

Learning from lives and deaths – people with a learning disability and autistic people (LeDeR) in Staffordshire and Stoke-on-Trent

2022/23



Easy Read

What this is about



The different organisations involved in 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**.



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.



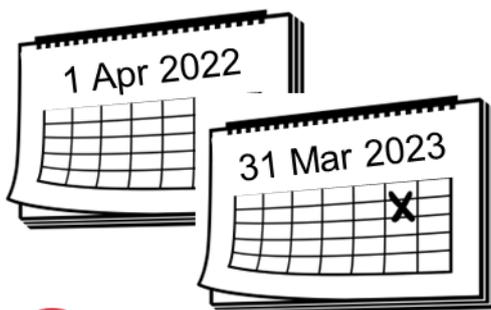
In England, people with learning disabilities and autistic people die at a younger age.



We want to stop this from happening and make health and social care services better.



LeDeR is about learning from the lives and deaths of people with a learning disability and autistic people across England.

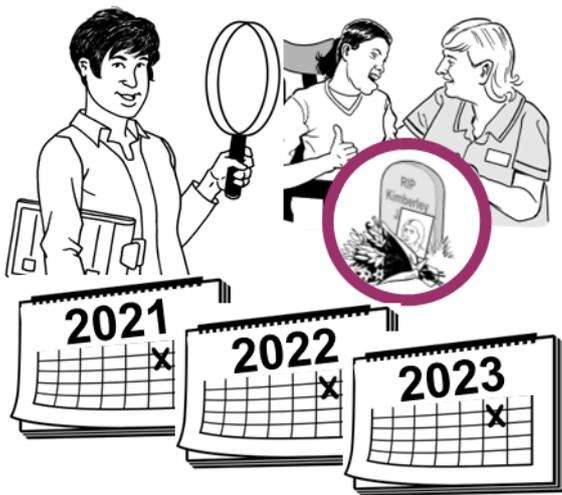


This document is about LeDeR in Staffordshire and Stoke-on-Trent from 1 April 2022 to 31 March 2023.



**Staffordshire and
Stoke-on-Trent**

What we do



Each year, we look at the care given to a person with learning disabilities or an autistic person in our area who has died.



We need to make sure that:

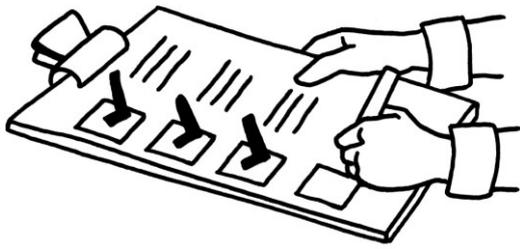
- We know when someone has died.



- The review of their death is done on time.



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



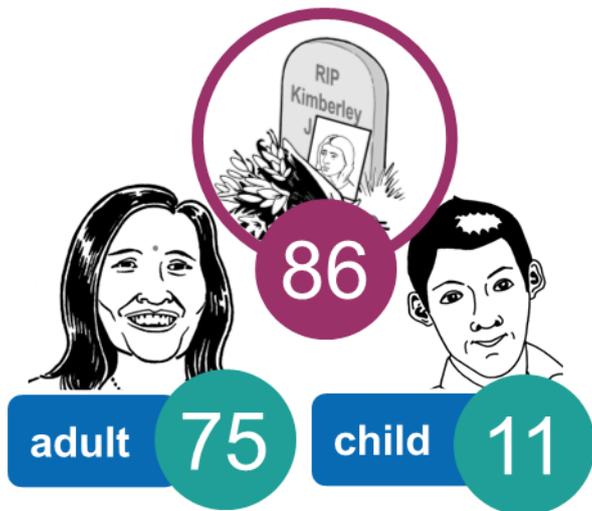
- We check that any actions recommended in the review are completed.



- Local people know about the programme.



Our reviews last year

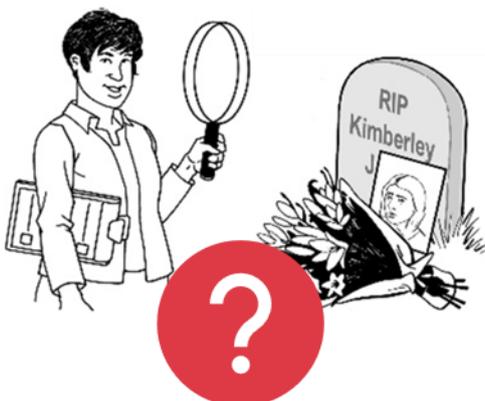


Last year, we knew of **86 people** who died, who either had a learning disability, were autistic, or both. **75 were adults, and 11 were children.**

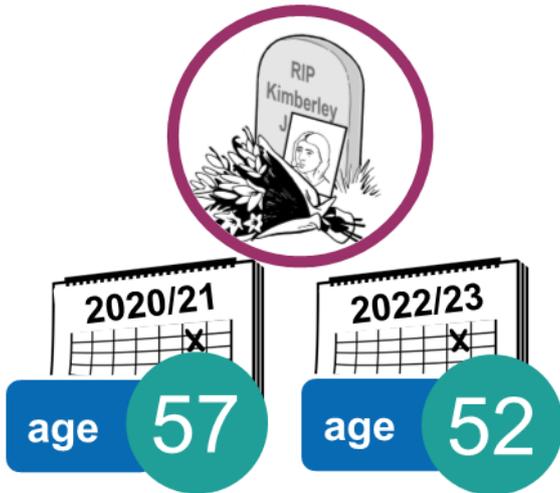


Only 5 were from ethnic diverse groups. This might be because:

- Some people from these groups have chosen not to have their ethnicity recorded.
- Not all deaths from these groups of people are reported to LeDeR.



