LEDER ANNUAL REPORT 2023–24

LEARNING FROM THE LIVES AND DEATHS OF PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE

September 2024

LeDeR Annual Report 2023–24

CONTENTS

LeDeR Annual Report 2023–24

1 EXECUTIVE SUMMARY

1.1 This report covers the period April 2023 – March 2024. There is an easy read summary of the report which can be found in Appendix 1. Additionally, a Makaton signed summary is available on our website.

1.2 Learning from the lives and deaths of people with Learning Disabilities and Autistic People (LeDeR) is a national service improvement programme that was set up with the aim of reducing health inequalities and preventing premature mortality by making changes to services both locally and nationally.

1.3 The aim of this report is to share learning from the LeDeR programme in Somerset in order to promote change across the health and social care system. This report will summarise what we have found out from the LeDeR reviews carried out in the reporting period, highlighting good practice and areas for improvement. It will discuss key themes that have emerged from reviews and highlight work the LeDeR team have already done with system partners to promote change and improve outcomes for people with learning disabilities and autistic people. Lastly, the report will identify key improvement priorities for the next year.

1.4 The report has been written by Dr Rachel Donne-Davis, Local Area Contact for the LeDeR Team, with contributions from Lauren Newcombe, LeDeR Senior Reviewer, and Dameon Caddy, Mental Capacity and Deprivation of Liberty Strategic Lead. The LeDeR Team have provided case studies for the report. Discussions by the LeDeR Governance and Improvement Group have also been incorporated.

2 INTRODUCTION

National

2.1 LeDeR is a national service improvement programme looking at deaths of people with learning disabilities and autistic people. The programme was established in 2017 and is funded by NHS England (NHSE).

2.2 The LeDeR programme aims to achieve the following:

- Improve care for people with a learning disability and autistic people.
- Reduce health inequalities for people with a learning disability and autistic people.
- Prevent early deaths of people with a learning disability and autistic people.

2.3 Everyone with a learning disability aged four and above who dies, and every adult (aged 18 and over) with a diagnosis of autism, is eligible for a LeDeR review. Notifications of a death of someone with a learning disability or autistic people can be made by anyone through the LeDeR website *https://leder.nhs.uk/*

2.4 A LeDeR review takes a holistic approach, looking at key episodes of health and social care the person received that may have impacted on overall health outcomes. Key areas of improvement, as well as good practice, are identified for sharing across the system locally and nationally. Involving people who knew the person well is a key part of the process and care is taken to involve family members or others who knew the person so a pen portrait can be developed.

2.4 Every person with a learning disability that LeDeR are notified of will have an Initial Review. Reviewers will then use their professional judgement to determine whether a Focused Review (a more in-depth level of review) is required. Focused Reviews can also be requested by the family of the person who has died.

2.6 In certain situations, a Focused Review will automatically be carried out:

- Where the person is from a black, Asian or Minority ethnic group.
- Where the person has a clinical diagnosis of autism but not a learning disability. This is being piloted while the reviews for autistic people are introduced.
- Where a local priority area has been identified. For example, in Somerset, where dysphagia or choking is identified as a possible cause of death, a Focused Review will automatically be carried out.

Local

2.7 Within NHS Somerset, the LeDeR Team sits within the Quality Improvement and Patient Safety Directorate. The LeDeR Team consists of a Local Area Contact (LAC), Senior reviewer, Three reviewers and a team administrator. The Chief Nursing Officer for NHS Somerset is the Senior Responsible Officer (SRO) for LeDeR.

2.8 In 2022-23, we identified the following improvement priority areas:

- Professional Practice and the provision of care.
- Care Pathways.
- Learning Disability awareness.
- Autism reviews.

2.9 This report will update on service improvement work related to these priorities and identify new priority areas as highlighted in LeDeR reviews in 2023-23.

2.10 In the LeDeR programme locally, we are privileged to work with a range of system partners to quality assure our reviews and ensure that learning is translated into action. In the following pages we share some of the views of people involved in the LeDeR programme.

"I have been delighted to continue in the role of SRO for this really important area of work. The LeDeR process continues to enable us to learn as a system, implementing actions where improvement is required, learning from areas of good practice and monitoring the effectiveness of the improvements we make. Our continued focus on learning from individual experiences of the care and support we provide and improving the outcomes for our population is so important."

- Shelagh Meldrum, LeDeR SRO and Chief Nursing Officer & Director of Operations, NHS Somerset.

"It's been a brilliant experience working with colleagues from the LeDeR programme. There is a real desire to enact change, and being able to collaborate together on innovative education projects to help improve the healthcare experiences of those with learning disabilities and autism has been really fantastic. Our partnership has allowed our work to be put on a wider map and injected much needed awareness and enthusiasm into our content and curriculum. I am truly grateful to this inspiring group and I look forward to further collaborations and opportunities to work together in the future."

- Laura James, End of Life Care

"The LeDeR work continues to provide invaluable insight into the experiences of people with learning disabilities and autistic people, locally. Learning from people's experiences of the health and care services that they experience is key to helping us to improve how we provide care and achieve the wider goals outlined in our health and care strategy for Somerset.

By celebrating what has gone well and identifying areas for improvement LeDeR is able to inform service improvement with the aim of improving people's experience of our health and care system.

A highlight of the work that we have done in partnership with other local organisations in the last year was the launch of 'We need to talk about... Death'. A powerful film made with people with learning disabilities about death, dying and bereavement. The film aims to break down some of the taboo around death and dying and encourage people to have a conversation. The views expressed by the 'stars' of this film give us all food for thought and encourage everyone to talk about this subject that we often avoid. If you haven't watched the film I would encourage you to do so and I look forward to seeing where it goes next."

- Jonathan Higman, Chief Executive, NHS Somerset

Patient Engagement

2.11 Meaningful engagement of people with learning disabilities and autistic people is key to LeDeR being effective as a service improvement tool. This is an area we have been working on and are keen to improve upon further in the next year.

2.12 We have worked with OpenStoryTellers, Biggerhouse Film and My Day Care Services to better understand people's experiences and to start to understand how to have better conversations with people with learning disabilities and autistic people about death and dying. It has been great to speak to more people about their experiences, but we are keen to increase our work in this area. In particular, we want to involve people with lived experience more meaningfully in our governance processes. This is something that will be a key priority moving forward.

2.13 It is important to remember that this report is about the deaths of people with learning disabilities and autistic people. Whilst the case studies and data are anonymised, these are real people's stories. Their lives were important and of significant value and the impact their deaths have had on their family and loved ones will doubtless be substantial.

2.14 We would like to thank families and carers who have taken the time to speak to us during what has often been a really difficult time in their lives. Their contribution to this process has been invaluable and we feel privileged to share part of their story.

Quality Assurance and Governance

2.15 All LeDeR reviews in Somerset are quality assured via peer review and signed off by a combination of the LeDeR LAC, Senior Reviewer and another relevant health care professional. Additionally, Focused Reviews are further approved by a Focused Review Panel which is a subgroup of the LeDeR Governance and Improvement Group. The LeDeR Governance and Improvement group has representation from across the Somerset system. This includes health, social care, family carer and voluntary sector representation. This group reports to the ICB Quality Committee and NHS Somerset Board as needed.

3 LEARNING FROM DEATHS IN SOMERSET

Notifications

3.1 40 notifications were received between April 2023 – March 2024. Two of these notifications were later transferred to another ICB. These transfers occurred as whilst the patients died in Somerset, they lived in other ICB areas and received their care and support in those places for the majority of their lives. Of the 40 notifications, only one was received for an autistic person. Chart 1 details the frequency of notifications across the reporting period. Chart 2 illustrates where the notifications came from and as per

previous years the highest number of notifications came from the acute sector.

