Humber Clinical Commissioning Groups

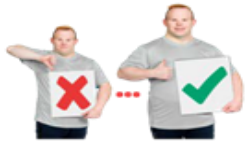
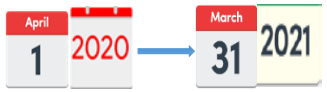
Learning Disabilities Mortality Review Programme Annual Report – Easy Read 1st April 2020 to 31st March 2021.

Hazel Moore
Head of Nursing - NLCCG (on behalf of the 4 Humber CCG's)
August 2021

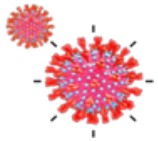
Contents

1. Introduction

	Each year, NHS Clinical Commissioning Groups (CCGs) have to write a report about the number of people with a learning disability who have sadly died in their area. This the 1st time the CCG's in the Humber have written a report together, looking at all the deaths of people with a learning disability in the Humber area.
	It is called the Learning Disabilities Mortality Review and known as LeDeR.
	We look at every death to see if anything could have been done better.
	Every person in England who is over the age of 4 years, who has a learning disability and sadly dies, has their death looked at in the same way.

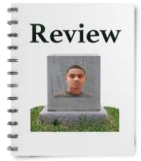
	The review is carried out by a person called a reviewer. They look at all the care the person who died received during their life.
	They do this by: Talking to the family or someone who knew the person really well and to people who supported the person during their everyday life.
	The reviewer looks for where changes need to be made to make things better for people in our area who have learning disabilities.
 	This report tells you a little about people who have died in the Humber area from 1st April 2020- 31st March 2021. It also tells you what learning we found and where we need to make things better from reviews we did 1st April 2020-31st March 2021.

2. What we know about the People who Sadly Died 1st April 2020 – 31st March 2021

	55 people who had a learning disability and sadly died had their death reported to the LeDeR programme.
	2020 was a very hard year for people. In England, more people than usual with a learning disability died because of COVID-19. In the Humber area, 8 of the deaths reported were said to be related to the COVID-19 virus.
 	**Of the 55 people who died:** 34 of them were men. 21 of them were women.
  	The average age of the 55 people who had died across the Humber area was 58.4 years. The average age of the men who died was 57.5 years. The average age of the women who died was 59.4 years.

	54 of the people were of white heritage and 1 person was from Black, Asian and Minority Ethnic groups.
	35 people died in a hospital.
	13 people died in the community, in a residential or nursing home.
	6 people died in their own home or supported living accommodation.

3. What we learnt from the Reviews we Competed 1st April 2020 – 31st March 2021

	60 reviews were completed 1st April 2020 – 31st March 2021.
	20 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.
	25 of the reviews were not finished in the time they should have been. This was called our 'backlog' and we had to finish these by 31st December 2020. We did this.
 	**Of the 60 reviews completed:** 34 of them were men. 26 of them were women.

  	The average age of the 60 people across Humber area was 56.8 years. The average age of the men whose death was reviewed was 56.8 years. The average age of the women whose death was reviewed was 58.3 years.
	32 people died in hospital.
	19 people died within the community, in a residential or nursing home.
	9 people died in their own home or supported living accommodation.

4. What the Reviews told us was the Cause of Death 1st April 2020 – 31st March 2021

	When a person dies, Part 1a of a Death Certificate tells you what the person died of; this is called cause of death.
	The most common causes of death for people with a learning disability across the Humber area were: • Aspiration pneumonia Aspiration pneumonia is when food or drink goes down 'the wrong way'. This can cause infection.
	• Pneumonia Pneumonia is an infection in a person's lungs and is caused by germs called 'bacteria'.
	Pneumonia is the highest cause of death for people with a learning disability in England.

5. What the Reviews told us about the Quality of Care Given to People 1st April 2020 – 31st March 2021

	When the reviewer has finished looking at all the information they have collected, they give the care the person received a score of 1-6.
1✓	1 means that the care the person was given was the best care possible.
6✗	6 means the care was not good and may be part of the reason why the person died.
✓	From the reviews in our area, the reviewers found: 7 people received care which was excellent. 29 people received care which was good. 16 people received care which was satisfactory.
✗	5 people received care which affected their well-being but was not part of why they died. 2 people received care which was very poor and affected their well-being and could have been part of the reason why they died.

6. Some Examples of Good Care Found in the Reviews 1st April 2020 – 31st March 2021

	Lots of the completed reviews showed good practice across all the areas within the Humber. Here are some examples: • Some GP practices had named nurses with good knowledge of learning disabilities to offer continuity and support for the person. • A carer who knew the person well visited them in hospital, taking food the person liked as well as helping with their care. This helped with the discharge planning. • Care staff visited the person when they were in hospital.
	• There was good communication and partnership working between services for the person with the learning disability. • Being able to have a personal budget meant care the person needed was able to be given by someone who knew them really well. • Supported to move into supported living together with other people the person knew. • There were well co-ordinated approaches to care, which meant the all the persons needs were met, keeping the person at the centre of all the care. • Having shared care records meant health professionals were able to provide seamless care.

	• Family were part of the end of life planning for the person, with the right paperwork in place to stop the person going back into hospital if it was not needed.

7. Some Examples of Things we need to do Better Found in the Reviews 1st April 2020 – 31st March 2021

	Some of the completed reviews showed where we need to do better across all the areas within the Humber. Here are some examples: • We found that not everyone with a learning disability who needs to go into hospital is seen by a learning disabilities nurse.
	• We found not all Capacity assessments and Best Interest meetings were recorded every time in a person's records. • We found that people were not always involved in deciding where they lived and if they moved. • We found that Mental Capacity documentation was not always completed to a good standard. • We found that not all staff had a clear understanding of Mental Capacity.

	• We found that not everyone with a learning disability who is entitled to an Annual Health Check has their check. • We found that not all the health action plans for people who had their Annual Health Check were fully completed and of a good standard. •
	• We found not everyone who went into hospital had a hospital passport.

8. Recommendations from the Completed Reviews 1st April 2020 – 31st March 2021

	There has been a lot of good work going on to make things better for people with learning disabilities living in the Humber area. From the reviews, we found 4 key areas where we need to do more work to make things better.
	• We need to make sure everyone who is 14 years old and over is on their GP learning disability register and is offered their Annual Health Check. • We need to make sure the reviews are completed really well and meet the person's needs.
	• We need to make sure all health and care staff are aware of their responsibilities and following the Mental Capacity Act.
	• We need to keep working to make sure people coming to the end of their life are recognised 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.