



*National Institute for
Clinical Excellence*

*National Institute for
Clinical Excellence*

11 Strand
London
WC2N 5HR

www.nice.org.uk

Treating and managing schizophrenia (core interventions)

**Understanding NICE guidance –
information for people with schizophrenia,
their advocates and carers, and the public**

December 2002



Corporate member of
Plain English Campaign.
Committed to clearer communication.

197

**Treating and managing schizophrenia (core interventions)
Understanding NICE guidance –
information for people with schizophrenia, their advocates
and carers, and the public**

Issue date: December 2002

To order copies

Copies of this booklet can be ordered from the NHS Response Line; telephone 0870 1555 455 and quote reference number N0177. A version in Welsh and English is also available, reference number N0178. Mae fersiwn yn Gymraeg ac yn Saesneg ar gael hefyd, rhif cyfeirnod N0178. The NICE clinical guideline on which this information is based, *Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care*, is available from the NICE website (www.nice.org.uk). Copies can also be obtained from the NHS Response Line, reference number N0176.

***National Institute for
Clinical Excellence***

11 Strand
London
WC2N 5HR

www.nice.org.uk

ISBN: 1-84257-258-X

Published by the National Institute for Clinical Excellence
December 2002

Design by Anytime After 9 Ltd

Printed by Abba Litho Sales Limited, London

©Copyright National Institute for Clinical Excellence, December 2002.
All rights reserved. This material may be freely reproduced for
educational and not-for-profit purposes within the NHS.
No reproduction by or for commercial organisations is allowed
without the express written permission of the National Institute for
Clinical Excellence.

Contents

About this information	2
Clinical guidelines	3
What the recommendations cover	3
How guidelines are used in the NHS	5
If you want to read the other versions of this guideline	6
About schizophrenia	6
Development of the first illness	7
When people have a 'breakdown' (the acute episode of schizophrenia)	8
Helping recovery	8
Guideline recommendations	9
Care you can expect in all stages	10
The first illness (leading up to the first breakdown)	13
If you have a breakdown (an acute episode of schizophrenia)	14
Helping you recover	23
Further information	34
Glossary	35

About this information

This information describes the guidance that the National Institute for Clinical Excellence (called NICE for short) has issued to the NHS on schizophrenia. It is based on *Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care*, which is a clinical guideline produced by NICE for health professionals working in the NHS in England and Wales. Although the information in this booklet has been written mainly for people with schizophrenia, it may also be useful for family members, those who care for people with schizophrenia, advocates (people who can liaise with the professionals on your behalf, especially if you are very ill) for people with schizophrenia, and anyone with an interest in schizophrenia or in healthcare in general.

This booklet briefly describes schizophrenia, how it starts and what life changes it may bring about. It also will tell you about the stages of the illness, and what treatment and care you should get when a person first becomes ill, when he or she has further breakdowns and what help a person should get to help him or her recover. It will tell you about the main treatments that should be available, including the teams and services who can help, the medicines that work best, and the psychological and family help.

There is also a glossary explaining some of the technical words used.

Clinical guidelines

Clinical guidelines are about improving the care and treatment provided in the health service. The schizophrenia guideline produced by NICE has been prepared by health professionals, a group of people who represent those who use the health service (known as 'service users') and scientists with knowledge of schizophrenia. The group has looked at the evidence available on the best way of treating or managing schizophrenia and made recommendations based on this evidence.

There is more about NICE and the way that the NICE guidelines are developed on the NICE website (www.nice.org.uk). You can download the booklet *The guideline development process – information for the public and the NHS* from the website, or you can order a copy by phoning 0870 1555 455 and quoting reference number N0038.

What the recommendations cover

NICE clinical guidelines can look at different areas of diagnosis, treatment, care, self-help or

a combination of these. The areas that a guideline covers depend on the illness or disorder. The recommendations in *Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care* cover psychological treatments, treatment with medicines, and how best to organise mental health services in order to help people with schizophrenia. The guideline concentrates on services for adults of working age with schizophrenia. It doesn't look at schizophrenia in childhood or schizophrenia that starts in later life (starting over 60 years of age). And it doesn't look at the special problems of people with schizophrenia who also have learning difficulties, or hearing or sight problems, or at the additional problems of people with schizophrenia who also have problems with alcohol or drug misuse, or who are homeless (although we say something about this, we don't look at their specific problems in a detailed way). The guideline will only tell you a little about diagnosis and assessment methods. These areas may be covered by future guidelines.