Chart 1

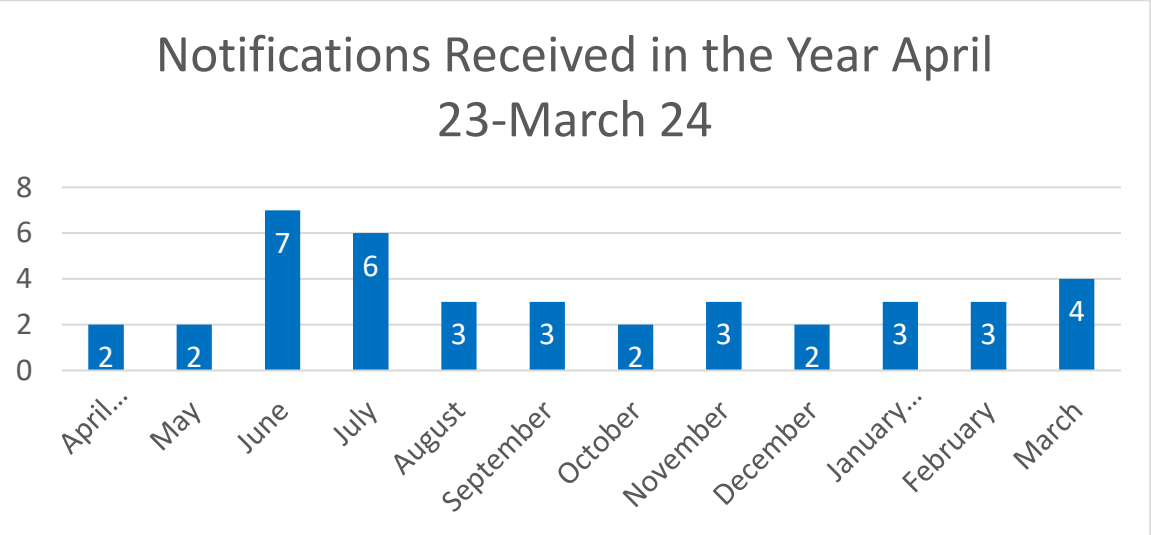
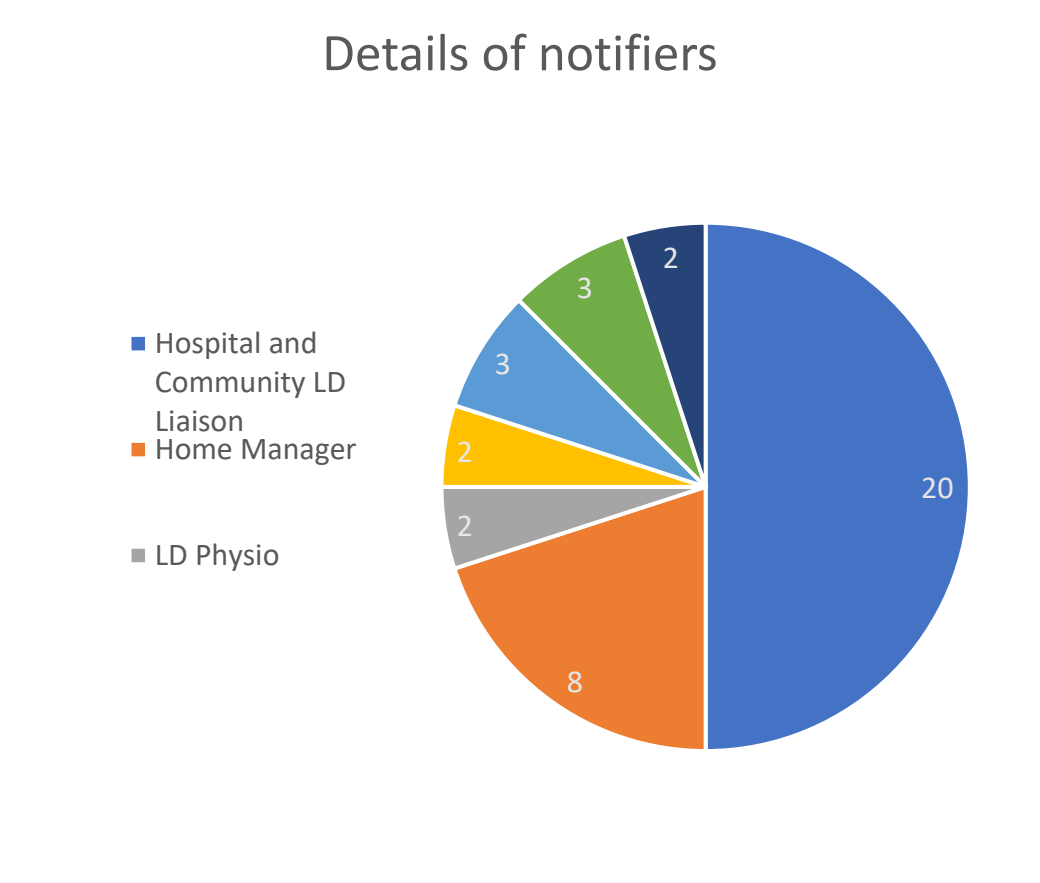


Chart 2



Autism Reviews

3.2 During the reporting period, we received one notification of the death of an autistic person, which was completed within six months of receipt. Additionally there was one review of the death of an autistic person which was received in 2022/23 and still on hold in the reporting period due to waiting for other statutory investigations to conclude. This review was completed in June 2024 and therefore not included in this annual report.

3.3 Locally we are still receiving a relatively small number of notifications related to deaths of people with a stand-alone diagnosis of autism. This reflects the national picture, however we are working locally to increase the awareness of the LeDeR programme with autistic people and services that support them.

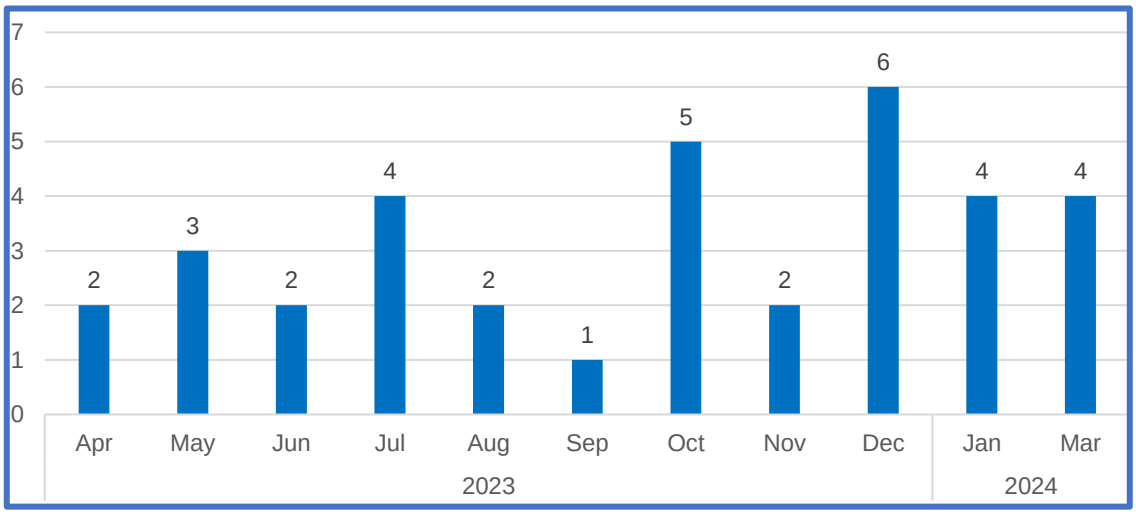
3.4 Due to the small number of reviews completed, we are unable to comment on themes arising from these reviews in this report, but learning from specific reviews has been taken forward.

Completed Reviews in 2023-24

3.5 There were 35 reviews completed in the reporting period. Of these, 17 were focused reviews.

3.6 NHSE suggest that a minimum of 35% of reviews should be Focused. Regional data from a six-month rolling period to April 2024 indicates that 48% of reviews completed in Somerset were focused reviews.

Chart 3



Key Performance Indicators

3.7 NHSE set two key performance indicators (KPI) for LeDeR teams:

- That all notifications will be allocated within three months of receipt.
- That all reviews will be completed within six months of notification.

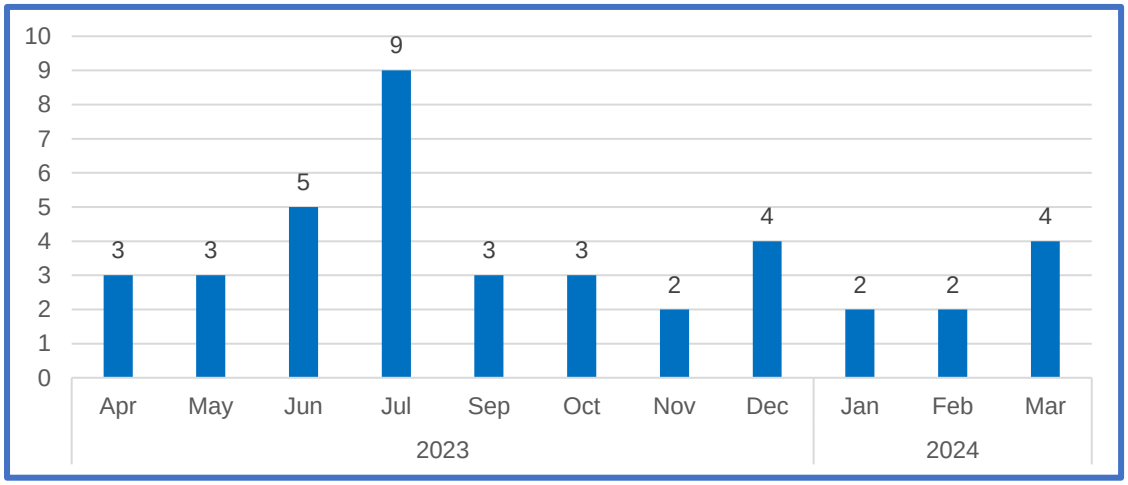
3.8 Of the 35 reviews completed in the reporting period, all were allocated within three months of notification.

