

Plain English newsletter

Number 18, November 2024





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1. Who should read the newsletter

- autistic people and people with 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.

Who developed this newsletter

This newsletter is created by the NHS England Learning Disability and Autism Engagement team and the wider programme, with member representatives from the Learning Disability and Autism Advisory Group.

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. We explain the hard words.

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

Sometimes you will see blue weblinks. Click on them to find out more information.



3. The Dynamic Support Register (DSR) and Care (Education) and Treatment Review (CETR) policy

The policy is about autistic people, people with a learning disability and people who have both, if they are at risk of going into or are in a mental health hospital.

This policy helps make plans to support them at all ages - children, young people and adults.

The policy helps health services to work well. It should help people to get the help they need in the community and not go into hospital.

Guides for young people

NHS England has guides for young people (16 to 25 years old) who are autistic or who have a learning disability. The guides help them to make decisions about:

- Care (Education) and Treatment Reviews (CETRs) and
- Dynamic Support Registers (DSRs)

The guides help young people to:

- understand the Dynamic Support Registers and Care, Education and Treatment Reviews
- understand the good things about them
- decide if the person should be on the register
- decide if a review is needed
- decide if the person wants to be involved



Making the guides with young people

We made the guides with young people who are autistic, or who have a learning disability or both.

Nurses, the people who pay for services (commissioners) and parent carers also helped to write the guides.

Read the NHS England [Dynamic Support Register \(DSR\) Care Education and Treatment Review \(CETR\) young person guides](#)

Go to our [newsletter, number 16](#) (getting the right support at home so you don't have to go into hospital) if you want more information.



4. What is LeDeR and why is it important?

LeDeR means learning from the lives and deaths of people with a learning disability and autistic people.

LeDeR is for adults with a learning disability or autistic people who have died.

LeDeR reviews the care they had before they died.

The information from LeDeR reviews helps improve services.

Who leads the LeDeR review?

The reviewer is a professional working for the local health and care service.

Only the professional will know the name of the person. Personal information is not shared and stays confidential.

The importance of LeDeR for minority ethnic communities

Ethnic minority communities are where people live in a place where most of the other people are from a different background or race.

They may not speak the same language. Or they may not have the same religion as their neighbours.

LeDeR tells us that adults from ethnic minority communities with a learning disability die younger than white British people with a learning disability.

The average age of death of adults with a learning disability from an ethnic minority community is 34 years and for white British people it is 62 years.

For more information read the NHS Race and Health Observatory report

[We deserve better: ethnic minorities with a learning disability and access to healthcare.](#)

An [easy read version of the report](#) is also available.



Why is LeDeR very important?

LeDeR does not tell us enough about the health of adults from ethnic minority communities. We need to review more deaths of adults from ethnic minority communities. This is so we learn how to make things better and improve services.

Why is LeDeR also very important for autistic people?

We also review the deaths of autistic adults.

We need to learn about why autistic adults die younger. We need to improve the services that autistic people use.

Reporting the deaths

All deaths of adults with a learning disability and of autistic adults can be reported to LeDeR.

You can report it yourself or ask a health professional or someone else to report it.

Please tell us by [completing this online form](#).



5. Understanding diabetes

When you eat sugar, it goes into your blood and then to your muscles and brain. Sugar in your blood is called glucose.

Too much sugar (glucose) in your blood can cause you to be unwell.

Too much blood sugar in your blood is called diabetes.

There are two types of diabetes

Diabetes means your body cannot cope with sugar like in other people.

There are two types of diabetes: type 1 and type 2.

People with type 2 diabetes can do things to help their diabetes, for example, improve their diet and exercise more.

Read our [newsletter, number 17](#), it talks about type 2 diabetes.

Type 1 diabetes

Type 1 diabetes is a problem with your immune system. Your immune system helps you fight germs and viruses, if it is working well.


People usually find out they have type 1 diabetes when they are children or as a young adult. If you have type 1 diabetes, you will have it all your life.

Learning about insulin

Insulin helps your body to lower the sugar (glucose) in your blood.

In type 1 diabetes there is too much sugar because your body does not make enough insulin.

If you have type 1 diabetes, you will take insulin every day to keep your blood sugar right.



Here are some signs of diabetes type 1 diabetes.

