

5

Steps to Health

Supporting good health for people

with learning disabilities

**A guide for families, friends and health
and social care staff.**



Research Sources

The information and statistics used in this booklet come from the LeDeR 2019, LeDeR 2018, NHS Digital, www.nhs.uk, Mencap's 'Treat Me Right!' Report, 2004, sepsistrust.org and Options' own research and data. Where statistics are used, their sources are noted at the bottom of the page.

A Note on Language

In this booklet we will use the phrase 'the person you support' and talk about your role as a supporter. This applies to family, friends and anyone else who is involved in the support of a person with a learning disability - whether in an official or unofficial capacity - not just support workers.

When we refer to 'people we support', this means people who are supported by Options.

Some of the statistics we use will compare data between 'people with a learning disability', and 'the general population'. Generally, we find the idea of a 'general population' can be exclusionary. When it is used in this booklet it is used to convey secondary research concisely, so we do not skew the data. In the case of this booklet, the term 'general population' applies to people who do not have a learning disability.

Introduction

People with learning disabilities are significantly more likely to have poorer health than the rest of the population. This is because people with learning disabilities face many barriers and inequalities within health and social care systems which often lead to inadequate care and treatment of health problems.

In 2019 people with learning disabilities in the UK died an average of 24 years younger than the general population, and were twice as likely to die from an avoidable cause.*

The 5 Steps to Health are 5 things we can do to support people with learning disabilities to live longer and healthier lives. In its 2019 Long Term Plan, the NHS has committed to improve its understanding of the needs of people with learning disabilities and reduce the health inequalities they face. Despite this progress, things can still go wrong and people with learning disabilities sometimes experience inadequate care and treatment – the 5 Steps to Health are things we can do to help prevent this happening.





Mencap's 'Treat Me Right!' report (2004) found that some of the barriers to good health faced by people with learning disabilities are:

Poor access to health care services:

Lots of health services do not meet the needs of people with learning disabilities. Previous experiences of poor care can put people off accessing services.

Diagnostic overshadowing:

This happens when healthcare professionals look at a person and assume that their symptoms and behaviour are a result of their learning disability, not an illness.

A lack of professional understanding about learning disabilities:

Some healthcare professionals do not receive enough training about treating people with learning disabilities, and support needs that they might have.

All these barriers contribute to symptoms and illnesses going undiagnosed or health problems going untreated or mistreated.

The 5 Steps to Health are:

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Life expectancy for
people in general
population in 2019

60

Life expectancy for
people with a
learning disability
in 2019

40

Life expectancy for
people with a
profound learning
disability in 2019



“ I felt nervous and agitated

going in the surgery

to see the doctor ”

*We asked people we support how they felt during their last GP appointment

Step 1: Health Action Plans

A **health action plan** is a document about the person you support's health needs. During the person's **Learning Disability Annual Health Check** a doctor or nurse should work with the individual to produce a health action plan.

The person you support should be invited to attend a Learning Disability Annual Health Check every year. It is important that we empower people to attend these health checks. People with learning disabilities often have unmet health needs, and delays in diagnosing and treating these needs are a contributing factor to the excessive number of avoidable deaths. Attending an annual health check and having a copy of a health action plan can help identify and treat any health problems before they become serious.

Learning Disability Annual Health Checks:

- Learning Disability Annual Health Checks are for anyone aged 14+ on their GP's learning disability register
- Most GP practices offer this service and the person you support should be invited to attend one once a year
- The person you support does not have to be ill to attend the appointment - they are there to keep people well

Only
53%
of eligible people attend their learning disability annual health check*

If the person you support has not been invited to attend a learning disability annual health check in the past year, you should support them to contact their GP practice and ask them to provide one. If they say no, you should contact your local learning disability team for more advice on how to access one.



Scan here to find out what to expect during the appointment

A support worker here at Options says: 'After people we support went for their learning disability annual health check, it was found that they had a vitamin D deficiency. Now they receive the right medication, they get fewer coughs and colds and are generally healthier'.