3.9 There were 28 of 35 reviews completed within six-months of notification. The 11 reviews that missed the KPI deadline did so because new information came to light that meant that the reviews were escalated to a Focused Review at quite a late stage.

About People Who Died

3.10 The following demographic information is based on date of death as opposed to date of review completion or date notification was received. This brings our reporting in line with national data analysis and allows for more timely learning from deaths. 40 deaths occurred during the reporting period and these are detailed in Chart 4.

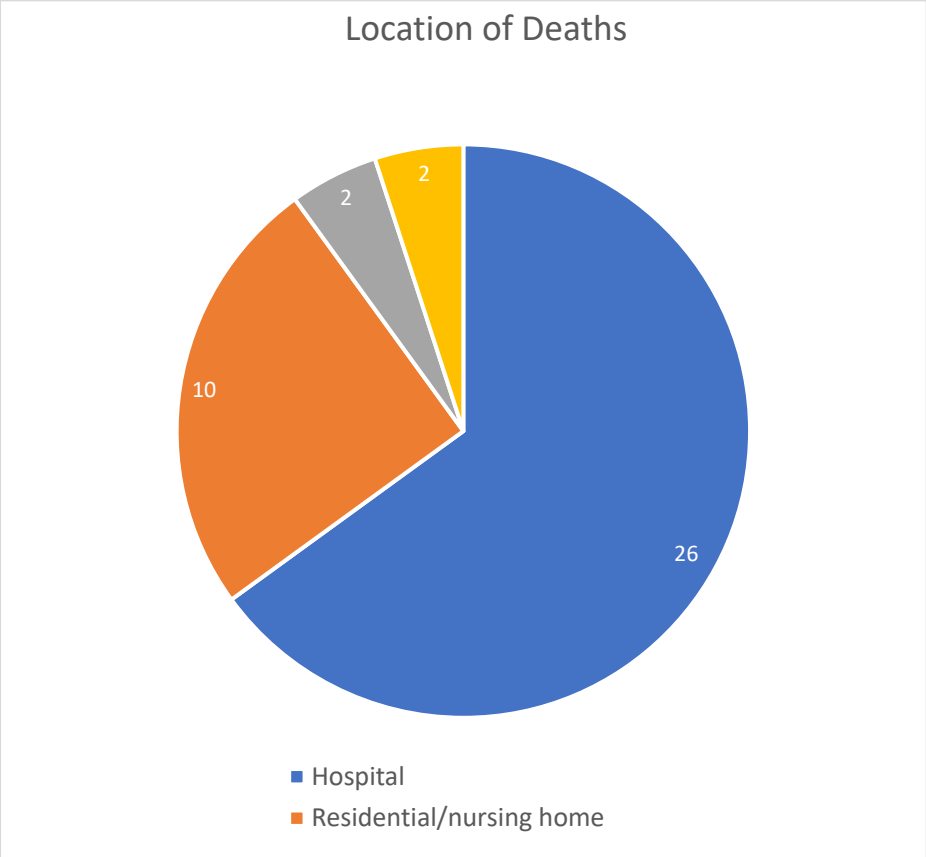
Chart 4



Location of Death

3.11 Similarly to the previous reporting period the highest number of deaths occurred in a hospital setting. This is in line with national findings which reported that 57% of deaths occurred in a hospital setting. (*1)

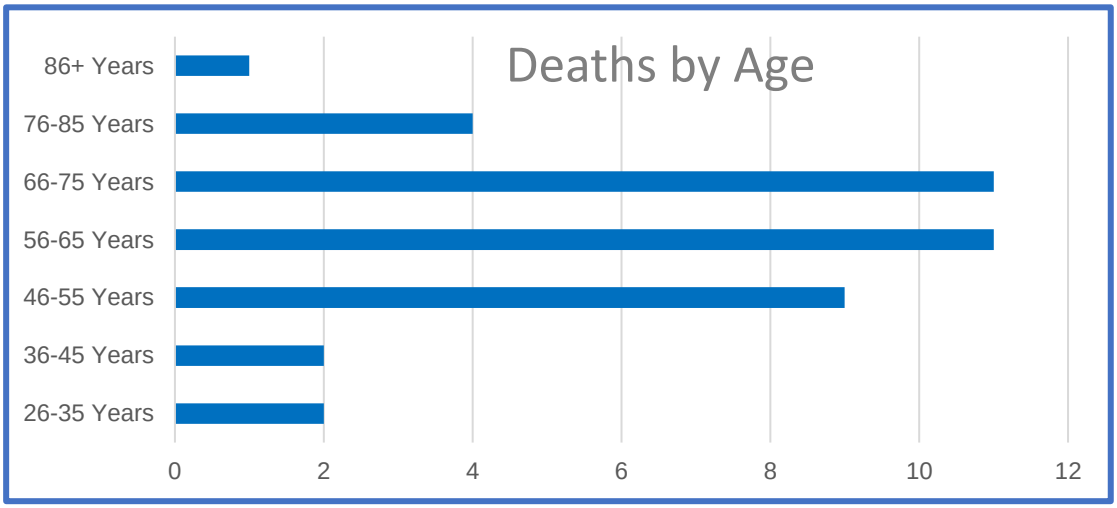
Chart 5



Age at Death

3.12 The highest proportion of deaths occurred in the 56-65 and 56-75 age ranges. This is detailed in Chart 6 and mirrors the data presented in the national LeDeR data (*1). This also reflects a slight increase in the average age of death since the last reporting period, but not a significant one.

Chart 6



Gender

3.13 Of the 40 deaths that occurred in the reporting period, 28 were for people who identified as male and 12 were for people who identified as female.

Ethnicity

3.14 Of the 40 deaths in the reporting period, 38 were for people whose ethnicity was recorded as white British. One individual's ethnicity was recorded as mixed/multiple and two deaths did not include any ethnicity data.

3.15 The 2021 census (*2) indicated that in Somerset 91.3% of the population would describe themselves as White British. Whilst LeDeR data from the current reporting period does not differ significantly from this it is important to interpret ethnicity data with caution due to the small numbers involved.

Cause of Death

3.16 Chart 7 details the main Cause of Death as grouped by International Classification of Disease (ICD-10) chapter codes for each death in the reporting period. Please note: this only includes information for 39 deaths as one review was transferred to a team in another ICB prior to receiving the cause of death information.

3.17 The ICD-10 is a standardised tool used to code and understand medical conditions and causes of death. Grouping the data in this way brings us in line with the national LeDeR report and allows for ease of data analysis.

3.18 The cause of death data from 2023/24 is similar to that of the previous reporting period with 'diseases of the respiratory system' being the most commonly recorded cause of death, albeit with fewer deaths in the category than 2022/23 (12 deaths compared to 20 deaths). The next most common cause of 'death categories recorded are 'diseases of the circulatory system' (eight deaths) and 'infectious and parasitic diseases' (eight deaths). Of note is the fact that five of the deaths in the 'infectious and parasitic disease' category related to sepsis. Whilst these five deaths differed in their contributing cause of death, we propose to carry out a deep dive into these deaths to ensure any thematic learning has been identified and followed up appropriately.