This guideline will help you understand what kind of treatment (medicines and psychological therapy) and services are of most help to people with schizophrenia, and whether treatment is given as an outpatient, by a community mental health team, as an inpatient or in any other mental health service. It will also tell you about

what your GP can do to help. A glossary describing some of the unfamiliar words and phrases used is included at the end.

The information that follows tells you about the NICE guideline on schizophrenia. It doesn't try to explain schizophrenia or describe the treatments in detail. If you want to find out more about schizophrenia, NHS Direct may be a good starting point. You can call NHS Direct on 0845 46 47 or view the NHS Direct website at www.nhsdirect.nhs.uk.

How guidelines are used in the NHS

In general, health professionals working in the NHS are expected to follow NICE's clinical guidelines. But there will be times when the treatments recommended will not be suitable for some people because of their specific medical condition, their general health, a person's wishes or a combination of these. If you think that the treatment or care you (or someone you care for) receive does not match the treatment or care described in the pages that follow, you should discuss your concerns with your psychiatrist, GP, advocate or other members of the mental health team.

If you want to read the other versions of this guideline

Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care, a guide for professionals, and the full guideline (which contains all the details of the guideline recommendations and how they were developed) are both available from the NICE website (www.nice.org.uk).

About schizophrenia

Schizophrenia is a serious illness that affects about 1 in every 100 people at some time in their life. When people are ill with schizophrenia they usually hear voices (hallucinations) and develop strange ideas and beliefs that others don't agree with (delusions), although exactly what types of symptoms a person has is very individual. The first illness most commonly starts when a person is between 20 and 30 years old, although it may begin in the teenage years. Although schizophrenia is a serious illness there are many ways to help and a number of people get better, sometimes for good.

After the first breakdown, around one person in five is never ill again. But seven out of ten

people have at least two breakdowns (known as 'acute episodes'), with the second usually happening within 5–7 years of the first. Although typically there's a pattern of repeated acute episodes, schizophrenia varies considerably between people. For example, some people may have only one relatively brief episode, while others experience symptoms for an extended period of time. Some people recover completely between episodes of illness, while others continue with some symptoms even when they're not acutely ill. For a small number of people, the illness develops into a chronic (long-lasting) disorder in which a person is never free of symptoms despite treatment. However, with treatment, the majority of people tend to improve or recover.

Development of the first illness

When the symptoms of schizophrenia first begin to develop, many people lose interest in ordinary things and relationships. They may appear odd and different to others. The symptoms may also come and go in the early stages of the illness – often they're noticed by a person's family or friends before the person becomes aware of them. When this happens, people with schizophrenia often feel that their world has changed and may say this is because of reasons that might seem far-fetched or odd to

others, or reasons that might not appear to connect to the problem. Usually relatives and friends also notice that the person has changed 'in themselves'. Quite commonly, the illness will affect the person's ability to work, go to school or college or relate to friends and family. Without treatment, most people become much more obviously ill, and this is what's known as an acute episode.

When people have a 'breakdown' (the acute episode of schizophrenia)

When people become unwell, they may hear voices, have strange thoughts and ideas, and feel and behave differently. The symptoms can be very distressing for the person affected, their family and friends. At times, people who are ill may become very withdrawn and have trouble talking to other people, and even neglect themselves. The illness can also make people do or say things that they would not normally do, including unexpected outbursts of anger or upset. It can be difficult to understand them and their experiences.

Helping recovery

When people have been unwell, it's very important to make sure they can continue to get

help and treatment to aid recovery and lower the chances of them becoming ill again. Treatment is sometimes necessary for quite a long time after they have recovered. They may also need help building up their lives again, and are likely to need support to do this. Exactly what and how much treatment and support a person needs will vary from person to person, and for the same person from time to time. This will need to be discussed at length by the person with schizophrenia and the healthcare professionals who have helped them. With the right help, treatment and support, people with schizophrenia can live normal lives. About a quarter of people will recover altogether, even after a number of years of illness.

Guideline recommendations

The following advice is written for people with schizophrenia, and their carers, and will tell you what help, treatment and care you can expect. At this point in time, not all the treatments outlined below are available in all parts of the country. This guideline will help services and health professionals to provide better treatment and care.

The first section outlines some issues that are important throughout all stages of the illness.

Care you can expect in all stages

The relationship with professionals

Whatever the stage of illness, it is very important that the professionals who work with you develop a supportive and caring relationship with you. They should be engaging and kind, and work in a constructive partnership with you and, preferably, with your family and/or carers. The effects of schizophrenia on a person's life experience and opportunities are considerable. Service users and carers need help and support in dealing with their future, and to be able to cope with the changes the illness brings. Professionals should work with you in a partnership and in an atmosphere of hope and optimism.

