

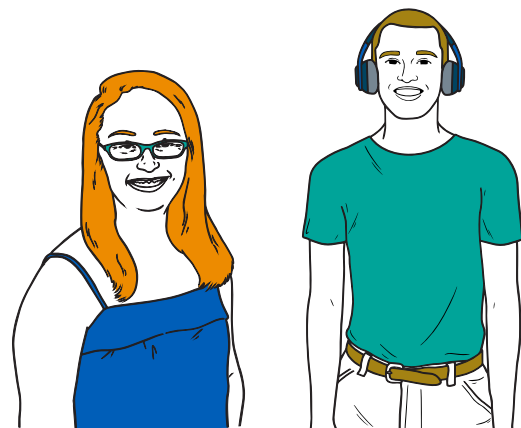


**Staffordshire and
Stoke-on-Trent**
Integrated Care System

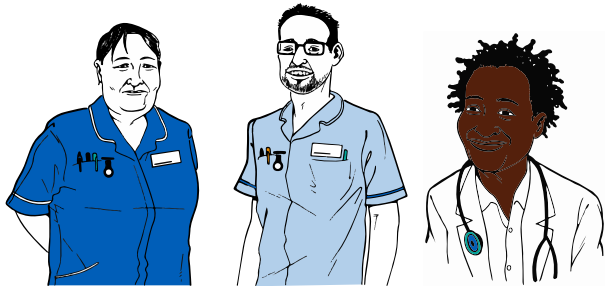
Learning from the lives and deaths of people with a learning disability and autistic people (LeDeR)

2023/24

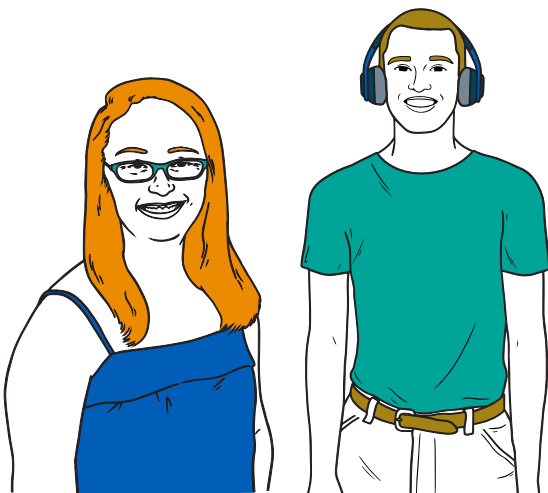
Easy read



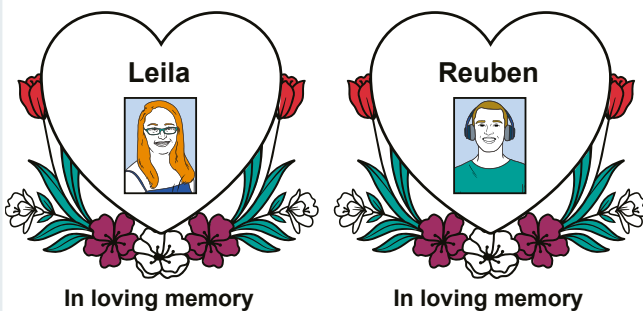
What this is about



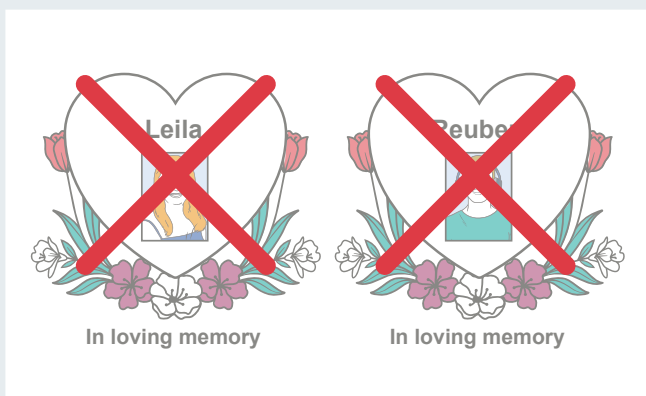
The different organisations involved in providing care work together as an **Integrated Care System (ICS)** to plan and deliver services for a local area. We are **Staffordshire and Stoke-on-Trent ICS**.



Some people with **learning disabilities** and **autistic people** may find some things harder to do – like communicating or being with other people. But everyone's needs are different.



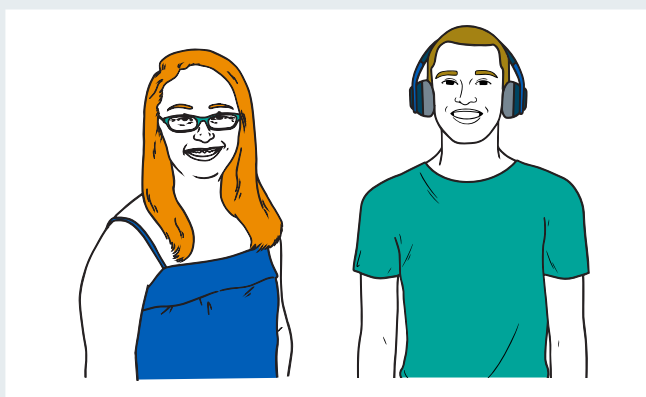
In England, some people with learning disabilities and some autistic people die at a younger age.



This is not right, and we want to stop it from happening by making health and social care services better.

