



# People growing older with learning disabilities

**Our advice about good support**



**EasyRead version of NICE guideline NG96**  
**April 2018**

# What is in this guide?



About this guide

1



Having choice and control

3



Support from staff and services

6



Checking you have the right care and support as you get older

9



Planning your care as you get older

12



Keeping well

16



Having check-ups

19



Caring for a health problem

22



Care near the end of your life

26



How to find out more

28



## About this guide

**NICE** National Institute for Health and Care Excellence

**NICE** wrote this guide. **NICE** is the short name for the National Institute for Health and Care Excellence.



We find out what works well in health and social care and write guides to give **advice** about it.



This guide says what care and support people with learning disabilities should have as they grow older.



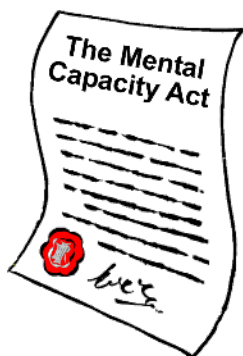
Everyone who works with people with learning disabilities should know what NICE says. It helps them give good care and support.



People and their families and carers should know what NICE says too. It can help them get the right care and support.



## Having choice and control



A law called the Mental Capacity Act says you should make all the decisions you can yourself.



You should have the support you need to make your own decisions.



You might sometimes need help to make a decision. Or other people might need to decide for you if you cannot do it yourself.

But staff must always make sure you have a say.



Staff should work with your **support network** too, if you are happy with this.

A **support network** is everyone who helps you, like friends, family and carers.

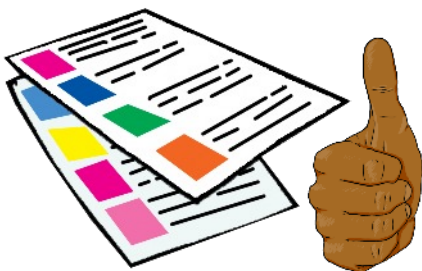


Staff should listen to your **support network**. But they should not treat other people's views as more important than yours.



## Help to speak up

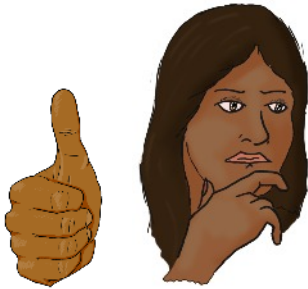
Staff must help you to say what you think in the way you want. It is the law.



You should be given clear information in a way that you can understand.



You might need more help to say what you want as you get older.



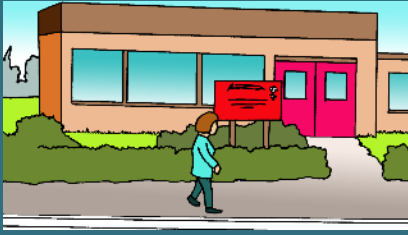
Staff should always be thinking about better ways to help you say what you want.



You should have an **advocate** if you want one.

**Advocates** help you speak up. They do not work for the service that supports you.





## Support from staff and services



You should be given clear information about what different **services** are for and how to use them.



**Services** mean things like healthcare, housing and social care.



The law says that you must get the help you need to use the same services as everyone else.



The staff and services where you live should:

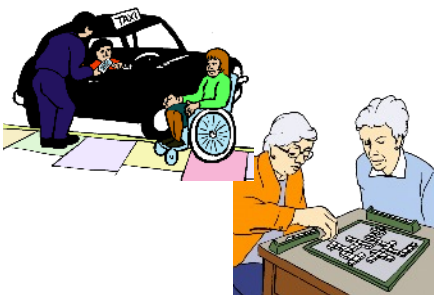
- find out what kinds of help and support you need



- make sure you and your family or carer can get all your help and support close to home



- help you choose where you want to live and who you want to live with



- help you get around and do things you like doing



- help you stay active

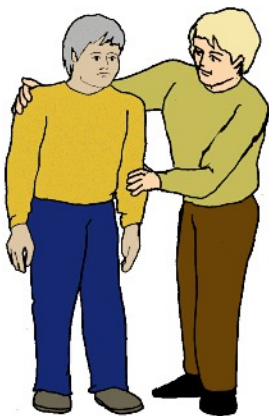


- support you to go to social clubs or support groups where you can meet people and see friends.