Health Action Plans

A health action plan provides key action points about what needs to be done about any health needs a person might have. It should signpost what services and support the person needs to keep healthy. A health action plan should be accessible to the person, and use things like simple language and pictures. With the person's consent, a copy of their health action plan can be shared with other health professionals and those involved in their support like family members and support workers. This can help to ensure that we are providing the right support the person needs to stay healthy.

60% of people we support didn't get a copy of their health action plan during their last annual health check*.

The person should receive a copy of their health action plan to take home with them after the appointment so they have the information they need to stay healthy. If the person does not have a copy of their health action plan, then you should support them to contact their GP practice to request one.



Scan here to see what a health action plan looks like

Step 2: Reasonable Adjustments

Reasonable adjustments are small, helpful changes to a service which make it just as easy for people with disabilities to use them as it is for anyone else. They are a legal requirement under the **Equality Act, 2010** which says that all public service providers have a duty to make reasonable adjustments whenever it is possible.

The Act says that 'health and social care providers must make reasonable adjustments to remove any barriers - physical or otherwise that could make it difficult for disabled people to use their services or prevent them from using them altogether'.

The right reasonable adjustments can help reduce anxieties many people with learning disabilities face when it comes to accessing health care, and make it easier for them to attend appointments.

Reasonable adjustments are person-specific, and depend on what the individual finds helpful. This will differ from person to person. Types of reasonable adjustments usually fall into 3 main categories:

Changes to the way things are done.

This means changing policies and practices that make it harder for people with disabilities to use a service. These reasonable adjustments include things like:

- Double appointments
- Appointments at the start or end of the day
- Providing a quiet place to wait before appointments
- Home appointments

Changing a physical feature.

This means removing or changing any physical features that create barriers that prevent people with disabilities from accessing health services. These include things like:

- Providing ramps and lifts
- Providing accessible toilets
- Using doors that don't have to be opened manually
- Accessible parking

Providing extra aids or services.

Sometimes people with disabilities will need extra aids or services during health appointments. These include things like:

- Sign language interpreters
- Bringing a family member or support worker to an appointment
- Inviting a learning disability nurse to attend the appointment
- Providing information in an accessible format



Scan here to find out how to ask for reasonable adjustments to be made

Accessible Information:

The **Accessible Information Act, 2016** is a law that says that people with a learning disability should be given information in an accessible way that they can understand. This means that health services should provide people with information that can be easily read or understood. Accessible information is a reasonable adjustment. The person you support is entitled to ask for information in whatever way they prefer. Having information they can understand empowers people to make decisions about their health and manage their health themselves.

Only 39% of people we support think that they get information they can understand about their health*.

- 
- Ask doctors to explain things using clear, simple terms and no jargon
 - Work with the person you support to find what kind of information works best for them
 - Some people might prefer easy read information or information using pictures, symbols or videos
 - If the person you support agrees beforehand, it is okay for supporters to talk with doctors/nurses on their behalf

“

The doctor talked to me in doctor terms that I didn't understand. I had to ask my support worker what he meant.

- Giz

”

Emily's Story:

Getting the right reasonable adjustments and support helped Emily to go through with her smear test - something she hadn't been able to do before. Emily had previously tried to get a smear test at her GP surgery, but felt too uncomfortable and anxious to go through with it.

When Emily was due her next smear test, lots of reasonable adjustments were made to make sure she felt comfortable enough to go through with the appointment. Instead of her GP surgery, the appointment was arranged at her local hospital where there was extra support available for Emily. Prior to the appointment, Emily had talked with her GP about getting a prescription for Diazepam to take before her smear test. Taking Diazepam the morning of her smear test helped Emily to stay calm during the appointment. Two of Emily's support workers who she trusted and felt very comfortable with accompanied her to the appointment. On their way to the hospital, Emily and her support workers talked about what to expect. The support workers shared their experiences

of what getting a smear test was like, and Emily felt like this helped to prepare her for the appointment. Emily's support workers also talked to her about what the room in the hospital and the chair she would sit in would be like. Emily says that she trusted that her support workers were telling her everything she needed to know.