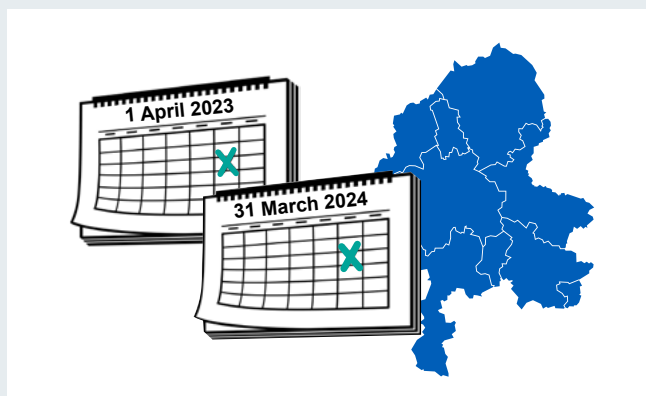


Each year, we look at the care given to a person with learning disabilities or an autistic person in our area who has died. This work is called **LeDeR** for short.



Doing LeDeR reviews helps us to:

- Make our services better
- Help people to live healthier lives
- Help people to live for longer.



This is a summary of what we have done in Staffordshire and Stoke-on-Trent from 1 April 2023 to 31 March 2024.

What LeDeR does

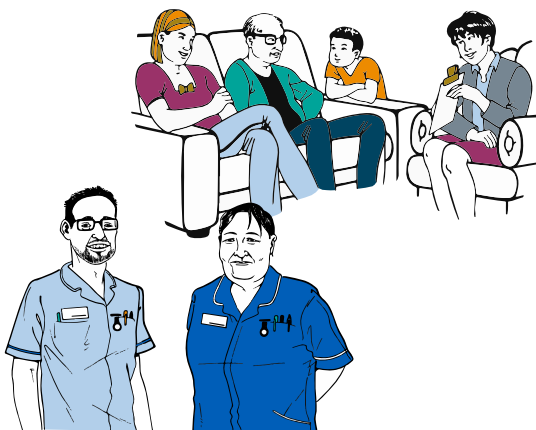


We need to make sure that:

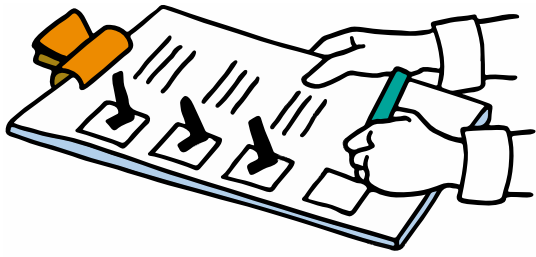
- We know when someone has died.



- The review of their death is done on time.



- We speak with the family, friends, and health and social care professionals who were involved in their care.

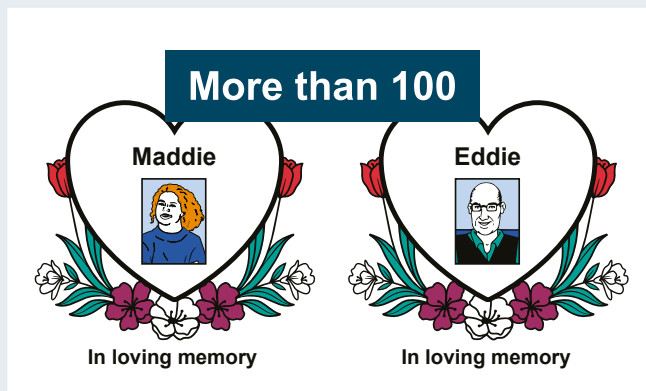


- We check that any actions recommended in the review are completed.

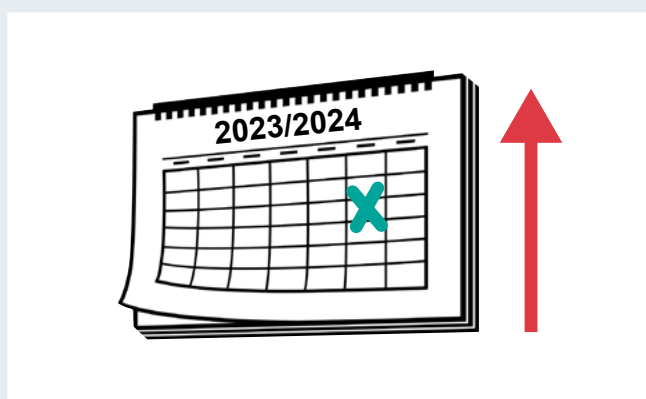


- Local people know about the programme.

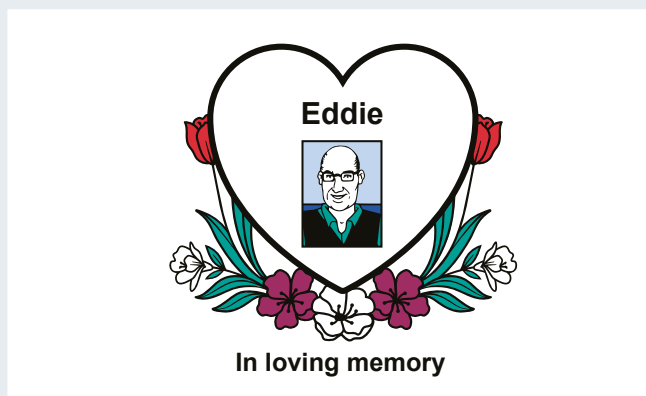
Our reviews last year and what we found out



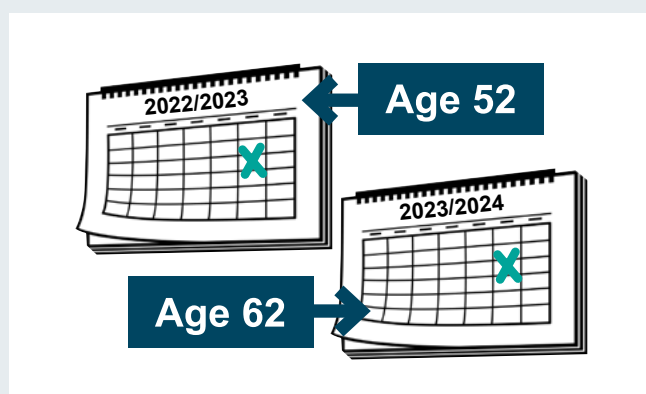
Last year, we were told about more than 100 deaths.



