

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.

Denise

Denise lived in supported living where she sadly died. She was proud of her independence and liked to be helped by carers who knew her well. She had help from the same care provider for the last 43 years.

Denise loved books, puzzles and enjoyed nature. She liked birdwatching and gardening. Denise went to church, a weekly sewing group and visited charity shops to buy books.

Denise had a mild learning disability, managed anxiety and depression and during her life got chronic kidney disease, type 2 diabetes and other health conditions. Her carers worked closely with other healthcare workers to make sure her changing needs were met. Denise had a health action plan and attended annual health checks until 2022.

Cervical screening was offered to Denise but this was declined from 2005 onwards. Denise had a breast cancer screening in 2019.

About her death

In 2021 doctors found that Denise had a type of kidney cancer. She had treatment for this until 2024 when she then had end of life (palliative) care. Her doctor gave her 'just in case' medication. Her care was paid for by the NHS, meaning she could stay at home with the help of specialist nurses.

In 2025, Denise was spending most of her time in bed but was not complaining about any pain.

Denise was visited by her GP and sadly passed away two days later.

Learning Points

- It is important for health professionals to record the reason why someone no longer wants to have their health screenings. This is so they can make sure they do not have any unfair differences (health inequalities) in their treatment.
- Raising awareness of joint funding between the council and NHS and Continuing Health Care process to ensure care providers are able to get additional help for people when they need it.

Good Practice

- Denise's care was person-centered
- Denise had the same carer provider for a long time, 43 years.
- Easy read information was shared in Denise's health folder, explaining her cancer diagnosis. This is really good practice and something we would like to see more often.

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.

Chronic Kidney Disease - Easy Read Resources

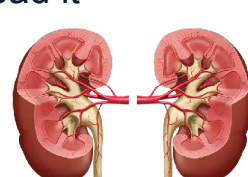
Denise had Chronic Kidney Disease and the panel felt it would be useful to share some information about it.

- Information booklet from the UK Kidney Association and Kidney Care UK: <https://bit.ly/3OQ9xw5>
- Keeping yourself well with chronic kidney disease information from the National Kidney Federation and The Leeds Teaching Hospitals NHS Trust: <https://bit.ly/4tZkev7>
- Information hub on your kidneys, what they do, how they work and managing kidney disease: <https://bit.ly/4vPSnzw>

Kidney Cancer - Resources

Denise also had Kidney cancer. We have shared some information about this below:

The National Kidney Foundation have created a resource all about kidney cancer, the symptoms, treatment and the support you can get. Whilst this is not in easy read it contains some really useful information and explains some of the big words <https://bit.ly/4mRI7Te>



The panel also wanted to share an easy read leaflet on 'Speaking to your doctor if something in your body does not feel right' <https://bit.ly/42ILubk>



Numbers to Date (May 2026)

92%



Complete

422 reviews done since 2017

Out of a total of 457.

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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