



**North Central London**  
Clinical Commissioning Group



# LeDeR

Learning from lives and deaths:  
People with a Learning Disability  
and autistic people



**Annual report**  
**2021 - 2022**

## About us



**NHS**  
North Central London  
Clinical Commissioning Group

We are the North Central London Clinical Commissioning Group.

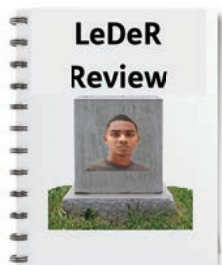
We plan and buy health and care services for the people in these areas:

- Camden
- Islington
- Haringey
- Enfield
- Barnet



## About LeDeR reviews

When a person with learning disabilities or autism dies, we find out about the care and support they got.



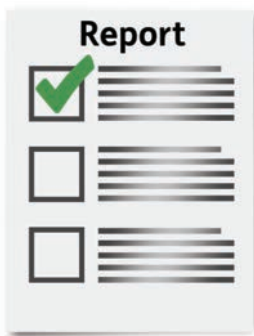
This is called a **LeDeR** review. We say LeDeR like this: **lee-der**.



In a review we often find examples of good care and support.



We also find examples where care and support could have been better.



Every year we write a report about what we have learnt from the reviews.



In 2021 the NHS said changes needed to be made to the way LeDeR works.



This report shows how we will follow the new rules and make LeDeR better in our area.



We make sure we include local people with a learning disability and autism in all our LeDeR work.

## Reviews in 2021 to 2022



40 deaths of people with learning disabilities were reported to us this year.



The number of deaths over the past year is much lower than in 2020 to 2021.



The highest number of deaths was in people aged 60 to 69.



We had slightly more women die than men.

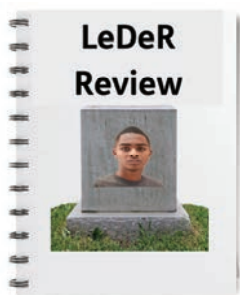


Most of the deaths reported to us were from people who were white or from mixed ethnic backgrounds.

Mixed ethnic background might mean one of your parents is White and the parent is Asian.



Of the 40 deaths, we have done 33 LeDeR reviews.



Next year we want to start doing LeDeR reviews for people with autism who have died.

# The main 5 reasons people died

## 1. Lung problems

Most people from the reviews we did died of problems with their lungs.

The main lung problem was **aspiration pneumonia**.



- We say **aspiration** like this:  
**ass per A shon**
- We say **pneumonia** like this:  
**new mow nee a**



**Aspiration pneumonia** is when you breathe things into your lungs instead of swallowing them.

Germs in food and drink start an infection in your lungs.



## 2. Covid-19

Covid-19 is a virus. It is also called **Coronavirus**.

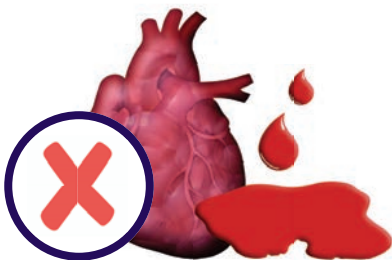


People can get a cough and a high temperature. It can make some people very ill.

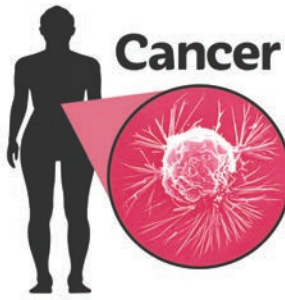


## 3. Heart problems

This includes things like a **heart attack**.



A **heart attack** is when the blood to part of your heart stops suddenly. If this happens your heart stops working.



## 4. Cancer and Sepsis

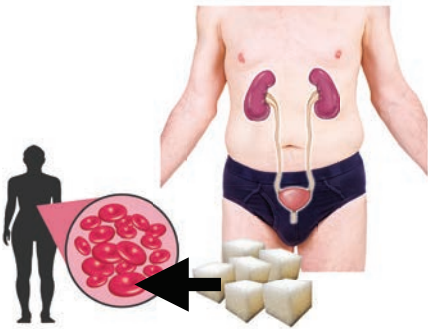
Cancer changes the cells in your body and makes them stop working properly. This can be really serious.



Sepsis is a serious infection in your blood.