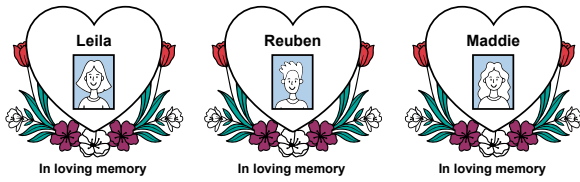
This number is higher than the year before. It may be because more people have died, or because more people know about LeDeR.



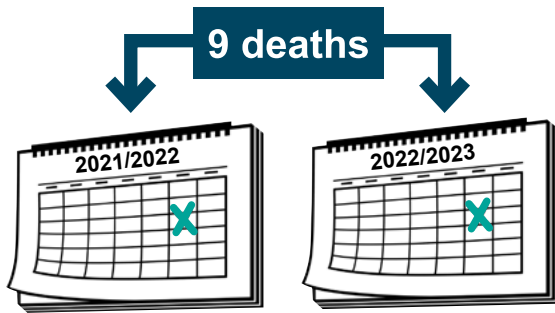
Our reviews showed that the average age at death last year was 62.



This is 10 years older than the year before. This is good, but we know there is still more work to do.



From the deaths we reviewed, 3 were young people aged up to 18.



This number is lower than in the 2 previous years. In both those years, we saw that 9 young people aged up to 18 had died.



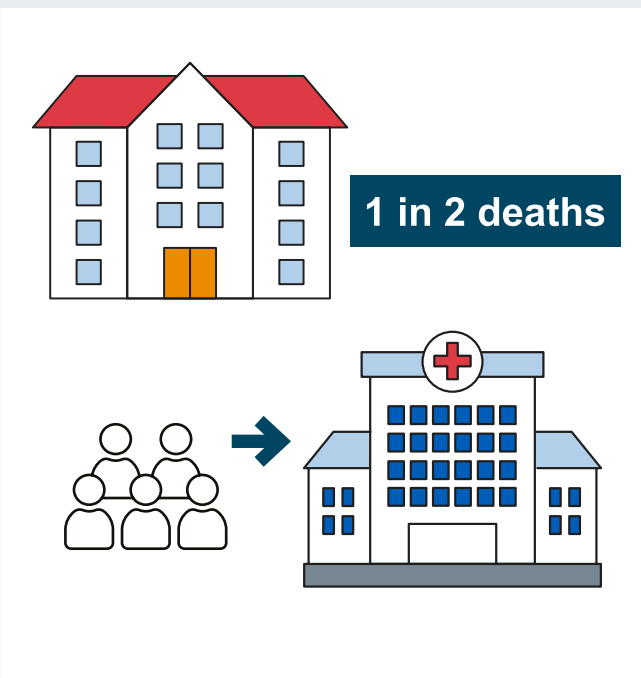
Last year, only 1 of the deaths we reviewed was of someone from an ethnic minority group.



- This number is very low every year. This could be because:
- These communities do not know about LeDeR, or
- Deaths of people with a learning disability and autistic people are not being reported to us from people in these communities.



To help more people who are from ethnic minority backgrounds know about LeDeR, we have translated our information into other languages, and we are working closely with these local communities.

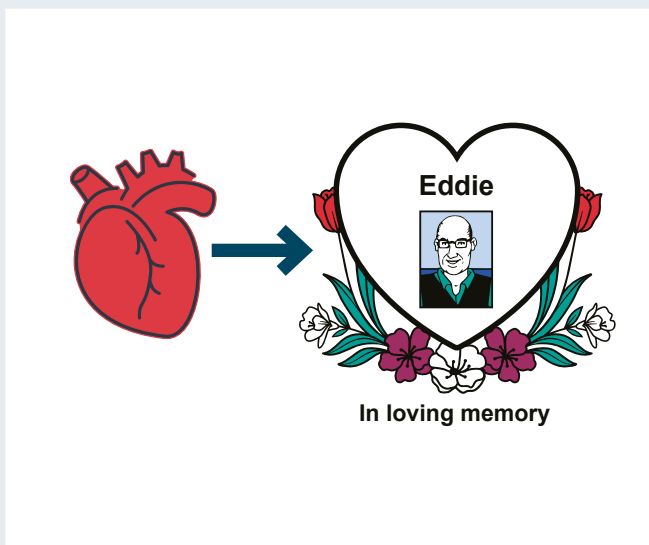


Last year, half the deaths we reviewed were in nursing or residential homes. This is higher than the year before, but a lot of people are still dying in hospitals.

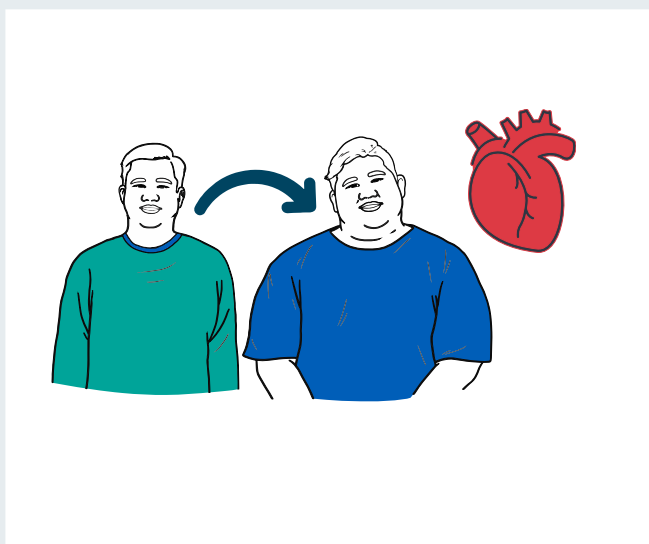


We are working with learning disability nurses and care providers to make sure that people are involved in their end of life care plans, so they can die in their own home or in a hospice if they want to.