The signs of diabetes are sometimes called the 4 t's

- thirsty - feeling very thirsty all the time
- tired - feeling more tired than usual
- toilet - weeing more often
- thinner - losing weight without trying

If you have any of these signs

You should talk to your doctor (GP). Your doctor (GP) will ask you to do a wee (urine) test. They will check your blood sugar levels.

You will learn how to check your blood sugar levels.

Using a meter to measure your blood sugar levels

You can use different things to measure your blood sugar levels.

You can use a meter or a blood monitor.

To use a meter, you prick your finger.

You put a small drop of blood onto the strip and push the strip into the meter.

Using a blood sugar monitor

Or you can use a blood sugar monitor, which is a small object that you stick to your skin and does not hurt.

You can use your phone to check the sugar level in your blood.



What are ketones?

Your body makes ketones when it breaks down fat. Sometimes this can happen when you are unwell.

You do not have to check ketones regularly, only when you are unwell or if your glucose is very high.

If you have too many ketones, it can cause serious health problems.

You should speak to your diabetes nurse or doctor (GP) about your blood sugar and ketone levels.

If you have type 1 diabetes

There are lots of ways to manage diabetes.

You should go to your diabetic appointments. You should get your eyes and feet checked to keep you healthy.

You can speak to a pharmacist, your diabetes nurse, doctor (GP), or learning disability nurse about your diabetes.

More information on diabetes

Jodie, one of our learning disability and autism network managers, has type 1 diabetes. She says you can live a normal life.

If you have diabetes, Jodie wants you to attend your diabetic checks and look after yourself by managing your diet and exercising.

For more information, have a look at [type 1 diabetes UK video](#).

Read this [guide about managing type 1 diabetes](#), it is translated into different languages.



6. The importance of health and care passports

NHS England worked with people with lived experience and staff to make a health and care passport template that people can use. A template is something you can fill in.

A health and care passport gives important information about you to professional people you meet.

It helps them to give you the right care.

Why are health and care passports helpful?

The health and care passport can be used at a doctor's (GP) practice, when you go to a hospital, or for social care.

It should help staff to understand more about your needs and wishes and what reasonable adjustments they should make for you.

A reasonable adjustment is a change that staff should make, to help people with a disability use health and care services more easily.

Read our [newsletter, number 17](#) and look at the article about the reasonable adjustment digital flag.

Hospital passports

Health and care passports and hospital passports are not the same.

You can still use a hospital passport in a hospital.

If you already have something that works for you, you don't need to fill out another one.

Whatever you use, it should help staff to communicate with you and learn about you and your needs.



How to fill in a health and care passport

If you don't have anything, you can fill in the health and care passport on your own, or with support.

Read the [NHS health and care passport and guides](#) to help you know how to fill this out.

You can either print it out on paper, or you can save it on your phone or tablet to show staff.

7. 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.

Called 'Ask, listen, do', this process aims to make it easier for people to give feedback, raise a concern or complain. The NHS has made a [booklet and a form](#) in accessible formats to help you do this. It helps you tell staff or a service what you think could be done better.

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

People who can help you

- [advocates](#) - they can help you with writing letters, attending meetings, or explaining your options
- the [NHS Patient Advice and Liaison Service](#) (PALS) to find your nearest PALS office, or ask staff how to get in touch with PALS. They help with any queries or problems if you are in hospital
- your local [Healthwatch](#) can help with questions about your GP, 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 services in their area meet the needs of disabled children and their families

8. Give feedback on our newsletters

We continue to improve our newsletter. We need your feedback to help us make it better.

We want to know if our newsletters are useful to you, as well as groups you may be part of, so we can make the newsletter better.

Please click on this [feedback form](#) to give us your views.

You can tell us how the articles have helped you, or someone you know.

We won't print or share any feedback without your permission.

Feedback on our newsletters

You can read some feedback we have already been given, here:

“I was pleased to see there were accessible options to note any comments or concerns about my care with '[Ask, Listen, Do](#)'.

“There is clear information how to get support and speak up, as well as the guidance for support from advocacy services. It's from [newsletter number 17](#), easy read page 32”.

9. Connect with us:

- Facebook: [NHS England Learning Disability and Autism programme](#)
- X (was called Twitter): [@NHSAbility](#)
- Email: 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 all in one place. To register to receive this, email us at engage@nhs.net