

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.

Bonnie

About her

Bonnie was a very friendly and gentle person who liked watching other people be nice to each other. Family were very important to Bonnie and she was close to them. Bonnie was one of five children in her family.

Bonnie loved knitting and was part of a knitting club. She spent time at home knitting blankets and other clothes. Bonnie also enjoyed learning about other cultures.

In 2020, Bonnie's support needs were reviewed, as she wanted to move closer to her family. It was felt Bonnie understood why this needed to happen and she was supported by a Care Act Advocate from POhWER. After talking with Bonnie and her family it was decided it would be best for Bonnie to stay living in Gloucestershire. An Amazon Echo was set up so Bonnie could speak with and see her mother more often. This made Bonnie feel better. She also used the Amazon Echo to watch knitting videos and research Indian culture.

About her death

Bonnie's physical health and wellbeing got worse after the death of her mother in May 2023. Bonnie had COVID-19 twice in June 2023, which led to a chest infection.

Bonnie went into hospital a lot before she died. She went into hospital four times because of dizziness and a racing heartbeat. Hospital doctors felt her heart was failing. The hospital said they had referred Bonnie to a heart specialist, but when Bonnie's social worker checked this, the team had not got the referral. The social worker got the heart failure team to see Bonnie, but by this time her health had got worse.

Bonnie needed an ambulance to be called three times whilst she was at home. She became weak and was spending a long time in bed or in a chair.

Bonnie went into hospital three more times from September 2023 until she died in November 2023. She sadly passed away in hospital.

Learning

- Health professionals and different health services need to work together as this may help stop referrals getting missed. Working together would also help everyone to monitor someone's full health picture.
- Hospital passports need to be kept up to date. They should include information, such as, the persons normal blood pressure or heart rate. Health passports should also explain how the person communicates pain and if they have a preferred pain scale.

Good Practice

- The use of a Care Act advocate through POhWER
- The use of a Hospital Passport.
- Good reasonable adjustments, such as Bonnie's cat being able to stay with her.
- Very good support from the same social worker.
- The use of an Amazon Echo device to support contact with family.

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.

My Health Passport

A Health Passport is an easy read document that lets professionals know what a person needs in order to feel supported. The health passport should be taken to any medical appointments or hospital admissions. Make sure to keep it up to date.

See the editable version here: <https://bit.ly/497UymW>

See the printable version here: <https://bit.ly/4i306mO>

See the My Health Passport Easy Read Guide here: <https://bit.ly/4eMixck>

My Health Passport is the most up-to-date document to use. It is checked and updated every year.

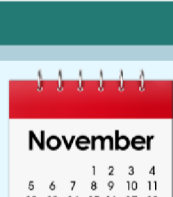
You can ask for a paper copy of 'My Health Passport' by emailing: simon.shorrick@ghc.nhs.uk.

We need to talk about death- a coproduced video by Biggerhouse Film

The panel wanted to share a short film called 'We need to talk about death'. The NHS in Somerset asked Biggerhouse Film's to coproduce this with some adults with learning disabilities. The film aims to remove the stigma around talking about death.

Watch the video here: <https://bit.ly/4gSOjHg>.

The film also has a BSL and audio described version.



Numbers to Date (November 2024)

95%



Complete

365 reviews done since 2017

Out of a total of 385.

Please let people know 'autism only' reviews are part of LeDeR

Autism only reviews of 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 only'.

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

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