Main causes of death

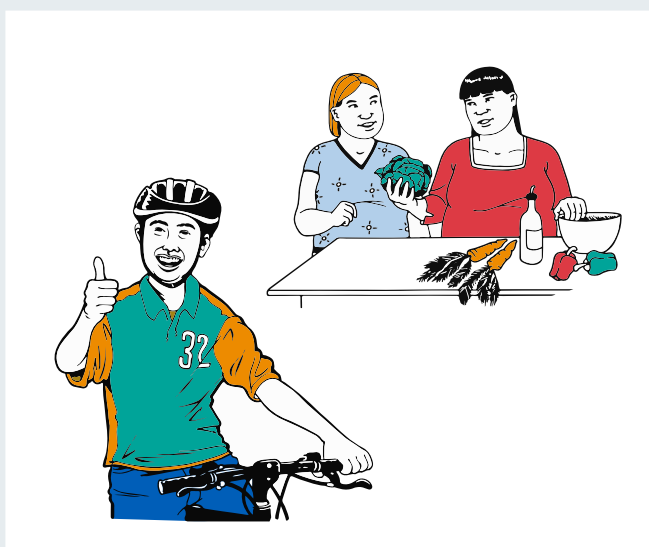


Our reviews showed that the biggest number of deaths last year was caused by a group of illnesses like heart disease.

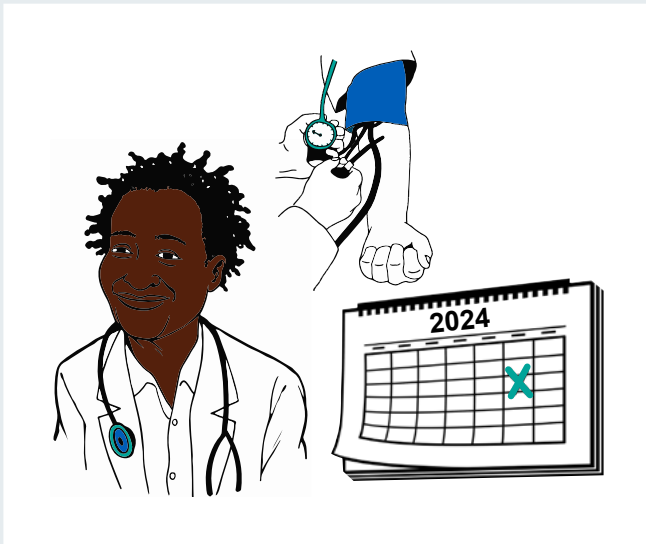


These illnesses can be caused by:

- being overweight
- high blood pressure
- having diabetes.



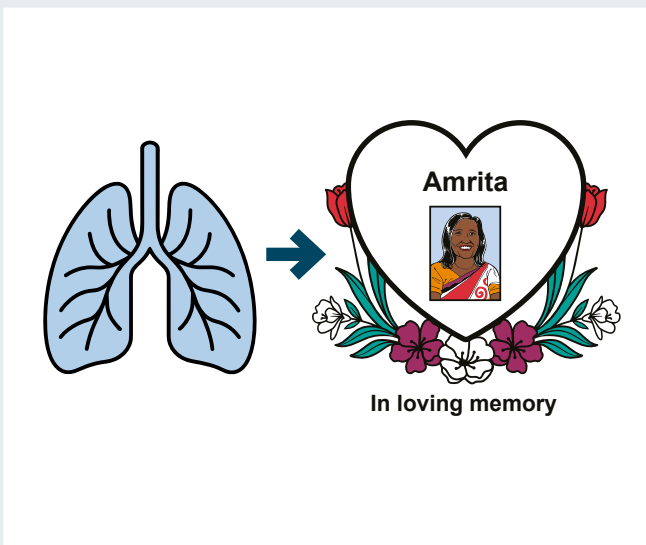
Our reviews showed that the number of people who died from these illness went up last year. To stop this happening, we want to offer people more help with healthy eating and keeping fit.



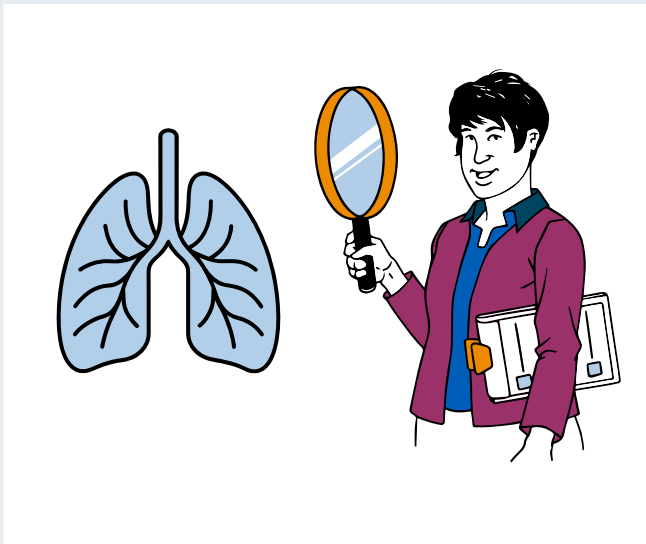
It is very important to see your doctor every year for your annual health check. If a health problem is found, you will be able to get help quickly.



