

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.

Marcus

Marcus was a kind and gentle person, who loved comedy and being with people. Marcus liked playing games, such as noughts and crosses and Connect 4. He always had pen and paper near him to help him communicate. Marcus had a moderate learning disability, type 2 diabetes and was blind in his left eye.

About death:

Marcus lived in supported living until May 2022 but because he was at risk of falling, he moved into a Nursing Home. He needed support for all parts of his life, including his diet and moving around.

In December 2023 Marcus choked during a meal at the nursing home. Staff tried to help him, and paramedics gave extra support. Marcus was taken to hospital to have oxygen.

Marcus' health was getting worse, and he had crackles in his chest. This is a sign of aspiration pneumonia, where food or drink gets into your lungs and can cause an infection.

He was given medicine, oxygen therapy and chest physiotherapy but he wasn't getting better. Marcus' ReSPECT plan was updated.

Marcus sadly passed away a few days later.

Good Practice:

- Great involvement from lots of different people and services.
- Use of best interest decisions following moving to a new home.
- Marcus was supported to live his best life. He had help to stay in contact with his family and his care staff used to show him photographs of them.
- Marcus had a ReSPECT Plan and a Hospital Passport.

Learning (Positive):

- Marcus had help from lots of different community health services to stay healthy. It is good that Marcus got help before he became very unwell.

*Physiotherapy: Helps people who have problems with moving part or all of their body.

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 Diabetes Resources

Marcus had type 2 diabetes and the panel felt it would be useful to share some information about what diabetes is and how it can effect the body. The easy read resources below also share tips for people living with diabetes and what they can do to help.

What do you need to know about diabetes - a guide from Leeds and York Partnership NHS Foundation Trust: <https://bit.ly/4aMa6O9>

What do you need to know when you have type 2 diabetes - a guide from Diabetes UK: <https://bit.ly/3WPjU45>.

Aspiration Pneumonia Resource

Sadly, aspiration pneumonia is one of the biggest causes of death seen by the LeDeR programme.

This is why the Gloucestershire LeDeR team made this easy read presentation: <https://bit.ly/4jSpZqk>.

Aspiration Pneumonia



Food or drink going into your lung can cause an infection called Aspiration Pneumonia.



This is a cause of death for many people with a Learning Disability. Sometimes this can be avoided.



Numbers to Date (February 2025)

93%



Complete

370 reviews
done since
2017

Out of a total of 399.

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

Roberts via email: harrietr@inclusion-glos.org



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

