

Mental health problems in people with learning disabilities – what care you should expect

Information for the public

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Important information about this guidance

This information explains the care that NICE has said works best for people with learning disabilities who have mental health problems. It is written for the parents, family members, carers and care workers of anyone with learning disabilities and mental health problems. It will help you find out what care you should expect from health, social care and educational services. An easy read version of this information for people with learning disabilities is available [here](#).

Family members and carers will normally be involved in care for people with learning disabilities. However, there may be rare situations when a person with learning disabilities who can make decisions about their own care does not want their family or carers to be involved.

Staff should be aware of what NICE has said. Talk to your doctor if you don't think the person you care for is getting the care NICE has said they should have. The person you care for may also be able to get help from an advocate. NHS Choices has more information about [advocates](#).

This information is about the extra things staff need to do for people with learning disabilities. It doesn't go into detail on different mental health problems (such as depression or anxiety). If the person you care for has a mental health problem, your healthcare professional should give you more information about it.

Why is this important for you?

NICE aims to help people to get the best possible care no matter who they are or where they live.

The guideline aims to:

- help stop people with learning disabilities from getting mental health problems
- help staff to recognise when people with learning disabilities have a mental health problem
- help doctors and other staff who work with people with learning disabilities to assess mental health problems
- make sure parents, family members, carers and care workers have the support they need
- recommend treatments.

Mental health problems

Mental health problems are common in people with learning disabilities, but it can be hard to tell if the person you care for has one. This could be because problems with their physical health or their behaviour are making it hard to notice the symptoms, or because they can't show or tell you how they are feeling. All staff who care for and support people with learning disabilities need to understand this, and take extra care to pick up on problems.

Who will be involved?

Depending on the type of help that is needed, you may work with lots of different professionals.

They could include:

- GPs, nurses and specialist doctors such as psychologists and psychiatrists (who specialise in mental health) or paediatricians (who specialise in caring for children)
- speech and language therapists, physiotherapists (who help with movement) and occupational therapists (who help with normal daily activities)
- social workers
- teachers and other people working in education.

Everyone involved should know how the person you are caring for is affected by:

- their learning disabilities
- any physical health problems
- any mental health problems, and how they can get help with these.

Key workers

People with learning disabilities and serious mental health problems should have a key worker. They make sure that all staff involved are working together, and that the [care plan](#) is being followed and is helping. The key worker is your main contact, and should make sure any assessments, care and treatments are explained clearly to you and the person you care for.

Leadership team

The leadership team organises all care for people with learning disabilities and mental health problems in your area. It's their job to make sure that care is available for people who need it, and that all staff know what their responsibilities are.

Working with you

Staff should involve you and the person you care for in all decisions, and answer any questions you have at any point. When talking to you and the person you care for, they should:

- find out what matters to you
- give you all the information you need, so you can decide what to do
- explain why they think a treatment that is mentioned here won't work
- give you details of who to contact if you have any questions
- make sure that you understand what they are saying, and have enough time to discuss everything you need.

When discussing possible care and treatments, staff should explain all the options, including the advantages and disadvantages of each. They should make sure that you and the person you care for understand what all meetings, care and treatments are for before they start, and again while they are going on.

Staff should encourage you to get involved, and provide training and support to help you contribute to any care and treatments.

There is more information about how you should be involved in care on our [website](#).

Preventing mental health problems

There are some things that can help people with learning disabilities live more happily and healthily, and stop them from getting mental health problems. Staff should have a plan to help the person you care for:

- live where they want and choose who they live with (if they are an adult)
- spend time with their family and other people who are important to them
- plan for big changes to their home life, such as moving house
- get out and about to places such as sports centres and libraries
- get involved in hobbies and activities they enjoy.

Organisations have a legal responsibility to help people with learning disabilities use their services (this is called making reasonable adjustments). For example, they may need to let someone go along as a buddy, or help with organising transport. You can find more information about the legal responsibilities of organisations on [NHS Choices](#).

