

Plain English Newsletter number 16 - December 2023

This newsletter includes things around your rights when in, or going into, a mental health setting:

- Getting the right support at home so you don't have to go into hospital
- Knowing your rights when you are in hospital or a residential home
- Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

This newsletter is for:

- autistic people
- people with a mild learning disability
- family carers
- advocates
- community groups
- charities

It has been made with people with lived experience including a self-advocacy group, called [Speakup](#).

There is lots of information in this newsletter. We have tried to make it plain English.

Sometimes you will see blue web links to find out more. You can click these on your computer.

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Getting the right medication

STOMP stands for stopping over medication of people with a learning disability, autism or both.

STAMP stands for supporting treatment and appropriate medication in paediatrics.

STOMP and STAMP are about making sure people with a learning disability and autistic people are only prescribed:

- the right medication
- at the right time
- for the right reason

This is mainly about the use of psychotropic medicines.

These are medicines used to treat mental health conditions.

Sometimes they are also given to people because their behaviour is seen as challenging.

People with a learning disability and autistic people are more likely to be given these medicines than other people.

These medicines are right for some people. They can help people stay safe and well.

If you are taking these kinds of medication, you can ask your doctor for a medication review.

This will check if the medicines are still right for you.

If you want to know more about [STOMP and STAMP](#), you can look at the resources and videos on our website.

My Rights

My name is David Gill. I am autistic.

I am a Lived Experience Adviser in the Children and Young People's team in the Learning Disability and Autism Programme at NHS England.

We asked children and young people who were in mental health hospitals what they knew about restrictive practices.

These are things that limit the freedom of a person, like being able to move around freely.

We found out that many children and young people did not know their rights around restrictive practices.

They said they would like to have better information about these.

I worked with young people who have experience of being in a mental health hospital, and with nurses who work in hospitals to create a magazine.

The magazine includes information about

- rights
- types of restrictive practice
- real stories
- and top tips from young people about ways to speak up

The magazine has been written in plain English and in a style that allows young people to easily turn to the topic they need and to personalise it through writing and doodles.

It includes information about rights, types of restrictive practice, real stories and top tips from young people about ways to speak up.

You can read the [magazine](#) by visiting our website.

Getting the right support at home so you don't have to go into hospital

In January 2023 the NHS made a new document called

- the Dynamic Support Register (DSR) and Care (Education) and Treatment Review (C(E)TR) policy

A policy can be a plan, or a list of rules used to make decisions.

The new policy said that the NHS must keep a list of people who are at risk of going into hospital if they do not get the right care and treatment in the community. This is called the Dynamic Support Register.

The new policy will try to help people, to get

- the right care
- the right support for the right amount of time
- high standards of mental health and physical healthcare if they do need to go into hospital

One way of making sure this happens is through a community Care (Education) and Treatment Review C(E)TR.

A C(E)TR is for people who are at risk of going into hospital or who are in already in hospital, which includes:

- children
- young people and
- adults with a learning disability or autism

The new policy said that people should have a C(E)TR

- six weeks after going into hospital
- if someone moves to another hospital or moves to a different ward in the same hospital with higher or lower security
- if a review by doctors shows that someone is not autistic or does not have a learning disability when they have been told before that they are autistic, or they have a learning disability

We spoke to lots of people about the questions to ask in the reviews and people said they wanted

- questions to look at a person's physical health and make sure people could access things they enjoy
- reviews to be carried out in a person-centred way

Person centred care means the right care for what each different person needs

People told us that C(E)TRs should always include the panel talking to

- the person
- their family
- people involved in their care and support
- and an advocate if they have one

An advocate is a person who can help you with writing letters, attending meetings, or explaining your options.

We have made lots of [information and videos](#) to help people and families, including Plain English and easy read of the policy.

Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

LeDeR is the name given to the work that reviews the lives and deaths of people with a learning disability and autistic people.

The reviewer finds out about their care and why they died.

Every year the NHS writes a report about the work that is being done to make services better for people with a learning disability and autistic people.

This year's report is called Action from Learning 2022 to 2023.

On the LeDeR website you can find the

- [Action from Learning Report](#)
- Videos which explain more about our work:

[What is LeDeR](#)

[Good work being done to support people with a learning disability and autistic people across England](#)

How to get support and speak up

If you have any problems or concerns about the care and treatment the NHS is giving you, tell someone straight away.

Click on the blue web links to find out more about the people and organisations who can help you, if you need support to give your feedback, raise a concern or make a complaint.

- [Advocates](#) – they can help you with writing letters, attending meetings, or explaining your options
- The NHS [Patient Advice and Liaison Service](#) (PALS) can help with any queries or problems if you are in hospital. Ask staff how to get in touch with PALS
- Your local [Healthwatch](#) can help with queries or problems with GPs, hospitals, dentists, pharmacies, care homes or other support services. A list of local Healthwatch organisations is available on their website
- If you are a parent carer, you can contact your [local parent carer forum](#). Parent Carer Forums try to make sure that services in their area meet the needs of disabled children and their families
- The NHS worked with [Speakup](#) to develop information for autistic people. It includes useful advice and information about feedback, concerns and complaints from autistic people. It also has a separate form you can use for reporting your feedback, concerns or complaints

[Top tips for autistic people](#)

[A form for your feedback, concern or complaint](#)

Winter coronavirus and flu vaccines

Every year we need vaccines to protect us from flu and coronavirus.

The coronavirus vaccine is different from the flu vaccine.

Getting both the coronavirus vaccine and the flu vaccine will help keep you safe.

People who can get free flu and coronavirus vaccinations from the NHS are:

- People who are autistic and have some types of health conditions which could make them more poorly if they got coronavirus
- People with a learning disability
- Carers

Speak to your pharmacy or GP practice to find out if you can get a free vaccine.

For more information about flu you can visit the NHS website [flu page](#).

For more information about the winter coronavirus vaccine you can visit the NHS website [coronavirus pages](#).

Constipation

Constipation is when you find it hard to poo or poo less often than usual.

If you are constipated, you need to get help to make sure you don't get ill.

Signs you might be constipated

- sore tummy
- pooing feels sore
- poo is hard or lumpy
- poo is runny
- pooing less than usual

Tell someone you trust if you have any of these signs, this could be someone in your family, or a carer.

They will arrange for you to get the help you need.

You can help to keep your poo healthy by:

- eating a balance of different foods. This should include fruit and vegetables.
- drinking plenty of water.
- doing something active every day, like going for a walk or dancing.

The NHS has made a [film about constipation](#) and lots of other [resources](#) to help people:

- know the signs of constipation
- understand the importance of getting the right help

Keep updated

Follow us on **Facebook** and Twitter, now known as **X** to get more information and updates about how the NHS is making services better.

- Click on [Facebook NHS England Learning Disability and Autism Engagement](#)
- Click on [Twitter](#) - our Twitter handle is @NHSAbility

NHS England website <https://www.england.nhs.uk/>

Read our '[get involved](#)' pages

Read our previous [easy read newsletters](#)

Thank you

This newsletter was produced by the NHS England Learning Disability and Autism Engagement team and the wider programme together with Speakup self-advocacy group.

Get in touch if you have any feedback on this newsletter.

You can phone us on 0113 824 9686.

Or email us at engage@nhs.net