

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.

James

For much of his life James lived in the countryside, with his parents and sister. He liked being outside, watching animals and spending time with his sister's dog. James also liked people watching, bowling and having books read to him.

James moved into residential care in 2008. James' family thought it would be best for James to stay at home with his mum and have the support there. After James left his family home, he lived in a number of different residential placements. The changes in different care providers seemed to affect the care James had.

James had severe learning disabilities and was an autistic person. He also had Cerebral Palsy and Epilepsy. James needed two carers to support his daily living.

About his death

One morning when James was having breakfast, he vomited. His carers called the doctor, but then James' heart stopped. His carers called 999. James had a DNACPR in place, but the 999 call handlers told the care staff to start CPR. When the Paramedics got to James, they gave him suction. James had a ReSPECT form. It said he wanted to pass away comfortably at home. James was given end of life care and died with his sister by his side.

Learning

Carers need to know if the person they are caring for has a DNACPR when calling 999 for them.

Good Practice

- James was well supported by community health services, including the Community Learning Disabilities Team (CLDT).
- Care staff had clear guidance and consistent approach about what to do when James behaved in a certain way.
- He was well cared for at his last home.
- James had a behaviour support plan and ReSPECT form.

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.

NEW ReSPECT films

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. We want to make sure healthcare workers and people with Learning Disabilities and Autistic people understand the ReSPECT conversation.

To help people learn more about ReSPECT we have made films of two different ReSPECT conversations.

Jenny's conversation: <https://bit.ly/3GoLSuw>

John's conversation: <https://bit.ly/3Cpn9oH>

ReSPECT Recommended Summary Plan for Emergency Care and Treatment		Preferred name
1. Personal details		
Full name	Date of birth	Date completed
NHS/Health and care number	Address	
2. Summary of relevant information for this plan (see also section 6) Including diagnosis, communication needs (e.g. interpreters, communication aids) and reasons for the preferences and recommendations recorded.		
Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.		

RESTORE 2 Mini Film

RESTORE2 mini is a health toolkit that can be used by parents, carers and support staff to help monitor a person's soft signs. Soft signs can show someone is becoming unwell. They can be seen as changes in someone's physical health, mental health or as a change in behaviour

We have made a film to show how RESTORE 2 mini can help.

Watch it here: <https://bit.ly/3ID6Kka>



Numbers to Date (January 2023)

90%



Complete

249 reviews
done since
2017

Out of a total of 278.

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

