

# Learning from lives and deaths – People with a learning disability and autistic people

## The LeDeR Programme 2024-2025





This report is about people with learning disabilities and autistic people who have died

These people were loved and will be missed by their families, friends and people who cared for them



Thank you to everyone who helped with this report, including families, carers, doctors, social workers and staff in care homes and hospitals.


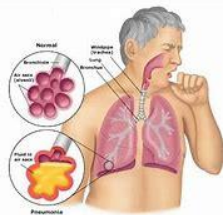

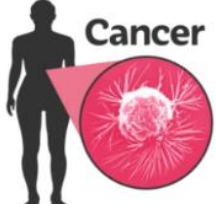






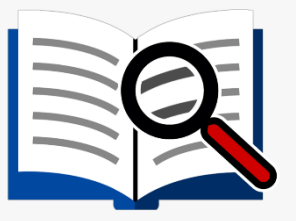

This is the sixth annual report for Derbyshire



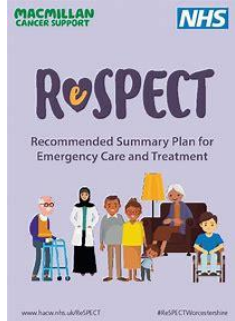


The report will be about people who had a LeDeR review completed between 1st April 2024 and 31st March 2025

<b>Contents</b>	
	<b>Page Number</b>
Some difficult words we use	4
<b>Chapter 1</b> Introduction	7
<b>Chapter 2</b> The deaths the LeDeR programme has been told about	8
<b>Chapter 3</b> The people who died who were from a minority ethnic background	9
<b>Chapter 4</b> The people who died who were autistic but had no learning disability	11
<b>Chapter 5</b> The people who died who had a learning disability	12
<b>Chapter 6</b> The deaths of people with learning disabilities	13
<b>Chapter 7</b> Things that need to get better	16
<b>Chapter 8</b> What has been happening to improve care and services	19
<b>Thank you</b>	21
<b>Where you can get more information</b>	22

## Some difficult words we use

<b>Annual health check</b>	<p>An annual health check helps you to stay well by talking about your health</p> <p>You have chance to find problems early and get the right care</p>	
<b>Aspiration Pneumonia</b>	<p>A lung infection that develops after you inhale food, liquid, or vomit into your lungs</p>	
<b>Bacteria</b>	<p>Very small living things that can be found in all natural environments</p> <p>They are made of a single cell</p> <p>Most bacteria can be seen only with a microscope</p>	
<b>Cancers</b>	<p>Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body</p>	
<b>Coroner</b>	<p>An official who looks into why somebody died</p>	

<b>DNACPR</b>	<p>This stands for Do Not Attempt Resuscitation</p> <p>Where a decision has been made that if the person's heart stops beating then no attempt will be made to re-start it</p>	
<b>Frailty</b>	<p>Some people may get more poorly because they already have health problems</p>	
<b>Initial review</b>	<p>A first check on a person's death</p>	
<b>Focused review</b>	<p>A more detailed check on a person's death</p>	
<b>Heart Disease</b>	<p>The heart pumps blood around the body but if the heart or arteries become weak, blocked or damaged, it is harder to pump blood around the body</p> <p>This will cause damage to major parts of the body (organs) and can even cause death</p>	

<b>LeDeR</b>	Learning from lives and deaths – people with a learning disability or autistic people	
<b>Pneumonia</b>	Swelling of the tissue in one or both lungs	
<b>ReSPECT</b>	<p>ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment</p> <p>The ReSPECT form is part of a process where your care in an emergency is agreed</p> <p>The form is filled out by you and a healthcare worker together</p> <p>The form asks about what is important to you and the kinds of treatments you would want to have in an emergency</p>	
<b>Review</b>	A check on a person's death	
<b>Reviewer</b>	Someone who checks up on a person's death	

# Chapter 1: Introduction



The aims of the **LeDeR** programme are:

1. To help improve health and social care services for people with learning disabilities
2. To stop people with learning disabilities dying too soon



All deaths of people with learning disabilities (aged 18 years and over) have a **review**



Everyone in Derbyshire has their death looked at in the same way



Every death has a first check

We call this an **initial review**



The **reviewer** might need to find out more information about the person who has died

