

LeDeR Newsletter

A newsletter brought to you by CWICB – February 2024

Welcome to our eighth issue of the Coventry & Warwickshire Integrated Care Board (ICB) LeDeR newsletter.

What is the LeDeR programme?

Learning from lives and deaths – people with a learning disability and autistic people (LeDeR).

LeDeR is a service improvement programme for people with a learning disability and autistic people.

Established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

- improve care for people with a learning disability and autistic people.
- reduce health inequalities for people with a learning disability and autistic people.
- prevent people with a learning disability and autistic people from early deaths.

LeDeR Reviews:

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. We look for areas that need improvement and areas of good practice. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying sooner than they should.

Anybody can make a referral to LeDeR if they believe that a person that has died had a learning disability (and was aged 18+) or had a diagnosis of autism (and was aged 18+).

This can be done via the following link:
<https://leder.nhs.uk/report>

LeDeR Governance:

We have a dedicated LeDeR Governance Group which takes place on a monthly basis. Senior health and social care representatives from across Coventry and Warwickshire attend the meeting, consider findings of reviews, and oversee an action plan linked to the learning.

LeDeR Subgroup:

It was recognised that a dedicated space was needed to work on the key themes coming from the LeDeR reviews, and so our LeDeR Subgroup was launched in May 2023.

The purpose of the LeDeR Subgroup is to ensure that the broader thematic findings and SMART actions from reviews are recognised by health and social care providers across the system, acted upon, and that meaningful changes are made to improve the quality of health for individuals with a learning disability and autistic people.

We are coming towards the end of our focussed work on *constipation*. This has looked at the training and resources currently available across health and social care to create an action plan with the goal of upskilling clinicians, carers, and people with a learning disability and autistic people, on the proactive care for constipation and the signs and symptoms to be aware of.

In December 2023, we produced a Constipation Information and Resource Pack, which you can see further details on in the 'Other News & Information' section of this newsletter.

Our next focus in the LeDeR Subgroup will be on the topic of *pneumonia*.

Between 1st April 2023 and 31st January 2024 the Coventry & Warwickshire LeDeR Programme has received:

46 Notifications.

44 reviews have been completed (21 Initial and 23 Focused).

Three were marked out of scope due to there being no evidence of a learning disability or autism diagnosis.

There are currently 31 adult reviews open, with six reviews on hold whilst we await the outcome of other investigations.

Key themes taken from reviews:

- We continue to see examples of good, empathic and holistic care being provided throughout the system. One care provider in particular has been identified through a number of reviews, as delivering consistently high standards of care. Over the coming months we plan to work with this provider to learn more about and share their success.
- A gap in knowledge around organ donation services was identified, leading to work being undertaken around the referral processes within acute hospitals.
- We continue to see a lack of planning ahead for end of life decisions (refer to the guidance in the '*Spotlight on*' section of this newsletter for further information). We are feeding back any of our findings into the ICB's Palliative and End of Life Care programme.

Examples of positive practice taken from reviews:

- ✓ The person received individualised, respectful and caring support from her GP practice, including the provision of home visits when her mobility began to deteriorate.
- ✓ Excellent care was received by the person. Her wish to remain at home where possible was adhered to and respected and the care was delivered in a person centred way, with care and empathy. Every member of the Community Learning Disability Team, primary care, secondary care and social care teams worked closely with the care provider to ensure that this person received a standard of care that any person would hope to receive for themselves or their family member.
- ✓ Reasonable adjustments were made for the person by the GP practice and the person was always able to voice his own opinions. He also contributed to his own ReSPECT form.

In each issue of this newsletter, we will share information based upon a key theme of our LeDeR learning.

Spotlight on:

ReSPECT and DNACPR

ReSPECT: *Recommended Summary Plan for Emergency Care and Treatment.*

DNACPR: *Do Not Attempt Cardiopulmonary Resuscitation.*

What is the ReSPECT process and who is it for?

The ReSPECT process enables a plan to be made for an individual in the event of emergency care or treatment being required, where the person is not able to make or express their wishes. The process is for anyone; however, it has increased relevance for people who have complex health needs, people who are likely to be nearing the end of their lives and people who are at risk of sudden deterioration or cardiac arrest. The ReSPECT process is more than just the decision regarding resuscitation.

