Easy read newsletter

Number 18 - November 2024

This newsletter includes information about:

Dynamic Support Register / Care (Education) and Treatment Review guides for young people

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

Type 1 diabetes

Health and care passport

Who should read the newsletter

People with a learning disability and autistic people with a learning disability.

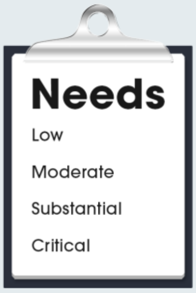
Families, carers, and advocates.

Community groups, charities and advocacy groups who can explain to their members any difficult ideas and use these for information sessions.

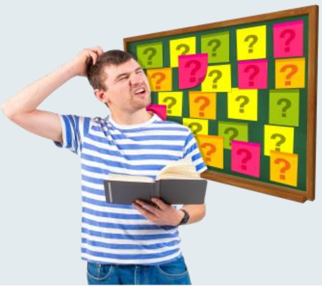
You may find some of the information in this newsletter upsetting, so please make sure you can talk to someone, if you need to.

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

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.

In this newsletter

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 who are autistic or who have a learning disability about:

- Care (Education) and Treatment Reviews (CETRs) and

- Dynamic Support Registers (DSRs)

The guides help young people (16 to 25 years old) to make decisions about DSRs and CETRs.

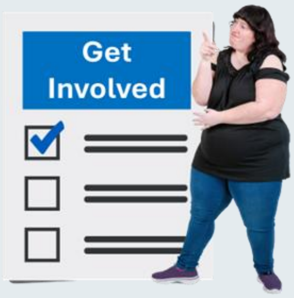
The guides help young people:

- to understand the Dynamic Support Registers and Care, Education and Treatment Reviews

- to understand the good things about them

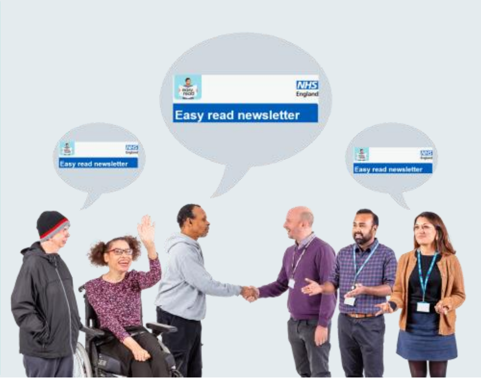
- to decide if the person should be on the register

- to decide if a review is needed



- to 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] or

NHS England

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)

Read our newsletter number 16 and go to article "Getting the right support at home so you don’t have to go into hospital".

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.

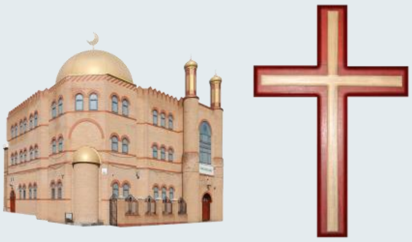
Only the professional will know the name of the person.

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.

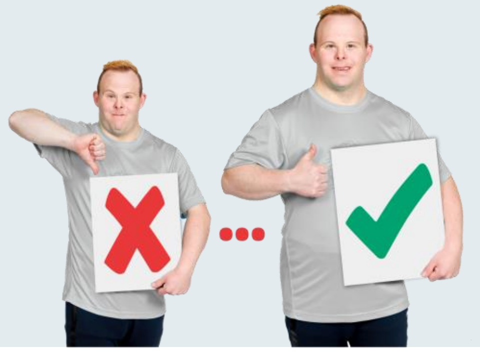
LeDeR tells us that adults from ethnic minority communities with a learning disability die younger than white British people with a learning disability.

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.

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.



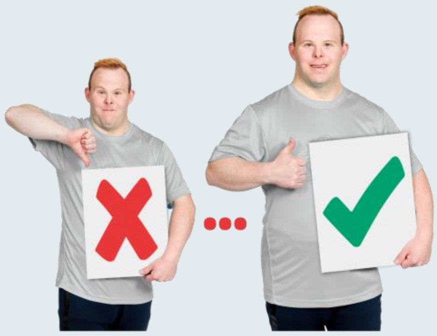
This is so we learn how to make things better and improve services.

Read the NHS Race and Health Observatory report in easy read.

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.

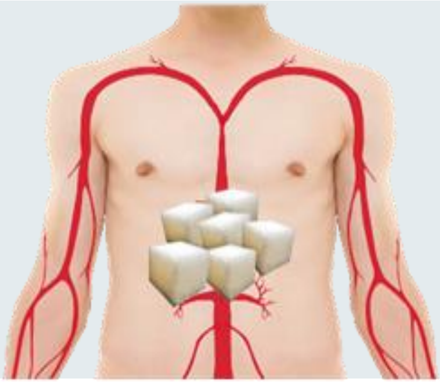
Please tell us by completing this online form.

Understanding diabetes

When you eat sugar, it goes into your blood and then to your muscles and brain.