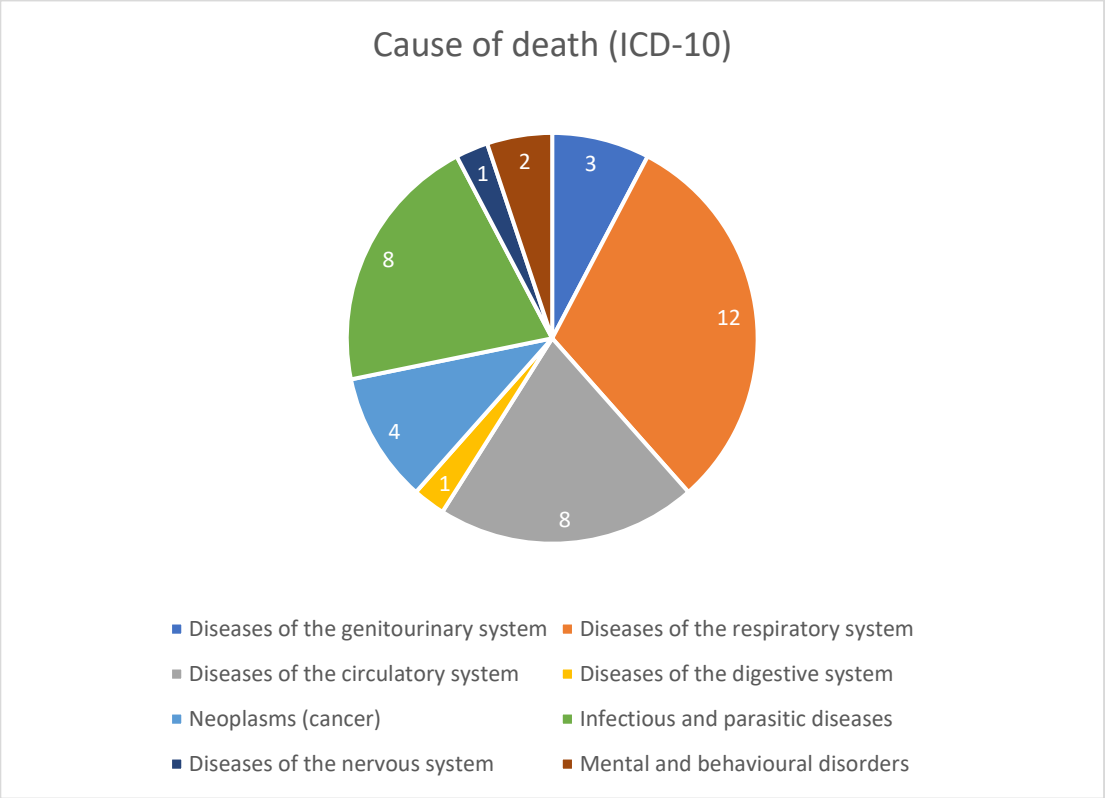
3.19 There were no deaths where epilepsy was indicated as a primary cause of death. As such we did not carry out any Focused Reviews, even though this was previously determined as a priority area locally. Going forward we will only carry out Focused Reviews for epilepsy related deaths if significant learning is identified.

3.20 The local data closely mirrors national data. The most recently available national data also indicated 'diseases of the circulatory system' and 'diseases of the respiratory system' as the most commonly reported causes of death based on ICD-10 chapter codes.

3.21 Regarding respiratory deaths we will continue to carry out Focused Reviews of respiratory deaths where significant learning is indicated.

3.22 There are further recommendations relating to the prevention of respiratory deaths which are detailed later in this report as a result of our deep dive into the 20 respiratory related deaths in 2022-23.

Chart 7



4 PEOPLES' STORIES

4.1 At the heart of LeDeR are people - real people with real stories and we are uniquely privileged to be able to hear these stories and learn from them as we conduct LeDeR reviews. Spending time with family members and other people important to the person who died gives us a unique insight into that person. We are so grateful to all the people who have given their time to speak to us. Below are just a few examples of some of the stories we have had the privilege of sharing as a team. The stories highlight areas of both good practice and areas for improvement. Names and other identifiable details have been changed to enable the stories to be shared anonymously.

David’s Story

4.2 David was an independent man with a moderate learning disability. He was described as a cheerful character who loved banter. He lived in a flat on his own and received 1.5 hours daily support. David had Type 2 diabetes and obesity which were longstanding health issues along with leg and feet ulcers. Treatment and management of this condition was impacted by David not always attending health appointments, attending late, or not being willing / able to comply with treatment. After warnings from his GP practice about non-attendance, he was removed from their list despite ongoing health needs in relation to his leg wounds. He was not known to the Community Team for Adults with Learning Disabilities and there was a lack of effective reasonable adjustments made to support David with accessing mainstream services. He was eventually admitted to hospital with concerns about extensive bilateral foot and leg ulcers responding poorly to dressings and antibiotics and complicated by poor engagement and self-neglect. Sadly, David did not respond to treatment and found it hard to comply with treatment in the hospital at times. The LD liaison team were involved and reminded the medical team of the need to follow the MCA. David's condition worsened and it was agreed with his mother, that it would be in his best interest to be placed on palliative care. He passed away in hospital of cardiac and renal failure, aged 62 years old.

Claire’s Story

4.3 Claire had diagnoses of cerebral palsy and scoliosis. She lived in a supported living setting and was very close with her family. She was described as a lovely person who smiled a lot, she enjoyed going out shopping and loved the company of others. She did not use speech to communicate but was able to vocalise, use key word signing and had an app on her iPad to support her communication. She developed what appeared to be a blood blister in her mouth which grew considerably and was initially treated as an abscess. Following tests, Claire was diagnosed with oral cancer. It was decided that she would have palliative care as treatment would not have been curative and would have been very difficult for Claire to cope with. Claire later died peacefully in a hospice at the age of 57. There were concerns about the quality of oral care and monitoring and if the increasing area in Claire’s mouth could have been noticed earlier. There were also concerns that she had a lack of daytime activity following the Covid pandemic. Positive practice was seen from LD health professionals who provided good support after Claire was diagnosed with cancer.

Robert's Story

4.4 Robert was a man who had profound learning disability who died at the age of 77. He had very limited ability to communicate and relied on people that knew him well to understand his needs. He had lived in a specialist learning disability residential home. He had epilepsy, suffered two strokes and had significant problems with his heart and respiratory health. After time in intensive care, he was placed on palliative care. There was good multi-agency working between primary and acute care during the final stage of his life. He had a very detailed, bespoke Treatment Escalation Plan. This meant that Robert was able to be cared for by his familiar care team in his own home and die surrounded by people that he knew rather than suffer repeat inappropriate hospital admissions.

Emma's Story

4.5 Emma was a lady with Down's syndrome and a moderate learning disability. She was the youngest of eight children. She moved from the family home into a specialist residential home where she lived for 30 years. She remained close with her family, particularly her Mum who visited often. She lived a very full life including working in a local school and holidays abroad. People started to notice changes in how Emma was behaving, and she was eventually diagnosed with Alzheimer's dementia and later with epilepsy. Following two hospital admissions due to seizure activity and a deterioration in Emma's mobility she was put onto palliative care. Emma developed pressure sores which were managed by input from District Nursing. She was also having increasing difficulties with eating and drinking. She was prescribed thickener but was not referred to Speech and Language Therapy for assessment. Emma had a Treatment Escalation Plan completed with input from her family and care provider in a timely way with a focus on quality of life. There was a proactive plan to support at home and not to be admitted to hospital. It was agreed that Emma could stay in her residential home for end of life care rather than be moved to an unfamiliar nursing home. She died at the age of 53.

5 LEARNING INTO ACTION

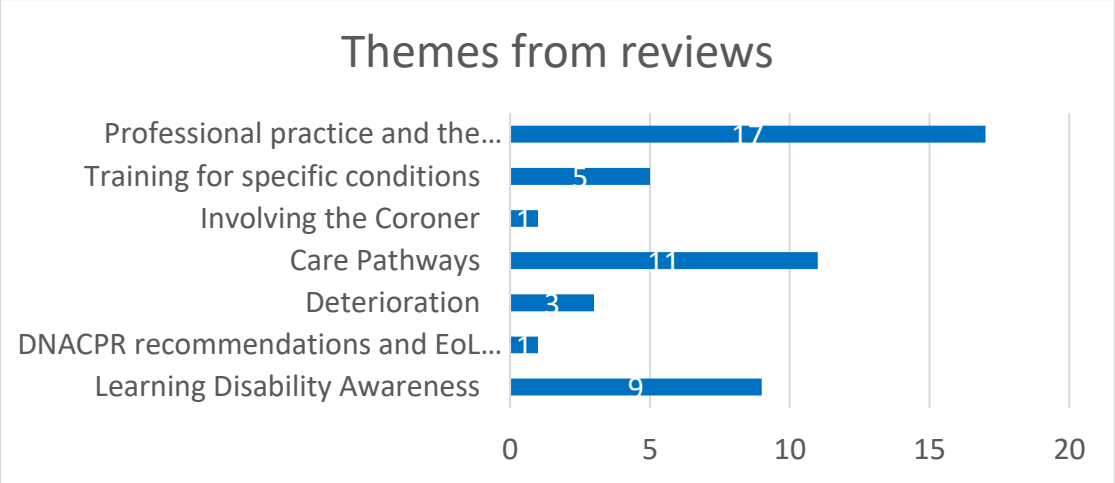
5.1 LeDeR is a service improvement programme so ensuring that learning from the reviews leads to changes in practice locally is at the core of what the programme is trying to deliver in Somerset.

