

Themes and important resources for advice and support.

LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autism. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

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>

5 cases quality checked in all.

(1 returning to next panel)

Numbers to date

What the panel said.

What we can learn.

Good practice in action.



Numbers to Date (as of 09 December 2021)

95%

Complete



55 reviews done in 2020.

2 more on hold.



218 reviews done since 2017

Out of a total of 230.

22 so far in 2021.

5 more open, 5 on hold from this year.



Early Signs and RESTORE 2

Early signs (also called 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.

RESTORE2 is a tool, used by healthcare workers, to help monitor a person's soft signs and record things like a person's pulse. RESTORE2 can help work out a person's 'unique wellness'.

Video explaining more about Soft Signs (by Geoff Cooper at Wessex AHSN): <https://bit.ly/3GHZFu0>

RESTORE2 Explainer Videos and Case Studies (by the Hampshire, Southampton and Isle of White CCG): <https://bit.ly/3ysQtr5>

Short training videos by the West of England AHSN and Health Education England:

The soft signs of deterioration: <https://bit.ly/31T0Etc>

Recognising deterioration in people with a Learning Disability: <https://bit.ly/3yiJn8A>



Bereavement Support

In two cases the panel felt bereavement support was an important learning point.

Below are some accessible bereavement support resources as well as a link to the national charity Cruse Bereavement Care. Cruse offer support through their website, a national helpline, and with one-to-one support sessions. Due to COVID-19 the support is on the telephone or a video call. Cruse can only initially offer 6 one-to-one sessions.

Cruse Bereavement Care: <https://bit.ly/3IP2gF8>

More information about Gloucestershire Cruse (by Glos Families Directory): <https://bit.ly/3INfzpu>

Grief and loss when someone dies (by Change/ Macmillan Cancer Support): <https://bit.ly/3ESwAw4>

How you may feel when someone dies (by Change/ Macmillan Cancer Support): <https://bit.ly/3dK7e7N>

Grief chat - for those grieving and would find it helpful to text a qualified counsellor: <https://bit.ly/3INjSkE>

Dementia and Down's Syndrome

In one case someone with Down's Syndrome developed Dementia and their family did not know how common it is for people with Down's Syndrome to develop Dementia. The panel felt more people should know about this and the early diagnosis assessment pathway available to people with Down's Syndrome.

An Easy Read guide to Dementia (by a Picture of Health South West): <https://bit.ly/3m2spq1>

An easy read webpage about Dementia and Down's Syndrome (by easyhealth.org): <https://bit.ly/3s1JMeI>

Information leaflet for carers and families about the Memory Assessment Pathway (MAP) by NHS Gloucestershire Health and Care Foundation Trust: <https://bit.ly/3Fmly1k>

The MAP is available to people with Down's syndrome from the age of 30.



Annual Health Checks and Other Appointments

Anyone with a Learning Disability aged 14 or over can have an Annual Health Check. This is an appointment with your doctor every year that you can have even if you feel well. Your doctor will check your physical health and ask you some questions. Even if you see a doctor regularly, it is still important to have an Annual Health Check to help stay well.

This video by the Misfits Theatre Company, the AHSN Network and the NHS explains more about an Annual Health Check, including: what to expect, how it will help you and the questions you may be asked: <https://bit.ly/3IERgtP>

It is important that everyone with a Learning Disability can go for their Annual Health Check and any appointment no matter where they live. This film shows the difficulties of people who need help getting to Doctors' appointments: <https://bit.ly/33s7vu3>



Keeping your Mouth Clean

Keeping your mouth clean can help stop infections such as sepsis or aspiration pneumonia.

Aspiration pneumonia is a type of infection that happens when someone breathes something into their lung instead of swallowing it.

Easy Read guides about keeping your mouth clean (by Community Dental Services): <https://bit.ly/3JKLuY0>

Video about what to expect when you go the dentist: <https://bit.ly/3DKRZ92>

Sepsis information for People with a Learning Disability (video by NHS Sherwood Forest Hospitals): <https://bit.ly/3DQs1RA>

Easy Read information about Aspiration Pneumonia (by Inclusion Gloucestershire): <https://bit.ly/33BbRIK>

Mouthcare Assessment Poster (by Mouthcare Matters and NHS Health Education England): <https://bit.ly/3K2thp4>



Good Practice in Action

- The panel noted someone had a good standard of healthcare from their GP and the Community Learning Disabilities Team (CLDT).
- Someone received bereavement support from the Community Learning Disabilities Team (CLDT). Grieving can take a long time, but the CLDT can support people with this.
- Carers found different ways of helping someone manage their mood, as they did not want to take medication.
- In three cases a ReSPECT form had been completed. This is an advanced care planning tool.
- In two cases a DNACPR was in place and had been written down correctly. A DNACPR is a way of recording someone's wishes should their heart stop.



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

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