















Introduction

This is an easy read booklet called 5 Steps to Health.

Sometimes things get in the way of people with learning disabilities getting good health care.

People with learning disabilities do not always get the help they need to stay healthy.

People with learning disabilities are more likely to die from **avoidable** causes.





Avoidable means they might have got better if they got the right care and treatment.



We want people with learning disabilities to get the care and treatment they need, just like everybody else.



This booklet is about 5 things we can do to help people with learning disabilities live longer and healthier lives.





Health action plan





Health Action Plans

The 1st step to health is having a copy of your **health action plan**.

A health action plan is a document about your health that you work with the doctor to make.

You should get a copy of your health action plan during your learning disability annual health check.

A learning disability annual health check is an appointment about your health that happens once a year.





You will be invited to one if you are aged over 14 and are on your doctor's **learning disability register**.



The learning disability register tells your doctor that you have a learning disability and might need extra support during appointments.



You should get a letter inviting you to go to an annual health check at your doctor's surgery every year.



During an annual health check you will meet your doctor or a nurse and talk about your health.





It is your chance to talk about any worries and health problems you might have.



The appointment will usually last between 30 and 60 minutes.



It can also help you get to know your doctor better which will help if you ever do get ill.



It can help your doctor spot any health problems early and treat them before they get serious.













During an annual health check the doctor or nurse will:

 Check things like your weight, blood pressure and heart rate.

 See if your vaccinations are up to date.

 Talk to you about any medications you might take.

 Check up on health problems like asthma and diabetes if you have them.

• Take blood and wee samples.





During the appointment the doctor or nurse will help you to make a health action plan.



It tells you things you can do to stay healthy and what support you might need.



It will give you information about the right foods to eat and exercise to do.



It will tell you how to look after any health problems you might have and any medication you need to take.





It will give you information about other health appointments you have, like eye tests and dentist checkups.



The doctor should give you a copy of your health action plan, so you can take it home with you.



You can share your health action plan with people that you trust so they can support you to stay healthy.











Reasonable Adjustments

Reasonable adjustments are the 2nd step to health.

Reasonable adjustments are helpful changes that make it easier for people with disabilities to use a service.

Reasonable adjustments can help break down the barriers to good health faced by people with learning disabilities.

Going to appointments about health can sometimes be hard for people with learning disabilities.





Asking for reasonable adjustments can help to make going to these appointments easier.



Reasonable adjustments are a legal requirement.



The Equality Act, is a law that says services must make reasonable adjustments so people with disabilities can use them.



It says that health care services should make reasonable adjustments when it is possible.











In health care settings there are 3 types of reasonable adjustments that should be made for people with disabilities.

Changing the way things are done means changing rules that
make it harder for people with
disabilities to use a service.

An example of these reasonable adjustments are things like giving longer appointments to people with learning disabilities.

Changing a physical feature
means removing physical barriers
that stop people with disabilities
using a service.











An example of these sorts of reasonable adjustments are things like building wheelchair ramps and accessible toilets.

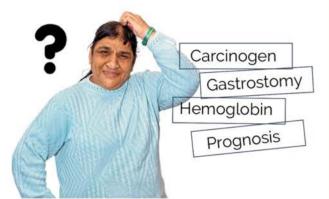
Providing extra aids or services
means giving people with
disabilities any extra support they
need to use a service.

An example of these sorts of reasonable adjustments are things like providing sign language interpreters for deaf people.

The Accessible Information
Standard is a law that makes sure
that people with disabilities are
given information in a way they
understand.











Getting information that you can understand is important when it comes to making good decisions about your health.

Doctors sometimes talk using medical words that are hard to understand.

Asking doctors to explain things in a clear and simple way is a reasonable adjustment.

Asking for information in a different way is another reasonable adjustment.





The way we understand information best will be different for every person.





Some people might prefer information using pictures, videos or easy read guides.



You can ask doctors and nurses for information in whatever way you like best.



The reasonable adjustments that we find helpful will be different for every person.

Some examples are:

- Bringing a support worker or someone else you trust to an appointment
- Longer appointment times
- A quiet place to wait before appointments
- Asking to see a familiar doctor or nurse
- Asking for easy read information
- Asking the doctor to be clear and use simple words

My reasonable adjustments are:





Learning Disability
register

- —
- —

To ask for a reasonable adjustment to be made you need to be on your GPs learning disability register.