Themes from Reviews

5.2 All learning generated from reviews is grouped into themes to allow us to pick up on patterns. Chart 8 illustrates what themes have most commonly been identified during 2023-24.

5.3 Similarly to the last reporting period, the most common theme was professional practice and the provision of care, followed by Care Pathways and Learning Disability awareness. This is not a surprise and our current and planned service improvement projects are designed to address this across the Somerset system.

Chart 8

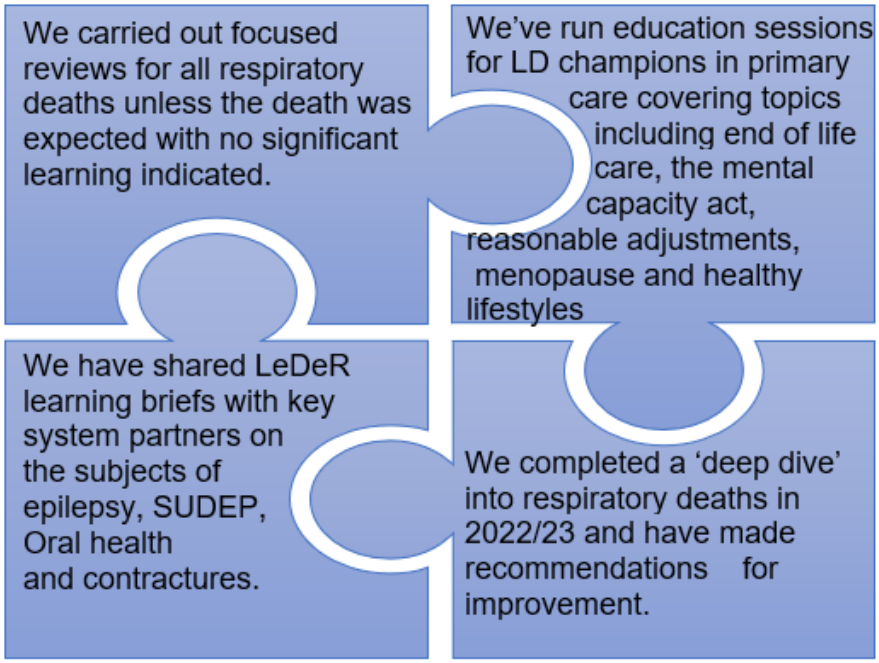


Update on Learning into Action

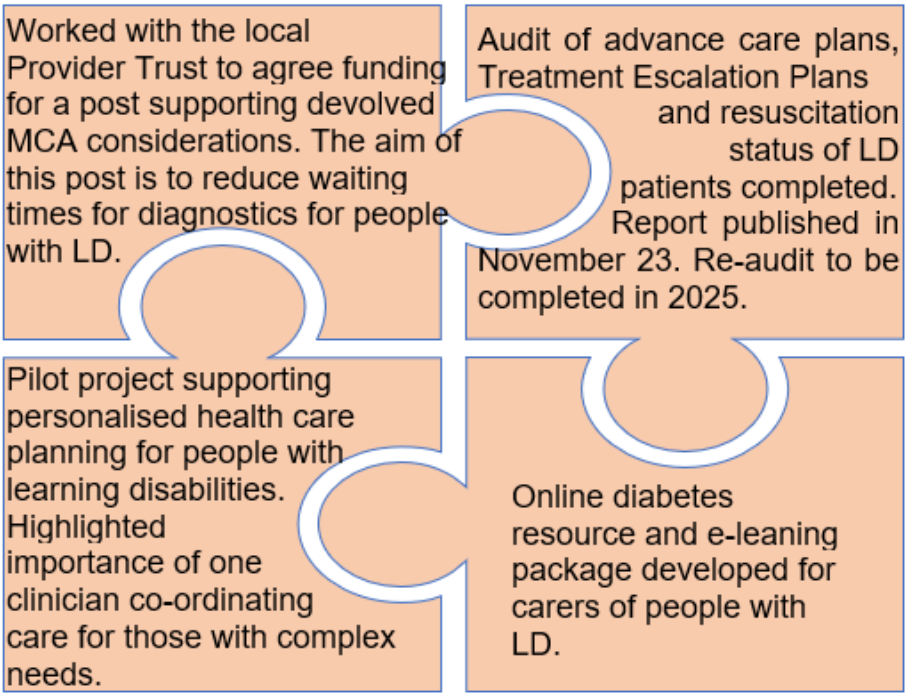
5.4 The following is a summary of what has been achieved across the Somerset system against the service improvement priorities identified in our last annual report. We have used the image of jigsaw puzzle pieces as it is only when these developments work together that they are truly effective in improving outcomes for people with a learning disability and autistic people.

5.5 In addition to the overview there is further information provided on our review into respiratory deaths and the work we have carried out in relation to the Mental Capacity Act, (MCA)

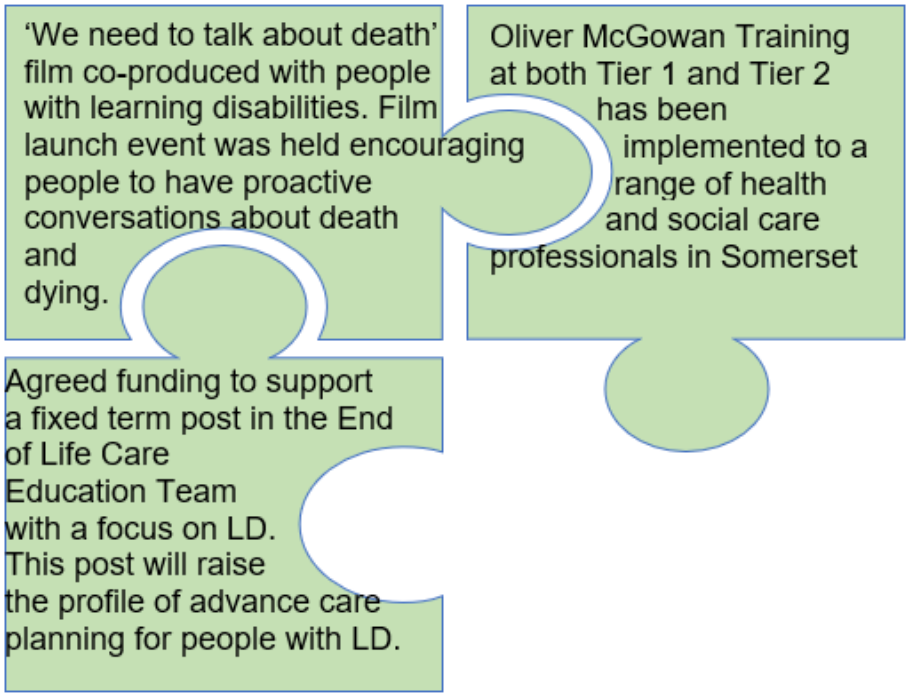
Professional Practice and the Provision of Care



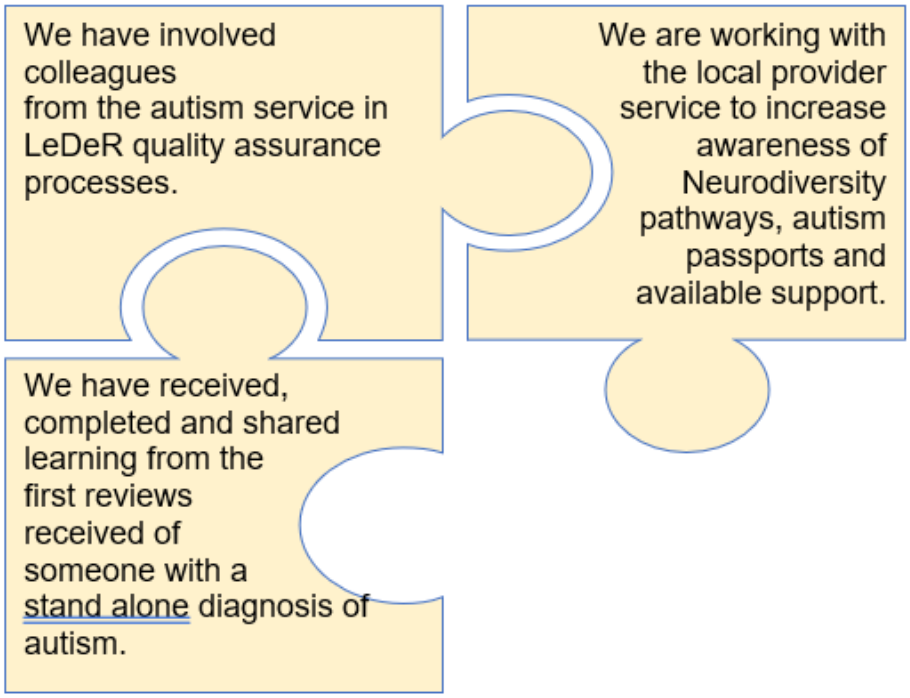
Care Pathways



Learning Disability Awareness



Autism Review



LEARNING INTO ACTION: RESPIRATORY DEATHS

5.6 As an outcome of our previous annual report, we carried out a deep dive into the 24 respiratory deaths that occurred in 2022/23. The full report can be viewed in Appendix 2, but a summary of the findings and relevant recommendations can be found below.

