

## Understanding NICE guidance

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Information for people who use NHS services

# Treatment and support for people with psychosis who use drugs and/or alcohol

*NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.*

This booklet is about the treatment and care of people with psychosis who use drugs or alcohol (or both). It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with psychosis who use drugs and/or alcohol, but it may also be useful for their families or carers or for anyone with an interest in psychosis and drug and alcohol use.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe psychosis and drug and alcohol use or the treatments for them in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 16. Medical terms printed in **bold type** are explained on pages 14–15.

## Contents

Your care	3
Psychosis and drug and/or alcohol use	4
What should happen when I first see a healthcare professional?	6
Who will provide my treatment and care?	8
What treatments should I be offered?	9
Taking care of your physical health	11
What are my rights regarding my treatment and care?	11
Information for families, carers and significant others	13
Glossary	14
More information	16
About NICE	16

### The advice in the NICE guideline covers:

- The treatment and care that should be offered to adults and young people aged 14 years and over with psychosis and drug and/or alcohol use, and the support that should be offered to them and their families, **carers** or **significant others**.

### It does not cover:

- The treatment and care of children and young people under 14 years.

## Your care

In the NHS, patients and **healthcare professionals** have rights and responsibilities as set out in the NHS Constitution ([www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm](http://www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm)).

All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain psychosis and drug and alcohol use and the possible treatments. They should discuss with you how the treatment may affect you personally, including possible benefits and risks. You should be given relevant written and verbal information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have a physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or **advocate** (someone who helps you put your views across) if needed.

Your family, carers or significant others should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance decision' (known as a 'living will' in the past) in which you have already given instructions about any treatments that you do not wish to have, healthcare professionals have a legal obligation to take these into account.

If you are being treated under some sections of the **Mental Health Act**, healthcare professionals may override your decisions. They should only do this in specific circumstances and if it is in your best interests. If this does happen, they should fully explain the reasons why and your rights to appeal and advocacy.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, healthcare professionals have a duty to talk to your family, carers or significant others unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent ([www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk). In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government ([www.wales.nhs.uk/consent](http://www.wales.nhs.uk/consent)).

In an emergency or when being treated under the Mental Health Act, healthcare professionals may give treatment immediately, without obtaining your informed consent, when it is in your best interests.

If you are under 16, your parents or carers will need to agree to your treatment, unless it is clear that you fully understand the treatment and can give your own consent. In an emergency, if the person with parental responsibility cannot be contacted, healthcare professionals may give treatment immediately when it is in the child's best interests.

## Psychosis and drug and/or alcohol use

Many people with psychosis use drugs and drink in a way that is harmful (sometimes this is called having a 'dual diagnosis'). Having psychosis and using drugs and/or alcohol (sometimes called 'substance misuse') can lead to difficulties in the person's life and with their health and can complicate their treatment. The aim of this booklet is to explain the treatment and care people should receive when they have both psychosis and a drug and/or alcohol problem.

### Psychosis

Psychosis is a condition that affects a person's mental state, including their thoughts, mood and behaviour. The symptoms of psychosis are:

- hearing voices and sometimes seeing things that are not really there (called **hallucinations**)
- having fixed beliefs that are false but which the person believes in completely (called **delusions**).

People who have psychosis are often diagnosed with **schizophrenia** or **bipolar disorder** (sometimes called 'manic depression').

### Drug and alcohol use

Drinking and drug use is harmful when it has a negative effect on a person's life, including their physical and mental health, relationships, work, education and finances or leads to offending behaviour. Examples of drugs used include illegal drugs (for example, cannabis, cocaine, crack cocaine and heroin), prescribed drugs that are not taken in the way that was intended (for example, diazepam) and 'over the counter' medicines that you can buy from the chemist (such as codeine linctus).

If a person becomes used to the effects of drink and drugs they may need to use more to feel the same effect (this is called developing tolerance). Repeatedly using alcohol or drugs can result in the person becoming **dependent** so that it is difficult to live their life without drinking alcohol or taking drugs, and difficult to stop. Alcohol and some drugs (for example, heroin and diazepam) can create physical dependence and when the person stops taking them, or reduces their use, they will almost certainly experience **withdrawal symptoms**. To manage these withdrawal symptoms safely medication is prescribed to help the person stop using.

NICE has produced separate guidance about schizophrenia, bipolar disorder, drug misuse and alcohol misuse (see [www.nice.org.uk](http://www.nice.org.uk)).

