Humber and North Yorkshire
Health and Care Partnership

NHS
Humber and
North Yorkshire
Integrated Care Board (ICB)

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

Annual Report – Easy Read
1st April 2023 to 31st March 2024

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15th May 2024

Content

We would like to take this opportunity to thank our experts by experience who are active members of the LeDeR Governance Panel meeting and the LeDeR Steering Group.
They have been passionate advocates in promoting the rights of people with learning disabilities and autistic people within both meetings throughout the year.
We appreciate their commitment to attending these meetings and the support they have provided and look forward to continuing to work with them as we strive to improve both the patient experience and local services within our ICS.

1.0 Introduction

	This is the 3rd annual LeDeR report NHS Humber and North Yorkshire Integrated Care Board (ICB) have written on the Integrated Care System (ICS) footprint known as NHS Humber and North Yorkshire Health and Care Partnership. This report is about the number of people with a learning disability and autistic people who have sadly died in our area.
	The LeDeR programme was set up 8 years ago and looks at the care every person in England who is over the age of 18 years who has a learning disability and sadly dies has received. This is to see what we can learn to make care better in our area. Since January 2022, autistic people who sadly die have their death looked at in the same way too. In July 2023, children who sadly die were removed from the LeDeR programme as these deaths are looked at through a different way.
	We 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.
	The review is carried out by a person called a reviewer. They look at all the care the person who died received during their life but mainly in the care they received in their last year.

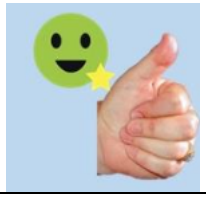
	They do this by: Talking to the family or someone who knew the person really well and to people who supported the person during their everyday life.
Medical Records …… … …… ……	They will look at the persons medical and care records to look at the care provided to them.
	The completed review looks for where changes need to be made to make things better for people in our area who have learning disabilities and autistic people.
 	This report tells you a little bit about people who have died in the Humber and North Yorkshire Health and Care Partnership area from 1st April 2023 - 31st March 2024. It also tells you about the learning we found and where we need to make things better from reviews we did from 1st April 2023 - 31st March 2024.

2. What we know about the People who Sadly Died 1st April 2023 - 31st March 2024

	116 people who had a learning disability and sadly died, had their death reported to the LeDeR programme.
 	**Of the 116 people who died:** • 63 of them were men. • 53 of them were women.
  	• The average age of the 116 people who had died across the Humber and North Yorkshire Partnership area was 61.5 years. This is a bit better than we found in last year's report (60.1 years). To work out the average age we add up all the ages of everyone who has died. Then we divide that number by the number of people who have died. • The average age of the men who died was 64 years. This is higher than we found in last year's report (62.8 years). • The average age of the women who died was 59 years. This is lower than we found in last year's report (63.2 years).

	• We have seen very low numbers of people who identified as being non white British again in our notifications and completed reviews. This is the same as we saw in last year's report. We need to do more work to understand our non-white British population to make sure that all people from our communities who sadly die have their death reported to the LeDeR programme so that we can find the learning to improve our services.
	Where people sadly died from the information provided in the reviews notified: • We found 65 people died in a hospital. This is more than we found in last year's report (54 people).
	51 people died in the community; this is lower than we found in last year's report (65 people). • 5 of the 51 people died in a hospice. This is a little bit lower than we found in last year's report. • 27 of the 51 people died in a residential or nursing home. This is a little bit lower than we found in last year's report.
	• 17 of the 51 people died in their own home or supported living accommodation. This is a little bit lower than we found in last year's report.

3. What we learnt from the Reviews we Completed 1st April 2023 - 31st March 2024

	We completed 126 reviews from 1st April 2023 - 31st March 2024. This is a lot more than the 85 we completed in last year's report.
	52 of these were completed in the time they were meant to be finished in. This is 6 months from the time we know the person died.
	74 of the reviews were not finished in the time they should have been. Some of this was because: • We had a lot of reviews which were already over their date to be completed before we started to review them. • Some reviews were completed in time, but it showed there was more learning which we could find and so a deeper look at the care the person received was needed. This made the review late. • Sometimes the review could not be started because of other legal investigations like the coroner who is an official who looks into why somebody dies.
 	**Of the 126 reviews we completed:** • 77 of the people were men. • 49 of the people were women.

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- The average age of the 126 people across the Humber and North Yorkshire area whose death we reviewed was 63.2 years. This is higher than we found in last year's report (57 years).

To work out the average age we added up all the ages of everyone whose death we reviewed, then we divided that number by the number of reviews we completed.

- The average age of the men whose death we reviewed was 64.4 years.

This is higher than we found in last year's report (56.7 years).

- The average age of the women whose death we reviewed was 61.2 years.

This is lower than we found in last year's report (63.2 years).
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<td>Where we found people sadly died in the reviews we completed:

- We found 58 people died in hospital.

This is higher than we found in last year's report.</td>
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<td>68 people died in the community. This is higher than we found in last year's report (44 people).

- 8 of the 126 people died in a hospice. This is higher than we found in last year's report.

