

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.

Amy

Amy lived with her parents and sister. They enjoyed lots of holidays together. Amy liked to go bowling, swimming and to visit wildlife parks.

Amy's family were her advocates. They felt she was well looked after as a child. The move to adult care was very difficult, as there were lots of different people involved. They thought it would be better if one-person organised Amy's care and treatment. The family were happy with the support of the Learning Disability Liaison Nurse in the Hospital.

Amy had profound and multiple learning disabilities, which meant that she needed help with all her care and daily living needs. She sometimes had to wait a long time to get the equipment she needed. Decisions were made in Amy's Best Interests, involving her family and the people looking after her medical needs. She had a tube fitted into her tummy which helped to feed Amy pureed food.

About her death

Amy died in June 2022. Amy's health was getting worse in the 10 months before she died. She had lots of visits from her Doctor (GP) and spent time in hospital.

She was being looked after by the district nurse at home in the week before she died, but then went into hospital. It was thought Amy might be bleeding in her digestive system.

Amy had to wait a very long time in the ambulance. The staff in the ambulance changed 3 times.

Hospital doctors found that Amy had a hole in the wall of her bowel, an infection in her bowel and an infection in her blood (sepsis).

Hospital Doctors couldn't do any more to help Amy get better again. They felt Amy was nearing the end of her life. Her family were involved in these conversations and in updating her ReSPECT form. Amy's ReSPECT form had been filled in before she became unwell. Amy was given end of life (palliative) care before she passed away at Gloucester Hospital.

Learning

People with complex needs should have a smooth move to adult services. It would be good if one-person organised care and treatment and was the main point of contact. Amy's family said her move from child to adult services was a "nightmare".

There is a need for hospital staff to have training on how best to communicate with people who have profound and multiple learning disabilities. When Amy was unable to respond verbally to hospital staff, some hospital staff used a louder voice, because they thought Amy could not hear. **The staff on the ward did not see there was a problem in how they were communicating with Amy.**

Amy's Hospital Passport was not read by staff on the ward.

A long wait for equipment (for up to a year) impacted on Amy's quality of life. This is not good.

Amy had to wait 7 hours in the ambulance before entering the hospital. This is too long. Where possible, as a reasonable adjustment, people with profound and multiple learning disabilities should not have to wait so long to get into the hospital.

Good Practice

- Amy's had strong advocacy through her family who knew her well.
- Amy had a hospital passport.
- Amy's family had written an End-of-Life plan and ReSPECT forms were completed before she became unwell.

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.



Numbers to Date (February 2023)

91%



Complete

259 reviews
done since
2017

Out of a total of 285.

If you have any feedback on this newsletter, please contact Paul Tyrrell
via email: paul.tyrrell@inclusion-glos.org

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>

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