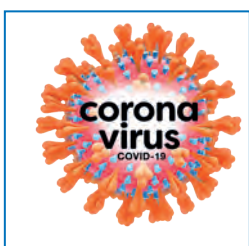


Action from Learning LeDeR Report





What's inside?

Welcome 3

Margaret's Story 5

Introduction 7

Coronavirus 10

Managing Health Problems 14

Find out more 35



Welcome



We would like to say thank you to:



- **Families** and **health and care workers** who have taken part in a **LeDeR review**



- **Families** who have shared their **memories** and **experiences** in this report



- The LeDeR team at **University of Bristol** for their hard work over the last **6 years**



- **Health and care workers** who have made the lives of people with a learning disability and autistic people better during coronavirus.



Margaret's story

Margaret had a learning disability and lived in supported housing.



She died from **cancer** in **April 2020**.



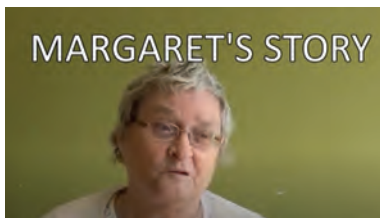
Margaret thought that her doctor **did not understand her needs**.



She **was not** on the **learning disability register**.



Margaret went to the **hospital** on her own but **did not understand** the **information** they gave her.



She agreed to tell her story in a short film called **'Margaret's story'** to help people with a learning disability get **better care in the future.**



You can watch the video on **You Tube:**

[www.youtube.com/
watch?v=J5wJYGltA6o](https://www.youtube.com/watch?v=J5wJYGltA6o)

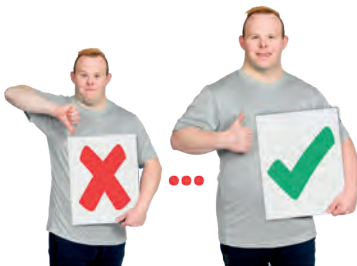
Introduction



During coronavirus
some **NHS** workers:



- Moved to work on coronavirus services



- carried on making health services better for **people with a learning disability** and **autistic people**.



By **March 2021**



Nearly all **LeDeR reviews** were
completed within 6 months.



A new **LeDeR policy** came out in **March 2021**.



A lot of the **LeDeR policy** is about making sure action is taken locally after **LeDeR reviews** are completed.



This report explains how the **NHS** is making services better for **people with a learning disability** and **autistic people**.



What is in this report?



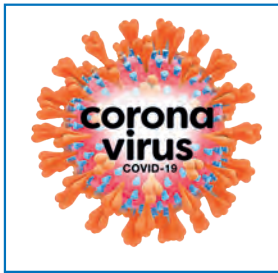
- **New work** that health and care services have carried out since **last year**



- Updates from the coronavirus **Action from Learning Report** that came out in **November 2020**.



[Link to useful information](#)



Coronavirus



People with a learning disability have been at a **high risk** from coronavirus.



The **NHS** has learned a lot about the best ways to support vulnerable people.



What did the NHS do?



- Since **May 2020** the **NHS** has put out the numbers of people with a learning disability who died after getting coronavirus.



- Set up **online wards** to check on people at home or in a care home because they have **coronavirus**.

7000



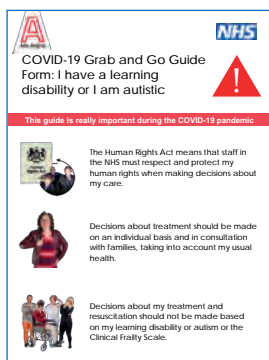
- Trained **seven thousand carers** to help them notice when the person they care for is **starting to get ill** and **report it quickly**.



- Worked to make the **NHS 111** telephone service **easier to use** for people with a learning disability and autistic people.



- Held monthly online meetings with **GPs** to make sure their learning disability registers included people at high risk from coronavirus.