### Questions you could ask your healthcare team

- What is psychosis?
- Is my drug and/or alcohol use a concern?
- Why am I being offered an **assessment**?
- What could have caused my mental health problem?
- Will my psychosis and drug and/or alcohol use remain confidential?
- Who can provide my treatment and care?
- Will someone coordinate my care if different services are involved?
- Are there any support organisations specifically for people with both psychosis and drug and/or alcohol use in my local area?
- Who can I contact in a crisis?
- Have you got any information for my family, carers or significant others?

## What should happen when I first see a healthcare professional?

When you first see any healthcare professional about your mental health or your drug and/or alcohol use, they will want to know about what is happening in your life.

If you see a healthcare professional because you have been having hallucinations and/or delusions, they may ask you if you drink alcohol or take drugs. They will want to know about what you drink or the drugs you use, how much and how often you drink or take drugs, and how long you have been drinking or taking drugs.

If you see a healthcare professional about your drug and/or alcohol use, they may ask you if you have hallucinations and/or delusions.

With your agreement, your family, carers or significant others may also be asked their views about your mental health problems and your drug and/or alcohol use.

If a healthcare professional in **primary care**, such as your GP, thinks that you may have psychosis with or without a drug and/or alcohol problem, you should be offered an appointment for an assessment with mental health services (for adults or for children and young people).

### Your relationship with your healthcare professional

It may be difficult for you to discuss your mental health and drug and/or alcohol use. Your healthcare professionals should be aware of any sensitive issues relating to being diagnosed with psychosis and a drug and/or alcohol problem and should build a relationship with you based on respect, trust, understanding and being hopeful about the future. You may be worried about being labelled as 'mad' because of your diagnosis. Your healthcare professionals should reassure you about your diagnosis and make sure you have access to all the support and services you need for both the psychosis and your drug and/or alcohol use.

Your confidentiality, privacy and dignity should be respected at all times.

## What can I expect during an assessment with mental health services?

During the assessment, which may take place over several meetings, healthcare professionals will want to get to know you and find out more about your psychosis and your drug and/or alcohol use. They will want to know about your mental and physical health, how severe the problems are and what treatments would suit you best. They may also ask you about your relationships, living arrangements and background, about your drinking or drug use and how this has affected your life and health. In addition, they may ask whether any treatments you may have had for psychosis and drug and/or alcohol use have helped you. They may also want to know whether you have been in trouble with the police or courts and whether you feel ready to make positive changes to your drug or alcohol use and your lifestyle. You may be asked to have a blood or urine test as part of your assessment. Your agreement should be asked before the test is carried out and your healthcare professional should tell you the results of any tests conducted.

With your agreement, your family, carers or significant others may also be asked about your mental health problems and your drinking or drug use. You should be shown a record of what your family, carers or significant others said.

Healthcare professionals will want to make sure that you or other people are not at risk of harm because of your psychosis and alcohol or drug use. Risks might include harming yourself, wanting to end your life, not looking after yourself, physical illness, accidental injuries, being taken advantage of by others or offending behaviour.

## Who will provide my treatment and care?

Most treatments for psychosis and drug and/or alcohol use can be provided by mental health teams in your local community, rather than in hospital. Some people may be seen by an **early intervention in psychosis service**. Mental health teams can provide treatment for your psychosis and help you to control, reduce or stop your drug and/or alcohol use.

More than one healthcare professional will usually be involved in providing your treatment and care. This might include a psychologist, psychiatrist, nurse, social worker, occupational therapist, or a drug and/or alcohol worker. If you see more than one healthcare professional you should have a person organising your care (called a '**care coordinator**'). Healthcare professionals should actively involve you in decisions about your care, identify your needs with you, and develop a care plan with you, which is reviewed regularly.

If you live in accommodation that has care staff on site, the staff should also help provide treatment for your psychosis and drug and/or alcohol use. Your GP will be involved throughout your treatment and care to check your physical health (see page 11).

For young people, child and adolescent mental health services and children's services should be involved.

## Will I need to have treatment in hospital?

Some people with psychosis and a drug and/or alcohol problem need treatment in hospital. This may be because they need treatment for drug and alcohol use (such as **detoxification**), they are being treated under the Mental Health Act, or they have asked to be admitted to hospital. Young people with psychosis and a drug and/or alcohol problem may be admitted to hospital if there is risk they may harm themselves or others.

If you need treatment in hospital for drug and/or alcohol use, healthcare professionals should give you information about the hospital's rules about drug and/or alcohol use and how they can help you to stay drug and/or alcohol-free during your admission. When you arrive, healthcare professionals should check whether you are using drugs and/or alcohol and whether you are having withdrawal symptoms. You may be asked to have a blood or urine test as part of your assessment in hospital. Your agreement should be asked for before the test is carried out and your healthcare professional should tell you the results of any tests conducted.