At the hospital, the two nurses who were treating Emily made her feel very comfortable, asking her lots of questions about herself and what she did and didn't like. Her support workers were with her throughout the whole appointment, holding her hands and distracting her by singing songs and making her laugh. Emily says she felt relieved when it was over, and it wasn't as bad as she thought it would be.

Emily's advice to other people who might be feeling anxious about going to a difficult appointment is to make sure that you take somebody with you who you trust and feel comfortable around.

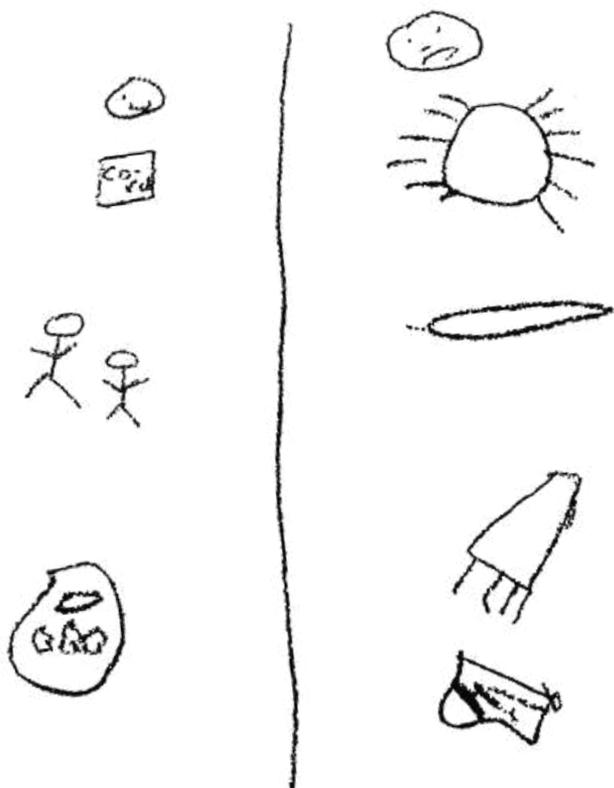
Step 3: Hospital Passports

Going into hospital can be stressful for a person with a learning disability. If the person ever has to go to hospital for either an emergency or a routine visit, their **hospital passport** should go with them and a copy should be put into their notes.

A hospital passport contains information about the person's health, their likes and dislikes, and their communication needs. This information helps the hospital staff to understand the person better and make the right reasonable adjustments, so the person receives the care and treatment they need while in hospital. It will also include information about daily living which helps staff understand what support the person may need, and what they can do independently. When used correctly, hospital passports can make hospital visits significantly easier for people with learning disabilities.

A hospital passport template can be found on the website of the person you support's local hospital. You can also get one from your community learning disability team, or from a GP. If the person does not already have a hospital passport, you should work with them to create one. A hospital passport should be written with the person, their family, support workers and anybody else who is important in their lives.

A hospital passport should be updated every time a person is discharged from hospital, or once a year if the person has not been to hospital. You should clearly state emergency contact details in the person's hospital passport. These should include full names and phone numbers for relevant contacts. Details of the person's next of kin should also be listed.



*We asked people to draw what would be in the likes and dislikes section of their hospital passport

Sam's Story:

This story might be upsetting to some people so please read it with caution.

After experiencing ongoing symptoms in 2019, Sam was diagnosed with a chest infection by his GP. The symptoms continued to persist so – after three separate visits – Sam's GP finally sent him for an X-Ray. The X-Ray revealed that Sam had Bullous Lung Disease and that his left lung had collapsed. After Sam's lung was re-inflated at his local hospital, he had to be transferred to another hospital for a procedure to remove bullae (air filled spaces) from the lung to prevent it collapsing again.

In the second hospital, the doctors treating Sam looked at a copy of his X-Ray and told him they were going to carry out the procedure on his right lung. Sam tried to tell the doctors over and over again that it was his left lung that needed the procedure, not the right one, but they didn't listen. Sam underwent the procedure while he was under local anesthetic in his hospital bed. The procedure was so painful that Sam tried pushing the doctors away from him.

