

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.

Betty

Betty was a cheerful person who always made people smile. She communicated using her face and hands. Betty had two sisters, who visited her. Care staff would let her sisters know if Betty was unwell or in hospital.

It was important to Betty she was supported by staff who knew her well. She had lived in the same home for 22 years and felt the other people who lived there were 'part of the family'. Betty liked to visit cafes, pubs and restaurants and before COVID-19 went on holidays to Weston-Super-Mare. Betty had a Learning Disability, Dementia and Downs Syndrome. She had no teeth and had Speech and Language Therapy guidelines in place.

Betty's physical and mental health had got worse in the last 3 years. She was given equipment to help keep her safe at home and was moved to a downstairs bedroom. Betty had the support of a Dementia nurse and was on the Community Learning Disabilities Team's (CLDT) Memory Assessment Pathway (MAP). Betty also had an advocate.

About her death

In March 2022 Betty tested positive for COVID-19 and got two chest infections. In the same month the paramedics needed to be called after Betty had a seizure. In June 2022, Betty went into hospital with another chest infection and shortness of breath. She was sent home the next day with antibiotics. Betty was admitted again to hospital and again she was sent home. 11 days later Betty was back in hospital. Her health continued to get worse. Her sisters visited regularly. They wanted Betty to be comfortable and the Palliative (end of life) care team got involved. Betty died just over a week later.

Learning

- **Communication between the hospital and the manager of Betty's home was not as good as it could have been.** The manager of Betty's home said that they were told different things by different members of staff. For example, it was not clear if Betty had COVID-19 or not.
- **It is good practice for hospital staff to have the right information about a person's health to share with relatives and carers.**
- **Betty's hospital passport was not read.** This would have helped hospital staff to know everything about Betty's needs and make reasonable adjustments for her. **It would be good to have a flag on the computer system to remind staff to read the hospital passport.**
Learning into Action: the hospital Learning Disability nurse now puts things from the hospital passport onto the persons electronic hospital notes.

Good Practice

- Betty had an advocate.
- Betty had good relationships with trusted care staff and other people where she lived.
- All manual handling equipment was provided, as her health got worse, and Betty was moved to a downstairs bedroom.
- A decision about Betty's feeding, during her last stay in hospital, was made in her Best Interests, involving her advocate and family. This was done because Betty couldn't make the decision herself.
- Betty had a ReSPECT form which was completed before her health began to get worse and she was able to make decisions for herself.
- She was on the Community Learning Disabilities Team's (CLDT) Memory Assessment Pathway.
- The hospital Learning Disability nurse made a positive difference to this person's time in hospital.

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.

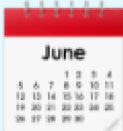
CLDT Memory Assessment Pathway Easy Read Leaflet

It is common for people with Down's Syndrome to develop Dementia. In Gloucestershire the Community Learning Disability Team (CLDT) have a Memory Assessment process. This is for adults with Down's Syndrome (from the age of 30) and any adult with a Learning Disability who has possible memory issues.

Working with the CLDT we have coproduced an Easy Read leaflet to help explain more about the Memory Assessment Process and how it can help people.


Read it here: <https://bit.ly/43SrMCN>





Numbers to Date (June 2023)

90%



Complete

270 reviews done since 2017

Out of a total of 299.

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>

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>