This is called a **focused review**

## Chapter 2: The deaths the LeDeR programme has been told about



In 2024 to 2025 we were told about **97** deaths of people with learning disabilities in Derbyshire

This is 14 more deaths than we were told about last year

This is good because it means more people know about LeDeR and to tell us about the deaths

**55**

In the year we finished 55 **reviews**

3 of the reviews were for autistic people who did not have a learning disability

52 of the reviews were for people with a learning disability



There are some deaths that are still being reviewed

Some deaths take longer to **review** as they are being investigated by police or by the **Coroner**



## Chapter 3: The people who died who were from a minority ethnic background

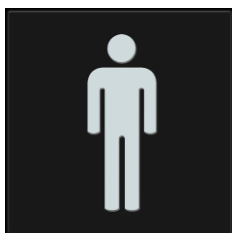


During 2024/25 there were 2 reviews of deaths from Black, Asian and Minority Ethnic groups

This is the less than last year

4% of the reviews were people from Black, Asian and Minority Ethnic groups

96% of the reviews were people from White British ethnicity



One of the individuals was autistic with no learning disability

The person was male



One of the individuals had a learning disability

The person was female

## Chapter 4: The people who died who were autistic but had no learning disability

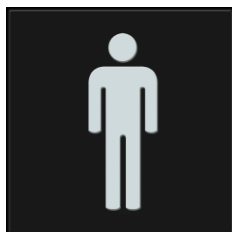
3

3 of the reviews completed in the year were for autistic people who did not have a learning disability

5

There have been 5 reviews in total completed for autistic people in Derbyshire who did not have a learning disability

This is since 2022 when we started to review the deaths of people who were autistic but had no learning disability



All 5 people were male and between the ages of 18 and 45



All 5 deaths were investigated by the Coroner

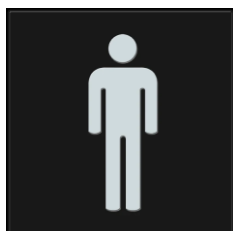
Four of the deaths were suicide

Suicide is when someone has killed themselves

## Chapter 5: The people who died who had a learning disability

52

52 of the reviews were for people with a learning disability



63%

33 of the people who died were male



37%

19 of the people who died were female



### The age of people when they died

The average age at death was 62 years for female and 66 years for male

This is a better average age than last year

In last year's report the average age at death was 61 years for female and 60 for male

## Chapter 6: The deaths of people with learning disabilities



### Where did people die?

Half of the people died in the place they usually lived (their home)

This was 26 out of the 52 people



25 of the people died in hospital

This was just under half of the 52 people that were reviewed



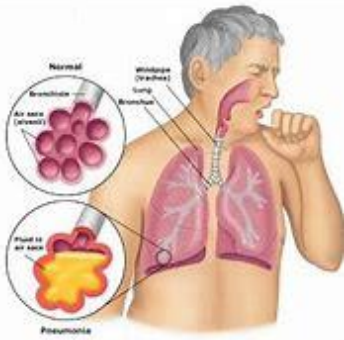
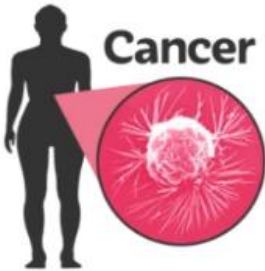


One person died overseas



### Was a coroner told about their death?

Some deaths were reviewed by the **Coroner**

	<p><b>Causes of death</b></p> <p>The most common causes of death were:</p>
	<p><b>1. Respiratory infections</b></p> <p><b>Respiratory infections include different types of Pneumonia</b></p> <p><b>Pneumonia</b> is swelling (inflammation) of the tissue in one or both lungs</p> <p><b>Pneumonia</b> is usually caused by an infection of <b>bacteria</b></p>
	<p><b>2. Aspiration Pneumonia</b></p> <p><b>Aspiration pneumonia</b> is a lung infection that develops after you inhale food, liquid, or vomit into your lungs</p> <p>If you are not able to cough up the food or liquid, <b>bacteria</b> can grow in your lungs and cause an infection</p>
	<p><b>3. Cancers</b></p> <p>Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body</p>

Heart conditions and Frailty had the same number of people die so both were the fourth top reason for death



#### **4. Heart Conditions**

The heart pumps blood around the body but if the heart or arteries become weak, blocked or damaged, it is harder to pump blood around the body



