

Update on learning using a case study

LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autistic Adults. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

Henry

Henry liked meeting people and was a big part of his family. He lived with his parents until he was 50. He then moved to a residential home where he was happy and did lots of social activities.

Henry liked to look smart. Henry liked cake as a treat and his family would always bring him a bar of chocolate.

Henry had a mild Learning Disability, Down Syndrome, Autism and Alzheimer's Dementia. Henry had many health problems, including problems swallowing and a broken hip.

Henry had help from Speech and Language Therapy (SALT), the Community Learning Disabilities Team (CLDT) and had regular medical checkups. His family were grateful for the care he had during the last months of his life.

About death

Henry's health got worse in the last months of his life. He had to go into hospital in February 2023 as he had aspiration pneumonia. This is an infection caused by food or fluid going into your lung. When Henry was in hospital, his SALT guidelines weren't followed. He was given a lunch which was a choking hazard. He did not eat this but if he had this would have been dangerous for him.

Henry sadly died at his residential home from chronic bronchial pneumonia. This is a type of chest infection. Henry had a DNACPR in place, which means that he did not want doctors to restart his heart if it stopped.

Family and care staff were with Henry at home in his last days of life. He had medication to make sure he wasn't in pain. The staff understood his needs and were very supportive.

Learning

- SALT guidelines were not fully followed during his time in hospitalisation. We need to make sure hospital staff are told about SALT guidelines and that they can be read in someone's 'My Health Passport' or similar.

Good Practice

- Henry was on the Memory Assessment Pathway.
- Staff spoke to Henry in a way he could understand, using Easy Read information to help.
- Help from the Community Nursing Home Dementia Team
- Henry died in familiar surroundings as were his wishes.
- Had a ReSPECT plan and the staff were supported with his end-of-life care.
- An 'Understanding You' form was completed. This explains what is most important to the person so care providers can draw up a person-centred plan. Not all care providers use this form and have different ways of collecting this information.

We would like to thank the families who have kindly given us permission to share the stories of their loved ones to help improve services. The name of this person has been changed to protect their identity.

Learning Disability Liaison Nurses

The Learning Disability Liaison nurses at the hospital can find out who is getting support from the Community Learning Disabilities Team (CLDT) or Speech and Language Therapy.

This team are important. They can give the CLDT or Speech and Language Therapy updates on patient progress. They help to make sure everyone has the most up to date information about the patients eating and drinking requirements and help the Speech and Language Therapists in the community and in the hospital work together.

Contact numbers:

0300 422 4985
0300 422 4953

CLDT Memory Assessment Pathway Easy Read Leaflet

It is common for people with Down's Syndrome to develop Dementia. In Gloucestershire the Community Learning Disability Team (CLDT) have a Memory Assessment process. This is for adults with Down's Syndrome (from the age of 30) and any adult with a Learning Disability who has possible memory issues.

Working with the CLDT we have coproduced an Easy Read leaflet to help explain more about the Memory Assessment Process and how it can help people.

Read it here: <https://bit.ly/43SrMCN>



Numbers to Date (April 2024)

96%



Complete

311 reviews done since 2017

Out of a total of 324.

Please let people know 'autism only' reviews are part of LeDeR

Autism only reviews of people over the age of 18 has been part of the LeDeR process since January 2022. However, Gloucestershire LeDeR are yet to be told about the death of anyone who had 'autism only'.

We can only do a review if LeDeR is told about someone's death. The reviews help improve services and reduce health inequalities. You can tell LeDeR about a death through their website: <https://leder.nhs.uk/report>

Please Note: The notifier will need the person's NHS number.

For more information on LeDeR or to report a death to the programme please visit this website: <https://www.leder.nhs.uk/>

To view the national LeDeR policy in full please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>

To view the national LeDeR policy in easy read please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf>

If you have any feedback on this newsletter, please contact Harriet

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