If you have stopped using drugs or alcohol, or you have used them less, while in hospital, you should be warned of the risks of overdose if you start using drugs or alcohol again when you leave hospital. You should have a care coordinator who will organise any further treatment and care you may need in your local community.

### An equal right to treatment and care

You should receive all the care you need for both your psychosis and your drug and/or alcohol use, and you should not be excluded from services or accommodation because of either problem.

## What treatments should I be offered?

The treatments you should be offered depend on the type of psychosis you have (schizophrenia or bipolar disorder) and whether you are using alcohol, drugs or both. If you are offered medication as part of your treatment, your healthcare professional should tell you about any side effects of the medication and how using drugs and alcohol can interact with the medication and affect the way it works. Your healthcare professional should also discuss the problems and dangers of using drugs and alcohol to relieve any side effects you may have while taking medication.

You should be offered information about the risks of using drugs and alcohol and the effect that even small amounts of drugs and alcohol can have on the symptoms and treatment of psychosis.

### Treatments for young people

The treatments for young people are similar to the treatments for adults, but healthcare professionals may adjust the treatment to suit your age and your needs.

Your healthcare team should make sure you receive all the help and support you need after you turn 18, which may include treatment and care from adult services.

*Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your healthcare team.*

### Treatments for schizophrenia

The treatments for schizophrenia include both **antipsychotic** medication (usually in tablet or liquid form) and **psychological therapies** (sometimes called 'talking treatments'). For further details see the 'Understanding NICE guidance' on schizophrenia:

[www.nice.org.uk/guidance/CG82/PublicInfo](http://www.nice.org.uk/guidance/CG82/PublicInfo)

### Treatments for bipolar disorder

The treatments for bipolar disorder include psychological treatments and medication for the **manic** episodes (or psychosis) and **depression** and to help you to stay well in the long term. For further details see the 'Understanding NICE guidance' on bipolar disorder:

[www.nice.org.uk/guidance/CG38/PublicInfo](http://www.nice.org.uk/guidance/CG38/PublicInfo)

## Treatments for drug use

The treatments for drug use depend on the kind of drug you are using, but may include:

- detoxification
- taking a drug substitute such as methadone or buprenorphine if you are dependent on heroin
- an **incentives programme**
- psychological treatments.

For further details see the 'Understanding NICE guidance' on drug misuse:

[www.nice.org.uk/guidance/CG51/PublicInfo](http://www.nice.org.uk/guidance/CG51/PublicInfo)

[www.nice.org.uk/guidance/CG52/PublicInfo](http://www.nice.org.uk/guidance/CG52/PublicInfo)

## Treatments for alcohol use

The treatments for alcohol use may include detoxification to help you safely stop drinking, and psychological and drug treatments to help you to control, reduce or stop alcohol use. There are also treatments for physical health problems caused by alcohol use.

For further details see the 'Understanding NICE guidance' on harmful drinking and alcohol dependence:

[www.nice.org.uk/guidance/CG100/PublicInfo](http://www.nice.org.uk/guidance/CG100/PublicInfo)

[www.nice.org.uk/guidance/CG115/PublicInfo](http://www.nice.org.uk/guidance/CG115/PublicInfo)

*If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.*

### Questions about treatment

- What are the treatments for psychosis?
- What are the treatments for drug and alcohol use?
- Can I have treatments for psychosis and drug and/or alcohol use at the same time?
- Do I have a choice about which treatment I have?
- What will the treatment involve?
- Can you give me a leaflet explaining the treatment?
- What are the advantages, disadvantages and risks of this treatment?
- What are the side effects of the medication I am being offered?
- When should I start to feel better? What should happen if I don't start to feel better by then?
- Would it help to make changes to my current treatment?
- What other treatment options are there?

## Taking care of your physical health

People with psychosis who use drugs and alcohol may develop physical health problems. This may be because of their lifestyle (for example, poor diet, lack of exercise, smoking cigarettes), the side effects of some medications used to treat psychosis, or the effects of drug and/or alcohol use.

Physical health problems caused by drinking include inflammation of the pancreas (called pancreatitis), high blood pressure, cirrhosis of the liver, heart disease and some types of cancer. If you are dependent on alcohol and stop drinking suddenly you may have seizures (fits) and **delirium tremens** (sometimes called DTs). Physical health problems caused by taking drugs include lung problems, contracting viruses such as hepatitis and HIV, and accidental overdose. Healthcare professionals will want to make sure that you are not at risk of developing such health problems and will monitor you regularly.