5.7 There were a range of causes of respiratory death, but aspiration pneumonia and pneumonia were the most commonly reported. There were a number of individual issues raised in reviews including delays in the funding of specialist equipment, Speech and Language Therapy and Physiotherapy care plans not being followed and lack of proactive support around weight management. Additionally, there were some common themes that ran through a number of the reviews which have informed our recommendations.

- Challenges regarding the use of Treatment Escalation Plans (TEP). These included TEP forms not being easily accessible, significant information being missing and the forms being completed without involvement from the person or someone who knew them well.
- Lack of advance care planning ahead of patient deterioration so patients weren't able to be supported in the way they wanted at End of Life.
- Lack of recognition of patient deterioration and the appropriate use of patient deterioration tools.

Recommendations:

- There is an End of Life Learning Disability Practitioner in post carrying out work regarding Advanced Care Planning (ACP) and TEPs. This is currently only a fixed term post. However, evidence from the review of respiratory deaths would support the need for this to become a permanent post.
- There has been a pilot of 'No Barriers Here' which is a creative approach to ACP with people with learning disabilities living in residential care in Somerset. This has led to an increased number of ACPs and TEPs being completed. There may be funding available to train more people in this approach and increase availability.
- Further work is needed to raise awareness and increase use of appropriate patient deterioration tools in a consistent way.
- We will work with our vaccination team to increase the uptake of influenza and pneumococcal vaccines in high-risk groups within the learning disability population.
- We will share information across the system about the importance of Multi Disciplinary Team (MDT), working and a holistic approach regarding the risk factors and management of respiratory health.

LEARNING INTO ACTION: THE MENTAL CAPACITY ACT

5.8 Several key themes relating to the Mental Capacity Act became apparent through LeDeR reviews in 2023/24.

Treatment Escalation Plans / Do Not Attempt Resuscitation

5.9 There were a number of cases where individuals were simply not consulted when these documents were written, which is a finding mirrored in the Somerset contribution to the SW LeDeR Tep Audit. This data and learning from LeDeR has helped inform the recent redesign of the STEP process (Somerset Treatment Escalation Plan). Key changes involve:

i) Making explicit the difference between patient and clinical decision making.

ii) Introducing prompts not to override good quality TEPS completed in the community.

iii) Making explicit how the MCA applies differently in respect of the TEP and DNACPR elements of the document.

Disputes in regard to MCA responsibility

5.10 One case drew panel members attention to the scope for clinicians abdicating MCA responsibility. Here the individual failed to receive timely diagnostic intervention due to a delay in agreeing MCA responsibility. Further enquiry through the LeDeR process revealed a more nuanced picture, with hospital staff struggling to make reasonable adjustments due to the fact that they are not community based. Following on from this, a business case for a LD liaison post responsible for devolved MCA considerations was submitted and accepted. Funding was agreed for a fixed term post for a year, with a view to its effectiveness being evaluated.

Presumption of Capacity

5.11 A common theme in many cases is simply where the MCA has not been considered where there was a clear indication that it should have been. Examples here include; i) clinicians failing to explore an individual's choice to make themselves bedbound, ii) removing individuals from GP list due to non-attendance (see David's story). This links to wider work being carried out by the Somerset Safeguarding Adults Board which made similar observations. LeDeR Reviewers received additional training in 2023/2024 enabling them to better understand and interrogate MCA consideration as it can sometimes be more difficult to explore what is NOT there rather than what is present. LeDeR learning has also helped to inform sessions offered to GPs in regard to the MCA.

Ethical Tensions regarding MCA implementation

5.12 Aside from practical or knowledge-based concerns, sometimes cases drew attention to the fact that the MCA was not implemented due to moral tensions. For instance, one case involved an individual not being informed of a serious diagnosis due to the distress it would cause, only to find out in another hospital in an unplanned distressing manner. The LeDeR process considered how reasonable adjustments might have been considered alongside links to operational forums (i.e. clinical ethics committee).

LEARNING INTO ACTION: PLANS FOR THE FUTURE

5.13 Based on key themes coming out of LeDeR reviews in 2023-24, learning from other sources such as Safeguarding Adults Reviews, and specific discussions at the LeDeR Governance and Improvement Group, we intend to focus on the following areas of work in 2024-25:

Patient engagement

- Work to increase the involvement of people with learning disabilities and autistic people in LeDeR processes.
- Work to increase awareness of the LeDeR programme with autistic people and those that are significant to them, as well as those that provide health and care services for them.
- To involve people with learning disabilities and autistic people in the production of next year's annual report.

The Mental Capacity Act

- Review the Mental Capacity Act Competency Framework.
- Establish the Mental Capacity Act Learning Disability Liaison Nurse post and begin evaluation of its effectiveness.
- Continue to disseminate good practice in terms of the Mental Capacity Act, in relation to LeDeR learning.

End of Life Care

- Clarify and promote consistent use of patient deterioration tools in Somerset.
- Complete re-audit of Treatment Escalation Plans, advanced care planning and resuscitation decisions for adults with learning disabilities in Somerset.
- Implementation of the new Treatment Escalation Plan form and associated electronic form.

- Take the ‘We Need to Talk about… Death’ film on tour and use as a platform to share End of Life care good practice.
- Increase awareness of the End of Life Care needs of people with learning disabilities and autistic people.
- Continue to evaluate the End of Life Care Practice facilitator role to evidence impact.
- Expand the ‘no barriers here’ advance care planning project to increase access to advance care planning for people with learning disabilities.

5.10 Additionally, we will carry out the recommendations from the review into respiratory deaths, as well as carry out a deep dive into the sepsis related deaths that occurred in 2023-24.

6 CONCLUSIONS

6.1 2023-24 has been a time of growth for the LeDeR programme in Somerset. Despite considerable changes and challenges it has been encouraging to see system partners continue to engage with and support the LeDeR process, leading to some meaningful change in Somerset.

6.2 Working with Biggerhouse Film and My Day Care Services to launch the film ‘We Need to Talk about… Death’ was a particular highlight culminating in a celebration event with the cast, their family members and health and care professionals from across the South West. This resulted in some media coverage and has certainly started a conversation about death, dying and bereavement and the importance of having those conversations with those with learning disabilities and autistic people.

6.3 David, Claire’s, Robert’s and Emma’s stories highlight that while some improvements have been made, we still have a long way to go to ensure that people with learning disabilities and autistic people receive the best possible care and support. We hope that the areas of service improvement we have chosen to focus on moving forward will go some way to addressing this.

References

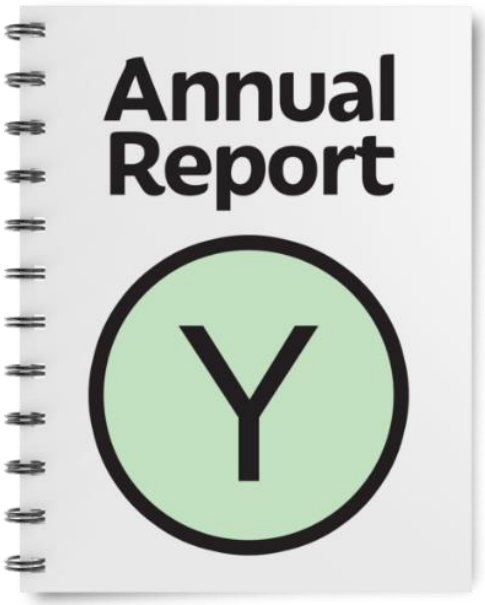
1) Kings College London (2023) Learning from Lives and Deaths – people with a learning disability and autistic people.