## 5. Kidney problems and diabetes

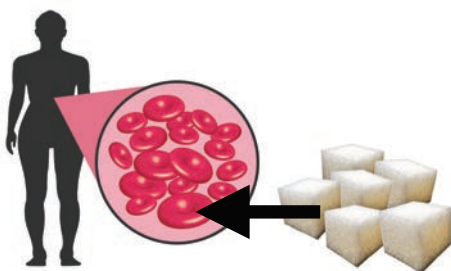
A small number of people died from problems with their kidneys or from **diabetes**.



Your **kidneys** help to keep your blood clean. They help your body pass water as wee.



**Diabetes** is when your body cannot control the right amount of sugar in your blood.



# Things that need to get better

## 1. Health checks



An **annual health check** is when you get checked every year by your local doctor or nurse.



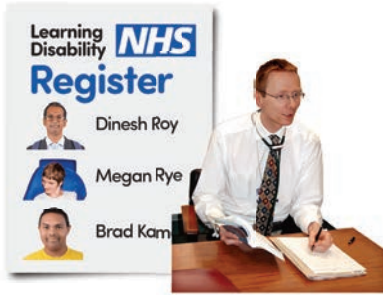
It helps to catch any health problems early. Then you can quickly get the help you need.



We have done some good work to get more people to have **annual health checks** in our areas.



We still need to get more people to have their health check.



A **learning disability register** is a list that local doctors have of patients with a learning disability.



People are only asked to come for a health check if they are on the register.



We need to check our **learning disability registers** have the right information.



## Other ways we are getting more people to have health checks:

- more training for staff about annual health checks



- setting up new health checks for people with autism



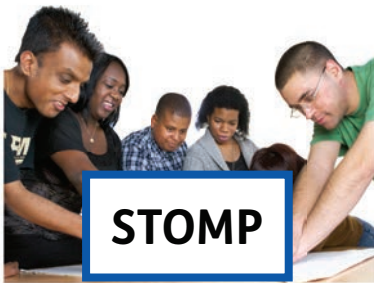
- making sure everyone in our area is offered an annual health check and **health action plan**.

A **health action plan** is a list of things you need to do around your health.

## 2. Stop giving people too much medication



People with learning disabilities and autistic people are given too much medication that makes them sleepy.



There is a big project called **STOMP** that is trying to stop this from happening.



There is also project to stop children from having too much medication. This is called **STAMP**.



To help with these projects, we will:

- keep an eye on what medication is being given to patients



- give staff like doctors and pharmacists training about **STOMP** and **STAMP**



- check people's medication often to make sure it is still right for them

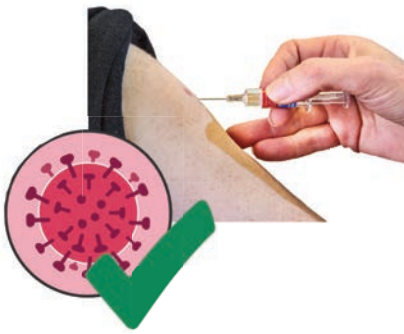


- work with local doctors and pharmacists to support them to do checks on medication



- speak to people about how taking their medication makes them feel

### 3. Vaccinations



A **vaccine** helps your body to fight off illnesses.

It is usually done through an injection in your arm.



During the Covid-19 pandemic, our learning disability services wrote new rules about vaccines.

The rules include things like:

- making sure people with a learning disability have extra support



- giving **consent**. **Consent** means agreeing to do something.

It is important people give consent when they have a vaccine





- giving information about vaccines in easy read



- supporting people who cannot speak for themselves to decide about having the vaccine



#### 4. The Whzan project

We say **Whzan** like this: **wuh-zan**.



A **whzan box** is a blue case that has equipment in it.



Care homes can use it to do health checks on the people who live there.



It can help to spot any problems earlier or if someone's health is getting worse.



The information from these checks is shared on a computer.



Doctors, nurses and ambulance staff can see the information too.



This helps to make sure patients get the right care at the right time.



Staff in other services will be trained in how to use Whzan boxes with the people they support.

# Good work happening across North Central London



Here is some of the good work services are doing in our area. This work helps our LeDeR work.

## Camden

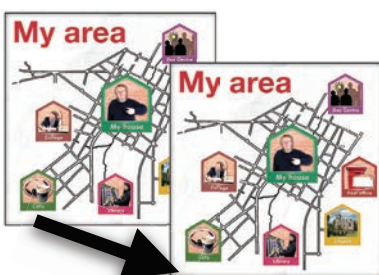
Some work Camden is doing includes:

- training for care homes about how to stop trips and falls.