Getting help early

When you need help, especially if things are going wrong, you can expect help at an early stage. When most people have a breakdown, the level of upset, anxiety and confusion, especially when they first become unwell, can lead to problems in getting proper help. Sometimes people feel suspicious of friends, relatives and professionals, and their distressed state can alarm others who may respond in a less than helpful way. Many people who are experiencing a breakdown do not agree with others around them about the events or experiences they are

having, nor with the explanations other people give. This means that people at the start of their illness can be misunderstood and they may be vulnerable as a result. Because of this, service users and their relatives seeking help should get the right help, treatment and care as soon as possible.

Full assessment

The first help you receive should be a full assessment. This is to make sure that the treatment and care you are offered are tailored to your particular needs and situation. At the assessment, you should be asked about your symptoms, how happy you are with your life, what your accommodation is like, your social life and how much or little money you have. The staff doing the assessment will also need to ask you about your physical health, your work and your skills. If there are any issues you think are important for you, including things like your culture and religion, tell the staff who should give you the chance to discuss them.

Information about treatments and consent

When you are offered treatments, you should be given as much information as you want about the illness and its treatments **before** the treatment is started, and treatment should be started only after you have given your consent.

The exception is if you have been 'sectioned' under the Mental Health Act – this is when you have been detained for assessment and/or treatment against your wishes, for example, because you are too unwell to make decisions. If you have been 'sectioned', you can expect as much care and help as anyone else, and that time will be taken to explain what is happening. The medical language used by doctors and nurses is sometimes very technical and can be confusing and so won't be used unless it is necessary. You will be given written material to explain things you don't understand. If you have trouble speaking and/or understanding English, an interpreter should be provided and information given to you in a language you can understand. Also remember that there are some very supportive voluntary organisations that may be able to help you and your carers at different times, sometimes with information, sometimes with family and carer support programmes.

Choosing treatments and advance directives

There are a number of different treatments for people with schizophrenia – many do the same things but have different side effects. It is important that the treatment you are offered suits you and doesn't give you unpleasant side effects. Once you have been ill, your doctors and other healthcare workers should try to help you write down which treatments you most

like or dislike so that if you become ill again, professionals will know your preferences. These written preferences are kept in your GP's notes and in your psychiatric notes, and are called advance directives. When you make an advance directive, you should have a copy and, if you would like, your team can give a copy to your relative, advocate or carer.

The first illness (leading up to the first breakdown)

Most people go to see their GP when they are first ill, either because their family want them to or because they are feeling that things aren't right. If your GP thinks that you are having a breakdown, you can expect to be referred to a psychiatrist quickly. Alternatively, your GP may ask a special team of doctors, nurses and therapists called an 'early intervention service' to see you.

If your GP thinks that you are very ill or there are problems with getting help very quickly, he or she may offer you some medicine to help calm you. The type of medicine you should be offered is called an antipsychotic. In your first breakdown you should be offered one of the newest types of these medicines, which are called 'atypical' antipsychotics (their individual names are amisulpride, olanzapine, quetiapine,

risperidone and zotepine); these tend to have different side effects from the older 'conventional' antipsychotics. Doctors usually prescribe low doses during a first illness, as you may be quite sensitive to them when you first take them. It might be that you always stay on low doses of medication but it could be that later in the illness you need higher doses. In any case, you should be told about the effects and side effects of these medicines and given written information about them. In other ways, your treatment during the first breakdown will be similar to that for the second or subsequent illnesses (see 'If you have a breakdown', below). After you have recovered from your first breakdown and the mental health team has discussed the diagnosis with you, and your carer if you wish, you may want to have a second opinion (when you are seen by another consultant psychiatrist). You should have help in getting to talk to another psychiatrist about the diagnosis. You may want to ask the psychiatrists looking after you to make the referral, or perhaps your GP.

If you have a breakdown (an acute episode of schizophrenia)

The teams who provide treatment

After your GP has seen you, you may be visited at home by a psychiatric nurse, a psychiatrist or other mental health worker, or you may be

invited to come to a clinic. At this stage, your GP or other health professional may tell you that you are ill and will need further help and treatment. The teams who might see you include community mental health teams, early intervention teams, crisis resolution and home treatment teams or an acute day hospital. If you have been ill before, you may already be getting help from an assertive outreach team, who will also try to help you during a crisis. It is very important that you meet with them quickly as this may help more in the long run. When you meet the mental health team they will undertake a detailed assessment of your health, life situation and need for help. The different teams available to help people with schizophrenia are described in the glossary.

