

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.

Tegan

Tegan had a close relationship with her mother and loved to spend time with people.

Tegan loved shopping trips for clothes and was very proud of them. Tegan liked to dance, especially to dancing queen, one of her favourite Abba songs.

Tegan was Black African, a minoritised ethnic community. Tegan had a severe Learning Disability and was an Autistic Person. Tegan used vocal tones, noises, and Makaton to make themselves known.

Tegan's sister didn't know if Tegan had enough Vitamin D but felt she would have benefited from taking extra Vitamin D. The NHS say that people who 'have dark skin, for example are from an African, African-Caribbean or South Asian background may not make enough Vitamin D from sunlight'.

Tegan had a Care Act advocate through POHWER and had help from the Community Learning Disabilities Team (CLDT), Speech and Language Therapy (SALT), Occupational Therapy (OT) and other health professionals. Tegan benefited from reasonable adjustments to help meet her needs, make sure she was comfortable, and improve her wellbeing.

About death

Tegan was diagnosed with breast cancer in 2021. She had surgery to remove a breast, but sadly her cancer came back in 2023. Tegan couldn't have further treatments for her cancer as she would not have understood what was happening, and the treatment would have been too much for her. Different health professionals worked together to help Tegan.

Tegan's health got worse, and a ReSPECT Plan was made with a best interest DNACPR decision. This means that Tegan did not want doctors to restart her heart if it stopped.

Tegan sadly died peacefully three months later, at the age of 61, surrounded by her care staff.

Learning

Less women from ethnically minoritised groups have breast cancer, however, when they are diagnosed, the outcome is usually worse for them than for white women with breast cancer.

Breast health is a topic that isn't talked about with some ethnically minoritised communities.

- Better awareness and communication is needed for care providers about the bigger risk of certain breast cancers in women from Black and Minoritised Ethnic (BME) communities.
- More accessible information is needed about nutrition, including the need for extra vitamins.
- Better awareness of breast cancer symptoms and, finding ways to be healthy and check your body for anything different, for ethnically minoritised communities.
- Better communications for ethnically minoritised communities on understanding around Learning Disabilities and Autism.

Good Practice

- Use of a Care Act Advocate via POhWER.
- The Palliative Care Team gave training to care staff.
- The Disability Distress Assessment tool was used to ensure good pain management.
- Good consistency of care.
- Help from SALT, CLDT, Palliative Care Nurse*, District Nurses*, GP, Stoma team*, and OT.

* Palliative Care Nurse- A nurse that helps you when you are at the end of your life.

* District Nurses- Nurses that may visit you at home.

* Stoma team- The Stoma Team cares for people that have a stoma. A stoma is a bag on the outside of your body that helps take away waste if your bowel doesn't work. There are different illnesses which may lead to a stoma.

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.

Advocacy Videos

Gloucestershire County Council worked with Inclusion Gloucestershire to coproduce some short videos explaining the different types of advocacy and the impact that these have on people's lives.

Watch the videos here: <https://bit.ly/4g1bQFo>

Some of the videos include real life stories.



Awareness of Breast Health

The panel wanted to share some accessible resources about breast health. Breast screening is an important part of keeping healthy and looking after yourself.

- An Easy Read guide about breast cancer screening. This explains what happens and how to check your breasts: <https://bit.ly/3T6DmHK>
- A video about going to your breast screening and people's experiences of this: <https://bit.ly/4clVX3p>

Content warning: This video has some nudity as it shows what happens at a breast screening and uses some language that refers to different names for breasts.



Numbers to Date (August 2024)

95%



Complete

343 reviews
done since
2017

Out of a total of 361.

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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<https://www.inclusiongloucestershire.co.uk/engagement/leder/>