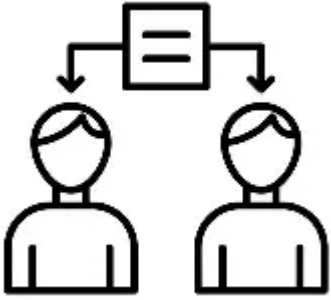

This will cause damage to major parts of the body (organs) and can even cause death





#### **4. Frailty**

Some people may get more poorly and die because they already have health problems

## Chapter 7: Things that need to get better

<p>I need help</p> 	<p>Some people find it harder to get the help or services they need</p> <p>They need to be given more help</p>
	<p>Some people find it hard to understand information</p> <p>They need reasonable adjustments to be made to help them</p>
	<p>Sometimes information is not shared with the individuals</p>
	<p>Staff may need more chances to learn so they can do their jobs better</p>

 <p>The diagram illustrates the process of aspiration pneumonia. It shows a person's head and torso. A circular inset labeled 'Normal' shows food (green) being swallowed into the stomach. Another circular inset labeled 'Pneumonia' shows food (yellow) entering the lungs, which are depicted as inflamed and red. Labels include 'Normal', 'Food (green)', 'Pneumonia', 'Windpipe (trachea)', 'Lungs', and 'Food (yellow)'.</p>	<p>For people with learning disabilities we want to understand why we have a lot of deaths from aspiration pneumonia</p> <p>We want to help people to understand how to reduce the risks of aspiration pneumonia</p>
 <p>A graphic featuring a black hand with a yellow ribbon tied around the index and middle fingers. Below the hand, the words 'STOP SUICIDE' are written in bold, black, capital letters.</p>	<p>For autistic people with no learning disability we want to understand why we have a lot of deaths from suicide</p> <p>We will continue to work with our suicide prevention team to share the information we find out</p>
 <p>An illustration of a woman with brown hair, wearing a red dress, sitting on a blue toilet. She has a distressed expression, with a red squiggle indicating pain or discomfort.</p>	<p>Constipation was a health condition for people in over half (52%) of the reviews</p> <p>This is an increase from previous years</p> <p>We want people to understand what to do if they have constipation</p>
 <p>A group photograph of five people standing together. From left to right: a woman in a purple top, a man in a blue shirt, a woman in a black jacket, a man in a red shirt, and a woman in a black top. They are all smiling at the camera.</p>	<p>We must continue to remind workers and families to tell <b>LeDeR</b> about the death of a person with a learning disability from Black, Asian and Minority Ethnic groups</p> <p>This is important to learn and improve services and share good work</p> <p>This is very important for people with learning disabilities from Black, Asian and minority ethnic communities</p>



	Nationally there are more worries about the deaths of people from ethnic minority groups
--	--

## Chapter 8: What has been happening to improve care and services?



### Annual health checks

29% of people missed their annual health check in their final year before they died

This is an improvement from the previous year when 46% of people missed their health check in the final year before they died




Our Strategic Health Facilitation team continue to promote people with learning disabilities having their annual health check

They have been working with other services to make sure staff ask "Have you had your annual health check?" when people attend for other appointments



Our hospitals are working to give better quality of care to people with learning disabilities and autistic people

Some of the work is to improve the ReSPECT process and care planning

	<p>Easy read information has been produced to help people with learning disabilities understand tests that are carried out in hospitals</p> <p>Hospital staff are learning how to talk clearly and use hospital passports</p>
	<p>The Ageing Well Team in Chesterfield and Dronfield is working on a project to make services better for people with learning disabilities who live in care homes</p> <p>The team is having training to learn more about people with learning disabilities</p> <p>They do lots of work with care homes that support people with learning disabilities</p>
	<p><b>Training</b></p> <p>The local county council is training staff to understand autism and supporting people with a learning disability</p> <p>The Strategic Health Facilitation team are running training sessions in care and supported living environments</p> <p>They are also running sessions to teach people about constipation</p>

# Thank you



Thank you to the people who helped with our **reviews** and the annual report

## Where you can get more information



The **LeDeR** team  
Derby and Derbyshire  
Integrated Care Board  
The Council House  
First Floor  
Corporation Street  
Derby  
DE1 2FS



[ddicb.lederteam@nhs.net](mailto:ddicb.lederteam@nhs.net)



[www.leder.nhs.uk](http://www.leder.nhs.uk)