- Put out a **Grab and Go Guide** – which is a short hospital passport



- Put out a guide for **NHS** workers about supporting people with a **learning disability** and **autistic people**



Supported the coronavirus **vaccine programme** for:



- people with a **learning disability** and **autistic people** in a **high-risk group**
- **carers.**



The **NHS** worked with different groups to find out the **best ways** to tell people with a learning disability **how to get the coronavirus vaccine.**



Managing health problems



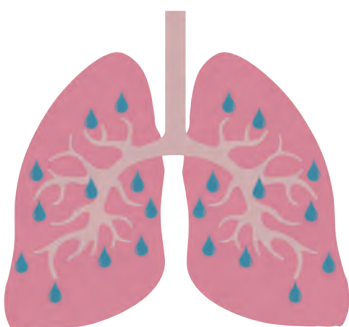
Breathing problems



Breathing problems cause a lot of people with a **learning disability** to **die early**.



When someone has **difficulty with swallowing** it is called **dysphagia**.



When food or other things get in your lungs it can cause an infection called **aspiration pneumonia**.



A guide on **pneumonia** and **aspiration pneumonia** will be written by the **British Thoracic Society**.



The **British Thoracic Society** is a group of

- **doctors**
- **nurses**
- **scientists.**



The guide is being **written** with support from **people with lived experience**.



The **NHS** is working on a guide for patients with **breathing problems** that will be completed later this year.



Flu vaccines



Flu vaccines are still very important for people with a **learning disability**.



LeDeR reviews say people with a **learning disability** sometimes **miss out** on things that help to stop serious illness like:

- **annual health checks**
- **flu vaccines.**





Getting more people to have the flu vaccine

In **winter 2020** the **NHS** and **Public Health England** ran campaigns to:



- get **more people** with a learning disability to have their **flu vaccine**



- get **more health and social care workers** to have their **flu vaccine**.



GPs got an **easy read letter** they could send to their patients with a learning disability about the **flu vaccine**.



GPs were asked to offer the **flu vaccine** to patients with a **learning disability** when they go to the surgery for an **Annual Health Check**.



Oximeters



An **oximeter** can be used to check if someone has **low oxygen levels** and needs medical help right away.



Three hundred thousand oximeters were sent to people across **England** so that they can check their **oxygen levels** at home.



Diabetes



The **NHS Long Term Plan** says that patients with **type 1 diabetes** should get **flash glucose monitors** if they meet **NHS** guidelines



such as not being able to check their **blood sugar levels** because of their disability.



In **autumn 2020** everyone with a learning disability who takes **insulin** for their **diabetes** was given a **flash glucose monitor**.



The **flash glucose monitor** can help people easily manage their diabetes.



Constipation

Constipation is when you find it difficult to poo.



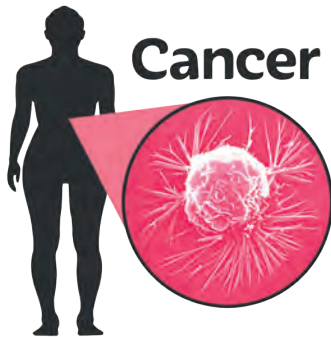
Some people with a **learning disability** are **at more risk** of **constipation** than the general population.



People with a learning disability are often given **medicine** to treat **constipation**.



A project to tell people more about the **risks of constipation** was **delayed** because of **coronavirus** but will start very soon.



Cancer

People with a learning disability are **less likely to die** of **cancer**.



But **LeDeR reviews** found out that it sometimes takes a **long time** for people with a learning disability to find out if they have got **cancer**.



One of the reasons for this is that a lot of people with a learning disability **do not get cancer screening**.



The **NHS** is running lots of projects to **get more people** with a learning disability to **have cancer screening**.



Epilepsy

Epilepsy is a condition that affects the brain and causes **seizures**.



Seizures can change how a person:

- behaves
- moves
- feels.



Lots of people with a learning disability have **seizures**.



Epilepsy is one of the **most common reasons** why people with a **learning disability** die.



