

Severe mental illness (psychosis)

Introduction

This leaflet is aimed at:

- the carers of people with severe mental illness (psychosis) who provide continuing help and support, without pay, to a relative, partner or friend;
- the psychiatrists and other members of the mental health team involved in the care and treatment of the person with severe mental illness.

It suggests ways of improving communication and liaison that allow mutual respect and real working partnerships to develop from the point of diagnosis.

For the carer

About psychosis

Psychosis is a word used to describe symptoms or experiences that happen together. Each person will have different symptoms, the common feature is that they are not experiencing reality like most people.

Some people only have a single episode and make a full recovery; for others, it is a longer process. As 1 in 10 people with psychosis commit suicide, it is important to recognise the symptoms of depression. A person with psychosis may:

- hear, smell, feel or see things which other people do not (hallucinations)
- have strange thoughts or beliefs which may make the person feel they are being controlled, persecuted or harassed (delusions)
- have muddled or blocked thinking (thought disorder)
- at times seem unusually excited or withdrawn and avoid contact with people
- not realise that there is

anything wrong with themselves (lack of insight).

Early changes in the person's behaviour

As a carer, you may notice that the person:

- has problems understanding reality and thinking clearly
- talks to themselves and/or appears to be listening to something else
- has problems communicating effectively
- loses interest in their personal appearance and life in general
- is restless, irritable or tense and anxious
- avoids other people
- is aggressive or violent (in a minority of cases)
- be very high 'manic' or very low 'depressed', or swing from one state to the other (manic depression).

Making a diagnosis

There is no single specific test for psychosis as the symptoms are common to a number of disorders, including schizophrenia, manic-depression/bipolar disorder and psychotic depression.

A diagnosis is made by talking to the person and a close relative or friend to get an understanding of the person's history, as well as considering all other possible causes for the symptoms.

Treatments

Medication should be started as soon as possible to help the most disturbing symptoms and can make it possible for other kinds of help to work. Other treatments used together with medication, or on their own, include talking therapies (psychotherapy), and

Cognitive Behavioural Therapy (CBT). Family Therapy can be an important part of the care package.

As the carer, you may feel:

- guilty
- worried that you are losing the person you knew
- wonder if anyone else in the family will be affected
- exhausted by caring and ensuring that the person is safe
- scared about admitting there is a problem
- worried about the long-term outcome for the person
- worried about coping and getting help
- worried about the long-term financial responsibilities of caring
- worried about people's negative attitudes towards mental illness and the stigma associated with it.

Tips for carers

In partnership with your doctor and members of the mental health team

Good communication between a doctor, members of the mental health team, a person with psychosis and their carer is important, but takes time and effort. Forming a positive, long-term relationship with all the staff and doctors involved in the care of the patient is especially important if the condition is long-term.

If the person has the symptoms for the first time, it is important to see the GP as soon as possible. The GP, or a member of the Community Mental Health Team (CMHT), will make the initial assessment before referring the person to a

specialist. If the person refuses to see a doctor, the carer or another trusted person should try to persuade them to accept professional help.

The person may not need to go into hospital, as assessment and treatment can now be done at home by CMHTs.

Some of the specialists you are likely to come across are: psychiatrists, psychologists, counsellors, occupational therapists, social workers, community psychiatric nurses and support workers.

Questions to ask the doctor

- What does the diagnosis mean?
- Can you explain it in a way that I will understand?
- Are there any treatments?
- Where can I get information about medication and possible side-effects?
- How long will it take for the medication to work?
- Are there other things we can do to help ourselves?
- What can we expect in the near future and over time?
- Will the person be able to continue in work or in education?
- Is it safe for the person to drive?
- Will the person I care for get better?
- How often should I come and see you?
- Can you give me an out-of-hours emergency telephone number?
- Do you have any written material on this disorder, if not who does?
- Is there anything that we can change at home to make things easier, or safer?
- Are there any organisations or community services that can help?

- Which health service worker is my main contact for guidance and advice?

Remember to arrange your next appointment before you leave.

Regular well prepared visits to the doctor, or other members of the mental health team, will help get the best care for both of you.

Advice which will help you prepare for follow-up visits

- Keep track of changes in behaviour and reactions to medication in a notebook, along with any concerns or questions since you last saw the doctor.
- Look at the information you have collected since your last visit and write down your top three concerns. This will make sure that you remember to talk about the things that matter. Your concerns may include questions about:
 - changes in symptoms and behaviour
 - side-effects of medication
 - general health of the patient
 - your own health
 - additional help needed.

During your visit

- If you do not understand something, ask questions. Do not be afraid to speak up.
- Take notes during the visit. At the end, look over your notes and tell your doctor what you understood. This gives your doctor a chance to correct any information or repeat something that has been missed.

Further tips for carers when dealing with doctors and other members of the mental health team

Doctors and healthcare professionals can be reluctant to discuss a person's diagnosis or

treatment with the carer. There is a real duty of confidentiality between the doctor and the patient. If the person is too ill to understand what is going on, doctors will usually involve the carer in discussions and decisions. (See our leaflet Carers and confidentiality in mental health).

If the doctor is unwilling to involve you as the carer, there are a number of things you can do:

- ask the person you care for if you can be with them at some of their appointments, or for a part of their appointment
- talk with other carers as they may have some helpful suggestions
- try to talk to other members of the mental health team
- contact mental health charity helplines (list at end of leaflet).

Don't forget to take care of yourself and make time for you

It is important that you also take care of your own needs, talk about your worries and don't struggle alone. If you live in England, you may be entitled to a carer's assessment to identify your needs. This can be arranged through the doctor or a member of the mental health team. They should also be able to refer you to your local carers' support organisation.

For the professional
As a professional working with people with psychosis and their carers, we hope that the following is a helpful guide to good practice.

When doing an assessment, do you?

- Try to see the patient and the carer separately, as well as together



- Try to see them at home first

Do you allow yourself enough time to?

- Listen, and, listen
 Obtain a life history
 Leave time for questions and discussion
 Explain how you arrived at the diagnosis
 Talk about the prognosis

In the management of the illness, do you?

- Discuss possible treatments
 Talk about the possible side-effects of drugs
 Talk about the importance of the patient maintaining positive social roles, work or education goals, if possible
 Spend time asking about the carer's health – physical and emotional
 Discuss how to meet the care needs of both the patient and the carer.

Points to remember

- Everyone needs some respite.
- Make it clear that you will be happy to talk to other members of the family.
- Refer everyone you see to a relevant mental health or carer organisation.
- Make it clear that someone will always be available.
- Give an out-of-hours telephone number.
- Make sure that there is a named professional person whom the family can contact at any time.
- When you write your letter to the GP, consider sending a copy to the patient and carer.
- Try to talk to the GP on the telephone as well as writing.
- Make sure the patient and the carer have adequate information about their care and treatment.

Further help

MIND

Granta House, 15-19 Broadway,
London E15 4BQ.

Mindinfo: 0845 766 0163.

Publishes a wide range of literature on all aspects of mental health. www.mind.org.uk

Rethink

30 Tabernacle Street, London
EC2A 4DD.

National Advice Service: 020

8974 6814. Voluntary

organisation that helps people with severe mental illness, their families and carers.

www.rethink.org

Manic Depression Fellowship

Castle Works, 21 St George's
Road, London SE1 6ES.

Tel: 08456 340540. National user-led organisation providing support and information.

www.mdf.org.uk

The Princess Royal Trust for Carers

Further information for carers is available from

The Princess Royal Trust for Carers,

142 Minories, London EC3N 1LB.

Tel: 020 7480 7788;

www.carers.org