Where you'll be treated

If all goes well, you may be treated at home. If a crisis resolution and home treatment team treats you at home, they will be careful to check regularly on you to make sure that you are safely treated at home (this is called a 'risk assessment'). If the team that is treating you at home can't provide all the treatment and care you need, you may be asked to come to an acute day hospital where you will receive treatment and help during the day and go home at night. Alternatively, if you are very ill, or you have been 'sectioned' under the Mental Health Act, you may be asked to come to an inpatient unit –

a hospital that you stay at during the day and night. If you are in an inpatient hospital, you should be offered a transfer to an acute day hospital or to treatment at home as soon as the hospital team treating you think you are well enough. This should keep the time you are in hospital to a minimum.

Wherever you receive treatment, part of your treatment programme should, if you want it to, include social, group and physical activities; this is especially the case as you begin to recover. The activities will be recorded in your care plans (the treatment and health record your team keeps about you). You may want to see these.

Medicines during a breakdown

After your team have discussed all the treatment options with you, and your advocate or carer if you so wish, and have discussed the effects and side effects of treatments, you will be offered antipsychotic medicines, either 'conventional' or 'atypical' (only atypicals if this is your first breakdown). Different antipsychotics have different side effects. You'll be given enough information about the different medicines for you to be able to make an informed choice as to which one you would most prefer. Whichever medicine you choose, you should only take one antipsychotic medicine at a time, unless for a short while when changing from one to another

(you may then take two while one is being reduced and the other is being started).

All medicines can have side effects, but if the medicine suits you, you may not experience any. If you do get side effects, they tend to be worse on higher doses, and using a lower dose may take them away. If the side effects don't go away it is usually best to try a different medicine. You should not be offered very high doses of these medicines. Usually your doctor will start you on a low dose and gradually increase the dose to a standard dose. If you are taking a conventional antipsychotic (such as haloperidol, chlorpromazine or trifluoperazine) that either gives troubling side effects or simply doesn't work very well, your doctors will suggest stopping the medicine and should offer you an atypical antipsychotic.

If you are unable to make a choice because you are very ill, the doctors should offer you an atypical antipsychotic because they tend to have different, and sometimes fewer, side effects. Whether you can choose or not, the team caring for you should regularly keep a check on side effects, and may use a questionnaire to help them do this. It usually takes about 3 to 6 weeks for antipsychotics (conventional or atypical) to work properly, although you may feel better sooner than this. The team looking after you will keep an eye on whether the treatments are

working or not. If the medicine you are given doesn't work by 6 to 8 weeks, you should then be offered a different antipsychotic medicine. If the medicine does work, your doctors will suggest that you take it for about 1 to 2 years after getting better so that you don't get ill again. If you are stable on an antipsychotic, with few or no side effects, it is best to stay on that medicine and not to change to another one.

Treatment for people whose behaviour is very disturbed

If you are ill enough to be admitted to hospital as an inpatient, especially if you have been admitted against your will under the Mental Health Act ('sectioned'), you may settle very quickly and feel better. However, sometimes the illness can make some people more likely to become very angry or upset, causing them to become threatening or even to hit others.

Preventing harm to you and others

The staff on the ward should make an effort to keep things as calm and as safe as possible around you. They will also try to talk to you and take time to explain all about what is happening on the ward and about your treatments. They will make every effort to clear up misunderstandings and to treat you respectfully and with dignity and kindness. If you do become very angry in these circumstances, the staff have been trained

to help you calm down by talking and listening to you. If you lash out at anyone, they will stop you. Staff are also trained in physical methods of restraining someone who is very ill and threatening. If things get very 'out of hand', they may put you in a room away from others to prevent you hurting anyone or yourself. This is called seclusion.

Medicines to help calm you down

Before seclusion is used, you'll be offered some additional medication. If extra medicines are needed, your doctors should offer you a medicine that you can take by mouth (an 'oral preparation'). This may be a sedative called lorazepam, or an antipsychotic, either olanzapine or haloperidol. They will not use high doses, just enough to calm you without 'knocking you out'. If you refuse to take the extra medicines by mouth, the staff may give you these medicines by injection into your thigh or buttocks ('intramuscular injection'). They may force you to have this if your illness has made you feel violent and act in a violent way.