Sam only had one reasonable adjustment listed in his hospital passport. It was written on a white board above his bed for everyone to see. It said 'please listen to what I'm saying'.

After the procedure, the doctors treating him realised that the X-Ray image was mirrored – Sam had been right all along. Sam believes that the doctors treating him didn't listen to him because they thought they were smarter than him and knew his body better than he did. Sam also thinks they didn't listen because he has a learning disability, and because he uses a wheelchair.

Later, Sam had the chance to tell his story to the Learning Disability Liaison Nurse at the hospital where his poor treatment happened. The nurse was shocked that this had been allowed to take place, and took measures to make sure nothing like this would happen again in the future. He also received an apology from the hospital. To stop this happening in the future, Sam says that doctors and nurses should always listen to people's reasonable adjustments in their hospital passports.

Step 4: Sepsis and Pneumonia

Sepsis and **Pneumonia** are two different types of infections that are leading causes of death in people with learning disabilities. Sepsis happens when the body overreacts to an infection and starts to damage the body's tissues or organs. Pneumonia is a type of chest infection that causes inflammation in one or both of the lungs. Both types of infection can become very serious, and even life-threatening if they aren't diagnosed and treated quickly.

It is important that you know the symptoms of Sepsis and Pneumonia, so if the person you support gets ill, you can help them to get timely care and treatment. Some of the symptoms can appear similar to other illnesses. You shouldn't worry if you're not sure if it's Sepsis or Pneumonia - you should still seek medical advice.

Symptoms of Sepsis

Call 999 if the person you support has any of these symptoms:*

- Acting confused, has slurred speech or is not making sense
- Blue, pale or blotchy skin
- A rash that does not fade when you roll a glass over it
- Difficulty breathing, breathlessness or breathing very fast
- Has not needed to pee all day

Call 111 if the person you support has any of these symptoms:*

- Feeling very unwell or like there is something seriously wrong
- Has not needed to pee for over 8 hours
- Keeps vomiting and can't keep food down
- Has swelling, redness or pain around a cut
- Has a fever or low temperature, can't stop shivering and feels hot or cold to the touch

Scan here to find out more about sepsis



Anne's Sepsis Story

“ I actually thought that

I was going to die ”

Anne was rushed into hospital with Sepsis - which developed from an infection in her leg - in 2019. Anne said 'the day before I was rushed in I actually felt fine, when I was starting to feel ill I thought nothing of it, I thought it was a tummy bug. The next day all I wanted to do was sleep, my support worker called the doctor and he called an ambulance'. Anne thinks that a lot of the time 'even support staff wouldn't know the symptoms' and thinks that it's really important that people learn to spot the symptoms of sepsis.

Symptoms of Pneumonia

If the person you support has any of these symptoms, you should contact their GP or 111:*

- A cough that can be either dry or phlegmy
- Rapid and shallow breathing, even when resting
- A rapid heartbeat
- A high temperature, and is sweating or shivering
- Feeling generally unwell
- A loss of appetite
- Chest pain
- Joint and muscle pain
- Headaches



Scan here to find out more about pneumonia

You should call 999 if the person:*

- Is coughing up blood
- Is struggling to breathe
- Has blue lips or a blue face
- Feels cold and sweaty with pale or blotchy skin
- Has a rash that does not fade when you roll a glass over it
- Collapses or faints
- Becomes confused or drowsy
- Has stopped peeing, or is peeing much less than usual

Soft Signs of Deterioration



If the person is experiencing any of the following symptoms, it could be a sign they are ill:

- Increased agitation
- Being withdrawn
- Altered sleep pattern
- Increased tiredness
- Being very restless
- Pain
- Confusion
- Shortness of breath
- Not passing urine
- Unsteady when walking
- Increased anxiety

You should seek medical advice if the person you support has any of these symptoms. Contact 111 or the person's GP immediately.

