With grateful thanks to Dr Mike Launer, Consultant Psychiatrist and Sheena Foster for producing this leaflet.

This leaflet has been produced as part of a joint campaign between the Royal College of Psychiatrists and The Princess Royal Trust for Carers. One of the aims of the campaign is to show that if all those involved in the care of people with mental health problems or learning disabilities can work together, a trusting partnership can develop between carers, patients and professionals which will be of benefit to all.

The Partners in Care campaign has produced a checklist for carers of people with mental health problems designed to help them get the information they need. This leaflet is part of a series of leaflets for carers of people with specific mental health disorders. www.partnersincare.co.uk.

For copies of this leaflet and details of other materials produced by the Partners in Care campaign, contact the External Affairs Department, Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG. Tel: 020 7235 2351 exts. 131 or 127; or e-mail: awedderburn@rcpsych.ac.uk or dhart@rcpsych.ac.uk.

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Severe mental illness (psychosis)

Working in partnership with psychiatrists and carers

Partners in Care

Working together to make a real difference
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 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.

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.

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.

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).

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 implications of caring
• worried about people’s negative attitudes towards mental illness and the stigma associated with it.

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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