



Learning from the Lives and Deaths of People with Learning Disabilities and Autism (LeDeR)

Newsletter – 12th edition – March 2024

Please remember to notify LeDeR when someone dies

It helps us all to have a better understanding of the needs of people with a learning disability and autistic people; helps improve services in Somerset and provides an opportunity to shout about good practice!

If you provide care or support to someone with a learning disability, or an autistic person, are a GP or other health professional, a family member, friend or carer **we need you** to notify us if someone dies.

It's very simple to do and will only take about 10 minutes. Here is the link to the form

[Report the death of someone with a learning disability \(leder.nhs.uk\)](https://leder.nhs.uk).



The seventh **LeDeR Annual Report** was published by King's College London at the end of November 2023, together with an easy read version. The 2022 LeDeR report, like those before it, seeks to investigate and learn from the deaths of people with a learning disability in England.

This is the first time the Annual Report includes autistic people, and a higher number of notifications and focused reviews were undertaken.

Researchers found that there has been gentle but continuous improvement in the median age of death for people with a learning disability in 2022.

- In 2018, the median age of death for adults with a learning disability was 61.8 years but has since risen to 62.9 in 2022. If children are included, the age at death increased from 60.1 years in 2018 to 62.7 in 2022.
- The team also found a drop in the number of avoidable deaths since 2021 – 42% of deaths were deemed “avoidable” for people with a learning disability in 2022 compared to 50% in 2021.
- The report also highlighted a sharp drop in the number of deaths due to Covid-19 – from 24% of all causes of death in 2020 to 19% in 2021 and 6% in 2022 for adults with a learning disability.

While there are positives, the findings also show more work still needs to be done. For example, people from ethnic minority groups died younger and as Professor Andre Strydom, Chief Investigator and Professor in Intellectual Disabilities at King's Institute of Psychiatry, Psychology & Neuroscience, summarises: “There is a need to improve access to care pathways to improve prevention and better manage some conditions in people with a learning disability, such as cancer, lung, heart, and circulatory conditions. We also identified a concerning effect on excess deaths of people with a learning disability during heatwaves. This means care homes and hospitals looking after people with a learning disability need to be better prepared for weather events in the light of climate change”.

Read the full statement from the team about the 2022 report [here](#).

NHS England has also published its fifth annual LeDeR '**Action from Learning**' report (also with an easy read version), which describes some of the work being undertaken across the country by the NHS to reduce health inequalities and premature mortality amongst people with a learning disability.

Please share these reports widely across your systems with reference to the key findings and examples of best practice. You can also access and share the **Take Home Facts** infographic which clearly outlines the key findings of the review of lives and deaths for 2022.

If you would like to get in touch about the reports, please contact england.lederprogramme@nhs.net.
[LeDeR 2022 Annual Report](#) | [LeDeR 2022 Annual Report – Easy Read version](#)
[LeDeR Action from Learning Report](#) | [Take Home Facts](#)

Learning Disability Screening Service

The Screening Liaison Nursing service is an integral part of Somerset's Community Learning Disability Services which provide a specialist service for people with a learning disability. The early detection of cancer remains a key priority nationally and locally and screening is essential in reducing the burden of morbidity and mortality related to cancer.

The service will be provided across Somerset to improve awareness and knowledge of the identified national screening programmes amongst people with learning disabilities. The service will also provide advice to primary care and screening teams to enable them to improve access to the screening programmes for Somerset's population of people with a learning disability and autistic people.

The aim of the service is to

- Improve the uptake of the FIVE identified national screening programmes
- Provide support to primary care, screening programme leads, secondary care, and community staff
- Deliver specialist learning disabilities education support to improve the uptake of and attendance at health screenings
- Provide better cancer health outcomes for people with a learning disability identified on the GP Learning Disability (LD) registers
- Work closely with LD patients and their carers to raise the awareness of the offer of cancer screening and cancer pathways
- Provide data on the levels of screening uptake and nature and frequency of support interventions for each national cancer screening programme

For further information please contact CTALDHealthReferrals@SomersetFT.nhs.uk

Obstructive Sleep Apnoea (OSA) Part II

In our last Newsletter (December 2023) we provided some links to resources on OSA and associated CPAP (continuous positive airway pressure) treatment. There is now an easy read guide available: <https://www.england.nhs.uk/wp-content/uploads/2023/11/A-guide-to-your-CPAP-easy-read.pdf>

The **End of life care: improving DNACPR conversations for everyone** report has been published today by the Parliamentary Health Ombudsman. A useful commentary by Alex Ruck-Keene and a link to the full report and exec summary can be found here:



[End of Life Care: improving DNACPR conversations for everyone](#)

Learning Disability Register

A person does not need a formal learning disability diagnosis in order to access the GP Learning Disability Register (GPLDR). Guidance, including a checklist, is available to support Primary Care where they believe someone meets the criteria and would benefit from an Annual Health Check (AHC), with the option of using a non-diagnostic SNOMED (*Systematised Nomenclature of Medicine*) code to support this process.

