



# Easy read newsletter

Number 16 – December 2023

## In this newsletter:



Getting the right medication



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



Knowing your rights when you are in or going into a mental health hospital, or a residential home



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

# About this newsletter



## This newsletter is for:

- people with a learning disability and autistic people



- family, carers and advocates



- community groups and charities



It has been made with people with lived experience including a self-advocacy group, called [Speakup](https://www.speakup.org.uk). Visit [www.speakup.org.uk](https://www.speakup.org.uk) for more information.

# About this newsletter



There is lots of information in this newsletter. We have tried to make it easy to read.



We make hard words **bold and purple**. We explain the hard words.



Sometimes you will see words that are blue and underlined. These are web links or email links. You can click these on your computer to find out more.

# In this newsletter



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# Getting the right medication

**STOMP**

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

**STAMP**

**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

# Getting the right medication



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.

# Getting the right medication



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.

**STOMP  
STAMP**



If you want to know more about STOMP and STAMP, you can:

- [visit the NHS England website](#) for more written information, [read our easy read leaflet](#)
- or [watch a short video](#)

# 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.

# My rights



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.

# My rights



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



You can find out more about restrictive practices [in our easy read leaflet](#).

# Getting the right support at home so you don't need to go into hospital for your mental health



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.

# Getting the right support at home so you don't need to go into hospital for your mental health



The new policy will try to help people to get:



- the right care and 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.

# Getting the right support at home so you don't need to go into hospital for your mental health



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



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



Care, Education and Treatment Reviews (CETR) are for children and young people with a learning disability or who are autistic.



Care and Treatment Reviews are for adults who are autistic or have a learning disability.

# Getting the right support at home so you don't need to go into hospital for your mental health



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

- six weeks after going into hospital



- 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 have a learning disability



- if someone moves to another hospital or moves to a different ward in the same hospital with higher or lower security

# Getting the right support at home so you don't need to go into hospital for your mental health



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.

# Getting the right support at home so you don't need to go into hospital for your mental health



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



- the person and 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.



Read our [easy read guide](#) or [visit the NHS England website](#) for more information.

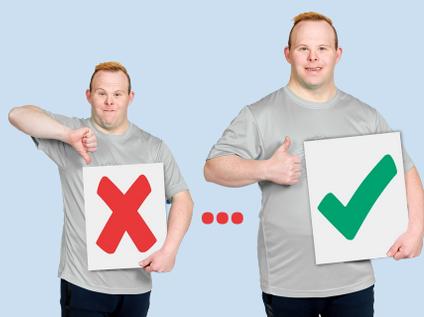
# Learning from lives and deaths of people with a learning disability and autistic people (LeDeR)



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.



A [new easy read report](#) and [video](#)

explain what LeDeR is and the work the NHS is doing to make services better for people with a learning disability and autistic people.



You can also [watch this video](#) about good work being done to give better care to 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.



The NHS has made [an easy read form](#) which can help you tell staff or a service what you think could be done better.



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

# How to get support and speak up – people who can help you



**Advocates** – they can help you with writing letters, attending meetings, or explaining your options.



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



**The NHS Patient Advice and Liaison Service (PALS)** – it can help with any queries or problems if you are in hospital.



Ask staff how to get in touch with PALS or [visit the NHS website](#) to find your nearest PALS office.

# How to get support and speak up – people who can help you



Your **local Healthwatch** can help with queries or problems with GPs, hospitals, dentists, pharmacies, care homes or other support services.



[Read the Healthwatch easy read leaflet](#) to find out more about what they do and how you can contact them.



National Network of Parent Carer Forums  
'Our Strength Is Our Shared Experience'

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.

# Winter coronavirus and flu vaccines



Every year we need a vaccine to protect us from flu.

You also need to have the coronavirus vaccine.

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

# Winter coronavirus and flu vaccines



Speak to your pharmacy, GP practice or learning disability nurse about how to get your vaccines.



[Watch this video](#) to see how Rachael and her mum had their flu and coronavirus vaccines.



You can also [watch this film](#) about what a vaccine is.

# 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.



Pooing regularly keeps you healthy.

# Constipation



Signs you might be constipated:

- sore tummy



- pooing feels sore



- poo is hard or lumpy
- poo is runny
- pooing less than usual

# Constipation



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.

# Constipation



You can help to keep your poo healthy by eating a balance of different foods.



This should include:

- eating fruit and vegetables



- drinking plenty of water



- doing something active every day, like going for a walk or dancing

# Constipation



The NHS has [made a film about constipation](#) to help people with a learning disability:



- know the signs of constipation



- understand the importance of getting the right help



Visit the [NHS England website](#) for more information and resources.

# Keep updated



Follow us on:

- [Facebook](#) and
- [Twitter](#) (now known as X) – our Twitter handle is @NHSAbility



Read our:

- [‘get involved’ pages](#) on the NHS England website
- previous [easy read newsletters](#)



This newsletter was produced by the NHS England Learning Disability and Autism Engagement team and the wider programme,



together with Speakup self-advocacy group.

# Keep updated



Illustrations on My Rights designed by David Gill, NHS England.



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

- phone us on 0113 824 9686



- email us at [engage@nhs.net](mailto:engage@nhs.net)



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