Children and young people should be able to go to a school or college that can provide an education that meets their needs and encourages them to learn.

Staff should take special care of children and young people who are taken into care or are moving between placements (for example foster care, adoption or going to a boarding school or college). This is because during these stressful and emotional times there is a very high risk that people can get mental health problems, or that problems they already have can get worse.

Help finding work

People with learning disabilities can get mental health problems for the same reasons anyone does – because of things like feeling lonely, having nothing to do or worrying about money. Getting a job or doing voluntary work can make mental health problems less likely, and help people to cope if

they do have a problem. If the person you care for is able to, you can help by encouraging them to look for work. They may be able to get practical help from staff on things like:

- finding out what they are good at and what sort of work they want to do
- writing application forms and CVs
- preparing for interviews.

Assessing for mental health problems

The first signs of mental health problems in people with learning disabilities can be changes in behaviour (for example, becoming withdrawn or anxious, forgetting skills or needing prompts to do things). If any staff (such as teachers or support workers) notice changes that concern them, they may arrange an assessment to check the person's mental health. If you are worried about the mental health of the person you care for, speak to their GP.

The person you care for should also have an assessment if they are having a crisis. This is to find ways to help with the crisis, and to stop it from happening again.

If there are any signs of a serious mental health problem or dementia, the person you care for should be referred to a psychiatrist who specialises in caring for people with learning disabilities and mental health problems.

What happens in a mental health assessment?

An assessment is a meeting to find out more about the problem and to decide what care and treatment is needed. It should be run by a professional who specialises in caring for people with learning disabilities and mental health problems, but other staff may be involved as well. You should be fully involved, and so should any other people (such as friends) that the person you care for wants to involve in the assessment. However, it's important the person you care for gets a chance to talk with staff alone if they want to. The assessment should take place somewhere the person you care for knows and is comfortable (such as their GP surgery).

Before the assessment starts, staff should explain what it is for, how it will be carried out and how long it will last. Staff should help the person you care for to prepare for the assessment if needed, and you should both have the chance to ask any questions you have.

During the assessment, staff will try to find out more about changes in behaviour and what might be causing them. They will ask about the person's current and past health and about any medication they are taking. They will need to ask sensitive questions (such as whether the person is drinking alcohol or taking drugs), to find out if there is anything in the person's life that could be causing the mental health problem or making it worse.

You should get a summary of the assessment results after it is done, and staff should make sure that you can both understand it. The summary should say what care and treatment could help.

You can ask for another meeting to talk about the assessment after it has finished, if you need one. You can also ask for another assessment, if you disagree with the decisions that were made. It can take more than one assessment to decide what the problem is and what care is needed.

Risk assessment

A risk assessment is a check to see if the person you care for might be unsafe while they have a mental health problem. This could be because they might hurt themselves (either on purpose, or by not looking after themselves properly), or because they might hurt other people (for example, because they are scared).

Staff should carry out a risk assessment if the person you care for has a mental health problem, and repeat it regularly to make sure there are no new risks. If needed, they should make a plan with you and the person you care for to reduce any risks.

Making a mental health care plan

After the assessment, staff should agree a mental health care plan with you and the person you care for. This is a plan for any care or treatments and what you and the person you care for want to get out of them (for example, help with specific symptoms).

It should be sent to everyone involved (including you and the person you care for, and any other people they involved in the assessment). The plan should explain how each person will help provide care. Staff should also agree a date to discuss the plan with you and the person you care for, to check how it is working and if any changes are needed.

Help for mental health problems

Psychological ('talking') therapies

All care and treatment should be designed around the needs of the person you care for, and should be understandable to them.

Staff should agree which care and treatments to use with you and the person you care for. They should also agree how care and treatment should be provided, for example:

- what to discuss in each session
- how long each therapy session should be
- how often the sessions should be.

