

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.

Andrew

Andrew loved spending time with people. Family was very important to him, and his brothers visited a lot. His family helped him live his best life. Andrew was loved by his family, friends, and support staff and he was helped to be part of the local community.

Andrew loved Dr Who and he could name every actor who had played them. He loved James Bond and had the theme songs played at his funeral.

Andrew liked animals and had a collection of soft toys; his favourite was a dog.

Andrew had a Learning Disability, Down Syndrome and Alzheimer's Dementia. Andrew communicated without words and had other complex health needs.

Andrew had help from the Community Learning Disabilities Team (CLDT), hospital doctors, Community Nurses, Speech and Language Therapy (SALT) and other healthcare professionals. Andrew benefited from reasonable adjustments to help meet his needs and improve his wellbeing.

About death

Andrew went into hospital with a chest infection where he was given antibiotics. When he left hospital, he went to a new home, that could give him more help as his health was getting worse. A blank My Health Passport was sent back with him for his support staff to fill in. Andrew arrived at his new home with no history or paperwork, making the transition between care providers difficult.

4 days later, paramedics were called to the home after Andrew had seizures and problems breathing. Paramedics gave Andrew oxygen but by the time the ambulance got to the hospital he had stopped breathing and Andrew sadly died. Doctors could see he had a DNACPR and a ReSPECT Plan. This means that Andrew did not want doctors to restart his heart if it stopped. The ReSPECT Plan was difficult to read because of the handwriting. This meant that the ambulance crew did not know as much as they could about Andrew's end of life wishes.

Learning

- Writing on a ReSPECT plan needs to be clear and easy to read in an emergency.
- The ReSPECT plan needs to be filled in by the people who know them best.
- There should be more than one copy of the ReSPECT plan
- More people need to use a My Health Passport
- People need to have a smooth move between care providers. A person's medical history, any equipment and medication should move with the person quickly.

Good Practice

- Excellent support to live in the community, which is what Andrew wanted.
- Reasonable adjustments to make sure Andrew had fair access to health services.
- Help from the Hospital Learning Disability Liaison Nurse.
- Help from Community Learning Disabilities Team (CLDT), hospital doctors, Community Nurses, Wheelchair Service, Continence Service, Falls Assessment and Education Service, Rapid Response, Podiatry, Physio and Occupational Therapy (OT).

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.

2022-2023 LeDeR Annual Report

We have just published our latest LeDeR Annual Report, which is also in an Easy Read format. This year both versions are in a presentation format following feedback from last year.

Download the report here:
inclusiongloucestershire.co.uk/engagement/leder/

The report covers:

- Background to the LeDeR programme.
- Case studies, explaining the stories of people who have sadly died.
- How we share the learning.
- The statistics from the year.

LeDeR is learning about people's lives and deaths so that we can make healthcare better for people with learning disabilities and autistic adults.

92% Complete

295 reviews done since 2017

Out of a total of 322.

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

Made by Inclusion Gloucestershire using Photosymbols and Venngage. Weblinks have been shortened to make the newsletter easier to read. Find previous newsletters here:

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

