

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.

Lucy

Lucy was a very happy person who loved life. She had a brother and sister and was cared for by her parents until 2002. Family was very important to Lucy.

Lucy always liked to wear smart clothes. She liked going to a singing group for people with Dementia and would go to church every Sunday.

Lucy had a Learning Disability, Cerebral Palsy, Spina Bifida and was registered blind. As well as other health issues she also had Alzheimer's Dementia.

Because of how Lucy communicated it was important that she had carers who knew her well. Complex decisions were made in Lucy's Best Interest.

Lucy was known to the local Community Learning Disabilities Team (CLDT), Occupational Therapy (OT), Physio and Speech and Language Therapy (SALT). Lucy benefitted from reasonable adjustments to help meet her needs.

About death

Lucy's health started to get worse after her mother died. She had end of life care for a few months and died peacefully at home.

Her care home had applied for Continuing Health Care (CHC) funding for Lucy but was told that she did not meet the funding requirements. The care home was worried that Lucy's needs were not understood.

Continuing Health Care is where the NHS pays for your care if you have certain health needs.

Learning

- The care provider did the first thing they needed to do to get Lucy the funding, filling in a form for her. The panel thought Lucy should have had a full assessment of her needs. This would have given healthcare professionals a better understanding of Lucy's needs.
- The care provider and family did not understand how to ask why Lucy did not get the funding.
- The panel think it would be good for care providers to have more training and information about how to apply for CHC funding.
- LeDeR will link with the Gloucestershire Carers Hub to help family carers understand the rules for applying for CHC funding.
- It is important for advocates to help families when they need to apply for CHC funding.

Good Practice

- A RESTORE 2 mini guide was written so that care staff could better meet Lucy's needs.
- Lucy had lived in the same home for 20 years. The care staff were able to carry on looking after her when her health got worse.
- Lucy's ReSPECT form was looked at again when her health got worse.
- Lucy lived for a long time with dementia.

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.

Resources about CHC funding

The panel wanted to share some accessible resources explaining the process of applying for CHC funding.

This video is a step by step guide to the process (by carehome.co.uk): bit.ly/3r3zRH2

The video talks about Clinical Commissioning Groups (or the CCG). This is an old name for those who manage and look to improve the NHS in a local area. They are now called an Integrated Care Board (ICB).

This easy read guide, by Bristol, Somerset and South Gloucestershire ICB, explains what Continuing Healthcare is: bit.ly/460AdNL

It is 44 pages long so it might be easier to read in sections.



Numbers to Date (September 2023)

92%



Complete

286 reviews
done since
2017

Out of a total of 310.

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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