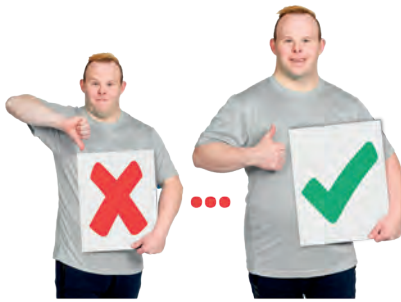
A project is making the **epilepsy checklist** used by GPs easy for **people with a learning disability** and **autistic people** to understand.



The project will help to make sure **people with a learning disability** and their **carers** have **better information** about **epilepsy**.



This could help to **stop** people dying **from epilepsy**.



Changing how we work

Do Not Attempt Cardiopulmonary Resuscitation or DNACPR

DNACPR



DNACPR is short for
**Do Not Attempt
Cardiopulmonary Resuscitation**

CPR



Cardiopulmonary resuscitation
or **CPR** is when someone tries
to make a person's **heart start again**
if it stops.



If people **do not** want to be resuscitated they can choose to have a **DNACPR**.

DNACPR



If you have a **DNACPR** it means a health professional **will not** try to start your heart if it stops.



A decision about **DNACPR** **should not be made without talking to:**

- the person
- their family
- carers.



DNACPR



The **NHS** has told **health and care organisations** about how to use **DNACPR**.

There is going to be

DNACPR



- **better information** about **DNACPR**



- **better training** for health and care workers on **DNACPR**



- the same way of making **plans** for people who might need a **DNACPR** all over England.



- a group led by the government to look into **DNACPR**.



Reasonable adjustments



The **NHS** is working to get more information about **reasonable adjustments** on to electronic patient records for people with a learning disability and autistic people.



This is called a **digital flag** and can help medical staff to:



- make the service easier to use and understand.
- make visits to the hospital more positive.



To watch a video about **reasonable adjustments** go to:

www.england.nhs.co.uk

and search for **reasonable adjustments**.



Annual Health Checks



The **NHS** wants **everyone with a learning disability** who wants an **Annual Health Check** to have one.



Annual Health Checks can find health issues **before** they become a **big problem**.



All **GP practices** were told last year that everyone with a learning disability should get an **Annual Health Check**.



In **October 2020** a new project worked with people with a **learning disability** and their carers to:

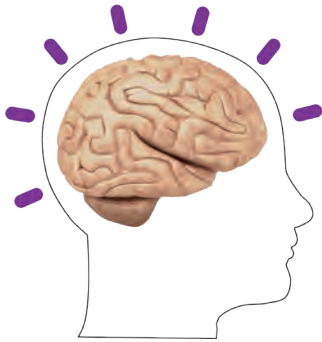


- get more people on their **GP learning disability register**



- get more people to have an **Annual Health Check.**

Medication



Psychotropic medicine is medicine that can change your

- thoughts,
- mood,
- feelings

and the way you behave.



This **medicine** is given for different reasons including:



- mental health conditions
- sleep problems
- epilepsy.





People with a learning disability and autistic people are more likely to be given these **medications**.



Sometimes people are given **medication** to change their behaviour.



Sometimes people with a learning disability are given **too much medication**.



Sometimes people with a learning disability take the **medication for a long time**.



A big campaign called **STOMP-STAMP** is trying to make sure that people have the **right medication** at the right time and only **when they need it**.



People with a learning disability from ethnic minority groups



Every **LeDeR group** is going to include someone who **looks into** the **needs** of people from **ethnic minority groups**.



NHS England and NHS Improvement is working with:



- Race Equality Foundation



- Learning Disability England



- to understand the **issues** for people with a learning disability from **ethnic minority groups**.



- to make sure **self-advocacy** support is better for people with a learning disability from **ethnic minority groups**.



In **August 2020** the **NHS** worked to get more people with a learning disability from **ethnic minority groups** to have a **flu vaccine**.





Find out more

You can find out more about:



- the **NHS England and NHS Improvement LeDeR programme** at:
www.leder.nhs.uk



- the **NHS England and NHS Improvement learning disability and autism programme** at:
www.england.nhs.uk/learning-disabilities



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