Injections that might be used

If intramuscular injection proves necessary, lorazepam, haloperidol or olanzapine are the preferred medicines. If haloperidol is used, the doctors should give you a second medicine to stop you going stiff or having a bad reaction to the haloperidol. These second medicines are

called anticholinergic medicines (such as procyclidine or benztropine). Sometimes the doctors may feel that two 'calming drugs' are needed, in which case they will give you lorazepam and haloperidol together. Again, if haloperidol is used, they will also give you an anticholinergic medicine. In very rare circumstances, when the doctors need to calm you very quickly, they may wish to give you these medicines into a blood vessel, usually in your arm ('intravenous injection').

Making sure you are OK

If you are given urgent sedation (sometimes called rapid tranquillisation), the staff should regularly check your pulse and other signs that you are OK, such as blood pressure. You should also be regularly checked for side effects. As soon as possible, staff will ask to examine you, both physically and mentally. This is important so that the staff can be sure that they are giving the right medicine for your illness, and to be sure that you are not ill in some other way.

Helping you afterwards

Rapid tranquillisation can be very upsetting. The staff know this. As soon as possible after you have calmed down, the staff should spend time talking to you about what has happened and give you an explanation about why you have been urgently sedated. You can expect staff to be very caring and supportive at this time, so as

to help you stay calm and understand what is going on. They will make detailed notes about what has happened, which you may wish to read. You may also want to write your own account in your notes. The staff should help you do this when you are calm enough to do so.

As you get better (towards the end of an acute episode)

As you begin to get better from your breakdown, your team will begin to plan what help you will need to help you recover.

Understanding your breakdown

Towards the end of an acute episode of schizophrenia, you should be offered help to understand the period of illness and given the chance to write your account in your notes, just as the doctors and nurses have done. You may well disagree with the staff working with you – they should discuss your disagreement and fully explain their position. Carers may also need help to understand the breakdown and your experience. Staff should be able to help your carers do so.

Assessing your needs for more help

After you have made a recovery, you will be assessed for what further help you might need, for example with difficult thoughts that trouble you, voices or other symptoms, which may not have completely gone away, or with

help to reduce the chance that you might get ill again. You may be offered psychological help fairly quickly, or perhaps a member of your team will spend a fair bit of time talking over what has happened and help you understand things better.

The staff should also talk to you about what help you might need to get back to work or to go into education. They should also help you plan how to get back on your feet socially, and to sort out any physical health problems you have.

Planning treatments for the future

The treatments you receive after your breakdown can make further breakdowns less likely. Although you will probably need to take your antipsychotic medication for 1 or 2 years after your last breakdown, you can also be helped even more by psychological treatments: the best ones to help you are family work (sometimes called 'family interventions') and cognitive behavioural therapy (or CBT for short). These psychological treatments can help you recover better and make it less likely that you will have another breakdown.

You should also be given help to plan for any crises, both in terms of how to get help quickly, and to plan your treatments should you become ill again (making advance directives). Your doctors will also discuss medication with you. Generally, it's better to keep taking

antipsychotics for 1 or 2 years after your last breakdown. When you decide to stop taking medication it's best to do this slowly and for one of the mental health team to see you to check if you start feeling worse. They will see you for about 2 years after your last breakdown.

Helping you recover

Services that can help

In the long term, there are a number of issues that a person with schizophrenia has to deal with over and above the problems other people have to deal with.

Once you have developed schizophrenia:

- there is a strong chance you'll have further breakdowns
- you may develop some long-lasting symptoms that can bother you
- your physical health may suffer over the years
- you may find it hard getting employment
- your carers may need help and support to help you better.

The services and mental health teams that can help you include your GP and the primary care team, community mental health teams, assertive outreach teams, crisis resolution and home treatment teams and early intervention teams.

Staying in touch with services is very important so that you can get the treatments that will help. Through these teams, you can get services and treatments that have been proven to be effective. It is also important for the teams to keep an eye on your physical and mental health, and to provide ongoing help and support, including during a crisis. The aim of treatment in the long term is to promote your recovery by:

- reducing the chance of you having a breakdown (this is called 'relapse prevention')
- reducing your symptoms and helping you cope with them better ('symptom reduction')
- improving your physical health
- helping you find work or other activities
- supporting your family/carers and helping them to help you.

Your physical health

Many people with schizophrenia are at risk of developing significant physical health problems (for example, heart disease from smoking, or increased weight and diabetes from some medicines), so it is very important that your physical health is checked regularly. These physical health checks should pay particular attention to things such as weight gain, blood pressure and heart problems, blood sugar and the side effects of your medicines. As well as closely monitoring these types of physical signs,

good advice on reduction of smoking, taking appropriate physical exercise and having a healthy diet are important aspects of physical health care in schizophrenia.