It is important that we know when anyone in our area with a learning disability or an autistic person dies, so that we can understand the reasons.

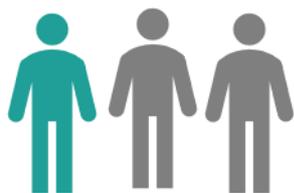


Last year, the average age of death was 52. This was worse than in the 2 years before, when the average age was 57. This means we have more work to do to help people live for longer.



We will keep telling people in our area about LeDeR, especially people from ethnic diverse groups.

The causes of death, and what we are doing to reduce or prevent them



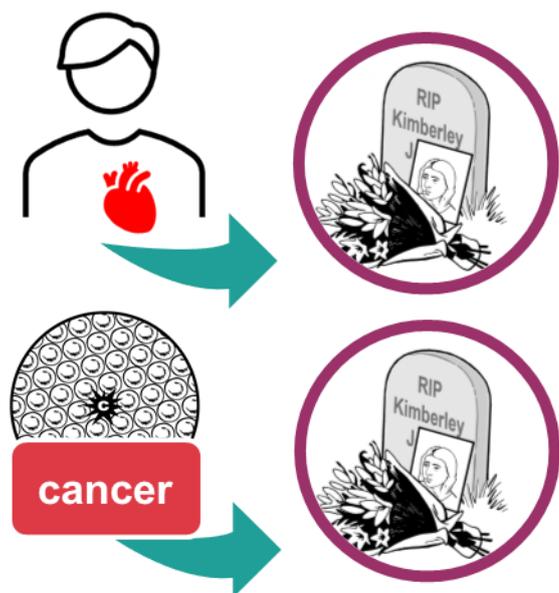
Last year, **pneumonia** was the main cause of 1 in 3 of the deaths we reviewed. Pneumonia is when an infection causes the lungs to be **inflamed** (swell up), making it harder to breathe.



This included **aspiration pneumonia**, which can happen when a person finds it hard to swallow their food and drink. Food or liquid can go into the airways or lungs, causing an infection.

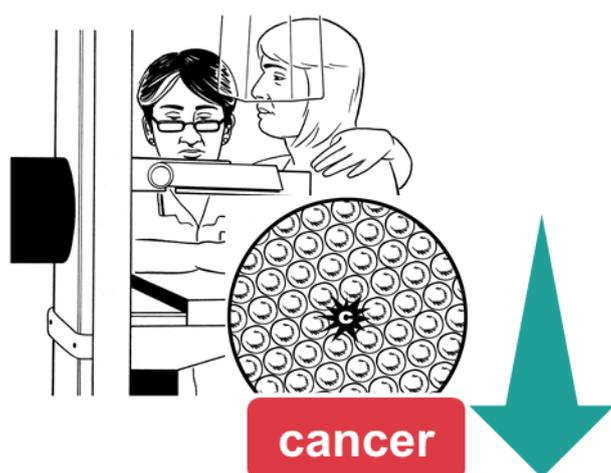


We want to help carers and healthcare staff have training to help people who find it hard to swallow.



The next most common causes of deaths were:

- **Cardiovascular diseases**
(which damage the heart and blood vessels)
- **Cancer.**



We will keep telling people about how they can reduce their risk of getting these conditions. We will make sure they understand about going to **screening checks** and checking for signs of cancer.



Last year, slightly more people died from **blood poisoning** than the year before. We will tell people and their carers about what signs to look out for, and to make sure they understand to get help quickly.

What we are doing well



From our reviews, we can see that we are doing well at:

- Giving good care, and sometimes excellent care.



- Giving excellent **end of life care**. This is healthcare provided when someone is suffering an illness that could end their life.



- Involving families.



Residential care homes are providing good support for their patients. This is housing for people who need extra help and support with their personal care – things like washing and dressing.

What we can do better



From our reviews, we know that our **services** (like hospitals and care homes) could do better when they communicate with each other and with families.



We want more people with learning disabilities to know about **advocacy**. This is where someone speaks for you to make sure your views are heard.



We also want to be better at completing important forms and documents. This includes information about medical treatment that a person wants or does not want.



Our reviews show that too many people are dying in hospital instead of the place they call home. We will do more to help people make plans for their end of life care.



Other changes we are making



Our reviews show that not enough people had a **health passport**. A health passport has important information about what a person likes and what makes them worried.



Health passports also list any **reasonable adjustments** a person may need. These are changes that make it easier for people to go to health and social care appointments.



Reasonable adjustments can be things like having appointments at quieter times of the day, bringing a carer or friend with them, or longer appointment slots.





We have done lots of work to tell carers and health and social care staff about health passports, so that more people can have them.



We have been working with children's services on **child health passports**. These are helpful for when a young person moves into adult care.



We will ask more people with learning disabilities, autistic people and people from ethnic diverse groups to join our **Steering Group and Governance Panel**. It will mean they can help decide plans for the future and be a voice for others like them.



We will keep working with doctors to help more people to have an **annual health check**.



Annual health checks are a chance for you to get to know your doctor better. This means any health problems can be spotted sooner. You can ask your doctor questions about your health and tell them how you are feeling.



We will make sure people have regular **medication reviews**. The reviews help make sure people do not take medication that they do not need.

What happens next



We will keep telling local people about LeDeR, and how it involves autistic people as well as people with learning disabilities.



We will make sure this information reaches lots of people. We will make it available in different languages and in lots of public places.



If you have any questions about this work, please contact us:



- Email ssotics.comms@nhs.net



- Call **0300 123 1461**



- Write to **Staffordshire and Stoke-on-Trent ICB,
Stafford Education and Enterprise Park, Weston
Road, Stafford, ST18 0BF**

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