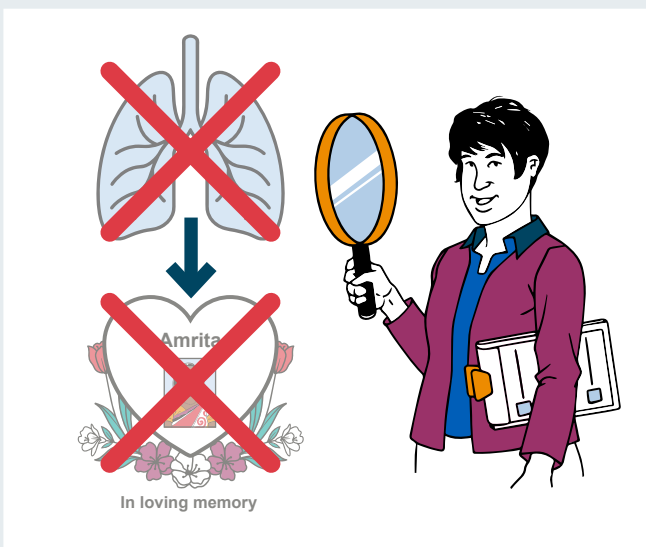
The checks are also a chance to ask questions about your health and tell your doctor how you are feeling.



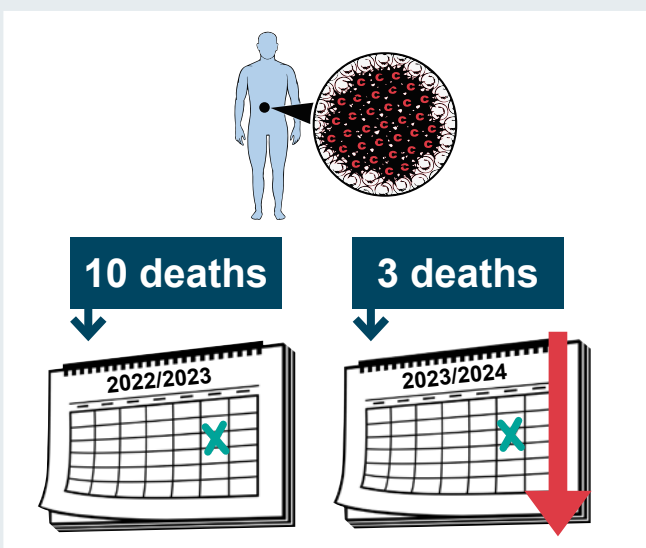
Our reviews showed that a lot of deaths last year were caused by illnesses that affect breathing, including pneumonia.



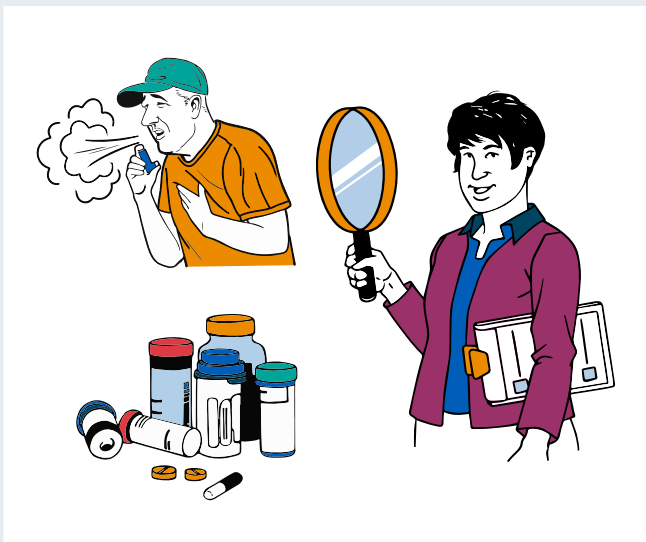
This year, we plan to look more carefully at cases where people have died from pneumonia and similar illnesses.



This will help us to see if there are any ways to stop people from dying from these conditions.



Our reviews showed that only 3 people died of cancer last year. The year before, 10 people died of cancer.



Our reviews show that we are good at lots of things:

- We regularly check that people are taking the right medication. If people have health conditions like asthma, epilepsy, dementia or diabetes, we check that they are not getting worse.

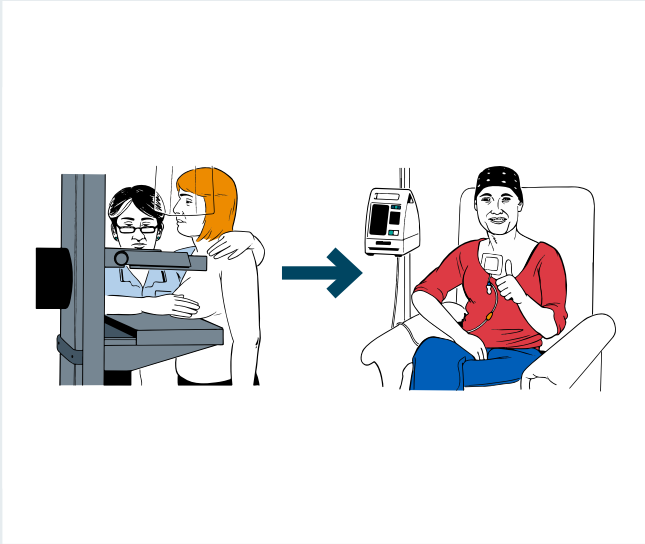


My Health Passport NHS	
	My name is <input type="text"/>
	If I have to go to hospital, this book needs to go with me. It gives hospital staff important information about me.
	Nursing and medical staff: This needs to hang on the end of my bed. A copy should be put in my notes.
	This passport belongs to me. Please return it when I am discharged.
	Nursing and medical staff: Please look at my passport before you do any interventions with me.

