

Understanding NICE guidance

Information for people who use NHS services

Improving your experience of mental health services in the NHS

This booklet is about making sure that people using adult mental health services in the NHS in England and Wales have the best possible experience of care. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for adults using mental health services but it may also be useful for their families or carers.

There are examples of questions you could ask health and social care professionals throughout this booklet. You can get more information from the organisations listed on page 15. Words printed in bold type are explained on page 13.

NICE has also produced a 'quality standard' made up of 15 statements describing high-quality care for adults using mental health services within the NHS in England. The quality standard, including a leaflet summarising these statements, is available at

www.nice.org.uk/aboutnice/qualitystandards

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Improving your experience of mental health services in the NHS

Over the past few years, there has been increasing recognition within the NHS of the importance of improving the experience of people using services. A major development was the publication of the NHS Constitution (www.dh.gov.uk/en/DH_113613), which sets out the rights of service users and the responsibilities of healthcare professionals. However, there is still more to do to make sure that everyone who uses NHS services has the best possible experience of care. This booklet describes NICE guidance to the NHS about the level of care you should expect from adult mental health services. This booklet covers care and treatment during and after your referral to NHS mental health services, and does not specifically cover 'primary' care from your GP.

Your relationship with health and social care professionals

Health and social care professionals should be easy to identify (for example, they should wear a name badge) and should be friendly and welcoming. They should address you using the name and title you prefer. Professionals should be aware that you may feel nervous about attending mental health services and should make you feel comfortable and at ease. Meetings should take place in private and you should be treated with respect and dignity. Professionals may need to discuss your treatment and care with other professionals sometimes, but this should be discussed with you first.

Professionals should work with you so that you can make decisions about your treatment and care. They should give you leaflets about your mental health problem and its treatment in a language or format you can understand, including any relevant 'Understanding NICE guidance' booklets (<http://guidance.nice.org.uk/Topic/MentalHealthBehavioural>). They should also give you details of organisations and websites that provide information and support, tell you how to find them, and support you if you use them. Professionals should clearly explain any medical language and check that you fully understand what is being said about your treatment and care.

Professionals should support you to feel optimistic. They should be understanding and not critical of you or your lifestyle. They should also encourage you to manage your own condition, if possible. This may include helping you to recognise warning signs of a worsening of your condition. Ideally once you and a professional have established a good working relationship this should continue throughout your care. Health and social care professionals should be trained in working with people from different cultures.

Professionals should ask how you prefer to be contacted, which may be by letter, phone, email or text message.

Involving your family, carer or an advocate

Health and social care professionals should discuss with you whether you would like your family or **carer** to be involved in your care; this discussion should happen more than once in case you change your mind. If you agree, professionals should talk to you and your family or carer about what information you would like shared with them, and when.

If you do not want your family or carer involved, your healthcare professional may give them information to help them understand the mental health problem and its treatments (such as the 'Understanding NICE guidance' booklets), but only if you agree.

You should be asked whether you would like a trained **advocate** to help you put your views across.

Capacity and decisions about treatment

Health and social care professionals should make sure that you are capable of making decisions about your treatment and care. However, your **capacity** to make such decisions may change over time. Health and social care professionals should explain any new treatment to you and should check that you have capacity to make a decision about it.

If you wish, they should help you to develop **advance statements** and **advance decisions**, especially if your mental health problem is severe or you have been treated under the **Mental Health Act**. Advance statements and advance decisions should be put in your **care plan** and you and the services responsible for your care should be given a copy of this plan.

If you can't make a decision about your treatment immediately, health and social care professionals should always check your care plan for advance statements and advance decisions before offering or starting treatment.

Helping you to get the treatment and care that you need

If your GP or another professional thinks that mental health services can help you, they should give you information about local services and will write to the service to ask for an appointment. They should give or send you a copy of this letter when they send it to the service. The mental health service should offer you an appointment that takes place within 3 weeks of your GP sending the letter. You can change the date and time of the appointment if you wish, but if there is a change there should not be a delay of more than 2 weeks before you see a professional in the service.

When you receive a letter from mental health services offering you an appointment it should give the name and title of the professional who will see you for an **assessment**. The letter should contain information about the service including a website address if available, details of how to get there, and a number to call if you have problems getting to the service or wish to change the appointment. It should clearly explain what happens during an assessment, which should include questions that health and social care professionals will ask you (for example, about any medication you are taking). You should be asked if you need any support during your appointment, for example, a hearing loop, wheelchair access or an interpreter (professionals should not use friends or family members as interpreters). Professionals should reassure you if you are worried about attending a mental health service. The letter should explain that you can have a family member, carer or advocate with you at the appointment, but professionals will prefer to see you on your own for some of the meeting. If you have children, you should be offered information about childcare so that you can attend the appointment.