- 40 of the 126 people died in a residential or nursing home. This is higher than we found in last year's report.</td>
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- 20 of the 126 people died in their own home or supported living accommodation. This is higher than we found in last year's report.
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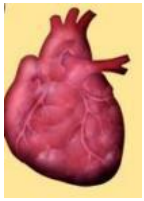
4. What the Completed Reviews told us was the Cause of Death 1st April 2023 - 31st March 2024

	When a person dies, Part 1a of a Death Certificate tells you what the person died of; this is called the cause of death.
 	From the 126 completed reviews, problems with people's respiratory systems were the most common cause of death within the Humber and North Yorkshire Health and Care Partnership. • A number of these were caused by pneumonia. This is an infection in your lungs and is caused by germs called 'bacteria'. • Others were caused by aspiration pneumonia. This is an infection in your lungs caused by food or liquid going down 'the wrong way'.
	• The second most common causes of death recorded were related to problems with people's hearts.
	• The third most common cause of death were cancers.

5. Some Examples of Good Care Found in the Reviews 1st April 2023 - 31st March 2024

Lots of the completed reviews showed good practice across all the areas within the Humber and North Yorkshire Health and Care Partnership. Here are some of them:

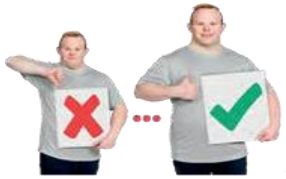
- There was evidence that reasonable adjustments had been made for the person.
- Some reviews identified good support and involvement of family and the person in the planning and DNA/CPR decision making. This is where we will talk with you about if you want us to try and start your heart beating again if it stops beating. People had ReSPECT documents in place; this is a form that asks about what is important to you and the kinds of treatment you would want to have in an emergency.
- Reviews identified people were provided with excellent care and other reviews identified high quality care was provided by care staff.
- Some reviews found that people were supported well to live full and active lives, whilst other reviews found people were supported to make their own choices and decisions.
- We saw an increase in the number of reviews identifying people had taken part in the bowel screening programme.
- We saw evidence of good liaison between services with a review identifying care staff who were familiar with the person supported to stay with them throughout their final illness.
- Some reviews noted robust processes around consent and understanding and evidence of Best Interest processes.
- Reviews highlighted improved uptake of Annual Health Checks with your doctor or nurse for people within the last year of their life

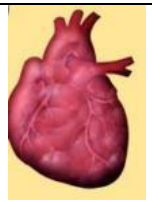
6. Some Examples of Things we need to do Better found in the Reviews 1st April 2023 - 31st March 2024

Some of the completed reviews showed areas where we need to do better within the Humber and North Yorkshire Health and Care Partnership. Here are some examples:

- The reviewers found some challenges with getting information from care home managers and GPs for them to be able to complete the review.
- We found not everyone had a hospital passport or sometimes it was not up to date when the person needed to go into hospital.
- A small number of reviews found that professionals were accepting of the family as the voice of the person with other reviews showing the persons voice was not heard or family members felt they were not always listened to as people who knew the person well.
- We still found in reviews that there was a lack of evidence of mental capacity assessments, or no capacity assessment completed. A mental capacity assessment is when we check to see what you understand. We also found lack of Best Interest decision making processes or lack of documentation in some reviews. To work out what is in your Best Interests, we must listen to what you want, ask people who know you and make sure you are involved.
- A small number of reviews saw a lack of reasonable adjustments, and a lack of understanding of what reasonable adjustments are. Reasonable adjustments are changes we can make to help you cope with your care and treatment such as more time or easy to understand information.
- Some reviews showed a lack of advanced care planning in end-of-life care or a lack of evidence of discussion regarding end-of-life care.
- We saw a small number of reviews showing people were not supported to complete bowel screening when it was offered, or there was no follow up when people did not complete the screening.

7. Recommendations from the Completed Reviews 1st April 2023 - 31st March 2024

	There has been a lot of good work going on to make things better for people with learning disabilities and autistic people living in the Humber and North Yorkshire Health Care Partnership area. From the reviews, we found some key areas where we still need to do more work to make things better.
	• We need to continue offering an Annual Health Check and making sure everyone who should be on their GP learning disability register is on the register. • When the Annual Health Check is completed, we need to make sure this meets the person's needs with a health action plan completed.
	• We need to continue making sure all health and care staff are aware of their responsibilities and are following the Mental Capacity Act. • We need to see Best Interest Decision meetings being undertaken and documented within records.
	• We need to keep working to make sure people coming to the end of their life are recognised early so that decisions can be made with them, and their family and plans made to stop them being taken to hospital if they do not need to go. • There needs to be earlier thought for completion of the ReSPECT document allowing good end of life conversations and early planning with people, their family and those who care for them.

	• We want the LeDeR Steering Group to have a focus on pneumonia and aspiration pneumonia with the learning we find in the reviews so that we can find any areas where we may need to do more work to reduce the risks, in particular for aspiration pneumonia.
	• We will be undertaking a more in-depth review for anyone who sadly dies during 2024/2025 from cardiac issues, and cancer as these are also priority areas for the ICB.
	• We want to offer the same recognition of the deteriorating patient training including the use of 'softer signs' to recognise deterioration to all care home providers across the ICS. This training will help staff to be able to recognise when someone with a learning disability is not well and may be getting worse as they may not show this in the same way as other people.