How your GP can help (primary care)

Your GP (rather than your psychiatrist) will usually look after your physical health. He or she should talk to you about your physical health, and the risks of illness. The GP should make an agreement with you to do physical health assessments at regular intervals agreed jointly between you and him/her. This might be as often as once a year if your GP thinks you are at risk of becoming physically ill. Whatever you decide, how often you have physical health checks should be written into your GP's notes and your psychiatrist will be told. To help your GP keep an eye on your physical and mental health, he or she should put your name on a register (this is just for the GP to keep a record of how and when he or she should be helping you).

Your GP or practice nurse should also help to look after your mental health. The GP may prescribe your medicines and ask about your mental health and progress. However, there may be times when your GP will want you to go back to your psychiatrist for assessment if you aren't already seeing him or her.

The main reasons for your GP to refer you to the mental health team are if:

- you are not taking your medicine properly
- the treatment isn't working very well
- you are developing a problem with alcohol or drugs (some people with schizophrenia take drugs or drink too much because they feel anxious or depressed, but the drink and drugs usually make things worse)
- the GP thinks that you are becoming a danger to yourself or others (and this includes neglecting yourself)
- you have just changed GPs (tell your new GP that you have had a breakdown and he or she will offer to organise a referral for assessment).

If your GP refers you, you can expect to see the mental health team quickly.

How your mental health team can help (secondary care)

Assessing your needs and organising your care

If you are seen by a mental health team (most people with schizophrenia are), your care will be co-ordinated through the Care Programme Approach (CPA). This means you will have a named 'care co-ordinator' who will make sure that you and your carers and all the services and people involved in your care know what they should be doing. Your care co-ordinator and

mental health team will make sure they know about your needs, and plan your treatment in detail with you. They should develop a care plan based upon an assessment of all your social, work, accommodation, financial, medical, psychological and cultural needs. If you don't see your GP or don't wish to, your psychiatrists could also do regular physical checks with you – they'll let your GP know that they are doing so. Your care co-ordinator and mental health team should decide with you how often these full assessments need to be done and write this in your notes. If you are on 'enhanced CPA' (usually because you need a lot of help) you may have full assessments every year.

Your carers/family can play an important part in helping your recovery. They also need help, especially in times of crisis. If you agree, the team who help you should contact your carers and provide information, support and develop a carer care plan to record the help they need.

The teams that will help, now and in the future

At the moment, most help will come from your community mental health team (CMHT for short). This will continue to be the case in Wales. However, in England other teams are being developed to give you extra help should you need it. For example, if you have had several breakdowns, have been on the wards a lot, have poor housing or are homeless, you should have

most of your care provided by an assertive outreach team. If you have only recently had your first breakdown, your care should be provided through an early intervention team (who specialise in working with people during and for 3 years after their first breakdown). If the team caring for you are unable to meet all your needs during a crisis, they may ask a crisis resolution and home treatment team (CRHTT for short) to help provide support. If the CRHTT also can't give you enough support, they may refer you to an acute day hospital. After a crisis, you will usually go back to your original team.

Psychological treatments to help recovery

CBT and family work, when given with antipsychotic medication, can help reduce the number of breakdowns you have, more than just medicines alone. They probably won't stop breakdowns altogether, but they can help them happen less often. At the moment they are not widely available, but this will change over the next few years.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy can help reduce the chance of another breakdown. It is also particularly useful if you have symptoms that won't go away and are troubling to you. CBT is also helpful if you are having trouble accepting

that you have schizophrenia (sometimes called 'lack of insight'), and it may help if you tend not to take your medicine properly (sometimes called 'poor compliance'). If you have CBT, it is better to have longer treatments than shorter ones. For it to make a difference, you should have CBT treatment for more than 6 months, meeting for more than ten treatment sessions. If you are offered shorter treatments, the CBT may help you feel a bit less depressed, but it is unlikely to help you with other symptoms.

Family work

Because schizophrenia affects both the individual and his or her family or partners, working with the family or partner can be very helpful to everyone. If you live with or are in close contact with your family (including carers and partners), family work can also reduce the chance of you having further breakdowns. Family work is especially helpful for people who have had a breakdown in the last 3 months or are at risk of breaking down (say, because things have gone particularly badly, or the person has had a lot of breakdowns over recent years). It is also helpful for people who have symptoms, such as voices or strange thoughts, that remain after a breakdown is over. Again, longer treatments are better than shorter ones. Family work should last for more than 6 months and include more than ten sessions of treatment. Family work also works better if you go for treatment with your family.