**Always
ask the
person
you
support
'how are
you
today?'**



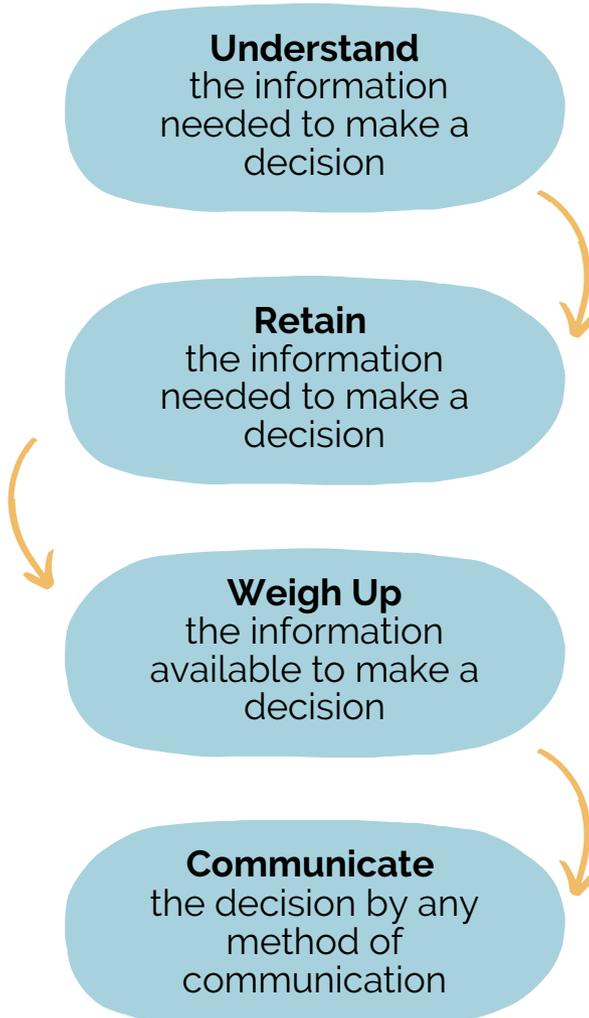
Scan here to view
the RESTORE2 mini
tool to recognise
deterioration

Step 5: The Mental Capacity Act

The Mental Capacity Act (MCA), 2005 is a law designed to empower people to make their own decisions wherever possible. It applies to all people over the age of 16 in England and Wales.

Sometimes people assume that just because a person has a learning disability, they are not capable of making complex decisions for themselves - this includes decisions about health, health care and treatment. We want people with learning disabilities to know their rights under the MCA, so they are empowered to make decisions about their own health. On some occasions, the person you support may not have the capacity to make a particular decision. We want people to be able to ensure the correct process is followed when somebody cannot make a decision for themselves.

The Mental Capacity Act says to be able to make a decision you must be able to:





The Mental Capacity Act covers all decision making, from everyday decisions like choosing what to wear, to life-changing decisions like choosing to get married. It has 5 principles:

Presume capacity - all adults have the right to make their own decisions unless they are found to lack capacity to do so

People should be supported to make their own decisions - all steps to help a person make a decision for themselves should be taken

Unwise decisions - all adults have the right to make decisions others might think are unwise or unusual, this doesn't mean a person lacks capacity

Best interest - when a person lacks capacity to make a decision, any decision made for them must be in their best interest

Least restrictive option - any best interest decisions must take account of all the circumstances, and take the least restrictive course of action available

Supporting Decision Making

We should support people with learning disabilities to make all decisions for themselves, however complex. If a person is finding it difficult to make a decision, you should take all steps possible to support them to make the decision for themselves before assuming they lack capacity. You should:

- Communicate with the person in the best way to help them understand
- Give the person all the relevant information they need to make the decision
- Provide information on alternative options
- Present the information in a way that's easier for the person to understand (easy read, talking to a person they are comfortable with, pictures etc.)
- Is there anybody who can help communicate the information such as a particular family member or other supporter?
- Is there is a particular time of day when the person's understanding might be better?
- Consider whether there are locations where the person might feel more comfortable to make the decision
- Consider if you could delay the decision until the person is more able to make it (capacity can fluctuate)



Scan here to find out about what happens when a person can't make a certain decision

Patrick's Story

This story might be upsetting to some people so please read it with caution.