There should also be help for families, like **respite care**.

**Respite care** means a short break away or extra help at home.



## Staff

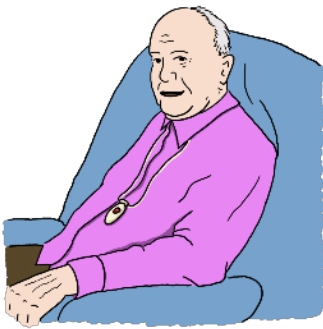
The staff who support you should get on well with you and understand your needs and what you want from life.



Staff in **learning disability** services and **older people's** services should be trained to give you the right support as you get older.



## Checking you have the right care and support as you get older

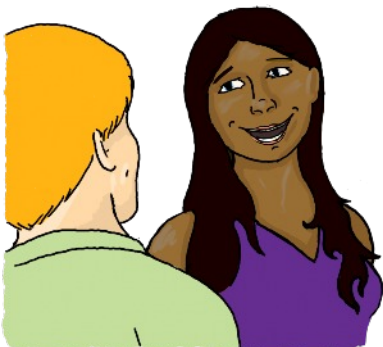


As you get older the care and support you need might change.

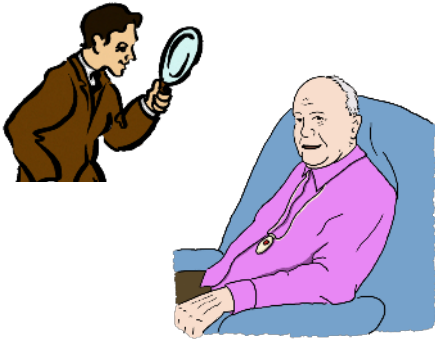


To check your needs are still being met, staff should offer you a check called an **assessment**.

An **assessment** means finding out about your needs.



Your **assessment** should be done by someone who knows you well.



Staff should look out for changes in you as you get older.

Changes could mean you have a problem or you are unwell.



Changes could be:

- feelings, like being worried or sad a lot



- physical changes, like pain or losing weight.



Staff should think about what these changes could mean.

They should not just think they are because you have a learning disability.



## Caring for your family

If you look after anyone else in your family it means you are a **carer**.



If you are a **carer** you should have a carer's assessment.

Staff should find out what help you need to look after the person you care for, now and as you both get older.



## Supporting families and carers

Staff doing assessments should also find out what help your family or carers need to support you.



Your family or carer should be asked if they want a carer's assessment. They can also register as a carer with their GP.



## Planning your care as you get older



Staff who know you well should help you and your family or carer write a plan for when you are older.



The plan should say things you want to happen, and things you **do not** want to happen when you are older.



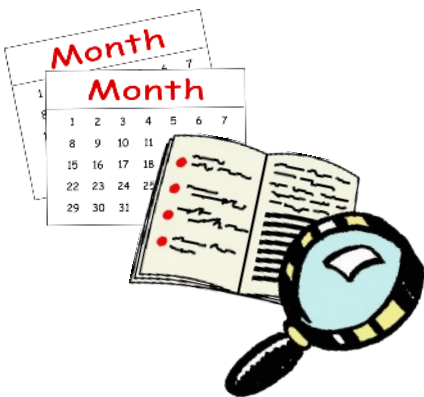
The plan should say who will help you make decisions in the future. And who to talk to if something goes wrong.



Your plan should say who will help you with money.



It should also say what will happen if the person who cares for you now is no longer able to do it.



Your plan should be checked once a year and when there is a big change in your life.



## Your life

Staff should also talk to you about what you want from your life and who you want to spend time with.





Making sure you have a **support network** will help you to have a good life as you get older.



Staff can help if you would like to meet new people and make friends in your community.