Sometimes, though, it's better for your family to receive help separately. You'll need to discuss this with the team who are treating you. Family work can be given to single families on their own or to a group of families. You and your family may prefer to have family treatment on your own.

Although counselling doesn't stop breakdowns or change symptoms, you may want to spend some time talking to a mental health specialist and your preference for this should be respected by your mental health team, especially if CBT and family therapy are not easily available. Over time, CBT and family therapy will be much more widely accessible.

Medicines to help recovery

Antipsychotic medicines by mouth

Oral antipsychotic medicines (those taken by mouth) help to stop you breaking down and help you to have a more stable life. Also, if you want psychological help, you will need antipsychotic medicines at the same time. Remember, the decision about which medicine to take is best made by you and your doctors together.

If you are happy with the antipsychotic you are already taking and you are not experiencing

troublesome side effects, then carry on with the medicine you are taking. If you are having a conventional antipsychotic and this has not suited you, you should be offered an atypical antipsychotic. If you are having an atypical that makes you put on weight, gives you diabetes, or causes sexual problems or excessive tiredness, you may be offered a different antipsychotic. Your doctors should keep a close eye on the side effects, as they are common and sometimes unpleasant. The lowest dose that keeps you stable is best.

Depot antipsychotics

If you find it hard to remember to take your medicines, or you stop taking them and break down more often, you may be offered regular injections of a long-acting antipsychotic. There are a number of different types that can be used. These are called 'depot antipsychotics' and are given every 2 to 4 weeks, depending on which type you take. The doctors and nurses helping you should talk to you about how and where (for example, in clinics or at home) depot injections can be given and ask you about your preferences. If you do decide to try a depot antipsychotic the doctors will give you a test dose first to check that it suits you. Once you are taking a depot you should have your treatment reviewed regularly.

When the usual medicines do not work (‘treatment-resistant schizophrenia’)

If you have tried two different antipsychotics, including an atypical one, each for at least 6 to 8 weeks and are still getting ill, it’s likely that your illness is resistant to the usual treatments. Your doctors will make sure that you are taking your medicines properly and re-assess you and your situation to check there aren’t other reasons for you not getting better, such as drinking too much alcohol or taking illicit drugs, which can stop the medicines working properly. They may suggest having (further) psychological treatment. You may be offered another atypical (olanzapine or risperidone) if you haven’t tried them already. If these don’t work, you should then be offered a medicine called clozapine. This is a special type of atypical antipsychotic, which can only be given when a person’s illness doesn’t respond to the usual treatments. You will have to have some blood tests before and while you are taking this medicine. Your doctors will discuss this with you and give you written information about clozapine.

Sometimes clozapine may not get you properly better even after several months at proper doses. Your doctors may then suggest that you take another antipsychotic as well as the clozapine. This is the only situation when two antipsychotics should be prescribed together over a long period of time. If this doesn’t work very well you shouldn’t carry on taking two antipsychotics.

Your doctors may suggest adding other medicines instead (these are called 'adjuncts' and are not covered here). They will need to discuss this with you at length before giving you other medicines.

Helping you get work

The overall aim of mental health treatment is to help people to get back to living an ordinary life as far as possible. This includes getting work of some kind. Unfortunately, people with schizophrenia find it very hard to get jobs, at least partly because of the stigma associated with schizophrenia. Your assessments by the mental health team should include a detailed assessment of your work history, skills and work potential, as well as what you really want to do. If 'supported employment schemes' are available, they should be offered to you if you want this. There are other types of work schemes that may also be locally available. If you want to try to get a job through these schemes, your mental health team will help you join one. Your local mental health and social care providers should also be helping develop local employment opportunities for people with schizophrenia.

Further information

You have the right to be fully informed and to share in decision-making about your healthcare. If you need further information about any aspects of your schizophrenia or treatment, please ask your specialist, GP or a relevant member of your health team. You can discuss this guideline with them if you wish, especially if you aren't sure about anything in this booklet they will be able to explain things to you.

For further information about the National Institute for Clinical Excellence (NICE), the Clinical Guidelines Programme or other versions of this guideline (including the sources of evidence used to inform the recommendations for treatment and care), you can visit the NICE website at www.nice.org.uk.

NICE has also issued guidance on the use of atypical antipsychotic medicines for the treatment of schizophrenia. This can be found on the NICE website at www.nice.org.uk/cat.asp?c=32878, and paper copies can be ordered from the NHS Response Line (phone 0870 1555 455). Quote the reference number N0106 for the health professionals' version and N0108 if you want the version for service users.

