

Plain English newsletter

Number 21, March 2026





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1. Who should read the newsletter

- people with a learning disability and autistic people with or without a learning disability
- families, carers, and advocates
- community groups, charities and advocacy groups who can explain to their members any difficult ideas and use these for information sessions

You may find some of the information in this newsletter upsetting, so please make sure you can talk to someone, if you need to.

We have included links to webpages so you can find out more.

2. Words we use

The newsletter is for people who have different needs and skills.

It can be difficult for some people to understand health services.

We try our best to use words that people know.

Hard words are in **bold** and **purple**. We explain the hard words.

If you don't understand any words, ask someone to explain them to you.



3. Learning disability register

The learning disability register is for

- babies, children, young people and adults
- who have a learning disability
- and are registered at their GP practice

NHS England has an information leaflet developed with

- people with a learning disability
- family carers
- people from charities
- NHS and local authority staff

This information can be used by

- GP practices and other health professionals
- schools, colleges and charities
- parents and carers of children who have a learning disability
- young people and adults who have a learning disability

The leaflet helps parent carers and other people think about whether their child or someone they care for, might have a learning disability.

If so, they should be on their local GP's learning disability register to help them get the help they need.

There are plain English and easy read accessible versions of the leaflet.

You can see all the versions on the NHS England website, [learning disability register leaflet](#).



If your child, or someone you care for, has a learning disability, it's important they get the right support.

It will help them have the same chances in life as everyone else.

If you think your child might have a learning disability and you're not sure if they are on your GP's learning disability register, speak to your GP practice.

4. Sepsis

Sepsis is when your body is seriously affected by an infection.

It can be hard to spot.

People can become unwell very quickly.

They will then need medical treatment urgently.

If people don't get the right care in time they could die.

Research has shown that people with a learning disability are dying from sepsis.

This could be avoided if everyone knew more about sepsis.

It is important to know how to spot the signs of sepsis in people with a learning disability.

Look out for these signs of sepsis

- feeling very hot
- feeling very cold and shivering
- having a very fast heartbeat
- breathing fast or feeling out of breath even if you are sitting still
- feeling confused

- 
- feeling sick or vomiting
 - fainting or falling for no reason
 - not able to have a wee or not going for a wee all day

What you should do if you think you, or someone you care for, has sepsis

- phone NHS 111 and say you are worried about sepsis
- you may need to go to hospital straight away

For more information about sepsis visit the [Sepsis Trust website](#) or phone 0808 800 0029.

5. STOMP and STAMP standards

What is STOMP?

STOMP stands for ‘Stopping Over Medication of People’ with a learning disability and autistic people.

It is about making sure that people use psychotropic medications for the right reasons only when they need them.

Psychotropic medicines are medications used to treat mental health conditions that affect how we think as well as our emotions.

They can also be given to help with our behaviour.

For information on STOMP, see the [STOMP leaflet](#).

What is STAMP?

STAMP stands for ‘Supporting Treatment and Appropriate Medication in Paediatrics’ (children’s health).

It is about getting the right medication at the right time.



It is about medication for children and young people, their families and staff.

For more information on STAMP, see the [leaflet](#).

What are the STOMP and STAMP standards?

- the standards help healthcare professionals to work with people with a learning disability to find the best ways to use medication for their mental health
- there are 9 standards
- each standard says what staff will do
- each standard includes a section for people and families to help them to understand what will happen

What you can do

If you are taking, or know someone who is taking medication for the mind, please ask your doctor, nurse or pharmacist to

- review the medication you are taking
- make sure it is still right for you or the person taking the medication

If you find it hard to understand the information, you should ask for help to understand it (reasonable adjustment).

A **reasonable adjustment** is a change that a service can make, to help someone with a disability.

To find more information about reasonable adjustments, see [NHS England newsletter 17](#).



6. How to get support and speak up

If you are worried about the care and treatment the NHS is giving you, tell someone you trust straight away.

The NHS has made an easy read form. It helps you tell staff or a service what you think could be done better.

Find the form by visiting the [speakup website](#) and click on projects and search for 'Ask, Listen, Do'.

Ask someone to help you fill in the form if you need to.

7. People who can help you

An **advocate** can help you to tell people what you need, to try and get you the right health and social care support.

Find out more about advocates on the [NHS website](#).

The NHS Patient Advice and Liaison Service (PALS) can support with healthcare questions or problems. If you are in hospital, you can ask staff how to contact PALS.

Or visit [What is PALS \(Patient Advice and Liaison Service\)?](#) to find out more and your nearest PALS office.

Your local Healthwatch can help with questions about your GP, hospitals, dentists, pharmacies, care homes or other support services.

To find out more about Healthwatch visit [Healthwatch easy read](#).

If you are a parent carer, you can contact your [local parent carer forum](#). Parent carer forums can help services in their area meet the needs of disabled children and young people and their families.



8. Keep updated

This newsletter was created by the NHS England Learning Disability and Autism Programme.

Get in touch if you want to tell us anything about this newsletter.

You can either phone us on 0113 824 9686 or email us at engage@nhs.net

Update email

Sign up for our monthly learning disability and autism update email which includes important health information.

Already shared on our social media pages, the update email provides this information, all in one place.

[Sign up to the Learning Disability and Autism Programme monthly update email](#)

9. Connect with us

- Facebook: [NHS England Learning Disability and Autism Programme](#)
- Email: engage@nhs.net