You can also talk to staff about relationships and sex if you want to.



When you get older you might need extra help to stay living in your house.

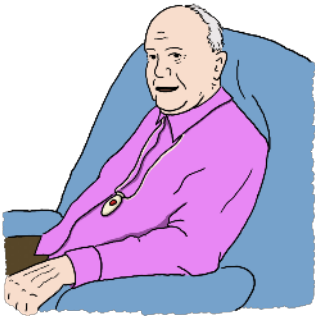
You should be able to have equipment like a support phone or a lift put in your house if you need them.



If you decide to move, staff should help you start planning for this early.



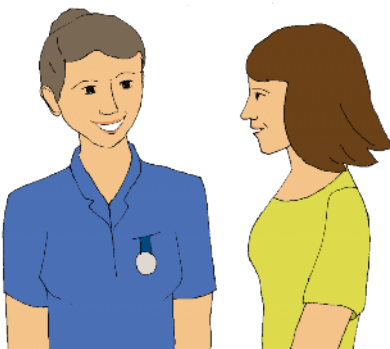
## Keeping well



As you get older it is important to look after your health.



You should have one person who you can always speak to about your health.



This person could be a nurse who works with people with learning disabilities.

Or it could be a member of your local learning disability team.



When you need to see a doctor or nurse you should have extra time in your visit.



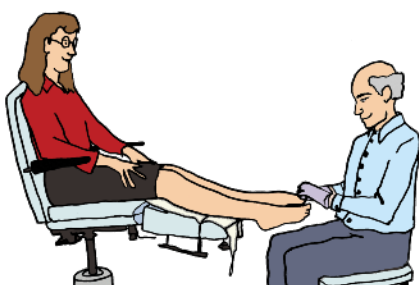
You should be able to see a doctor or nurse you know, if possible.



You can take someone who knows you well, like a friend or carer.



During your visit your doctor should make sure you understand what is happening.



If the doctor needs to examine you, they should do it somewhere you know or where you feel comfortable.



## Knowing your needs

Health staff should know you have a learning disability. It should be written in your notes. These are called medical records.



Your notes should say what help you need to say what you think and any other needs you have.

If you agree, your notes can be shared with other staff who can help you.



## Having check-ups



You should have the same health checks and **screening tests** as other people.

**Screening tests** check for health problems, even in people who feel well.



You should have a check-up called an **annual health check**.

It means seeing your local doctor once a year to check your health.



You should be told what will happen at your **annual health check** and how to book one.



At your annual health check your doctor will:

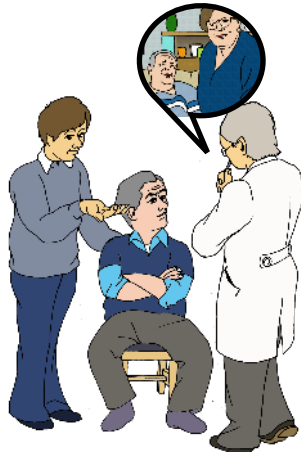
- ask how you feel and if you have had any health problems



- ask if you see a dentist regularly and know how to look after your teeth



- give you advice about keeping well as you get older



- teach you and your family or carer how to spot a health problem as you get older.



If you have any health problems you might need to see a specialist doctor. Your local doctor should arrange this for you.

## Dementia



**Dementia** is an illness that affects memory and how you think and feel.

It can happen earlier in people with learning disabilities.



Your doctor should tell you and everyone who supports you how to spot signs of **dementia**.





## Caring for a health problem

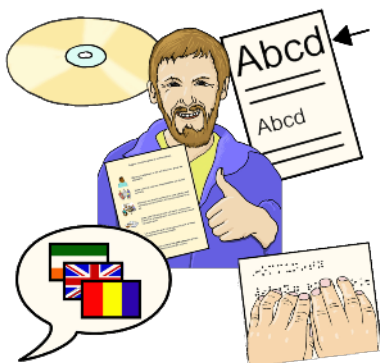


If you have a health problem all the different staff who support you should work together.

