



March 2026

Newsletter

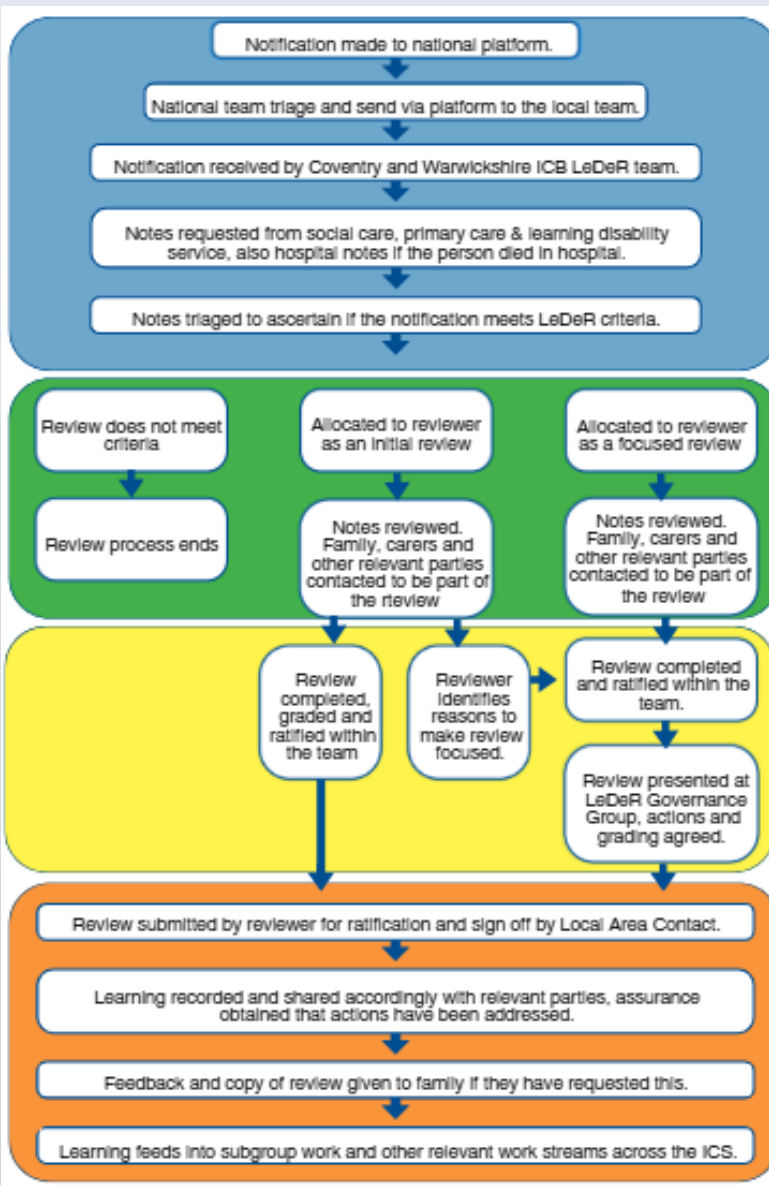
Issue 12

LeDeR (Learning from lives and deaths of people with a learning disability and autistic people) is a service improvement programme established in 2017 and funded by NHS England and NHS Improvement.

LeDeR works to improve care, reduce health inequalities and prevent early deaths for people with a learning disability and autistic people.

Anyone can make a referral to LeDeR if they are aware of a person who has died that is aged 18 and over, with a learning disability or autism. A referral can be made via the [national LeDeR website](#).

The LeDeR process



LeDeR Governance Group

We have a dedicated LeDeR Governance Group which takes place on a monthly basis. Our experts by experience along with 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.

Subgroup

Recognising the need for a dedicated space to address key themes from LeDeR reviews, we launched our LeDeR Subgroup in May 2023. Its purpose is to ensure that broader thematic findings and SMART actions from reviews are acknowledged across the integrated care system, acted upon, and lead to meaningful improvements in the health of individuals with a learning disability and autistic people.

Like our Governance Group, the subgroup includes representation from across health and social care, as well as invaluable input from our experts by experience.

Focus group

Currently we have no Experts by experience within the LeDeR Programme within Coventry and Warwickshire. We are working hard to try and rectify this, as we transition through the current period of change within the Integrated Care Board.



LeDeR Update

Notifications

29 notifications were made to Coventry and Warwickshire LeDeR team. Of these 26 were in scope, 3 were not in scope due to not having a confirmed diagnosis of a learning disability or autism.

Analysis of the –notifications that were in scope

Autism Only	Gender	Age	Place	Ethnicity
We received 6 notifications for a person with an autism only diagnosis.	Male = 17 Female = 9	Age of death ranged from 18 to 87. With the median age of death being 64 for males and 56 for females .	Coventry = 10 Rugby = 2 South Warwickshire = 5 Warwickshire North = 9	23 = White British 1 = White Irish 2 = Asian or Asian British

Completed Reviews

12 reviews were completed by the Coventry and Warwickshire LeDeR team

2 were initial and 10 were focused

The informatic below shows the reasons why the 10 reviews were completed at a focused level.



Analysis of the – completed reviews

Ethnicity	Place of death	Cause of death	Level of learning disability
11 = White British 1 = Asian British			PROFOUND 0 SEVERE 4 MODERATE 2 MILD 3 UNKNOWN 0

Care gradings for completed reviews

No Deaths reviewed during Q2 were seen to be avoidable.