- We use **health passports** to record important information about:
 - medication and allergies
 - communication needs
 - contact details
 - likes and dislikes.



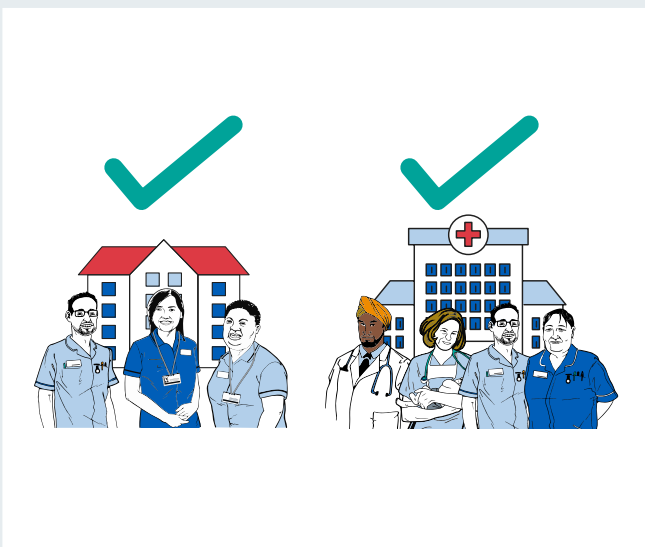
- We make sure people have vaccinations to protect them from illnesses and viruses like flu and COVID-19.



- We make sure we offer people any screening that they need to spot early signs of cancer – so they can get treatment quickly.



- GP practices keep in touch with care homes and other services. They share information to help the services do the best job of looking after people.



- Learning disability nurses, care staff and hospital staff are looking after people very well.



- We provide **advocacy** services (where someone speaks for you to make sure your views are heard).



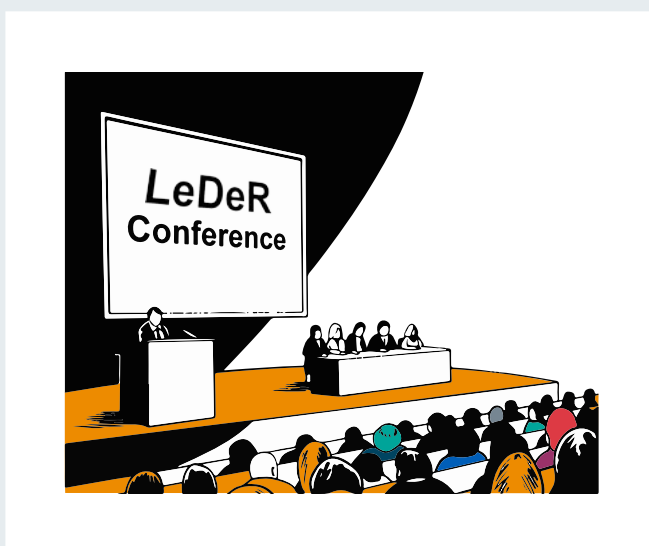
- We offer **reasonable adjustments** (changes that make it easier for people to go to health and social care appointments). This can be things like having appointments at quieter times of the day, bringing a carer or friend with them, or longer appointments.

Changes we have made this year



From our reviews in previous years, we agreed on things that could be done better. We have made lots of changes this year:

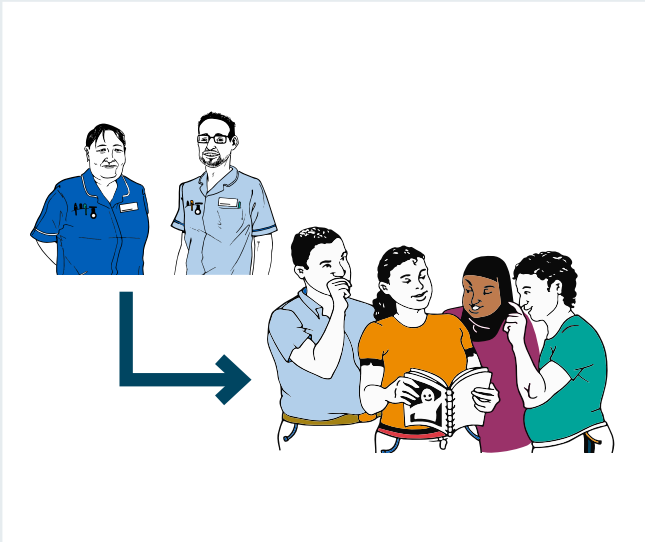
- We made a video explaining LeDeR: www.youtube.com/watch?v=Ml0jvuzuODA



- We held a **conference** (large meeting) for people who work in health and social care in our area. We told them more about LeDeR.



We made a LeDeR action plan. This explains to people who work in health and social care what the most important actions are for LeDeR.



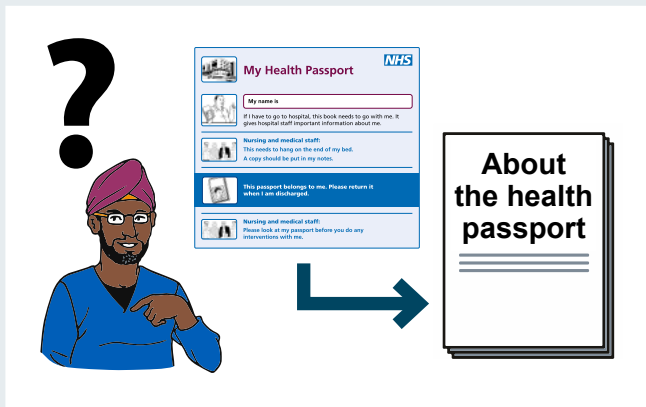
- More local health and social care providers are on our steering group. This means the group can share ideas with them about making services better.