This helps staff spot if people need extra support.



- Sometimes we don't have the right services to look after someone in our area.



We might have to send them to another area for the support they need.



If we do this, we will give the person a **named worker**.

The person and their family can contact the named worker if they have any questions.



- making sure staff in hospitals understand a patient can ask for **reasonable adjustments**.

This means extra things they need like extra time and support, or a quiet place to wait



- putting information for patients in easy read or a video



- hospitals working together with special learning disability workers at London Ambulance services



- having learning disability training for hospital trust staff



- setting up a new learning disability and autism register

## Islington

The work in Islington includes:



- holding meetings and working together with local doctors to make health services better



- finding new ways to help stop people from needing to go into hospital



- writing some new rules for nurses and pharmacists.

The rules say that the flu vaccine can be given as a spray that goes up your nose. This means more people can get vaccinated



- writing some new rules about giving medication to people who can be hard to treat. This could be because of their behaviour

# Haringey

## The Haringey Learning Disability Service has:



- been involved in a project about what happens when people leave hospital.

The project looks at ways to make it easier for people to get the right care and support



- set up epilepsy services for people in the local community. This work has been put forward for an award



- been put forward for an award in **person centred** services, and supporting people well at home.

**Person centred** means people getting the health and care services that are right for them.



- worked together with local doctors on a new annual health check project. The project includes training for nurses and health staff

## Enfield

Work in Enfield includes:

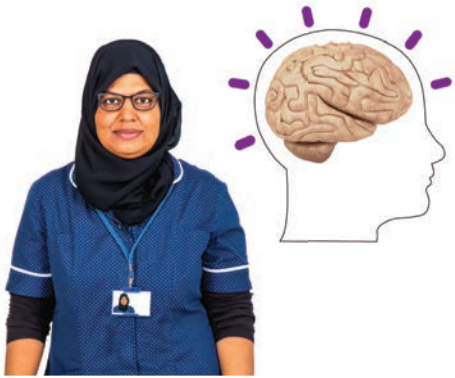


- setting up a new group called the **Enfield Joint Autism Steering Group**.

This group will look at making things better for people with autism in health and community services.



- community nurses are doing health check drop ins at 7 day centres.



- employing a new member of staff who is highly trained in supporting people with **epilepsy**.

**Epilepsy** is an illness that can affect your brain. It can cause you to have a seizure.



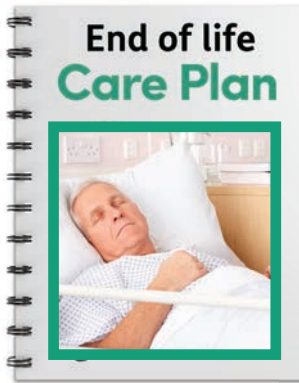
A seizure can affect people in different ways. Some people might feel a bit strange and not know where they are.



Some seizures make part of your body or all of your body jerk and shake.



This person has trained other staff and put information about epilepsy into easy read.



- starting to work again about **end of life care plans** for people with a learning disability.

These are plans for people about what they want to happen when they come to the end of their life.



Staff will have training about how to give the best care and support.

## Barnet

The **Barnet Learning Disability Service** has:



- put on special Covid-19 vaccine clinics for people with a learning disability.



At the clinics, learning disability nurses gave help and support about the vaccine



- given training to staff about learning disabilities and the **Mental Capacity Act**.

The **Mental Capacity Act** is a law that helps people to make their own decisions.



It also protects people who cannot make their own decisions about some things



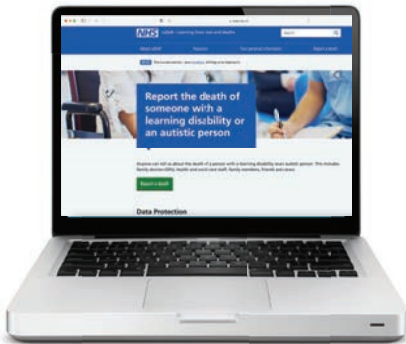
- made a leaflet for carers about **constipation** and what to look out for.

**Constipation** is when you cant go for a poo for a long time. This affects more people with a learning disability



## More information

You can find out more about the work being done on these websites.



The NHS England LeDeR programme

**Website:**

**[leder.nhs.uk/](http://leder.nhs.uk/)**



The NHS England Learning Disability and Autism Programme

**Website:**

**[www.england.nhs.uk/learning-disabilities](http://www.england.nhs.uk/learning-disabilities)**