What should happen during an assessment at mental health services?

When you first arrive at mental health services for assessment, all staff should welcome you in a warm, friendly, respectful and professional manner. The waiting room should be comfortable, clean and warm, and have a private area you can use if you are distressed, have children with you, or prefer to wait on your own. You should not have to wait for longer than 20 minutes after the agreed appointment time. If your appointment is delayed you should be told the reasons for this.

Before the assessment starts, health and social care professionals should explain what an assessment is, what happens and how long the appointment will last. They should also explain what information they may have to share with others, in what circumstances, and how they will keep the information about you safe. They should tell you that you will be asked about your life and experiences, and also that any decision about your treatment and care will be a joint one made by you and health and social care professionals. You should be advised that you can refuse permission for any other member of staff, for example a student, to be present.

During the assessment, you should be given enough time to talk about your problems, with time at the end for you to ask questions. If you are given a **diagnosis**, this should be clearly explained and you should be given a booklet or leaflet about it. The healthcare professional should discuss different treatments and give you information about each. You should also be offered time to talk after the assessment, especially if any sensitive issues were discussed. If you are unhappy about the assessment and diagnosis, you should be given time to talk about this and offered a second opinion.

Copies of all correspondence about your diagnosis, treatment and care between your health and social care professionals and other professionals should be sent to you, unless you decide against it. You should be told about your right to a formal **community care assessment**, and how you can get this. You should also be told how you can safely make a complaint.

You should not usually be assessed by more than one service unless you have a **crisis**.

Questions you could ask your healthcare team

- Why am I being offered an assessment?
- Will you tell anyone about my mental health problem?
- Who can provide my treatment and care?
- Are there any support organisations in my local area?
- Have you got any information for my family or carer?
- How can I manage my own condition?
- Who can I contact if I need help quickly between appointments (in a crisis)?

What should happen after I have been assessed?

Developing a care plan

After your assessment, you may be supported by a **community mental health team** who will develop a care plan with you. The plan should include:

- activities to increase or maintain your social contact, such as education, work, volunteering, caring for family members or leisure activities
- what you can do to keep well
- how to cope with and reduce any risks to yourself or others.

Health and social care professionals should support you in carrying out your care plan and should give you a printed copy. You should also be able to see or have a copy of your **care record** whenever you wish. This should contain a section where you can record your views and preferences. You can also record any disagreements between you and your health and social care professionals.

If there is a risk you may have a crisis, there should also be a crisis plan, which should include:

- how to manage your symptoms, such as recognising warning signs that might suggest a setback or a crisis
- details of any advance statements and advance decisions
- the support available to enable you to carry on your treatment in the community rather than in hospital
- whether your family or carer is involved in your care
- the names of professionals involved in your care
- where you would prefer to go if you need to stay in hospital for treatment and care
- details of any practical needs you have, such as care of children and other relatives or pets.

Treatment

You should usually receive all your care and treatment from one community mental health team.

You should be offered the **psychological treatments** and drug treatments recommended for your mental health problem in NICE guidance.

Psychological treatments should be culturally appropriate.

Other support

If you have children, you should be offered childcare so that you can attend appointments and support groups. If you are pregnant or have had a baby in the past year, you may be offered care in a local mother and baby unit.

If appropriate for you, health and social care professionals should advise you about having a **personal budget** or **direct payment** so you can choose and control any care and support from social services.

What should happen in a crisis?

There should be a local 24-hour helpline that you can call in a crisis. Your GP should know the telephone number.

If you have a crisis, and you are referred for assessment or treatment in mental health services, you should be seen within 4 hours. Health and social care professionals should first find out if you have details in your crisis plan (including advance statements or advance decisions) of what should happen. They should also find out if you have an advocate, and should contact them if you wish. If you are offered an assessment, you should be asked if you would prefer to see a male or female professional – your preference should be met wherever possible.

Professionals should be supportive and respectful and should give you clear information about the assessment (see pages 5–6). The professional assessing you will ask you about your living conditions, how well you are managing in everyday life, your relationships, symptoms, behaviour, diagnosis, and any treatment you are having.