- Our local area contact has gone to local events and meetings to tell more people about LeDeR and hear from local people.



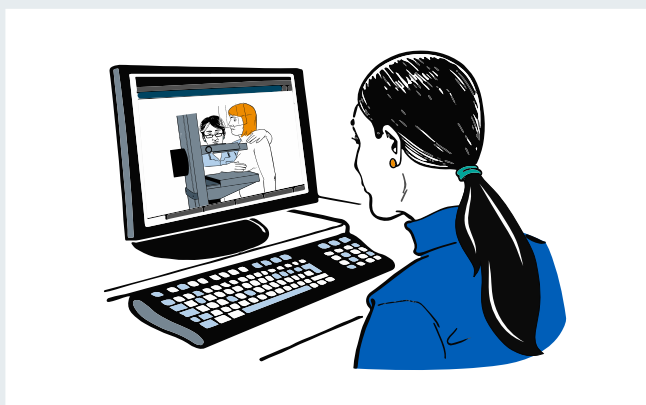
- A new website provides advocacy support for carers: www.theadvocacyhub.com



- We made a new document to answer questions about our health passport.



- **Dysphagia** is when a person finds it hard to swallow their food and drink. We provided dysphagia training for residential homes, care homes and supported living providers.



- We made an easy read video to promote breast cancer screening to people with a learning disability and autistic people: www.youtube.com/watch?v=DXqbNfdZQgA



- We are also working on a version in Makaton.

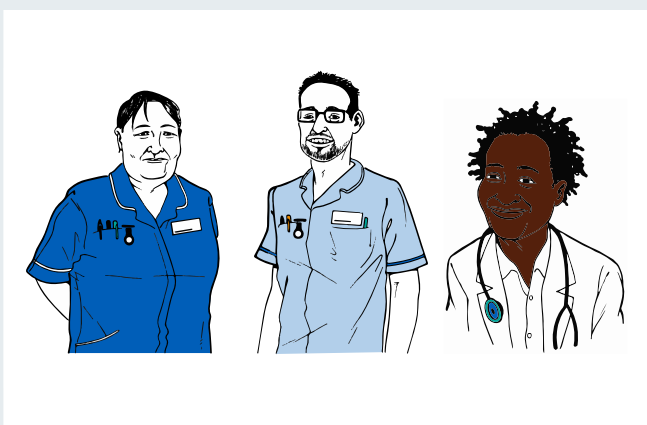
What we can do better

From last year's reviews, we saw some things that we can do better in future.

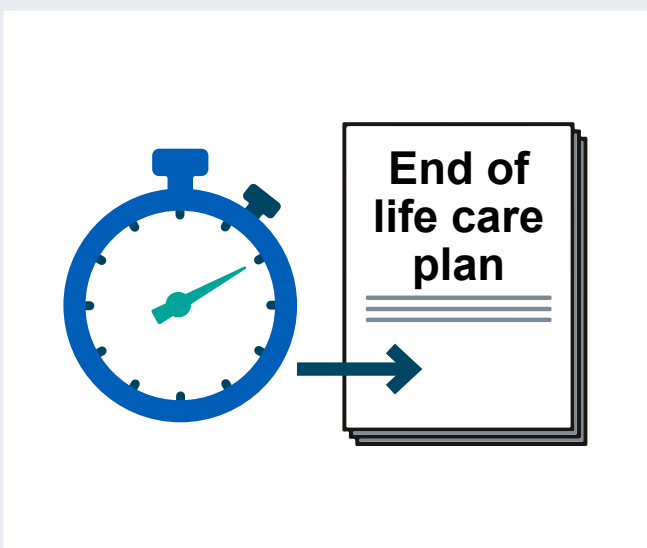


For example:

- Making sure more people have help from **acute liaison nurses**. These nurses work with other staff to help them understand the needs of people with a learning disability.



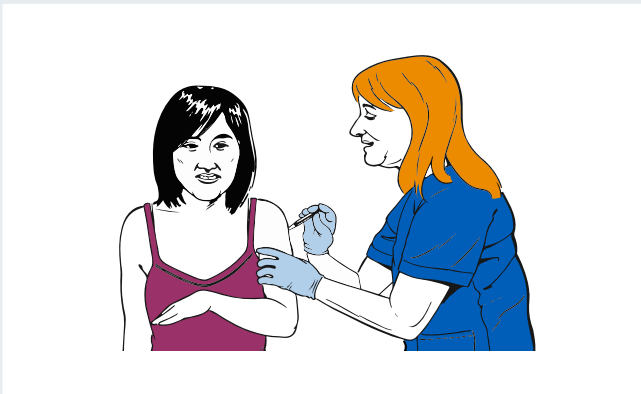
- Making sure more people have help from the Community Learning Disability Team.



- Thinking about end of life care plans sooner.



- Helping more people to get an autism assessment, if needed.



- Helping more people to get all the vaccinations they need.



- Giving people **bereavement** support when a loved one has died.



- Making sure people with epilepsy have an epilepsy care plan and can get the correct emergency medication, if needed.

Changes we will make next year

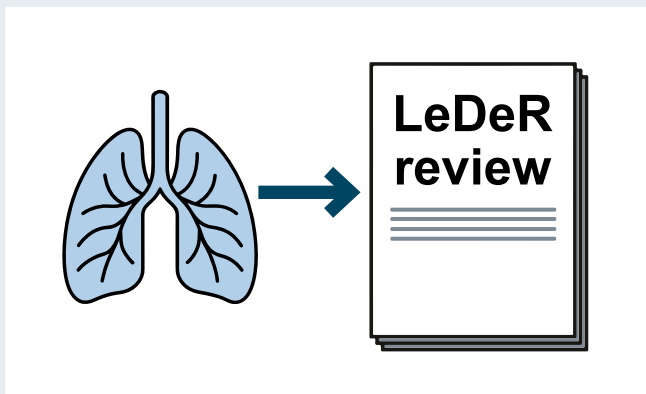


Next year, we will keep talking to care providers and other services about things like the best ways of working, health passports, and cancer screening.