They should talk to each other regularly about your care.



They should involve you and your family or carer.



Health staff should explain your health problem to you and give you and your family information you can understand.



They should teach you how to take and look after any medicines.



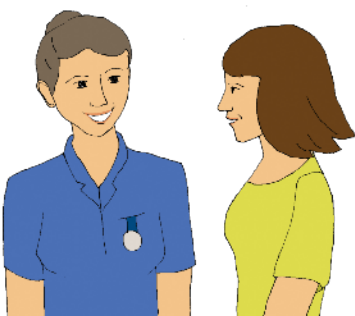
They should help you stay fit and well by doing things you enjoy, like sports and hobbies.

## Going to hospital



If you need to go to hospital, staff should help you plan any extra support you might need.

Staff should tell the hospital about how you say what you want and other important things about you.

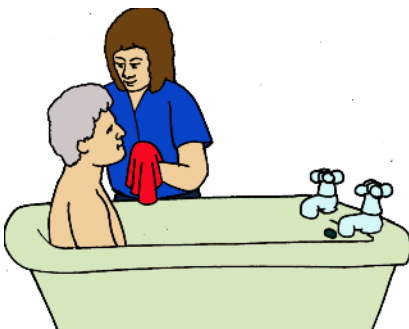


You should be able to visit the hospital first and meet the staff who will look after you.

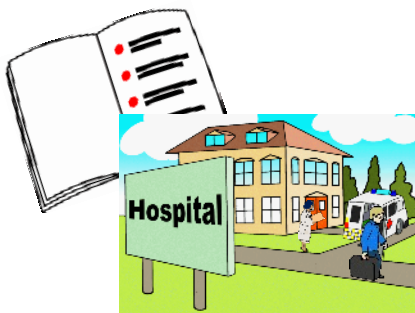


A family member or carer should be able to stay with you in hospital.

They should be able to sleep there too.



Hospital staff should still help you with things like eating or washing, even if a family member or carer is staying with you.



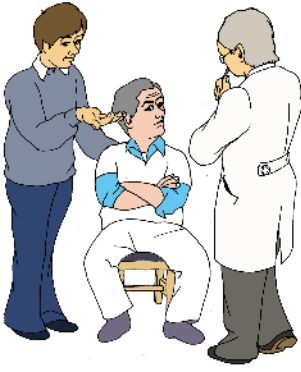
## Going home from hospital

Everyone should work together to make a plan for when you go home. This is called a discharge plan.



When making your plan:

- you and your family should be involved



- staff should check what support your family or carer will need



- hospital staff should talk to your local doctor or nurse.



You should be given a copy of your plan in a way you can understand.



When you get home everyone should follow the plan.



## Care near the end of your life



It might seem too soon but it is important to start thinking early about the care you will want near the end of your life.



Staff supporting you should:

- help you plan this and tell you about the different types of care you could have



- ask who you want to involve in planning this



- check every 6 months in case you have changed your mind about who to involve.

## Giving you the right care



Staff in different teams should work together to give you the right care near the end of your life.



You should be able to have care in the place you have chosen.



Staff should listen to your family or carer to help them give you the right care, because they know you best.



## How to find out more



These people can give you more information about support for older people with learning disabilities.



Their information is not written by NICE and might not be EasyRead.



### Mencap

Telephone:  
**0808 808 1111**

Website:  
**[www.mencap.org.uk](http://www.mencap.org.uk)**



### Foundation for People with Learning Disabilities

Website:  
**[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)**

## Credits



This information has been designed and produced for NICE by the EasyRead service at Inspired Services Publishing Ltd. Ref ISL196 17. April 2018.



[www.inspiredservices.org.uk](http://www.inspiredservices.org.uk)

It meets the European EasyRead Standard.



The **Making it Easier Group** making EasyRead information with **Leading Lives**.



Artwork includes material from the Inspired EasyRead Collection and cannot be used anywhere else without written permission from Inspired Services.

[www.inspired.pics](http://www.inspired.pics)