Assessment during a crisis can take place at home or where you live. If this is not possible, or you do not want an assessment at home, professionals should take full account of where you would prefer to have the assessment. A **crisis resolution and home treatment team** will usually be the first service to assess you. The team should be available 24 hours a day, 7 days a week, and should support you to stay at home rather than going into hospital if possible. The team may offer you treatment at home and should help you continue your day-to-day activities, including education, work, volunteering, caring for family members and leisure activities.

What should happen if I need to stay in hospital?

If you go to hospital for treatment and care, you should meet with a healthcare professional within 2 hours of arrival for an assessment. They should make sure that you feel safe. Shortly after you arrive you should be given information about the hospital and the ward, about the treatments, activities and services available, the rules of the ward, your rights, visiting arrangements and meal times. You should also be told how often you can expect to meet health and social care professionals. There should be enough time for you to ask questions about the information you are given.

You should also be shown around the ward and introduced to the team as soon as possible, and within the first 12 hours if you are admitted at night. You should also be introduced to the nominated healthcare professional who will care for you throughout your stay.

You should be offered one-to-one meetings with:

- a healthcare professional you know for at least 1 hour every day
- your consultant (for example, a psychiatrist or nurse) for at least 20 minutes each week
- a specialist mental health pharmacist to discuss any medication for your mental health problem, including the advantages and disadvantages of taking it.

You should be involved in making decisions about your treatment and care with health and social care professionals. You should be able to have the psychological treatments and drug treatments recommended in NICE guidance, and these may be provided by professionals who were involved in your care before you were admitted to hospital. Health and social care professionals responsible for your **community care** should visit you routinely.

You should have access to a phone and the internet and be able to join in a wide range of activities, including creative and leisure activities and exercise, 7 days a week, throughout the day and evening. A choice of foods should be available to suit a range of ethnic, cultural and religious backgrounds.

If you have children, there should be a family area in the hospital where you can meet them when they visit you.

You should be offered the chance to meet with an advocate. This might be someone who has previously stayed in hospital for a mental health problem and has been trained to help you put your views across, especially about any problems on the ward.

What should happen if I am treated under the Mental Health Act?

If there is a serious risk to yourself or others, you may be detained and treated under the Mental Health Act. Health and social care professionals should consider and discuss with you and your family and carer other options first; these may include a review of any medication you are taking, respite care (for example, social services accommodation where you can stay overnight), treatment in hospital as a 'day patient' (you stay during the day but go home at night), treatment at home or a 'crisis house' (safe accommodation for people in crisis).

If you are detained under the Mental Health Act, professionals should treat you with dignity and respect and address your needs. They should explain and make sure you understand why it is happening. You should also be given written information such as a 'patient rights leaflet' about the section of the Mental Health Act that applies to you and what your rights are.

If you are detained under the Mental Health Act you have the right to an Independent Mental Health Advocate (IMHA). Health and social care professionals should give you information about IMHAs and make sure you can get help from one.

The police will only be involved if your safety or the safety of others is a concern and cannot be managed by other means. If the police take you to a 'place of safety', you should be assessed under the Mental Health Act as soon as possible and within 4 hours of arriving there. Places of safety include hospitals or other healthcare services.

If you are detained under the Mental Health Act you will be taken to a hospital. Your journey there should be comfortable and without delays, and transition to the ward should be smooth, efficient and comfortable. Your family or carer should be able to travel with you if it is safe. When you arrive at the hospital, staff should welcome you.

If you are being treated under the Mental Health Act, you may not understand why, or you may disagree with the decision. You have a right to appeal to a **mental health tribunal**, and health and social care professionals should support you if you decide to appeal and tell you how the process works and how long it may take. If you wish to complain about care you are given while under the Mental Health Act, you can complain to the service detaining you; if you are not satisfied with their response you can then complain to the Care Quality Commission (www.cqc.org.uk). You should be told how to do this.

Questions about being treated under the Mental Health Act

- Why have I been detained under the Mental Health Act?
- Can I refuse treatment?
- Can I have 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?

Sometimes people with mental health problems may need to be controlled or restrained by staff when in hospital, or have treatment without their agreement (such as medication to calm them down quickly). This should be a last resort. If this happens to you, it should be done by trained staff, and preferably by staff you know and trust. They should act with your best interests at heart and will make sure you are safe while using minimum force.