Glossary

Advance directives

Written instructions agreed between a service user and health professional before treatment begins, in which the service user specifies his or her preferred treatments and identifies the treatments he or she does not wish to receive. They guide health professionals in the event that the service user becomes unable to make decisions for him or herself. Advance directives allow people, for instance, to set out treatment that they would not want to receive (for example, electroconvulsive therapy, or a medicine they know gives them bad side effects), or treatment preferences (for example, the service user may wish to be given lorazepam rather than haloperidol in the event of needing rapid tranquillisation). Doctors sometimes will not follow advance directives for medical reasons. If they don't, they will write this in a person's notes, explaining why they couldn't follow the directive.

Antipsychotic medication

There are two main types of antipsychotic medication, commonly referred to as conventional and atypical antipsychotics. Conventional antipsychotics have been around for many years while the atypical ones have only become available more recently.

Conventional antipsychotics cause more extrapyramidal side effects (see below) than atypical antipsychotics, whereas, on average, atypicals may cause more weight gain than conventionals. Atypical antipsychotics include amisulpride, clozapine, olanzapine, quetiapine, risperidone, sertindole (in special circumstances) and zotepine. Clozapine is only used for the treatment of treatment-resistant schizophrenia (see below). Conventional antipsychotics include chlorpromazine, haloperidol, trifluoperazine, flupenthixol and others. Your doctor or pharmacist will be able to tell you whether a medicine is a conventional or an atypical antipsychotic.

Assertive outreach team (also known as assertive community treatment)

This service delivers intensive, and often comprehensive, treatment and care in community settings for people with serious mental health problems, especially people needing a lot of help.

Cognitive behavioural therapy

A psychological treatment that helps people to establish links between their thoughts, feelings or actions and their current or past symptoms and to re-evaluate their perceptions, beliefs or reasoning about the target symptoms. It's useful for reducing symptoms, reducing breakdowns and helping to understand the illness and may help people take their medicines regularly.

Community mental health team

The standard community-based team that offers assessment, treatment, and care to adults with mental health problems in the community.

Crisis resolution and home treatment teams

Services that provide intensive home-based, crisis-orientated treatment of an acute episode by staff who deal with such situations during and beyond office hours. Teams can help manage acute episodes in the community rather than in inpatient care.

Depot antipsychotic

A special preparation of an antipsychotic in an oily solution, which is injected into the muscle. Following injection, the medicine is slowly released. This results in the medicine staying in the blood over fairly long periods, so that injections can be given every few weeks.

Early intervention teams/services

Services that provide early identification and initial treatment, during the first 3 years of illness, to people aged between 14 and 35 years who have the first symptoms of schizophrenia.

Extrapyramidal side effects

Problems with movement, such as parkinsonism (stiffness, shaking and slowness), akathisia (marked restlessness), and dystonia (altered muscle tension), which are common side effects

of antipsychotics (especially conventional antipsychotics).

Family work (or family interventions)

Family sessions providing support and treatment that are based on psychological principles.

Family work can improve symptoms and reduce the chance of breaking down. It's especially helpful for people who have recently had a breakdown, are at risk of having a breakdown, or have symptoms remaining after being ill.

Rapid tranquillisation

The use of medicine to quickly control extreme agitation, aggression and potentially violent behaviour that put the individual or those around them at risk of physical harm. The aim is to sedate the person to minimise the risk without the person losing consciousness.

'Sectioning'

When a doctor believes that a person is so ill that he or she is unable to make a decision about treatment, or if a person who is ill refuses to receive treatment, the doctor can 'section' him or her under the Mental Health Act. If this happens, you will receive your care in an inpatient unit. This allows the doctors and nurses to assess and sometimes to treat you against your will. They can only treat your mental illness without your agreement; they can't make you have treatments for anything else (such as operations).

Service user

In this booklet, a person with schizophrenia who is receiving care from the NHS.

Standard doses

The recommended dose range listed in the *British National Formulary* (or *BNF*), a reference book for doctors.

Supported employment

An approach to helping service users find and stay in work, without going through lots of training first.

Tardive dyskinesia

Abnormal movements of the lips, jaw, tongue and facial muscles, and sometimes the arms, legs and body, that the person can't help making. This can be a long-term side effect of antipsychotics, which can be irreversible.

Treatment-resistant schizophrenia (TRS)

Schizophrenia that doesn't appear to improve despite the person having tried a number of different antipsychotic medicines.

