



# Leicester, Leicestershire and Rutland

Learning from lives and deaths –  
‘People with a learning  
disability and autistic people’ (LeDeR).



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## Introduction



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

The LeDeR programme was set up in 2017.

If someone over 18 with a LD or autism in England dies, it can be reported to LeDeR.



2024



**LeDeR** is short for Learning from Lives and Deaths of people with a learning disability and autistic people.

It is a group of professionals that finds out how people with a LD or people with autism have died.

There is a separate group who looks at the deaths of children in Leicester, Leicestershire, and Rutland, called the Child Death Overview Panel.



The review is carried out by a person called a reviewer.

The reviewer will ask questions about how the person died and whether they got the care and support they needed.

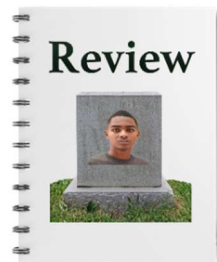
Sometimes LeDeR will decide to look more closely at a person's death.

This is called a focused review and goes into more detail about what happened to them.



LeDeR look at every death to see if anything could have been done better and take the learning from the reviews to make changes to the care we provide in our local areas.

This will help us to learn what we can do better in the future.



We write the report to follow the **LeDeR** programme - this is a government plan to improve the lives of people with learning disabilities and autistic people by providing better care.

This report tells you about people who have died in the Leicester, Leicestershire, and Rutland area from 1st April 2024 - 31st March 2025.

It also tells you about the learning we found and where we need to make things better.

## What we learnt from the completed reviews:

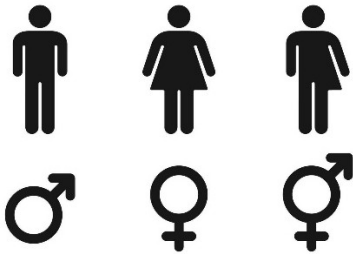


We were told about the deaths of 90 people:

- 4 people were autistic.
- 13 were not eligible for a review.
- 15 were adults with a learning disability and autism.
- 58 were adults with a learning disability.

The average age of death was 61yrs which is 5yrs younger than last year.

He      She      They



**Age and gender:**

- 60% were male,
- 38% were female,
- 2% were transgender.
  
- Most people who died were aged between 61 and 70 years old.



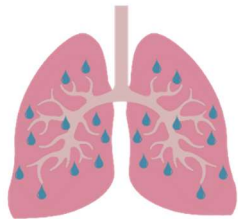
### **Ethnicity:**

- Ethnicity is your race or background. For example, Black, White, or Asian.
- The average age at death for those from a diverse ethnic background was 47yrs.
- Most people who died were White British. This is the same as last year's report.
- We need to understand local cultures and look at areas that affect people differently so that we can make sure everyone has good health and care.
- 89% of reviews were White British, 6% Asian or Asian British, 3% Black, African, Caribbean, Black British, and 2% other ethnic groups.

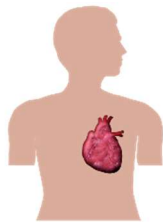


### Cause of death:

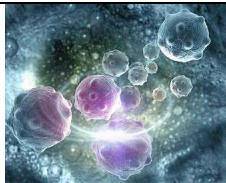
- When a person dies, Part 1a of a Death Certificate tells you what the person died of; this is called the **cause of death**.



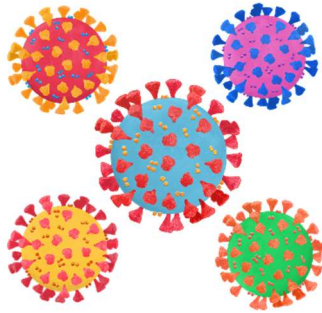
- The leading cause of death was from **respiratory illness**. For example, illness to do with breathing, like pneumonia or lung cancer. This is still the leading cause of death of people with LD or autistic people in Leicester, Leicestershire, and Rutland.



- The second most common causes of death was from **cardiovascular disease**. These are disorders that affect people's hearts.



- The third most common cause of death recorded were related to **cancer**.

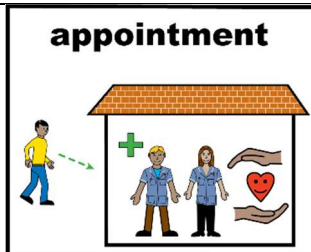


- 1 person died from COVID-19, and 1 person died from cardiovascular causes with COVID-19 being another factor.
- Most people this year have had 5 or 6 COVID vaccinations.

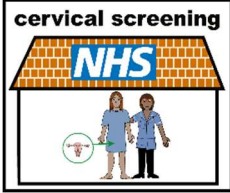
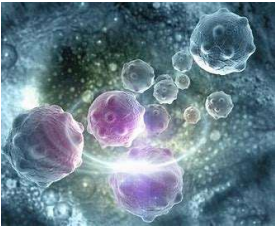
### What else we learned this year that could be done better:




- There were some issues with how the Mental Capacity Act (MCA) (2005) for people with a LD and autistic people was applied. These are tests to check if someone can understand and make their own decisions about their healthcare.
- This issue was identified last year also.

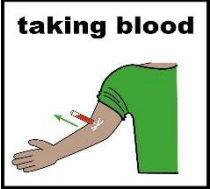





- The number of people with LD and autistic people accessing screening programmes remains very low compared with the general population.



