

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.

Gemma

Gemma was a bubbly, kind and caring lady who liked to be with other people and enjoyed trips out with her personal assistant.

Family were important to Gemma and she really enjoyed going out for lunch with her sister. She had lived with members of her family until October 2021.

Gemma liked listening to her favourite music; she really liked Cliff Richard and Elvis Presley.

Gemma had a moderate Learning Disability. She also had Type 2 Diabetes, Chronic Obstructive Pulmonary Disease (COPD)* and Sleep Apnoea. Sleep Apnoea is when your breathing stops and starts when you go to sleep.

Gemma needed help to get out and about in her local community as she was at risk of falling, had poor eyesight and did not always know how to keep herself safe.

Gemma had good support from her GP and the Learning Disability Liaison Nurses in the hospital.

About her death

Gemma's health got worse a few years before she passed away.

Gemma was supported by her GP to stay at home as much as possible. She also had treatment at home to help with her breathing. Rapid Response*, the District Nurses and the Speech and Language Therapist were involved in her care.

In April 2024, Gemma had a fall and hurt her head badly. She lost consciousness. An ambulance took Gemma to hospital where a scan showed that she had a bleed on the brain. Tests also showed she had a problem with her blood and her COPD had got worse. Gemma was given Oxygen to help with her breathing.

Gemma's health got worse despite having medical help.

A care plan for the end of her life was made for Gemma and she passed away peacefully in hospital from *Pneumonia.

Good Practice

- Gemma's care team knew her well and they helped her to get out and about in her local community.
- Gemma was cared for at home where possible.
- Gemma's GP used reasonable adjustments, including extra time to make appointments easier.
- Gemma had weekly calls from her GP to check her health.
- Her sleep apnoea was well managed.
- A learning disability liaison nurse helped Gemma when she was in hospital
- She had regular Annual Health Check's and dental care. Dental care helps keep teeth healthy.
- Gemma was well supported by social care.

Learning

- Continue to encourage people to use Hospital Passports.

*Rapid Response - The Rapid Response team provide urgent care to people who are very unwell. If needed they can quickly see people in the community, helping them stay out of hospital.

*Chronic Obstructive Pulmonary Disease – When your lungs get damaged and this can make it hard to breathe.

*Pneumonia - An infection in one or both lungs caused by bacteria, viruses or fungi. The air sacs in your lungs fill with fluid or pus to make it difficult to breathe.

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.

Gloucestershire Community Dental Service

Gemma had regular dental care. This was a good thing and is important for everyone.

Inclusion Gloucestershire have worked with the Community Dental Service to make an Easy Read leaflet about their service. The Community Dental Service work with people who need extra help to get dental care.

The leaflet explains what the service is, who it is for, what equipment they have and where they can see people.

View the leaflet here: <http://bit.ly/3LevpPK>



Numbers to Date (November 2025)

95%



Complete

401 reviews
done since
2017

Out of a total of 421.

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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