Panic or assuming that another acute episode is occurring Acting frightened Trying to figure out what the person is talking about or to whom they are talking Letting others laugh about these hallucinations or strange talk Asking them to try to force the voices to stop

**Managing ‘voices’** - In addition to the above strategies, you may find these useful:

- ☐ Providing distractions by deliberately shifting attention away from the voices and on to things outside themselves, e.g. keeping busy, or a change of environment
- ☐ Contact with other people
- ☐ Physical activity, either by increasing or decreasing
- ☐ Relaxation techniques
- ☐ Vocal activities such as talking or singing
- ☐ Changing the level of auditory stimulation they are experiencing eg. listening to music with headphones or reading in a quiet room
- ☐ Show some understanding of the person's feelings (eg. fear of the voices)

**Managing strange talk or beliefs** - Some people will say things in conversation that may seem bizarre

Try to:	Avoid:
Gently and matter of factly disagree with bizarre ideas Encourage the person to talk normally or sensibly Change the subject to something routine, simple or pleasant in real life (eg. what you are making for dinner) Say that you don't understand Say when you think something is not real, while acknowledging that they seem real to your relative Help the person to tell the difference between reality and fantasy by dispelling false ideas and beliefs, giving examples Encourage the person to talk about their strange ideas only to certain people, such as their doctor, case-manager or close, supportive friends and family	Allowing the family to make jokes or criticise the person Arguing about strange ideas Spending too much time listening to talk that makes no sense to you Pretending to agree with strange ideas or talk you can't understand Keeping up a conversation that you feel is distressing, or annoying, or too confusing for you Looking horrified or embarrassed by strange talk. It's better to say that you don't like what is being discussed

## ***Managing withdrawal***

Some people may withdraw or isolate themselves from family and friends.



### ***In the first 6 to 12 months:***

Try to	Avoid
<p>Allow them time alone, but make contact when they come out of their room. Let them know you are there if they need you</p> <p>Remember that some medications make people sleepy</p> <p>Gently encourage other activities that are not too physically demanding</p> <p>Go out with your friends, maintain contact with your supports</p> <p>Encourage healthy eating</p>	<p>Taking it personally or blaming yourself</p> <p>Trying to keep dragging the person out of their room</p> <p>Wearing yourself out trying to change them</p> <p>Worrying or fussing too much over them</p> <p>Inviting lots of visitors home. It may be too overwhelming</p> <p>Making them to talk to people</p>

### ***After 6 to 12 months:***

Try to	Avoid
<p>Slowly encourage an increase in activity throughout the day</p> <p>Encourage them to get up earlier in the day, perhaps with a promise of breakfast or going out</p> <p>Support and acknowledge their efforts</p>	<p>Thinking you always need to be protective</p>





### Managing inactivity

It is common for people to increase the times they spend sleeping or resting, often saying that they do not feel like doing anything.

**Try to:**

- Allow the person to be alone
- Offer or suggest simple activities such as watching television, listening to music, going for a walk
- Suggest a variety of activities, building up to those that take more effort
- Try to encourage a daily routine that includes the whole family so that things are predictable
- Encourage healthy eating, with fruit for snacks
- As the symptoms improve, encourage participation in the family routine and household chores
- Acknowledge the efforts being made
- Remember that they may be easily distracted, finding it hard to finish specific tasks
- Talk together and with their case manager or doctor about rehabilitation programs

**Inactivity: Avoid**

- Insisting that they are active
- Overwhelming them with too many suggestions at once
- Criticising them
- Forcing them to talk to people
- Expecting them to do things that may be too confronting (e.g. going out to a party) or those they find confusing
- Giving too many instructions at the one time
- Telling them they are lazy
- Wearing yourself out trying to do everything



### Managing dependency

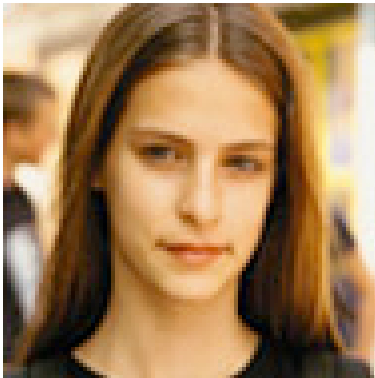
Some people will come to rely upon others, seeking comfort, reassurance and security.



Try to:	Avoid:
Gradually set clear limits that allow more responsibility without too much stress	Doing everything for the person
Allow some regular time just for yourself	Being the only one they socialise with
Be aware of the person's needs, but look for opportunities to encourage them to take responsibility	
Help them plan tasks in detail to assist in making tasks possible to achieve	

## Managing odd behaviour

Strange behaviour is caused by a variety of things, such as intrusive thoughts, compulsions, hallucinations or feelings of detachment from reality.