At least once a year, your GP should check your weight, blood pressure, blood sugar levels and cholesterol levels and you should be asked about any side effects of your medication. You should have more frequent checks if you have a significant physical health problem or there is a risk of you having a physical health problem because of alcohol or drug use.

## What are my rights regarding my treatment and care?

If you are concerned about not being able to make important decisions at any time (for instance during a period of psychosis) you can write some instructions for your healthcare team (called advance statements and advance decisions). The instructions can say what treatments and other help you want and do not want to be given. For example, you may not want to be given a particular drug again because of its side effects. Your healthcare team should discuss your instructions with you and they can help you to write them. An advocate may also help you with this. You should be given a copy of the instructions and your GP and psychiatrist should also have a copy. If you agree, your healthcare team can also give a copy to your family, carers or significant others. Your instructions may be overridden if you are being treated under the Mental Health Act, although healthcare professionals should only do this in special circumstances and when they believe it is in your best interests. You should be given an explanation about why it was necessary to override your instructions, should this occur.

*If you have talked to your healthcare team, and you think that a treatment is suitable for you but it is not available, you can contact your local patient advice and liaison service ('PALS') or NHS Direct Wales.*

## Decisions about your care if you are under 16

If you are under 16 and your healthcare team is sure that you understand a test or treatment that you are being offered, you will be able to decide on your own whether to have it. You can always involve your parents or another person with parental responsibility (someone who is responsible for looking after you) if you wish, and your healthcare team will encourage them to support you. If you decide to have the test or treatment, you will be asked to give 'informed consent' (see pages 3 and 4).

If your healthcare team is not sure you understand a test or treatment, one of your parents or a person with parental responsibility will be asked to give informed consent for you to have the test or treatment. In an emergency, if one of your parents or the person with parental responsibility for you cannot be contacted, healthcare professionals may give treatment immediately when it is in your best interests.

## Questions about being treated under the Mental Health Act

- Why have I been detained under the Mental Health Act?
- Do I have the right to refuse treatment?
- Do I have the right to an advocate?
- Do I have to go to hospital?
- How long will I have to stay in hospital?
- Can I leave the ward if I want to?
- How can I appeal against being treated under the Mental Health Act?

## Information for families, carers and significant others

If you are a family member, carer or a significant other of someone with psychosis who uses drugs and/or alcohol, you can play an important part in supporting them. Healthcare professionals providing treatment and care for your family member or friend should ask the person whether they would like you to be involved in their care. However, healthcare professionals should respect your family member or friend's privacy if they would prefer to cope on their own.

If your family member or friend agrees to you being involved, you should be given information about psychosis and drug and/or alcohol use and about how you can support them throughout their treatment.

As a family member, carer or a significant other, you may need help and support yourself. Healthcare professionals should give you information about local family and carer support groups and other voluntary organisations, and help you to make contact with them.

If you live with your family member or friend or are in close contact with them, you may be offered a treatment called **family intervention**.

Anyone with a caring role (that is, a person who provides regular and substantial care) has the right to a **carer's assessment**.

Healthcare professionals should discuss with you how the person's psychosis and drug and/or alcohol use is affecting you and other family members, especially children. Healthcare professionals should also make sure that your family member's or friend's children have their needs assessed and addressed if necessary.

### Questions for family members, carers or significant others to ask

- Can you give me some information about psychosis, about drug and alcohol use, and the treatments for them?
- Am I entitled to be told about the treatment my family member/friend is having?
- What can I do to support the person with psychosis and drug and/or alcohol use?
- Can you give me any information about specialist support for families and carers, such as helplines?
- Who can I contact for help during a crisis?
- Can I have a carer's assessment?

## Glossary

**Advocate** A person who can support patients in discussions with healthcare professionals to make sure that their wishes are made clear. Advocates may speak on a patient's behalf if they are not able to do so themselves. They will also make sure patients receive the information and level of care to which they are entitled.

**Antipsychotic** Medication used primarily in the treatment of psychosis.

**Assessment** A meeting with a healthcare professional in which they ask questions about a person's physical and mental health, their family background and everyday life, to establish what the illness is, how severe it is and what treatments would suit them best.

**Bipolar disorder** A serious mental illness in which a person has periods (or 'episodes') of mania and periods of depression. For this reason, it was once known as 'manic depression'.

**Care coordinator** A professional (usually a nurse, social worker or occupational therapist) who will make sure that a person who is being treated by more than one healthcare professional or service receives all the care and support they need according to their care plan.