Think about what reasonable adjustments would make going to health appointments easier for you.

My reasonable adjustments are:

You can write these reasonable adjustments down in the space on page 15.



Before the appointment, you should call up ask for your reasonable adjustments to be made.













Hospital Passports

The 3rd step to health is having a hospital passport.

Hospital passports are sometimes called health passports.

A hospital passport is a document about you, your health and your medical history.

A hospital passport is written with you, your family and your support workers.





Sometimes doctors and nurses do not understand the needs of people with learning disabilities.



This means that people with learning disabilities don't always get the care and treatment they need in hospital.

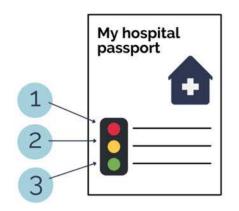


Hospital passports give the people looking after you the information they need to take care of you properly during a hospital stay.



When you go into hospital you should take a copy of your hospital passport with you.





Hospital passports are usually split into 3 sections.



The first section is called **things** you must know about me.



This part has important contact details and medical information about any health conditions and allergies you have.



The second section is called **things that are important to me**.











This includes things like how you communicate, any personal care you need help with, and if you need support to eat and drink.

The third section is about your **likes and dislikes** and helps hospital staff get to know you better.

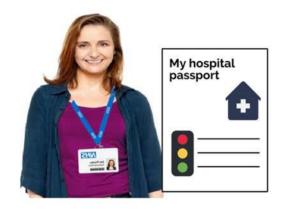
All this information helps to make sure that you get the care and treatment you need in hospital.

It also helps staff make reasonable adjustments to make your hospital stay comfortable.





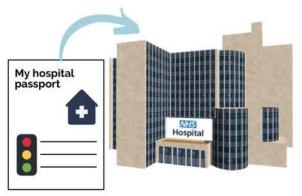
You can find a hospital passport template on your local hospital's website.



You can also ask your community learning disability team or your doctor for one.



You can download and print the template and fill it in with the help of your family and support workers.



You should take it with you if you ever need to go to hospital for pre-planned or emergency appointments.







The 4th step to health is knowing the symptoms of **sepsis** and **pneumonia**.



Sepsis and pneumonia are illnesses that can kill you if they get too serious.

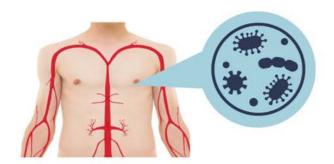


This means it is important to spot the symptoms early so you can get treatment quickly.



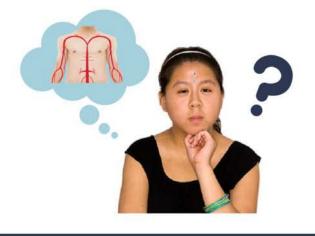
Knowing the symptoms of sepsis and pneumonia can save lives and help stop avoidable deaths.











<u>Sepsis</u>

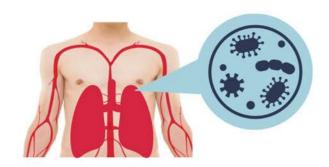
Sepsis happens when your body has a bad reaction to an infection.

It can make you ill very fast and can kill you if you do not get treatment quickly enough.

It is caused by an infection in the body and can not be caught from another person.

The symptoms of sepsis can be hard to spot and sometimes look like other illnesses.





Pneumonia

Pneumonia is an infection in one or both of your lungs and is caused by a bacterial infection or a virus.



Mild pneumonia can be treated with rest, antibiotics and drinking lots of water.

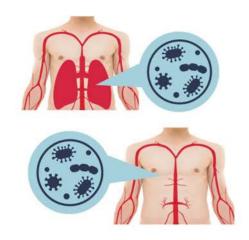


Pneumonia can become serious and even deadly if you don't get treatment quickly enough.



Sometimes pneumonia can be passed from person to person, but this does not happen often.





Some of the symptoms of sepsis and pneumonia are the same.



You should call 999 if you have any of these symptoms:



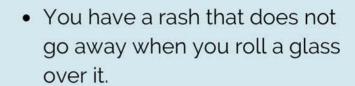
• Coughing up blood.



 Slurred speech, confusion, or not making any sense.

