

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



LeDeR Programme Coventry and Warwickshire Annual Report 2021–2022



Easy read version
September 2022

Dictionary

The words in **bold green** in the text are in the dictionary
at the end of the report.

What is LeDeR and this report about?



LeDeR is a national programme from NHS England. It looks into the lives and deaths of people with a learning disability. From January 2022 it also included autistic people.



In Coventry and Warwickshire, the LeDeR programme is run by people working in health and social care services.



This 4th LeDeR report is about the deaths of people with a learning disability who died in Coventry and Warwickshire between April 2020 and March 2021. It looks into what happened to these people, so that care for others can be improved.



There are 14,400 people with a learning disability and about 6000 autistic people living in Coventry and Warwickshire in 2020.

How does a LeDeR review work?



When a person with a learning disability or an autistic person dies, the death should be reported to the national LeDeR programme.



A local reviewer is given the job of finding lots of information about their life and death. This should happen in 6 months.



Sometimes there is a focussed review. This is when more information is found by talking to more people. This happens if the family want it, or the reviewer thinks there are special concerns.



Families often know the most about the person who died, and what care they got. The reviewers know this is a very difficult time for families.



Coventry and Warwickshire have recruited a senior LeDeR reviewer and other LeDeR reviewers.



They have worked with experts by experience from a local charity Grapevine to join a discussion group.

Deaths in Coventry and Warwickshire 2021–2022



62 people died.



19 reviews from the year before were also completed in this year.

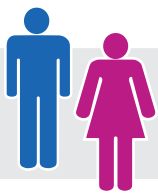
1 person was autistic.



3 children died who had a learning disability or a learning disability and autism.

7 deaths were reported, but as they were not a person with a learning disability or an autistic person living in Coventry and Warwickshire, they weren't reviewed.

More information about the people who died



There were 28 males and 27 females.



They were from 18 to 93.
The average age was 60.



Almost 90% were white British.



Children from the age of 4 are included in the LeDeR programme. These reviews are done by a different group.



Almost 70% of people died in hospital. This is more than the general population - only 48% die in hospital.



There were lots of reasons why people died. Breathing problems was the reason for about half of the deaths. But people also died from cancer, heart problems and other reasons. Only 3 people died when **Covid** was the only reason – much fewer than last year.

What did the LeDeR reviews find out?



There needs to be a better way of understanding and using the **Mental Capacity Act**. People with a learning disability and their carers don't always know about their rights. The Act can help when important decisions have to be made.



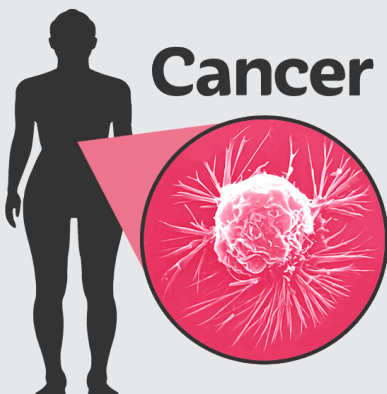
There were lots of good examples of how **reasonable adjustments** had helped people. These are small changes to make services easier to understand and to use. For example, using hospital passports. Sometimes **acute hospital services** didn't know straight away that their patient was someone with a learning disability. So, they were late in getting the specialist **liaison nurse** to support them.



Moving from children to adult services should be better. There should be better communication between all the professionals and the family carers.



About three quarters of the people who had died had their **learning disability annual health check**.

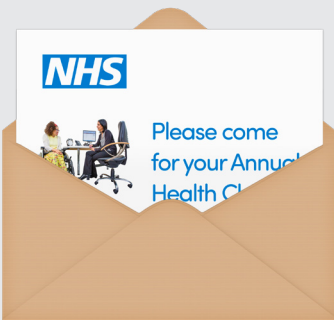


Cancer

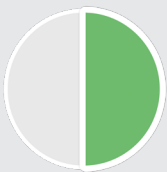
Before the **Covid pandemic**, cancer was the reason most people with a learning disability died. 3 people died from cancer, the same as the year before. But not everyone had cancer screening tests. The screening is for cervical, breast and bowel cancer. People get an invitation to go for screening at certain ages, and there is help for people with a learning disability to go to their screening appointments.



The reviews found that some people with a mild learning disability hadn't looked after themselves and this had led to health problems. This included not going to regular appointments. People have a right to choose what they do. But professionals should also pass on worries if there is a **safeguarding concern**. Learning disability training for healthcare staff now includes recognising and supporting this group.



The LeDeR reviews found many examples of good ways of working, where people had personal and high-quality care. For example, one GP used an easy read letter for the annual health check. These good examples have been shared in the LeDeR newsletter.



Half of the six focussed reviews found that people's care was graded as good. But the other three had care that wasn't as good.

Learning and changing how things are done



The LeDeR reviewers found small changes that could help make sure everyone gets good healthcare. This year the special things to learn are:



- ✓ More support for people with respiratory and breathing problems.



- ✓ Making sure people are supported to make their own decisions. And when they can't do this, make sure there is a **Best Interests** decision made.



- ✓ Make sure people get support and information to look after their own health.



- ✓ Make sure all healthcare workers know how to support people with a learning disability, autistic people and their family carers.



- ✓ Share information about what things work well to support people to get good healthcare. And say well done and thank you for staff who give good support.

Thank you



Thank you to everyone who has been part of the Coventry and Warwickshire LeDeR programme, including the people from Grapevine. It has helped to improve the lives of people with a learning disability and autistic people.

Dictionary

Best interest decision

A decision made by professionals and family for another person who can't understand enough to make their own decision. They agree what they think will be best for that person.

Cancer

When the cells in the body grow and multiply and make a tumour or lump.

Cancer screening

This is when a person has tests to check if they have any cancer.

Covid

A virus that spread across the world which makes breathing difficult. Many people have died from Covid. It started in 2020.

Hospital passport

A hospital passport is a document about a person with a learning disability and their health needs. It also has other information, such as interests, likes, dislikes and preferred method of communication.

Liaison nurse

A learning disability nurse who can help people with a learning disability use mainstream health services and follow up healthcare.

Mental Capacity Act 2005

The Act makes sure that people have the support they need to make as many decisions as possible. The Act also protects people who need family, friends or paid support staff to make decisions for them.

Dictionary

Reasonable adjustments

The things that can be done to remove the barriers to people using services.

This includes easy read information and more time for appointments.

Safeguarding concern

When a person with a learning disability may be at risk of harm, abuse or neglect.

This could be from other people or from looking after themselves.