Some treatments involve learning new skills, which people with learning disabilities can find difficult. Staff should help them to do this, and you can also help by reminding the person you care for to practise new skills between sessions.

These therapies can help for specific mental health problems:

- Cognitive behavioural therapy for people with depression. This involves finding negative thoughts and behaviour and learning to change them.
- Relaxation therapy for people with anxiety. This involves exercises such as breathing techniques.
- Graded exposure techniques for people with anxiety or fears (phobias). This involves finding out exactly what causes the anxiety and learning how to cope with it, until it is no longer a worry.

There are also other treatments that are used for mental health problems in people who don't have learning disabilities, and some of these may help the person you care for. Your healthcare professional should give you more information about any treatments that might help.

Medication

Medication can often help with mental health problems. However, a lot of the medication used to treat mental health problems can cause side effects. People with learning disabilities can find it

difficult to tell anyone if they are getting side effects, so healthcare professionals need to take extra care. After starting medication, the dose might need to be changed to find what works best. If needed, staff should also have a plan for when and how to stop the medication.

People with learning disabilities often take medication for physical health problems. Before prescribing medication for a mental health problem, healthcare professionals should think about how it would affect any other medication taken by the person you care for (for example, it might stop the other medication from working or cause different side effects).

Children and young people should only be given medication for mental health problems by a doctor who specialises in caring for people with learning disabilities and mental health problems.

The person you care for might also be offered help from local nurses who work with people with learning disabilities. They can help with things like taking blood tests to see if the medication is having any side effects. Staff should also offer support to make sure the person you care for can take their medication at the right time and in the right amounts.

When a hospital stay is needed

If the person you care for has a serious mental health problem and needs to stay in hospital:

- the staff at the hospital should have experience in caring for people with learning disabilities and mental health problems
- if possible, the hospital should be in your local area.

Yearly GP check-ups

People with learning disabilities should have yearly check-ups with a GP (unless they are a child or young person and are having check-ups with a paediatrician). You should be involved in these check-ups as well.

These check-ups are to talk about any:

- mental health problems (including signs of mental health problems that haven't been [assessed](#) yet), and whether any physical health problems could be causing them or making them worse
- physical health problems, and agree if any treatments are needed (such as painkillers)
- treatments (including medication) the person is having.

GPs should also ask people with Down's syndrome questions about changes in their behaviour or forgetting how to do things, which might mean they need a check for dementia.

Help for you

Caring for someone who has learning disabilities and mental health problems can sometimes be challenging and put you under strain. You should be offered your own support, including:

- a carer's assessment, to check how caring affects you and what help you might need
- support to take short breaks from caring
- groups that provide support and information
- help for any mental health problems of your own.

If you care for a child with learning disabilities, you may be offered a training programme designed for parents or carers of children with learning disabilities. This programme should help you to support your child's social and emotional growth, and teach you how to cope with problems you might have.

Questions you could ask

- How can I help the person I'm caring for to avoid getting mental health problems?
- What help can we get with looking for work?
- Could you go into more detail on how to tell if the person I care for might have a mental health problem?
- Can you tell me more about the mental health problem the person I care for has?
- Can you tell me more about what kind of treatments could help?
- How can I tell if the person I care for is having side effects from medication?
- How can I help with the treatments the person I care for is having?
- Can you tell me more about support for families and carers?
- Is there any information you can give me to take away?

What are NICE guidelines?

NICE gives advice to doctors, nurses and other staff working in health and social care. Our guidelines tell them about how to look after people with different conditions and needs.

We wrote this guideline working together with the carers of people with learning disabilities and mental health problems, and with staff who diagnose and treat mental health problems. All of the decisions are based on the best research available. You can read the [guideline](#) written for healthcare professionals.

More advice and support

- Mencap, 0808 808 1111
www.mencap.org.uk
- MIND, 0208 519 212
www.mind.org.uk
- Rethink Mental Illness, 0300 5000 927
www.rethink.org

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Accreditation

