

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.

Molly

Molly was a very happy person who loved to sing. She got on well with residents and staff at her home, and loved to watch people go by the window. People who walked past would wave at her. Molly loved watching television and liked to cross stitch. Molly loved being in the gardens and watching the squirrels and swans.

Molly had a Mild Learning Disability, had Chronic Kidney Disease*, Cerebral Palsy and Epilepsy. Molly used a wheelchair and had support from lots of different community healthcare services.

Molly had annual health checks and a good health action plan.

Molly was very frightened of the dentist, and she said no to dental treatment. The plaque on Molly's teeth was causing her lots of pain and difficulty closing her mouth. It would have helped if Molly had medicine to make her relax and sleep whilst having dental treatment.

About her death

In the last months of Molly's life her health got worse, and she was visited weekly by a GP and checked closely by the nurses at her home. Molly had some health problems including difficulties with swallowing, low blood pressure and weight loss. Molly was referred to Speech and Language Therapy (SALT).

Molly's health got even worse in December 2023, and she started refusing care. In January 2024 Molly wanted to stay at home and no longer have medical help.

A DNACPR and a ReSPECT plan were put in place and Molly's care focused on comfort. DNACPR means Molly did not want doctors to restart her heart if it stopped.

Molly died peacefully with her family friend by her side in January 2024.

Good Practice

- Molly died at home as she wished.
- Molly was treated with dignity. She benefited from good reasonable adjustments and ReSPECT* planning.
- Molly lived in the same place for many years, out of county.

Learning

- More awareness of community dental and specialist dental clinics that can offer extra support to people who may be struggling to go.
- Raise awareness about the importance of reasonable adjustments with the Safeguarding Team to help people with learning disabilities to access support which helps reduce harm and engage with support that will promote good health, in Molly's case this was related to dental care.

*Chronic kidney disease – a long-term condition where the kidneys do not work as well as they should. Your kidneys can not get rid of waste in your body properly, making it build up in your body.

*Neurology - focuses on the nervous system, including the brain, spinal cord and nerves.

*ReSPECT plan – A plan to tell health professionals what care you want or do not want in an emergency and what is important to you.

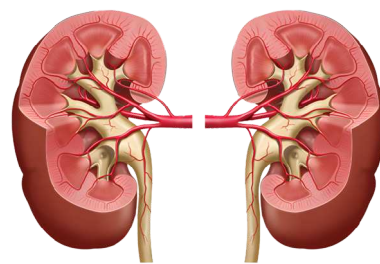
We would like to thank the families who have kindly given us permission to share the stories of their loved ones to help improve services. The name of this person has been changed to protect their identity.

Easy Read Chronic Kidney Disease Resource

Molly has Chronic Kidney Disease and the panel felt it would be useful to share some information about it. Here is an easy read information booklet from the UK Kidney Association and Kidney Care UK: <https://bit.ly/4jnhDqb>

It covers:

- What Chronic Kidney Disease is
- Symptoms and cause of Kidney Disease
- Treatment for Kidney Disease
- How to stay healthy



Community Dental Health Services

The Community Dental Health Service work with people who may need extra help to access dental care. The service works with the person themselves, families, carers and health professionals to make sure everyone has equal access to dental care.

Read more about Gloucestershire Community Dental Service here: <https://bit.ly/3ELkzxs>

Here is a coproduced video explaining what to expect when you go to the dentist (by Inclusion Gloucestershire): <https://bit.ly/3EOxBKN>



Numbers to Date (May 2025)

94%



Complete

389 reviews
done since
2017

Out of a total of 413.

LeDeR now reviews the deaths of autistic adults (without a learning disability)

Reviews of autistic 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 (without a learning disability).

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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