

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.

Oscar

Oscar lived at home for all his life and he was very close with his family.

Oscar enjoyed doing different things including swimming, tennis and bowling. He loved watching soaps like Eastenders and Emmerdale. He collected lots of DVDs including films about animals and James Bond films.

Oscar had a severe Learning Disability. During his life he had lots of health problems. He got Diabetes and had an eye condition because of this. The doctors found that Oscar had a type of cancer called Myeloma. He was given information to help understand his cancer and where he could go for help. Oscar also had 'Lymphoedema.

Oscar had help from Adult Social Care and the Carers Hub. His mother and sister had a carers assessment. Oscar's family met his needs with help from a day centre and respite care. He went to a day centre four days a week. Oscar had good reasonable adjustments to make health appointments easier. He always had someone with him for appointments and had extra time if he had any worries. He had appointments at a time of day that worked with his bus times.

About their death

In the last 10 years of his life, Oscar had lots of chest infections and would sometimes have to go to hospital because of these. He needed to go into hospital more during the last 3 years of his life.

In June 2024, Oscar had blood tests which showed that something wasn't right. He was seen by doctors who help people who have problems with their blood. Oscar also had test to see if he had blood in his poo. This is called a FIT test.

Oscar then had treatment because doctors thought he had cancer. It was found that he had a blood disorder and would need to be watched by the hospital.

Oscar had lots of help from expert doctors in the hospital, including a Learning Disability Liaison Nurse, but he had lots of different things making him unwell.

In December 2024, Oscar went to hospital because it was thought he had ²sepsis and ³pneumonia. Shortly after going into hospital his heart suddenly stopped beating.

Although doctors managed to restart Oscar's heart, he sadly passed away from pneumonia.

Good Practice

- Good reasonable adjustments in health care.
- Given accessible information to understand their cancer diagnosis.

Learning

- Raise awareness among family carers about the importance of bowel and other cancer screening.
- Look at the separation of health and social care assessments. Health questions should be included on the social care assessment forms and ⁴section 117 aftercare.
- Make carers more aware of the importance of Health Passports.

¹Lymphoedema - When the little tubes in your body that carry lymph fluid swell up. The small tubes usually move lymph fluid around your body and get rid of fluid your body doesn't need. When they swell it makes it hard for the lymph fluid to move. It can make your bones weak and hurt other parts of your body, including your kidneys.

²Sepsis – An infection in the blood.

³Pneumonia - 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.

⁴Section 117 aftercare – Free help for people for people who have been kept in hospital under the Mental Health Act after they leave.

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 Learning Disability Screening Team



NHS
Gloucestershire Health and Care
NHS Foundation Trust

Gloucestershire Health and Care Trust have created a leaflet about the Learning Disability Screening Team.

The leaflet explains what screening is and who it is for. It also explains five different types of screening, and how the team can offer support to make sure people have the right reasonable adjustments in place.

View the leaflet here: <https://bit.ly/45LnoJj>



Learning Disability Screening Team

New Service in Gloucestershire

My Health Passport

A Health Passport is an easy read document that tells professionals more about a person, their needs and how they prefer to be supported. The health passport should be taken to medical appointments or used when staying in hospital.

Gloucestershire Health and Care NHS Foundation Trust have made an easy read guide on the health passport for people with a learning disability which explains the benefits of it.

View the Easy Read guide here: <https://bit.ly/4tCPGzR>



My Health Passport is sometimes known as a Hospital Passport.

It is a very good idea to complete this document and take it with you if you go to hospital for an appointment or a planned admission.

By completing this document, you can tell hospital staff useful information about you.

Such as any communication needs, anxieties, likes or dislikes that will help you in a hospital setting.

My Health Passport is about you and your health needs.

It can help hospital staff to understand how to make things easier for you, like reasonable adjustments.

Reasonable adjustments are changes made by hospital staff to ensure people with a learning disability can access health services.

These changes can support personalised care and meet your individual needs.

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Numbers to Date (February 2026)

92%



Complete

410 reviews
done since
2017

Out of a total of 448.

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

Roberts via email: harrietr@inclusion-glos.org



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