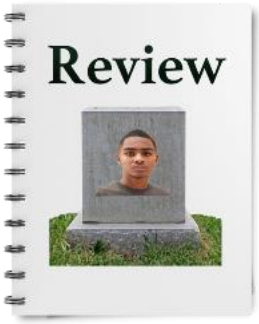
2) Census (2021) TSO30

APPENDIX I – Easy Read Summary

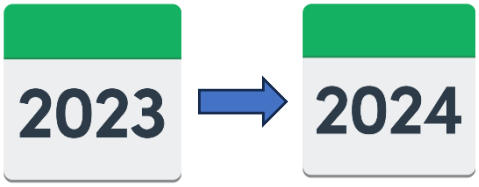
LEDER ANNUAL REPORT 2023-24

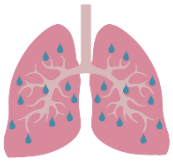
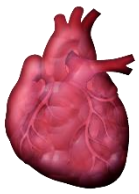
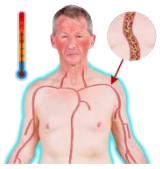
Learning from lives and deaths:
People with a learning disability and autistic people

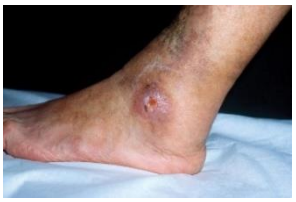
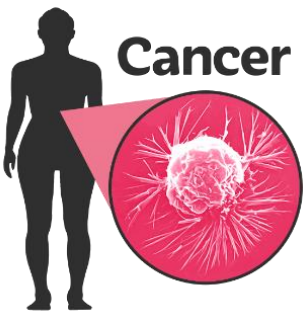


	**1. About our report**
	All adults with a learning disability and autistic people who die in Somerset have a review. This is called a LeDeR review.
	A LeDeR review looks at what care was good for the person who died.
	The LeDeR review looks at what could have been done better for the person who died.
	All LeDeR reviews are checked to make sure they are written well.

	We talk to the people who knew the person who died, like their family and carers.
	We want to say a big thank you to all families and carers who have taken part in our reviews. Sometimes it is really difficult to talk about the death of someone you have cared for.

	**2. The people who died**
	This report is about people who died between April 2023 and March 2024.
39 	We were told about 39 people with a learning disability who died.
1 	We were told about 1 autistic person who died.
	Most people died in hospital.
	Young and old people died. Most people who died were over 56 years old.

 	28 of the people who died were men. 12 of the people who died were women.
   	Most of the people died of: - Flu and lung infections - Heart problems - Other infections

<table>
<tr><td>  </td><td>3. People’s Stories</td></tr>
<tr><td> 
 
  </td><td>David’s Story
David lived in his own flat and did not have very much help.
He had diabetes and was overweight
He had sores on his legs and feet.
He found it difficult to get to appointments with his doctor on time.
He had to find a different doctor’s surgery.
People working with David did not give him the help he needed. This is called making ‘reasonable adjustments.’
David’s sores got worse.
He went to hospital and died. He was 62 years old.</td></tr>
<tr><td></td><td></td></tr>
<tr><td> 
  </td><td>Claire’s Story
Claire had cerebral palsy. She did not speak but used signing and pictures.
She had support where she lived and had help from her family.
She had a blister in her mouth which got bigger.
Claire had some tests. She had cancer in her mouth.
Doctors could not cure her cancer.
Claire had good support after she was told she had cancer.
Claire died in a hospice. She was 57 years old.</td></tr>
</table>

Robert's Story

Robert could not speak and needed a lot of support.

He lived in a special home for people with learning disabilities.

He had epilepsy, heart and lung problems and had 2 strokes.

Doctors said he was going to die.

People worked together to plan how to give him a 'good' death.

Robert died at home and was looked after by the people who knew him the best. He was 77 years old.

Emma's Story

Emma had Down's Syndrome.

She lived in a special home for people with learning disabilities.

She had a loving family.

Emma started to change and people were worried.

She had some tests and found out she had dementia.

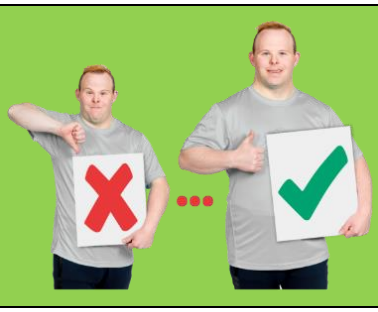
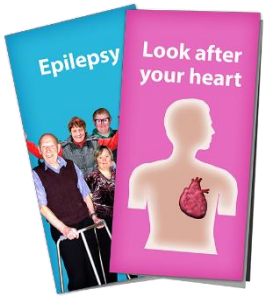
Emma started to have seizures. She had epilepsy.

Emma could not walk anymore and was not going to get better

People worked together to plan how to give her a 'good' death.

Emma found it difficult to eat, drink and swallow. She was not seen by a Speech and Language Therapist.

Emma died at home and was looked after by the people who knew her the best. She was 53 years old.

	**4. What we have done to make care better**
	We looked into the deaths from flu and lung infections in 2022-2023.
	We shared information with people about; - Epilepsy. - The Mental Capacity Act. - Oral care.
	We worked with staff in doctor's surgeries to help them understand more about people with a learning disability.
	We made a new job to help people understand the Mental Capacity Act.
	We made some information about diabetes for care staff.

	A doctor did some work about person-centred care plans.
	We did some work to help more people talk about death, dying and what is important to them.
	We made a film with people with learning disabilities called ‘We Need to Talk about… Death.’
	We made a new job to help people understand more about the care people with learning disabilities and autistic people need at the end of their lives.
	We carried on giving training to people about learning disabilities and autism. This is called Oliver McGowan Training.
	We worked with health and care teams who support autistic people to help us improve the work we do in LeDeR.

	**5. What we are going to do next**
	We will look closely at the deaths in 2023-2024 from sepsis. Sepsis is a type of infection. We want to make sure that care for people with learning disabilities and autistic people is good.
	We will keep working with health and care staff to help them to understand the Mental Capacity Act. We will help the person starting the new job about the Mental Capacity Act
	We will work with autistic people and the Somerset Autism service to tell them about LeDeR.
	We will work with people with learning disabilities and autistic people to help us make LeDeR better.
	We will tell people about the ‘We Need to Talk About... Death’ film and share information about how to look after people at the end of their life.

	We will help more people to talk about death and dying and to plan what they would like to happen.
	We will try to find out how many people have a Treatment Escalation Plan or Advance Care Plan. These are plans about what people want to happen when they get unwell and near the end of their life.
	We will try to understand more about the new job supporting people with learning disabilities at the end of their life.

- If you would like to see this report using Makaton signs, click here:

Signed report

- If you would like any more information on this report please contact the LeDeR team:

by email  somicb.leder@nhs.net

by phone  **01935 384000**

APPENDIX 2

ANNUAL REPORT – RESPIRATORY DEATHS

Literature Review

Truesdale et al (2021) carried out a systematic review into respiratory-associated deaths in people with learning disabilities: Respiratory disorders are a leading cause of death among people with learning disabilities and when compared with the general population, the relative risk of respiratory related deaths was 2.6 times higher for people with mild learning disabilities and 5.8 times higher for people with profound and multiple learning disabilities. Pneumonia was found to be major contributor to the higher respiratory mortality rate and there is evidence that highlights the need for work to reduce the risk of premature death including via vaccination programmes for influenza. They suggest that people with learning disabilities should be identified as a high-risk group and that vaccine uptake should be prioritised, for example via Annual Health Checks. NHS England (2023) also recommend that people with a learning disability should receive a pneumococcal vaccination if they are considered to be at risk **in addition to the childhood vaccination schedule.**

They also found that people with a learning disability are at an increased risk of recurrent chest infections which are secondary to dysphagia, with a high proportion of aspiration pneumonia-related deaths occurring among individuals with severe and profound learning disabilities. Aspiration pneumonia can occur after abnormal entry of material into the lower respiratory tract. The aspirated material may be food, drink, medication, secretions or gastric content. According to Glover and Ayub (2010), people with a learning disability are, on average, seven times more likely to die from lung inflammation caused by aspiration than people who do not have learning disabilities. Conditions that are associated with learning disability such as cerebral palsy, Down's syndrome, dementia and epilepsy can all impact on a person's ability to eat, drink and swallow safely which increases the risk of aspiration, and the subsequent risk of developing aspiration pneumonia.

