



Somerset LeDeR Newsletter

June 2019 - 3rd Edition

Message from Sandra Corry

**Chair of the South West LeDeR Steering Group and
Director of Quality and Nursing at Somerset Clinical**



Having been invited to Chair for the South West LeDeR Steering Group earlier this year, I am passionate about working with the wider healthcare community and system partners to turn the learning and examples of best practice from local LeDeR programmes into actions that make a real difference to the quality of life and services provided to people with learning disabilities. Across the region we

have already begun improvements within the system such as improving Annual Health Checks, supporting people with participation in screening programmes, making changes to content of safeguarding and equality training for healthcare professionals and promoting the use of hospital passports. There is however still much more that needs to be done. One particular area where there is an opportunity to make a big difference is through reasonable adjustments. People with a learning disability often face healthcare inequalities that result in around 1,200 avoidable deaths every year or take decades off their lives. This is why making reasonable adjustments is so important, simple changes made by even one healthcare professional can make all the difference to remove some of the barriers to access. Under the [Equality Act 2010](#), all services have a legal duty to make reasonable adjustments to ensure they are accessible according to individual needs. I am excited to see the actions and events being planned for the months ahead and look forward to working with you all to achieve a positive impact on the lives of people with a learning disability.

Somerset LeDeR Reviews

56 notifications reported 38 initial reviews completed
17 Reviews in progress 33 cases completed closed
0 unallocated cases

Main causes of death (where reported):

Pneumonia/Aspiration Pneumonia (17)	Chest/Respiratory Tract Infection (5)
Old Age (5)	Neurological Conditions (4)
Heart Disease/Cardiac Failure (3)	Renal Failure/Infection (3)
Pulmonary Embolism (3)	Cancer (3)

Call for more Reviewers

If you are interesting in learning more about care for people with a learning disability or are passionate about driving service improvement there is [training](#) available to become a LeDeR local reviewer.

For more information please contact us, details overleaf.



Learning Outcomes Around Reasonable Adjustments

Excellent examples of good care

- Care staff were with the patient for many hours while in hospital, initially for 3 consecutive days to ensure continuity of care. They also brought personal items such as soft toys and music that the patient liked.
- Consistent care staff made all the difference to an individual who was unable to communicate this verbally for themselves. Best interest decisions were able to be made by people that knew the individual well.
- The hospital team used analogies and language to give awareness of interventions, the reasons for them and simulated the process so the patient understood and knew what to expect, enabling procedures such as ultrasound scans to take place to support health.
- Staff at the care home made great efforts to meet the person's needs as their condition developed and reduced stress and anxiety. By doing this they helped to maintain independence, interest and dignity.
- Adjustments were proposed by the hospital to support treatment, including visits to the unit to meet staff, flexible times, a side room when possible, supporting the patient to wear their watch on the other wrist for accessing a viable vein.

Areas we can improve on

- Health care providers should ensure they have the right information and use the appropriate way of communication to enable people with a Learning Disability to attend and take part in health checks and screening programmes. For example, Easy Read letters or phone calls.
- Further training provided to staff to raise awareness and confidence in supporting the needs of someone with a learning disability.
- Increase the uptake and use of hospital passports and ensure that staff always read them to ensure the best possible experience for the individual.
- Clinicians should be fully aware of the need to actively engage with families and carers, especially when the person with a learning disability cannot express details of their condition and pain and a best interests decision needs to be made on their behalf.
- Learning Disabilities Nurse/Practitioner roles should be well understood, patient information leaflets and communications for families and carers with contact details and times of service provision needs to be developed.



National Update

The LeDeR programme welcomes the Government's announcement to consult on introducing mandatory learning disability training for health and social care staff. Read more about this at www.bristol.ac.uk/sps/leder/news/.

NHS England launched the Learning Disability Mortality Network for professionals across health and social care. To join, email england.ldmortalitynetwork@nhs.net

The Care Quality Commission (CQC) published a report on learning from deaths, read it here: www.cqc.org.uk/publications/themed-work/learning-deaths

Signs of Deteriorating Health

People with a learning disability, autism or both are more at risk from sepsis than other people and they are at higher risk of infection and get sicker, faster.

Liz Herriven is an emergency medicine consultant whose daughter Amy has Down's syndrome and autism. Amy has suffered sepsis several times in her 12 years. Listen Dr Rachel Marsden's podcast with her here: audioboom.com/posts/7004840-sepsis-listen-to-us-part-one

People often have trouble communicating when they are ill, or doctors may believe that signs of sepsis are a normal part of their pre-existing illness. This is called diagnostic over-shadowing, Liz talks about it in the podcast. When a person with a learning disability is unwell because of infection we want everyone involved to think 'could this be sepsis?' If we are all looking for it, we are less likely to miss it.

The LeDeR Programme has produced posters on sepsis and recognising deterioration: www.bristol.ac.uk/sps/leder/resources/information-and-resources-for-social-care-providers/

NHS England have produced a short film to raise awareness, watch it here: youtu.be/6XM6wLe8u6Q

The Sepsis Toolkit also provides information and resources for GPs and healthcare professionals as well as patients and those close to them: www.rcgp.org.uk/clinical-and-research/resources/

Learning Disabilities Training Pack

A free toolkit is available to any organisation wanting to improve the quality of care of people with learning disabilities in hospital: www.media.nhselect.nhs.uk/ldgwh/ldgwh.php.

The toolkit compliments the educational film, Matt's Hospital Visit: <https://youtu.be/vdXF7wZI2Bg>.

This newsletter can also be made available in Easy Read, please contact us for more information.

Key Principles for Reasonable Adjustments in Supporting People with LD

These are some practical examples of supporting people with a learning disability and their carers to meet their health needs.

Speak clearly with simple words — It is important to check that someone has understood information given to them rather than assume they have. Be careful not to be patronising.

Take your time — Just ten extra minutes can make a big difference for someone who may need a bit longer to understand information and to make themselves understood.

Work with carers and family — people supporting those with learning difficulties, especially with profound or multiple difficulties, can be great help when supporting the person to make a decision.

Be flexible with appointment times — offering appointments at the beginning or very end of a day when it is quieter can make it much easier for a person with a learning disability. Make sure the time is also suitable for their support person.

Make access as easy as possible — Remove physical barriers for those with wheelchairs or mobility issues and make sure signs are easy to read and understand.

Provide a quiet waiting area — busy and noisy places can be overwhelming for many people, having a quiet place can prevent anxiety and the person having to leave, especially if they have to wait a significant period of time.

Use hospital passports — having a personalised record of likes, dislikes, individual needs and how to communicate with a person will make hospital stays easier and less distressing.

Listen to your Learning Disability Nurse — they have good knowledge of reasonable adjustments and can help you to support your patient. If you know you are seeing a patient with a learning disability, ask the learning disability liaison nurse for advice and support.

Provide easy read information — people with learning disabilities are more likely to read and understand information about appointments, procedures and results in Easy Read format. This is also a requirement of the [NHS Accessible Information Standard](#).

Remember, reasonable adjustments is about the person in front of you, they will know best what they need along with their family or carers, so ask them and do your best to provide the support they need. More information on reasonable adjustments can be found online from [Public Health England](#), [NHS England](#), the [Care Quality Commission](#) and the [Royal College of Nursing](#).



Local Area Contacts

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