

LLR LeDeR Annual Report 2025-2026 Easy Read

Introduction



Some people will need someone to help them to go through this information so that they understand it.

This person may be a member of staff, someone from your family or a friend.



NHS Leicester, Leicestershire, and Rutland produce a report every year looking into the deaths of people with a learning disability (LD) and autistic people in our area.

The LeDeR programme was set up in 2017.



What is LeDeR?

- LeDeR means Learning from Lives and Deaths of people with a learning disability and autistic people.
- If someone over 18 with a learning disability or autism dies in England, it can be reported to LeDeR.
- Special reviewers look at the person's care and support.

The aim is to learn lessons and make care better.



About this report

This report looks at deaths in Leicester, Leicestershire, and Rutland from 1st April 2025 until 31st March 2026.

The report shows:

- How many people died
- What they died from
- What we learned
- What needs to change

What we found from the completed reviews:



- 97 people who died were reported to LeDeR
- 82 reviews were completed
- Most of these people had a learning disability
- The typical age of death was 63 years



Ethnicity

- Ethnicity means a person's race or background, e.g. Black, White or Asian.
- Most of the people who were reported to LeDeR were White British.
- It is important that more people from other races or backgrounds are reported to LeDeR when they die.



We need to understand different cultures better so everyone gets good care.

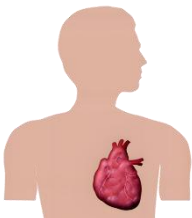
1.



Cause of death:

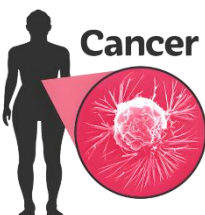
When a person dies, the Death Certificate tells you what the person died of; this is called the **cause of death**.

2.



- The most common cause of death was respiratory (breathing) illnesses.
- The second most common cause was heart problems (cardiovascular disease).
- The third most common cause was cancer.

3.



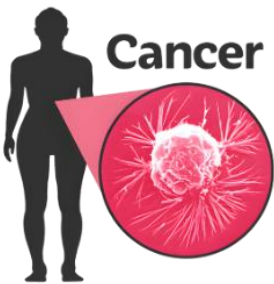
What else we learned this year that could be done better:



- There were some problems with the use of the Mental Capacity Act (2005) – this law checks if people can make decisions about their care.



- Fewer people with a learning disability and autistic people are using cancer screening programmes.



- There were delays in finding signs of cancer in people with a learning disability and autistic people.



- There were delays in referring people with a learning disability and autistic people for cancer tests or treatment.



- People with a learning disability and autistic people are more likely to be diagnosed with cancer at a later stage.
- This means people with a learning disability and autistic people have a higher chance of dying from cancer than people without a learning disability or autistic people.

Positive practice and what went well this year:



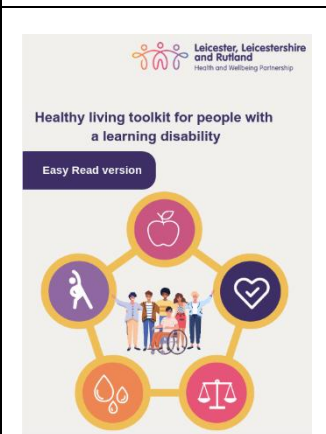
- Many people with a learning disability had annual health checks.



- An end-of-life group has been set up.
- The group will help make sure people with a learning disability and autistic people get the right support at the end of their life.



- More people now have a Reasonable Adjustment Digital Flag.
- This helps services know what changes a person may need when they go to appointments.



- Healthy living Toolkits are in place across Leicester, Leicestershire, and Rutland.

Top ten learning points from the completed reviews:



1. It is very important that more people from non-white races or backgrounds are reported to LeDeR when they die.



2. Staff need to understand the Mental Capacity Act (2005).



3. Guessing someone's weight is unsafe. Special weighing scales are available to use.



4. People with challenging behaviours need clear care plans and future planning.



5. End-of-life care should be talked about at the right time.

	6. More people need to go to cancer screening. • Information about cancer screening must be clear with reasonable adjustments.
	7. Some people with a learning disability and autistic people are not able to communicate when they are in pain or when they feel unwell. There are communication passports and a DISDAT (Disability Distress Assessment Tool) that are available to use.
	8. Breathing problems must be found early and treated.
	9. Heart disease is a major cause of death – healthy eating, exercise, and healthy weight are important.
	10. A specialist clinic is now available to help people with complex needs have a blood test.



The learning from this report will help improve care for people with learning disabilities and autistic people in Leicester, Leicestershire, and Rutland.

Useful links

[Annual health checks ER v3](#)

[Healthy Living ER v10](#)

[Resources – LLR HWP](#)

[Reasonable Adjustments Digital Flag – LLR HWP](#)

[Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) – LLR HWP](#)

[Support available for people with a learning disability – LLR HWP](#)