### Try to

- Remember that you are not responsible for this behaviour
- Ask the person clearly and kindly not to do that particular behaviour
- If they are unable to limit the behaviour, ask them to do it only in their room
- State clearly that the behaviour may seem strange to others
- Acknowledge them when they have been able to limit the behaviour
- If the behaviour seems to be set off by stress, see if the stress can be reduced

### Avoid

- Telling yourself that the behaviour is a reflection of you or your family
- Acting upset
- Getting into long discussions
- Letting the family pay attention to the behaviours or laugh at the behaviours
- Nagging the person about the behaviour

## Managing suicidal thoughts

People who experience mental illness sometimes think or talk about suicide. If this happens, do not worry about this silently, discuss it openly with the person and the **Mental Health Team**. They will provide advice and support.

Talk about these thoughts with the person. Stay calm and reassure them that such ideas are not uncommon for people who experience mental illness, and that the thoughts do not mean that they will really harm themselves

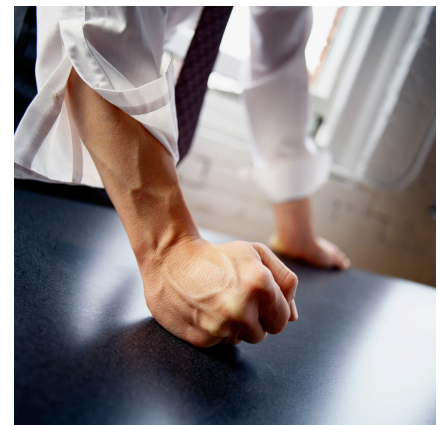
Discuss with the person why they have these thoughts. People often think this way at a particular phase of their illness. For example, in the early stage of a breakdown when the fear of losing control can be very frightening. They may also be

afraid of developing a severe or chronic illness. It will help to maintain a positive attitude and reassure them that they can get better, but it may take a little time

Suggest things to distract the person from these thoughts, especially things that are easy to do and which will encourage a sense of achievement

Maintain open communication with the Mental Health Team, tell them about all of your concerns, and ask for strategies to help

## Managing aggression



Behaviour that is aggressive (intimidates or makes you worried for yourself) or that is violent (where actual harm is done to you) can happen in a number of ways.

### **With psychotic symptoms:**

If this behaviour is associated with symptoms such as delusions, hallucinations or disordered thinking, then health professionals should be involved promptly to see what medication is needed. Aggressive behaviour can sometimes be a sign that someone has stopped taking their medication

**With extreme stress:** Outbursts of aggression sometimes occur because the person feels under great stress. This can happen because we are too demanding, critical or even too cautious. It is natural to do this when we are concerned about someone, but it is even more important to be open and relaxed. This means keeping calm and reacting to frustrations in as calm a way as possible

**With abuse of drugs or alcohol:** Aggression and violence are especially associated with these factors. It is very important that you get help from a health professional

**With helplessness or fear:** Aggression or violence can be a reaction to feelings of frustration caused by the mental illness. Try to find out what causes these feelings and encourage positive ways of handling them

**With manipulation:** Aggression can sometimes be a way of making you do what someone wants. If someone frightens us we are likely to do what he or she tell us. This of course, only encourages more of the same behaviour. A situation such as this can be very difficult to manage

## **Try to deal with aggressive behaviour in the following ways:**

**Avoid confrontation:** Sometimes it can be best to leave the person until they calm down and become reasonable again

**Speak firmly:** Sometimes a very firm "Please stop" helps a person regain control



**Have a plan:** If aggressive behaviour continues, make a plan that means people can be safe and call help quickly. This means planning what to do beforehand, with others who can be contacted, such as a mental health crisis team, police or a neighbour who can call for help

## **Suggestions to help things run more smoothly**

**Go slow:** Recovery takes time. Rest is important. Things will get better in their own time

**Keep it cool:** Enthusiasm is normal. Tone it down. Disagreement is normal. Tone it down

**Give each other space:** Time out is important for everyone. It's OK to reach out. It's OK to say "no"

**Set limits:** Everyone needs to know what the rules are. A few good rules keep things clear

**Ignore what you can't change:** Let some things slide, but don't ignore violence

**Keep it simple:** Say what you have to say clearly, calmly and positively

**Follow the Doctor's advice:** Take medications as they are prescribed. Take only medications that are prescribed but do not be afraid to ask the doctor questions

**Carry on business as usual:** Re-establish family routines as quickly as possible. Stay in touch with family and friends

**No street drugs or alcohol:** They make symptoms worse

**Pick up on early signs:** Note changes and tell your doctor

**Solve problems step by step:** Make changes gradually. Work on one thing at a time

**Don't expect too much too quickly:** Compare this month to last month rather than last year or next year

# Taking care of yourself



Family, partners and friends are important in the process of recovery. When a person is recovering from their psychotic episode you can provide love, stability, understanding and reassurance, as well as help with practical issues.