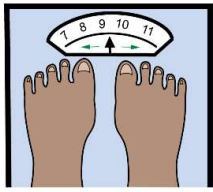
 <p>The logo features the text 'cervical screening' at the top, the NHS logo in the center, and an illustration of a female healthcare professional and a patient.</p>	<ul style="list-style-type: none"> <li>• The number of females having their cervical screening has reduced which is a concern.</li> </ul>
 <p>A microscopic image showing several large, purple, irregularly shaped cells with prominent nuclei, characteristic of cancer cells.</p>	<ul style="list-style-type: none"> <li>• There has been an increase in the number of people with LD dying from cancer.</li> <li>• Because of this next year the LeDeR team will carry out focused reviews for all cancer diagnosis.</li> </ul>

### Positive practice and what went well this year:

 <p>The logo is titled 'health check' and contains four icons: a blood pressure cuff on an arm, a syringe, a pair of feet on a scale, and a hand being examined.</p>	<ul style="list-style-type: none"> <li>• Annual health checks for people with LD remain high.</li> <li>• Leicester, Leicestershire, and Rutland have been selected to be involved with the DAPPLE research project (DAPPLE stands for Developing effective service models for Adult Palliative and end of care for People with a Learning disability) and the combined LD, SMI (severe mental illness) and autism health check.</li> </ul>
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 <p>taking blood</p>  <p>weight</p>	<ul style="list-style-type: none"> <li>• There was a specialist clinic set up for people with complex needs who need extra support to have a blood test.</li> <li>• The healthy weight toolkit is now available to help people with a LD.</li> </ul>
 <p>STOMP and STAMP</p> <p>NHS</p> <p>Get the right medicine for you - reduce over-medication.</p>	<ul style="list-style-type: none"> <li>• There has been an increase in people having STOMP (Stopping The Over Medication of People with a Learning Disability, Autism or Both) reviews when they are prescribed psychotropic medication.</li> <li>• Psychotropic medicines are used to treat mental health disorders.</li> </ul>
 <p>risk</p>	<ul style="list-style-type: none"> <li>• Respiratory remains the leading cause of death of people with a LD in Leicester, Leicestershire, and Rutland.</li> <li>• The development of the LAPPP (Leicestershire Aspiration Pneumonia Protection Plan) is in the initial stages but it is hoped this plan will help people to think about the things that can impact aspiration pneumonia in people with a LD.</li> </ul>

## Top Ten Learning Points from the completed reviews:

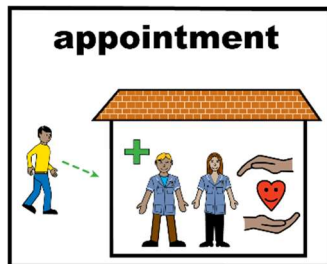
	<ul style="list-style-type: none"> <li>• Reporting the deaths of people with LD and autistic people to the LeDeR programme is essential, especially for people from diverse ethnic backgrounds.</li> </ul>
	<ul style="list-style-type: none"> <li>• Services need to make sure staff understand the Mental Capacity Act (2005) and how to use it correctly when making decisions about people's care and treatment.</li> </ul>
<p><b>weight</b></p> 	<ul style="list-style-type: none"> <li>• Estimating someone's weight can lead to significant risk to the person.</li> <li>• Wheelchair and hoist weighing scales are available across Leicester, Leicestershire, and Rutland and are free to use.</li> </ul>



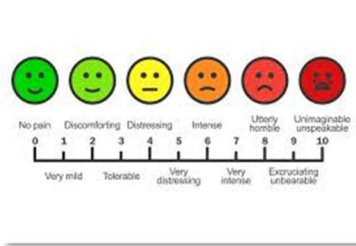
- Clear plans including advanced care plans should be created for every person with behaviour that challenges, highlighting the support they need and looking at what support they may need in the future.



- Talking about end-of-life matters and having these meaningful conversations at the right time is important.
- It is important that conversations happen about Advanced Care Plans and ReSPECT forms. These care plans and forms highlight what is important to the person and the kinds of treatment they would want to have in an emergency.



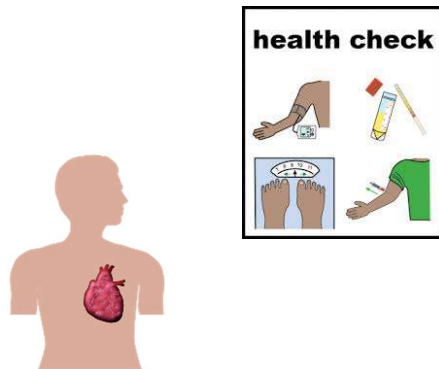
- The amount of people with LD and autistic people attending national cancer screening programmes remains low.
- How cancer screening is communicated is important, and so are the reasonable adjustments needed.
- The Reasonable Adjustment Digital Flag (RADF) should be filled in and used.



- Some people with LD 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.



- We need to make sure that risks linked with a person's lung problem (aspiration pneumonia) is found early and care and treatment is planned.
- The Leicestershire Aspiration Pneumonia Protection Plan (LAPPP) is being tested across Leicester, Leicestershire, and Rutland.



- Cardiovascular disease is the second highest cause of death among people with LD in Leicester, Leicestershire, and Rutland.
- A healthy lifestyle, which includes a healthy diet, physical activity, and a healthy weight are important to prevent things like cardiovascular disease.
- The 'Healthy Living Toolkits' are available to support people to have a healthier life.

**taking blood**



- Work is being completed on developing a specialist clinic for people with complex needs who need extra support to have a blood test.