It's also important to ensure that Children and Young People are captured on the Register so that eligible people are not missed.

[Guidance](#) | [Checklist](#)



Learning Disability and Dysphagia Thickened Fluids – Risks and Benefits

Thickened fluids are frequently recommended for people with dysphagia and aim to reduce the risk of aspiration (fluid entering the lungs).

The Royal College of Speech and Language Therapists (RCSLT) has published new guidance for clinicians and accompanying resources to help health professionals, carers and families understand why thickened fluids are not always suitable, as well as the potential benefits of using thickener:

[Clinicians briefing](#) | [Patient Leaflet](#) | [RCSLT Easy Read Thickened Drinks Adults](#)

It is recommended that thickener is not introduced or discontinued without a detailed drinking and swallowing assessment.

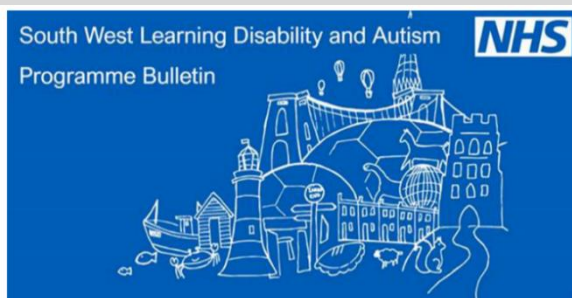
For further advice from the Speech and Language Therapists in the Specialist Learning Disabilities Health Team, please email: CTALDHealthReferrals@SomersetFT.nhs.uk

Makaton training available for nurses



A new eLearning resource for nurses has been added to the [NHS Learning Hub](#), designed to raise awareness among nursing staff of the ways they can provide care to people with different communication needs and styles.

In particular, this course will focus on developing nurses' understanding of Makaton, which is a multi-modal communication tool, and learn basic signs.



england.learningdisabilityandautism-sw@nhs.net

Email this address if you would like to keep up to date and be added to the distribution list.

The latest issue includes

- *A short film about the development in Sunderland of a reasonably adjusted clinic for patients with a learning disability*
- *A letter identifying five key actions with the biggest impact on supporting people with a learning disability and autistic people to leave hospital*
- *A survey about STOMP and STAMP*
- *An introduction to the new National Clinical Director for Learning Disability and Autism*

South West Learning Disability Nursing Showcase



LeDeR Reviewer Mel Axon attended this face to face event in February, which provided an opportunity for practitioners to share their good news stories and examples of best practice within their organisations.

An overview of the Learning Disability Nursing programme was followed by a national update and outline of the current position, showing a drop in numbers of LD nurses in secondary care over the past 15 years. However, leaver rates have also dropped in the past 10 years and training numbers have increased sharply in the past five years so it's not all bad news, and apprenticeships are growing too.

Learning Disability nurses have led some new service developments in areas across the south west, including new ways nurses are able to train, and innovations in recruitment and retention.

Kevin Elliott, Assistant Director of Nursing, Learning Disabilities and Autism Programme for NHSE presented a SW regional overview, which you can see here.



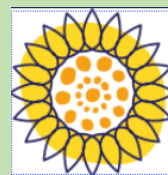
02-2024 SW LD
Nursing Showcase.pdf

Oliver McGowan Training

There are still plenty of spaces available on these training courses. Please sign up as soon as possible to ensure you and your team are fully trained. Bookings via training@autismsomerset.org and any queries to somicb.olivermcgowantraining@nhs.net



St Margaret's Hospice in Somerset provides specialist palliative and end of life care to patients who have a life-limiting illness, and their families. Their services are there for all patient groups, including those with a learning disability.



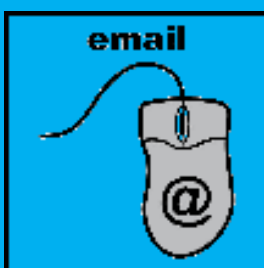
**St Margaret's
Hospice Care**

Over 85% of their patients are cared for within the community. For patients who need specialist symptom control or have complex end of life care needs, care may be provided within the 12 bedded in-patient unit located in Taunton.

The 24-hour advice line **01823 333822** is available for patients, carers, families, and Health Care professionals who require specialist palliative care advice or support. Calls are taken by experienced palliative care nurses.

You or the person you wish to discuss do not need to be known to St Margaret's Hospice but they do need to be registered with a Somerset GP and known to have a life-limiting illness.

The advice line can be busy, so there may be occasions when you need to leave a message. Staff will respond to your message as soon as they are able.



Contact Us

If you would like to contact our LeDeR team with any questions or queries please do so using the email address somicb.leder@nhs.net - we would love to hear from you.

And if there is anything you'd like to see included in a future newsletter, please let us know.