

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.

Jason

Jason lived at home with his family. Jason's parents had training to help deliver some of Jason's care and treatment at home. Jason communicated without words.

Jason loved music and watching cartoons because of the bright colours and movements on screen.

Jason had a family connection to another country. Jason and his family liked to spend time there and they were supported by Jason's medical team to make this possible for him.

Jason had a learning disability and was an autistic person. Jason was born with a rare, complicated condition that affects the brain. Less than 20 people in the world have this life-limiting condition. The health condition had a big impact on Jason's life. Jason also had lots of other medical conditions including epilepsy, *dystonia and issues with how food went through his digestive system.

Jason went to a specialist school in the week and had reasonable adjustments which allowed him to have medical care at home and in school.

Jason had lots of care, treatment and support throughout his life from Health and Social Care professionals. Jason had an Education, Health and Care Plan (EHCP) and a Clinical Management and Community Based Action Plan to support him to live his life.

About his death

Jason started to have problems with his breathing about 6 months before he died.

In June 2025, Jason suddenly became very unwell. He had a fever and he started having seizures. An ambulance was called for Jason, but on the way to the hospital his condition got worse and he sadly died in the ambulance.

Jason was 18 when he died.

Jason's parents had no concerns about Jason's medical care.

Good Practice

- Jason was given open access to the paediatric assessment unit. This is a separate area of the Children's Centre at the hospital.
- The support of healthcare professionals made it possible for Jason and his family to travel to and spend time in a country where they had a strong family connection. Jason's GP wrote a letter about Jason's medication and the equipment he needed to travel abroad.
- Involvement of the *Palliative care team. This is extra medical help for people with a serious illness.
- Jason had lots of reasonable adjustments. He had lots of care at home and at school, including Occupational and Physiotherapy sessions and community nursing appointments.

Learning Points

- This is a fantastic example of joined up care and support for someone with a rare condition.

*Palliative – end of life

*Dystonia - uncontrolled muscle spasms and cramps, tremors and unusual postures.

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.

Epilepsy - Easy Read Resources

Jason had epilepsy. Epilepsy is a condition that happens in your brain that causes seizures. A seizure is when there is too much electricity in your brain. This stops your brain from working as it should.

Mencap have created an easy read document on epilepsy and learning disabilities that the LeDeR team felt would be useful to share.

View the document here: <https://bit.ly/4wUVHcD>

End of life - Resources

Gloucestershire Integrated Care Board and Gloucestershire Health and Care NHS Foundation Trust created an A-Z resource list on end of life care in Gloucestershire.

This includes information on end of life care, education and training and what end of life support is available and how to access it.

View the resource list here: <https://bit.ly/4bJlIZp> (Page 7 of this document has information on Continuing Health Care)



Numbers to Date (September 2026)

92%



Complete

430 reviews
done since
2017

Out of a total of 467.

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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