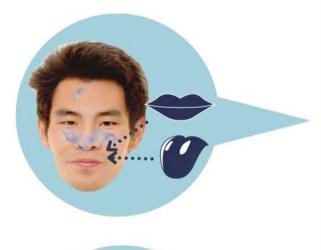








 Not being able to catch your breath, finding it hard to breathe, or breathing too fast.



 Your skin, lips or tongue look blue, pale or blotchy.



• You faint, collapse or have a fit.











Symptoms of sepsis

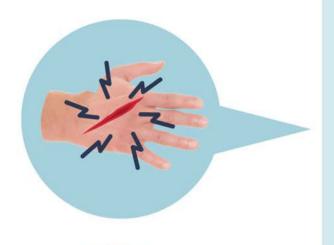
You should call your GP or 111 if you:

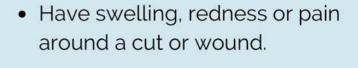
 Can not stop shivering, feel very cold, or feel very warm.

• Feel really unwell or feel like you might die.

 Can't pee or haven't needed to pee all day.









• Feeling very tired and drowsy.



Don't worry if you are not sure if it is sepsis, it is still best get help if you have any of these symptoms.











Symptoms of pneumonia

You should call your GP if you:

 Have a high temperature or can not stop sweating or shivering

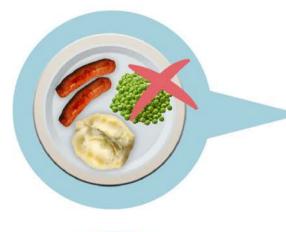
• Feel unwell or are being sick.

Have a cough.





 Have chest pain that gets worse when you cough or breathe.



• Don't have an appetite.



• Have a very fast heart beat.



Are getting headaches.





Avoiding sepsis and pneumonia

There are ways that you can avoid infections that can cause sepsis and pneumonia.



Washing your hands regularly for 20 seconds stops germs spreading.



Coughing and sneezing into tissues and then throwing them in a bin stops germs spreading.



Making sure your vaccines are up to date can stop you getting poorly in the future.











The Mental Capacity Act

The 5th step to health is about making decisions about your health.

The **Mental Capacity Act** is a law about making decisions.

It says that all adults have the right to make decisions for themselves whenever it is possible.

It says that nobody should assume that you cannot make a decision for yourself just because you have a learning disability.











It says that to be able make a decision for yourself you have to:

• Understand the information you need to make the decision.

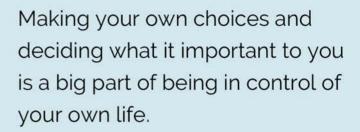
 Remember the information long enough to make the decision.

 Weigh up the information and use it to make a decision.

• Communicate your decision.









This is why making our own decisions about our health is so important.













Some decisions you might make about your health are:

 Making choices about what types of food you eat.

• Choosing whether to exercise.

 Making decisions about smoking or drinking.

 Choosing whether to follow advice from doctors.

Making choices about medication.













Sometimes people with learning disabilities need extra help when it comes to making hard decisions.

If you are finding it hard to make decisions about your health, the doctor should make reasonable adjustments to help you.

The doctor should communicate with you in the best way to help you understand the information you need to make the decision.

The doctor should give you lots of time to think about the decision.





The doctor should try breaking the decision down into simple steps.



The doctor should repeat the conversation lots of times if you need it.



The doctor should get help from the people who know you well to talk to you about the decision and to help you understand it.



Sometimes you might make unwise decisions that are bad your health, like choosing to smoke.





As long able able to make a decision for yourself you have the right to make choices that other people might not agree with.



Decisions about health can be hard to make and some people won't be able to make all decisions for themselves.



If somebody cannot make a decision for themselves, the doctor should make a **best interest decision** for them.



This is when a doctor works with the person's family and supporters to make a decision that is best for them.











What to do when things go wrong

We hope that this booklet helps you to know your rights when it comes to getting good healthcare.

Sometimes people with learning disabilities get poor healthcare that is not good enough.

Poor healthcare includes things like your doctor not listening to you or not making reasonable adjustments you need.

It is important to know how to complain when you feel like you have been treated poorly.





To find out more about how to make a complaint visit **cqc.org.uk**

Q how to complain about your health service

Search for 'how to complain about your health service'.

how to complain about your health service (easy to read) Open the link to the easy read guide to making a complaint - it should be the first thing that comes up.



It will tell you about how to make a complaint and the different ways you can complain.