If you are controlled, restrained or are given treatment without your agreement, the reasons should be explained to you and to your family or carer (if they are involved in your care). When you leave hospital, you should be offered the chance to discuss such treatment with professionals. You should also have the opportunity to write about your experience in your care record, including any disagreements with professionals.

If you witness someone else being controlled or restrained you should be offered support and time to discuss the experience if you find it distressing.

What happens when my treatment or care comes to an end?

Before treatment ends or your care is transferred to another service, this should be discussed and planned with you and your family or carer (if you agree) and should not happen abruptly. With health and social care professionals, you should agree steps to help you cope with any crises and you should be advised how to contact professionals if needed. If your care is being transferred to another service, you should be offered support during the transfer.

You should be told the date you will be leaving hospital at least 2 days before you go. Before you leave, health and social care professionals will want to check that where you live is safe and comfortable.

You should be given clear information about the support available after you have left mental health services or hospital, and you should be given a number to call any time of the day or night if you have problems.

Becoming involved in helping to improve mental health services

When your treatment and care comes to an end, you may be asked about the quality of your care by an interviewer who has used mental health services before. Your views will be taken into account to help improve the service.

Health and social care professionals may ask if you would like to help plan and provide training for professionals working in mental health services so that they can deliver better care. You may also be asked if you would like to interview other people using mental health services. You will be offered training to do this and you may receive payment for your involvement in helping to improve mental health services.

Before your treatment and care comes to an end you should be given information about your local patient advice and liaison service (PALS) and told that you can train to be an advocate if you choose or become involved in checking whether mental health services are providing a satisfactory level of care.

Information for families and carers

As a family member or carer, you may need help and support yourself, especially if your family member or friend is having a crisis.

Professionals should give you information about local support groups and services especially for families and carers, and about how to join these. Professionals should advise you that you have a right to a formal **carer's assessment** of your own physical and mental health, and help you to access this.

There is further information about families and carers on page 4.

Glossary

Advance decision A legally binding document that states the treatments that a person (aged 18 or over) does not want to be given if they lose the capacity to make decisions about their treatment.

Advance statement A general statement about a person's preferences for treatment and care. This should be used by healthcare professionals if the person loses the capacity to make decisions about their treatment and communicate their needs. Unlike advance decisions, advance statements are not legally binding.

Advocate Someone trained to help a person put their views across. An advocate can speak on a person's behalf if they find it difficult to communicate their needs, and can make sure the person receives the information and care they should.

Assessment Meeting with a health or social care professional to discuss your physical and mental health, family background and everyday life, to find out what the illness is, how severe it is and the most suitable treatments.

Capacity Being able to understand information and use it to make decisions about treatments.

Care plan A plan of your treatment and care, which also includes what you can do to keep well and how to manage your symptoms.

Care record A record (often in electronic form) kept by health and social care professionals about your treatment and care.

Carers People who provide regular and substantial care for people with a health problem.

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

Community care Treatment, care and support provided in a place that is not a hospital ward, such as the person's home, a day clinic, or a GP's surgery.

Community care assessment A formal assessment by social services of personal care needs.

Community mental health team Psychiatrists, psychologists, occupational therapists, nurses, social workers and support workers, who may visit a person with a mental health problem in their home or provide treatment and care at a clinic.

Crisis A level of emotional distress that may make the person feel that they are unable to cope, and which sometimes requires an emergency response.

Crisis resolution and home treatment team A service that provides intensive home-based treatment for people in crisis. The team can also provide care after a person has left hospital.

Diagnosis Identifying an illness or problem after having considered the person's symptoms.

Direct payment Cash payments made directly to eligible people so they can control and purchase their own social care and support instead of the council providing the service.

Mental Health Act A law that allows a person with a mental health problem to be treated against their will, or without their agreement, if they are judged to be a 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. They have a legal right to appeal to a mental health tribunal.

Mental health tribunal An independent panel to review the cases of people detained under the Mental Health Act. People who appeal to a mental health tribunal are entitled to free legal representation.

Personal budget Funding from social care that is allocated to eligible people who need services. They can choose whether to leave the council with the responsibility to commission the service or have a direct payment.

Psychological treatment 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.

More information

The organisations below can provide more information and support for people with a mental health problem. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Mind, 0300 123 3393
www.mind.org.uk
- Rethink Mental Illness, 0300 5000 927
www.rethink.org

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (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 service users and carers. They consider the evidence on the condition and treatments, the views of service users and carers and the experiences of doctors, nurses and other healthcare professionals. 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

This booklet and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/CG136

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2693). 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 mental health problems.