However, you may need your own period of recovery and adjustment to all that has happened. It can be useful to understand some of the stages you may have gone through. It is quite common for families

and friends to go through the following stages:

1. Initially you may be in crisis as you become aware that something serious is happening and your family member or friend is unwell. You may feel very anxious, worried and frightened at this time
2. As it becomes clear that something is not quite right you start to seek help. This is also a time where you may be adjusting to the fact that your family member or friend is unwell and the situation cannot be left to clear up by itself
3. As you find help you will probably have lots of questions and worries. What is happening? What is psychosis? What causes it? Will this happen again? How is it treated? What can we do to help? What will we tell other people? Will your family member or friend understand why help was needed? Should we have got help earlier? You will have mixed emotions and reactions during this time
4. As the person begins to recover and starts to show signs of being well, you may feel a lot of relief and pleasure. You may also have started to understand the illness more by this time and start to feel more hopeful about the future
5. As the person gets better you may find your anxiety, questions or worries start to increase again as they starts to reintegrate back into the family and community. Often family members find themselves watching the person for signs of relapse or strange behaviour. You may feel protective and anxious, wanting the patient to be well as quickly as possible and not do anything that may cause a relapse. It can be difficult balancing the needs for independence and care
6. As recovery continues, there is a gradual adjustment by everyone concerned. You feel reassured that recovery is occurring and some normality returns to your life. You speak with the patient about psychosis, what it was like for everyone and how to help each other in the future

Remember that families, partners and friends also need a period of recovery, some time to understand and accept what has happened.

## Carers New South Wales

National Carer Counseling Program 1800 242 636

This counseling program provides: short term counseling (up to 6 sessions) delivered by qualified, professional counselors. It targets the specific needs of carers. It is confidential, safe and non - judgmental. The counseling can be face - to - face, telephone or group telephone counseling.

### The 8 Stages of Healing

This course run by Carers NSW aims to assist carers to work through their own healing process by introducing alternatives to common patterns of coping. The course is based on the idea that healing ourselves assists with healing our family relationships & our community.



# Some ways to take care of yourself

**Talking** - Talking to friends, family or a counsellor about your thoughts and feelings can help sort out problems. It can also help relieve stress and anxiety.

**Eat, sleep and exercise** - often getting enough sleep, eating properly and exercising (even a little!) will help you feel better, even if it does not solve all your problems

**Relax** - Most of us need to learn how to relax. Choose a technique that suits your personality and lifestyle. There are many books, tapes and courses about relaxation.

**Seek help** - Sometimes a problem is hard to solve alone or with the help of friends and family. At these times it can be important to get professional advice or help.

**Think and feel** - Take some time each day to think or read. This helps us to get to know ourselves and perhaps change the way we see or feel about life.

**Join a support group** - Just talking to other people who understand what you are going through can relieve stress and help you to cope.



## The impact on the young person

A young person's first experience of a mental health problem often happens at a time when it can interrupt their personal development. The impact this may have on the young person (and their family) can be minimized and the longer-term outcomes improved by working out together, the different treatments needed and providing support services that best suits the person. The aims of developing programs is to halt the progression of an illness, promote engagement with health services, commence the recovery process and reduce any experienced trauma.

## The impact on the family / carers

What is crucial to appreciate and address is the impact and vulnerability of the family unit in its routine functioning, role changes, projected ambitions, emotional responses and perceived helplessness. The experience of an emerging mental illness, accentuates what is already a period of great change and uncertainty.

## Looking for more to read?

*The Guide for Carers: Family and friends of people with a mental illness. The Guide to Planning Ahead: Carers of people with a psychiatric disability. The Guide to Psychosis & The Guide for Brothers and Sisters.*

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



*Carer Support: Looking after Yourself.* From the Carer Resource Centre.  
1800 242 636

*Coping with Mental Illness: A handbook for family carers.*

*Hidden Victims - Hidden Healers*, an 8 step process (1989) Julie Talard Johnson, Pema Publications

*The 8 stage healing process - a guidebook for facilitators* (1989) Julie talard Johnson & Kristine Merrill Pema Publications

*(all of these 3 books are available through ARAFMI)*

# Sydney South West Area Health Service

From January 1st 2005, New South Wales Health combined the Central Sydney Area Health Service (CSAHS) with the South Western Sydney Area Health Service (SWSAHS) to become the Sydney South West Area Health Service (SSWAHS). However, services provided within Local Government areas will continue unchanged.

The Area Health Service provides different services for children and adolescents, adults and older people. Which service you go to depends on where you live and the age of the person who is ill and needs help. The staff member at a health service you first go to should be able to provide this information.

SSWAHS looks after all public hospitals and healthcare facilities in central and south western Sydney from Balmain to Bowral. The head office is located at Liverpool Hospital.

We provide healthcare to more than 1.3 million people over 17 local government areas. Further information on any changes is available from the website: <http://www.sswahs.nsw.gov.au> or by phone on 9828 5700.