In 2018 Patrick, who had a learning disability, went into hospital and later passed away. Before getting ill Patrick loved spending time in his home, and sometimes enjoyed visiting other people or going out for a meal. We spoke with one of Patrick's support workers about how he was treated in hospital.

Patrick went into hospital with a bad chest infection and while he was there his condition got worse, but nobody expected him to pass away. After a long time in hospital Patrick wasn't getting any better. When his supporters spoke to hospital staff, they were told that he wasn't likely to pull through. At times his supporters felt as though the hospital had given up on Patrick. When Patrick went into hospital a 'do not attempt resuscitation' order had been placed on him by a doctor at the hospital, meaning that if his heart stopped beating, CPR would not be attempted. This decision was made without any discussions with his support workers taking place. When his support workers found out about the 'do not attempt resuscitation' order, they challenged it and it was eventually revoked. Initially, the medical staff had decided not to give Patrick any antibiotics to treat his infection, because they thought the side-effects

outweighed the benefits. His supporters fought for the staff treating Patrick to do everything they could to help him, and eventually they did start to try antibiotics to treat Patrick's infection.

While he was in hospital, Patrick moved wards and rooms multiple times. Although a copy of his hospital passport went with him into hospital, it was felt by his support staff that all this moving about meant that important information about Patrick was not passed on to all the medical staff involved in his care. Patrick communicated without words, and sometimes hospital staff would talk in front of him like he couldn't hear them, or understand what they were saying. Before going into hospital, Patrick loved to walk around his house, going in and out of the different rooms – he was on his feet a lot. In hospital, Patrick spent all of his time in his bed. There were staff on the ward who didn't even know Patrick had been mobile before going into hospital.

Eventually, his support workers decided to put photos of Patrick before he was ill around his room – one was of him standing in his garden – so people knew that he had not always been stuck in bed. Patrick's support team had regular meetings with his physiotherapists to put plans in place for improving Patrick's mobility and welfare. At one point, Patrick began to get physio to help him regain his mobility, and he was able to occasionally walk up and down the corridor with support. Despite Patrick's

improvements, he developed other infections which set back his recovery.

Although Patrick was still unwell, hospital staff began to make plans for his future for if he became well enough to leave the hospital, without involving any of his support workers. Patrick would require much more support than before, and because his mobility had declined the decision was made that Patrick would not go home and go into a nursing home instead. None of Patrick's supporters believed this was the right decision for him. Patrick's supporters knew that he would not be happy in a nursing home where other people might not understand him. Patrick loved his home and was comfortable there. His supporters got everyone they needed involved including an Independent Mental Capacity Advocate, a hospital social worker, and a Community Learning Disability Nurse. Together they fought for Patrick's best interests and for his right to go home.

Unfortunately, Patrick got another infection and his chest continued to get worse. He died in hospital five months after he was admitted aged 65, and never got to return home. Patrick's support team were with him every day that he was in hospital. In its Long Term Plan, the NHS has committed to training it's staff on supporting people with learning disabilities, which means that - hopefully - cases like Patrick's can be avoided in the future.



A Bit About Us: Options

Options for Supported Living is a Merseyside-based charity that supports people with learning disabilities, autism and acquired brain injuries across Liverpool, Sefton and the Wirral. Our vision for the future is 'a better world where people with disabilities contribute as unique and valued members of dynamic and inclusive communities'. We're passionate about supporting people to live their lives to the full, and think that having good health is a really important part of this. We believe that everybody is entitled to good health, which is why developing the 5 Steps to Health project has been so important to us.

The production of this booklet was funded by NHS England. We have worked alongside many people in the process of developing the 5 Steps to Health project, including people we support, members of Mencap Wirral, Mencap Sefton and Liverpool and Blue Room Liverpool. We would like to thank everyone who has contributed to the booklet by sharing ideas, feedback, artwork and stories.





Options

NHS