LeDeR Reviews and what we are seeing:

The LeDeR annual report for 2022/23 highlighted some poignant facts from data gathered and reviewers' judgments:

- **74% of people who died in 2022 had a DNACPR in place at the time of their death.**
- **63% of completed DNACPRs were completed correctly. This was a slight improvement on the previous year.**
- **61% had documented evidence that a conversation had taken place with the person or those important to them.**
- **60% of reviews where a DNACPR was in place were provided with appropriate accessible information about the process.**

Locally, ReSPECT and DNACPR remain a key theme, with recognition that work as a system is required to improve the voice of the person with a learning disability and/or autistic people and their families. We strive to improve the understanding, process and documentation of ReSPECT decisions.

How can this be addressed?

We have put together some key areas of consideration when completing the ReSPECT process, along with some useful resources for professionals and service users:

- Involvement of the patient and anyone who is close to them in the ReSPECT process is vital.
- The process should be proactive, enabling people to plan ahead and allowing their voice to be heard when they are unwell.
- Providing information regarding the process and decisions that are required, in a format that suits the needs of the individual and the people close to them.
- Having a learning disability or being autistic is not a justified reason to exclude a person from the decision making process, nor is it an acceptable reason to withhold resuscitation.
- Remembering that the ReSPECT process includes care and treatment, not just the decision regarding resuscitation.

Step by step guides on how to complete the ReSPECT process and documentation are linked below:

- [ReSPECT Guide for Clinicians FINAL.pdf \(resus.org.uk\)](#)
- [ReSPECT-Clinicians-Guide.pdf \(worcslmc.co.uk\)](#)

Resources for services users:

- [ReSPECT Easy Read Guide: Leaflet 1 - Introduction](#)
- [ReSPECT Easy Read Guide: Leaflet 2 - Making choices](#)
- [ReSPECT Easy Read Guide: Leaflet 3 - Making a ReSPECT Plan](#)
- [ReSPECT Patient Resource v1.indd \(resus.org.uk\)](#)
- [ReSPECT Patient Guide FINAL.pdf \(resus.org.uk\)](#)

Resources for professionals:

- [20160123 Decisions Relating to CPR - 2016.pdf \(resus.org.uk\)](#)
- [NHS England » Do not attempt cardiopulmonary resuscitation \(DNACPR\) and people with a learning disability and or autism](#)

Other News & Information

- December was **Constipation** Awareness Month, and we asked people to 'Think Poo' with our [Constipation Information and Resource Pack](#), which was created in collaboration with members of the Coventry and Warwickshire Integrated Care System, as part of our recent work in the LeDeR Subgroup.

This pack includes:

- A4 Posters that can be printed off and used in public settings e.g. toilets, wards, notice boards etc
- Examples of Bristol Stool Charts, bowel management diaries and hydration charts
- The Poo Song; a song written and performed by Communicate2U and students studying Learning Disability Nursing at Coventry University
- An educational slide deck on bowel health awareness, which includes signs and symptoms of constipation for people with a learning disability, amongst many other important pieces of information
- Links to a wide variety of useful, related resources.

Constipation can be a life-threatening issue for people with a learning disability who are at heightened risk from complications if it is left untreated.

In fact, [23% of people with a learning disability who died in 2019 had constipation as a long-term condition](#).

Please share this information and resource pack far and wide with your health and social care colleagues.

- **Learning Disability Annual Health Checks** continue to remain a key focus and priority, both locally and nationally.

All people with a learning disability aged 14+ are eligible for this annual health check with their GP practice. The learning disability annual health check can help people to stay well by talking to their GP or nurse about their mental and physical health, having checks and tests done and to find and diagnose any problems early.

Please promote the importance of these learning disability annual health checks within your teams and organisations and with service users and patients.

[Easy-read Annual Health Checks Information - Mencap](#)
[Learning Disability Annual Health Check Resources](#)

USEFUL ONLINE LINKS

[LeDeR - Home](#)

(For more information about the national LeDeR programme)

[Coventry & Warwickshire Partnership NHS Trust - Learning Disability Services](#)

(Overview of services, contact details and Learning Disability Annual Health Check resources)

[What are Reasonable Adjustments and why are they important?](#)

KEY CONTACTS

For further information about our local LeDeR programme, please feel free to contact:

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Feedback on the usefulness of this newsletter would be welcomed and appreciated, such as whether you find the content useful, whether you feel that anything in particular is missing, or whether you feel that less or more detail is needed. Please email any feedback to dougie.philippou@nhs.net