**Carers** People who provide regular and substantial care to a person with a mental and/or physical health problem.

**Carer's assessment** An assessment by social services of a carer's physical and mental health and their needs in their role as a carer. Every person aged 16 years and older who cares for someone on a regular basis has the right to request such an assessment. There should be a written carer's plan, which is given to the carer.

**Delirium tremens (or DTs)** A sign of alcohol withdrawal, which can include hallucinations and feeling shaky, agitated, disorientated and confused.

**Delusions** Having fixed beliefs that are false but which the person believes in completely.

**Dependent** (often called 'addiction') Feeling a very strong desire to take drugs and/or drink alcohol and finding it difficult to stop or to take/drink less. Dependence on drugs and/or alcohol can mean a person loses interest in other things and will continue to take the drug and/or drink despite knowing about the harm it may be causing themselves and others.

**Depression** A common mental health problem, the main symptoms of which are losing pleasure in things that were once enjoyable and losing interest in everyday activities and other people. Many people with bipolar disorder also have depression.

**Detoxification** A treatment programme that helps a person to withdraw safely from drugs and alcohol. The treatment usually involves medication.

**Early intervention in psychosis service** A service that provides early identification and treatment to people who have symptoms of psychosis.

**Family intervention** A psychological treatment that helps families work

together to support the person with psychosis and drug and/or alcohol use and to reduce stress in family members. It aims to help families develop communication, problem solving, information sharing and coping skills as well as increasing their knowledge and understanding of the person's condition.

**Hallucinations** Hearing voices and sometimes seeing things that are not really there.

**Healthcare professional** A professional who provides treatment and care for health problems. For the treatment of psychosis and drug and/or alcohol use this may include a GP, a psychologist, a psychiatrist, a nurse, social worker, occupational therapist or a drug and/or alcohol worker.

**Incentives programme** A programme for people who use illegal drugs. The person is given a voucher or a privilege if they have a negative test, showing they have not used illegal drugs. Vouchers are worth a few pounds and can be exchanged for items that encourage a healthy, drug-free lifestyle. They increase in value after each negative test.

**Mania/manic episode** Symptoms of bipolar disorder including elation (extreme happiness or feeling 'high'), irritability and over-confidence. A person having a manic episode may not need as much sleep as usual, and may take unnecessary risks, have racing thoughts, fidget, gesture, or talk a lot, and have poor concentration. If the episode is severe they might behave in an inappropriate way and upset others.

**Mental Health Act** A law that allows a person with a mental health problem such as psychosis to be treated against their will, or without their agreement, if they are judged to be at serious risk to themselves or others. This is sometimes called 'being sectioned'. A person treated under the Mental Health Act will receive care in hospital where they can expect as much care and support as anyone else. People treated under the Mental Health Act have a legal right to appeal.

**Primary care** A part of the healthcare service that includes GPs and mental health teams (such as mental health workers, mental health practitioners, and psychologists).

**Psychological therapy** A treatment sometimes called a 'talking treatment' that involves meeting with a therapist to talk about feelings and thoughts and how these affect behaviour and wellbeing.

**Schizophrenia** A serious mental illness that affects a person's mental state, including their thoughts, mood and behaviour. The main symptoms are hallucinations and delusions. Because of these symptoms the person may not be able to think clearly or concentrate. They may lose interest in things, lack motivation and become withdrawn from other people.

**Significant others** People who provide support to people with psychosis who use drugs and/or alcohol. This might be a friend, a partner, an advocate, a mentor or a peer.

**Withdrawal symptoms** Symptoms experienced when stopping some drugs or when stopping drinking or suddenly reducing the amount that one drinks.

## More information

The organisations below can provide more information and support for people with psychosis and substance misuse. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Addaction, 020 7251 5860, [www.addaction.org.uk](http://www.addaction.org.uk)
- Adfam, [www.adfam.org.uk](http://www.adfam.org.uk)
- Mind, 0845 766 0163, [www.mind.org.uk](http://www.mind.org.uk)
- Rethink, 0845 456 0455, [www.rethink.org](http://www.rethink.org)

NHS Choices ([www.nhs.uk](http://www.nhs.uk)) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

## About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare staff. Staff working in the NHS are expected to follow this guidance.

*To find out more about NICE, its work and how it reaches decisions, see [www.nice.org.uk/AboutGuidance](http://www.nice.org.uk/AboutGuidance)*

*This booklet and other versions of the guideline aimed at healthcare professionals are available at [www.nice.org.uk/guidance/CG120](http://www.nice.org.uk/guidance/CG120)*

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and quote reference N2470. The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.*

*We encourage NHS and voluntary organisations to use text from this booklet in their own information about psychosis and drug and/or alcohol problems.*