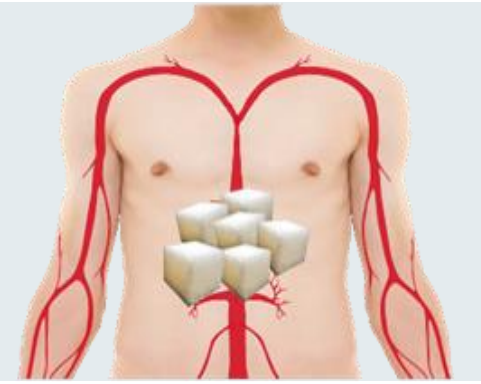
Sugar in your blood is called glucose.

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 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

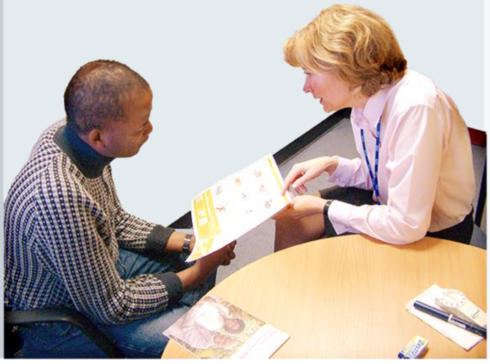
- Thinner - losing weight without trying

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.

The doctor 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 on to the strip.

You push the strip into the meter.

Using a blood sugar monitor

Or you can use a blood sugar monitor.

It is a small object that you stick to your skin.

It 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

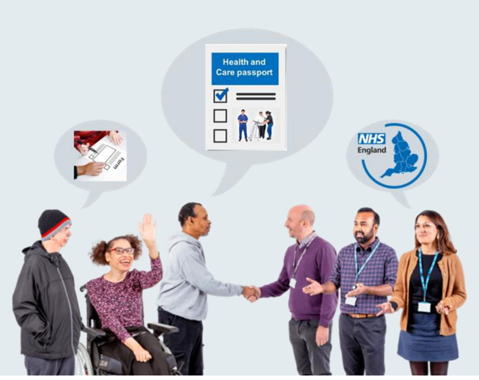
Jodie, one of our learning disability and autism network managers, has type 1 diabetes. Listen to this video where Jodie talks about how you can live a normal life.

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

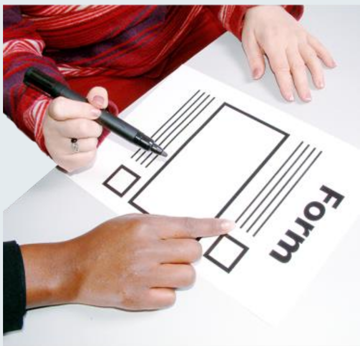
For more information, look at type 1 diabetes UK video.

Read this guide about managing type 1 diabetes, it is translated into different languages.

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?

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.

NHS England

Easy read newsletter

Number 17 - June 2024

This newsletter includes information about:

- The Reasonable Adjustment Digital Flag
- National guide for acute mental health inpatient services for adults
- What is Diabetes?
- How to get support and speak up - people who can help you

Read our newsletter number 17 and look at the article about the reasonable adjustment digital flag.

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

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, find out if you have any carers, and any other 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.

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.

It helps you tell staff or a service what you think could be done better.

easy read

Please fill in this easy read form

Your name

Address

Phone

The NHS has made a booklet and a form in easy read to help you do this.

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

People who can help you

Advocates can help you with writing letters, attending meetings, or explaining your choices.

Find out more about advocates on NHS website

PALS
Patient Advice and Liaison Service

The NHS Patient Advice and Liaison Service (PALS) can help with queries or problems if you are in hospital. Ask staff how to get in touch with PALS.

Go to the NHS UK website to find your nearest PALS office.

People who can help you

healthwatch

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

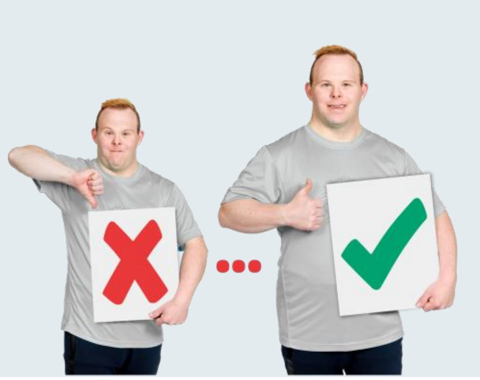
To find your local Healthwatch visit www.healthwatch.co.uk to find your local office.

N N P C F
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 can help services in their area meet the needs of disabled children and their families.

How to give your feedback on our newsletter



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

You can tell us if there are ways to help you to give us feedback. See how to contact us on page 35.

Feedback on our newsletter

We won’t print or share any feedback without your permission

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”.

Keep updated

This newsletter was 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.

The newsletter used photosymbols from their library. ‘Photosymbols’ agree that NHS England can use them.

If you would like to contact us, you can either phone us on **0113 824 9686**

or email us at engage@nhs.net

Facebook: NHS England Learning Disability and Autism Programme

X (was called Twitter): @NHSAbility

Email: engage@nhs.net