Focused reviews

Quality of the care the person received

Availability and effectiveness of services

Care gradings explained

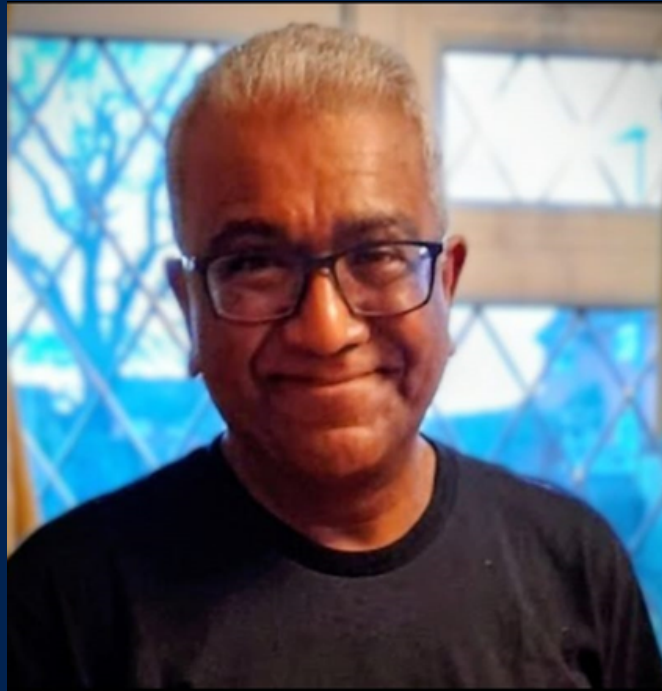
- 1** - Fall short of the expected standard, and this contributed to the cause of death
- 2** - Fall short of the expected standard and did impact on well-being and/or had the potential to contribute to the cause of death
- 3** - Fall short of the expected standard and did impact on well-being but did not contribute to the cause of death
- 4** - Fall short of the expected standard, but this did not significantly impact on the person's wellbeing
- 5** - Good and met the expected standard
- 6** - Excellent and exceeded the expected standard

Initial reviews

Quality of the care the person received

Availability and effectiveness of services

Meet Our Reviewer



My name is Bill Sandhu. I recently joined the LeDeR Team in November 2025. I am a Registered Mental Health Nurse with several years' experience working within the NHS Mental Health Services, South Warwickshire primarily.

My hobbies include cooking, running and golf, as well as spending time with my family. My passion is Liverpool Football Club!!

Spotlight on The Victoria Stuart Project

Supporting Better Conversations About End-of-Life Care



We're excited to share the work of the Victoria & Stuart Project; a co-designed initiative helping people with a learning disability talk about their wishes for the future, including illness and end-of-life planning.

Inspired by the lives of Victoria Wilson and Stuart Hasler, the project offers free, accessible resources to support person-centred conversations around care, dying, and funerals.

What's in the toolkit?

“When I’m ill” cards – picture-based prompts.

“My funeral” cards – to support funeral planning.

Conversation guides for families, carers and professionals.

Easy-read & pictorial materials.

Download for free: [here](#)

NEW - Free Print & Deliver Service from Marie Curie:

Marie Curie now offers a print and deliver service for the Victoria & Stuart Toolkit and other resources; perfect for care providers, community teams or families who need physical copies.

Why this matters for LeDeR:

Supports better communication and dignity in end-of-life care.

Empowers people with a learning disability to share their wishes.

Aligns with LeDeR priorities on reducing health inequalities.

Easy to introduce in reviews, care planning or training.



Other news and information



HEALTH AND SOCIAL CARE PASSPORT (HOSPITAL PASSPORT)

If you have your health and social care passport please let one of our team know.

Everyone with a learning disability is able to have a health and social care passport, it helps to inform us of the things you need to be able to access and get the most out of your health and social care experience.

If you don't have a passport the QR code or websites below will take you to the locally produced format. However, there are other versions available and we want you to use what ever version you are happy with.



<https://tinyurl.com/438c4axy>

<https://tinyurl.com/mr3mummh>

If you are currently at a hospital please ask to speak to the learning disability acute liaison nurse or please call the Coventry and Warwickshire learning disability team on 0300 131 2320 who will help you access a copy.

Other news and information



Referring to LeDeR

Anyone who is aware of a death of a person with a learning disability or autism can make a referral to the LeDeR programme through the national portal [here](#).

- Please try to include key details such as ethnicity, place of death, and next of kin. This helps us ensure each LeDeR review is as thorough and effective as possible.
- Don't worry if you're unsure whether the person had a formal diagnosis — we encourage you to refer. We will determine if they meet the LeDeR criteria during our review process.

Learning Disability Friendly Badge



The sixth panel evaluation meeting for this GP practice accreditation scheme took place in November, seeing three more practices receive the Learning Disability Friendly Badge.

To learn more about the scheme and view the 28 accredited practices, please follow the link [here](#).

Useful online links



[NHS England](#) - Learning disability and autism pages

[Coventry & Warwickshire ICB](#) - Learning Disability & Autism webpages

[LeDeR Coventry an Warwickshire ICB](#) Coventry an Warwickshire ICB - For more information about local work and resource packs

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

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

Contact us – cwicb.ledercwicb@nhs.net