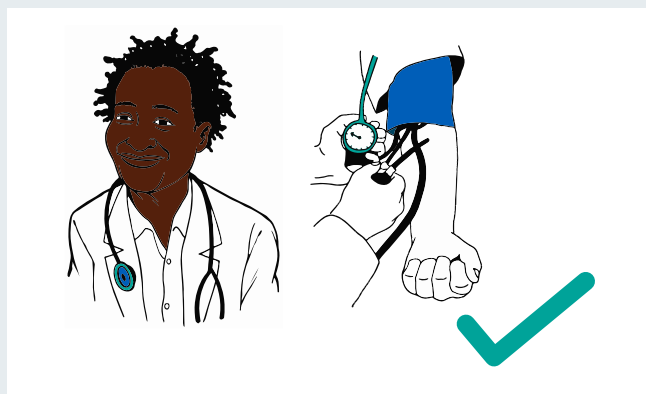


We also plan to:

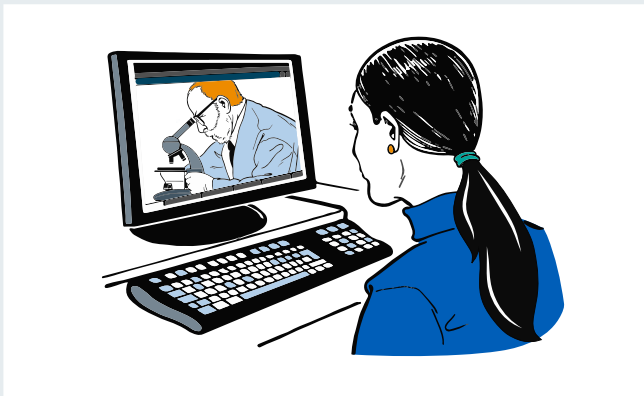
- Help care staff to have training about epilepsy.



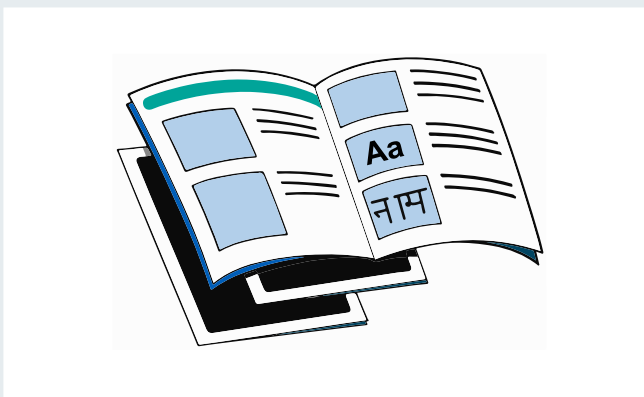
- Do more detailed reviews when someone has died from an illness like pneumonia.



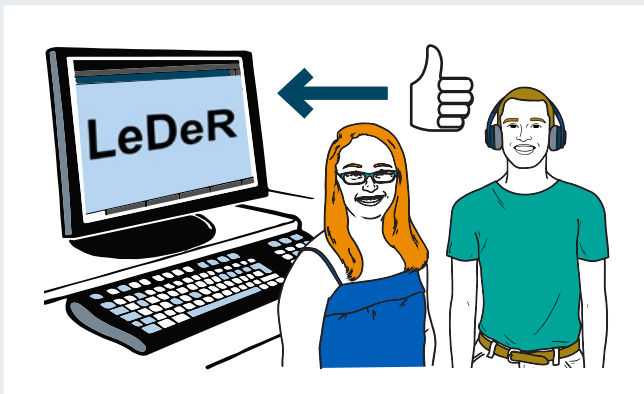
- Keep checking that annual health checks are being done well.



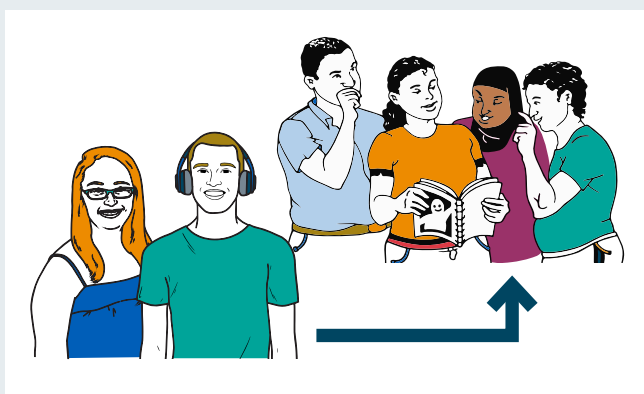
- Make more easy read videos about cancer screening for people with a learning disability and autistic people.



- Have easy read leaflets about LeDeR available in more languages.



- Make the LeDeR website better for people with learning disabilities and autistic people.



- Have more people with learning disabilities and autistic people on our steering group.

Find out more about LeDeR



Visit the Staffordshire and Stoke-on-Trent Integrated Care System website to find out more about LeDeR:

www.staffsstokeics.org.uk/leder



Visit the NHS England website to report the death of someone with a learning disability or an autistic person:

www.leder.nhs.uk

Produced by [NHS Arden and Greater East Midlands Commissioning Support Unit](#) and [NHS Midlands and Lancashire Commissioning Support Unit](#)

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