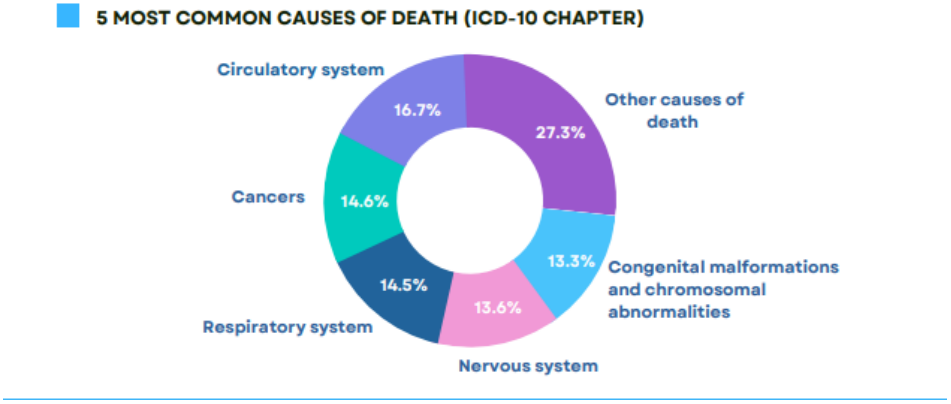
We have a limited understanding of the complex and multifactorial relationship between dysphagia, aspiration, respiratory infection and other health issues (Brown and Burnam 2021). Whilst there should be a continued focus on ensuring that people's dysphagia is managed effectively to reduce risk of aspiration as far as possible, it should also be recognised that other factors need to be considered in order to improve respiratory health. Aspiration pneumonia can occur when eating and drinking but can also occur during periods of impaired consciousness (e.g. during seizure activity), or due to other conditions such as gastro-oesophageal reflux. People receiving nasogastric feeds or with a tracheostomy are at particular risk, as are those with poor mobility or posture problems, frailty, poor oral health, or using certain medications (NHS England 2023). Ashford (2005) highlighted that aspiration does not always lead to aspiration pneumonia: 'Clinicians should be aware of the complexity of serious illness and how the alterations to major systems of the body can lead to dysphagia and pneumonia. Assessment and treatment should move beyond observations of potential aspiration events and their causes and place these findings within the context of the person's total medical condition.' The

importance of reducing the risk of aspiration pneumonia via a multidisciplinary approach is key, ensuring that factors as well as the person's dysphagia are well managed including but not limited to; chest management, positioning, seizure activity, oral health and gastro-oesophageal reflux.

Respiratory Deaths in Somerset – 2022-23

In 2022-23 the most common cause of death for people with learning disabilities in Somerset related to the respiratory system with 25 deaths being included within this category.

Whilst direct comparisons are not possible due to the difference in numbers, timeframes and definitions used it is worth noting that in the national data published in November 2023, Diseases of the Respiratory System was the fourth most common cause of death, behind other causes of death, diseases of the circulatory system and cancer.



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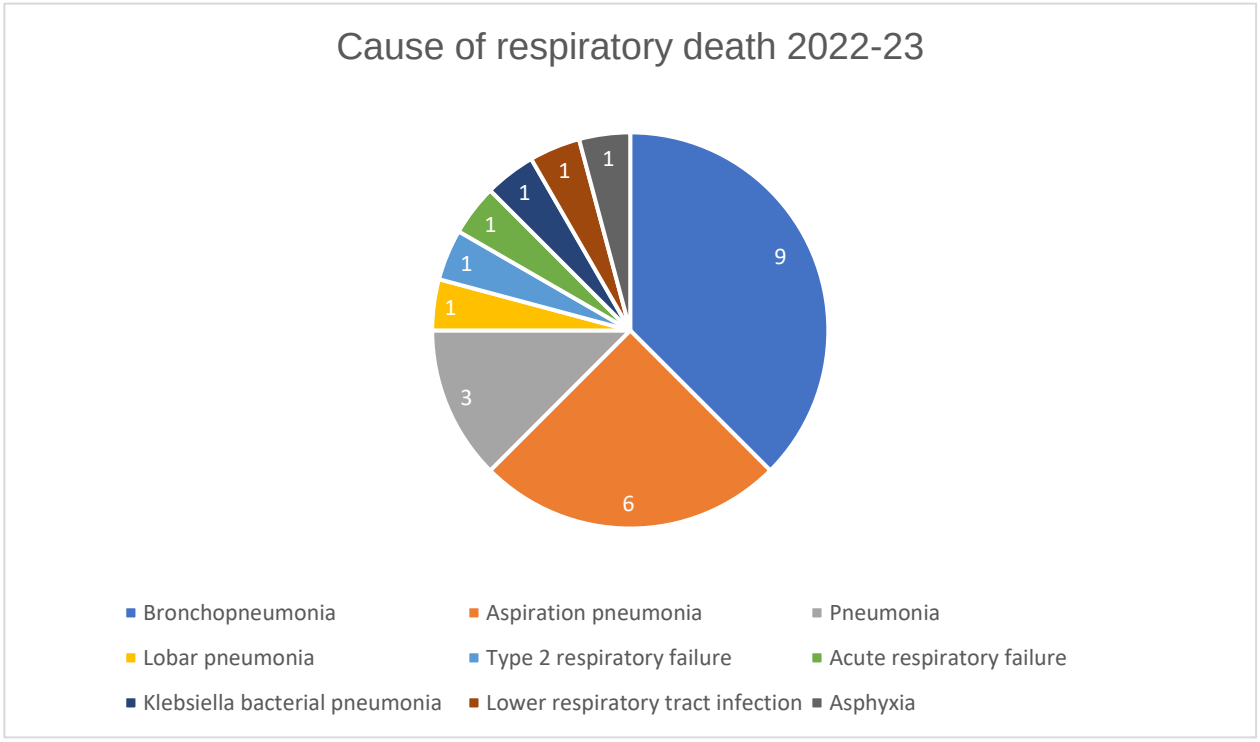
This combined with a slight increase in the numbers of deaths where the respiratory system is cited as a cause highlighted the need for a local focus on this area in 2023/24.

This year we have:

- Carried out a Focused Review for all deaths where the cause of death related to the respiratory system unless we identified that there was limited learning to be gained from the review.
- Shared information across the system regarding accessing the LD Specialist Speech and Language Therapy Team as well as updated guidance from the Royal College of Speech and Language Therapists (RCSLT) regarding the risks and benefits related to the use of thickener.
- Contributed to a system-wide group focusing on dysphagia and the provision of appropriate training for care providers.
- Carried out a 'deep dive' into the 24 deaths identified in 2022-23 to capture any thematic learning and plan areas for follow-up accordingly:

There were 25 respiratory deaths recorded in Somerset in 2022-23. One of these reviews is not yet complete due to being put on hold while another investigation took place so this death has not been included in the summary below. The below table shows the recorded causes of death for the remaining 24 people:



There was a range of contributing causes of death or other conditions recorded:

- seven with Down's syndrome
- five with dementia
- six with epilepsy
- three with cerebral palsy
- three with type 2 diabetes
- three with frailty
- two with muscular dystrophy
- two with pulmonary embolism
- two with COPD
- one with hiatus hernia
- one with chronic osteomyelitis
- one with type 2 respiratory failure
- one with schizophrenia
- one with suspected lower gastrointestinal cancer
- one with scoliosis of the spine
- one with asthma
- one with bronchiectasis
- one with metastatic kidney cancer
- one with obesity hyperventilation syndrome
- and one with congestive heart failure

The age of the people at time of death ranged from 31 to 94 years old. All apart from one person lived in a residential, nursing or supported living setting.

Themes

There were multiple individual issues raised in the reviews including delays in the funding of equipment, care providers not following Speech and Language Therapy and Physiotherapy Care Plans, lack of reasonable adjustments and lack of proactive support regarding weight management.

In eight of the 24 reviews there were issues regarding the use of Treatment Escalation Plans (TEPs), and a lack of proactive End of Life (EOL) care planning which are summarised below:

- Carers unable to locate TEP so Cardiopulmonary resuscitation, (CPR) was commenced.
- TEP and Do Not Attempt CPR, (DNACPR), completed with no one familiar to the person. Care team may not have been aware of subtle changes to health.
- Person died in the acute hospital setting after being discharged within a short timeframe with a lack of timely EOL care planning to prevent readmission.
- Lack of advance care planning and preparation to anticipate the person's deteriorating health needs which meant the person was unable to die at home where they wished.
- Person on a palliative care pathway was moved into a new home with an unfamiliar care team while his health was deteriorating rapidly and subsequently died within 11 days of moving in an unfamiliar environment.
- Person had a TEP which did not record information about who was involved in completing it, the person's capacity or ceiling of care. No evidence that the TEP was reviewed in the years prior to the person's death.
- Lack of preparation to support the person to have a dignified end of life at home. No plan in place to manage the increased risk of the person refusing to take epilepsy medication and carers not trained to administer medication in this event.

Three of the reviews also highlighted issues regarding the use of patient deterioration tools:

- Lack of recognition of patient deterioration and use of patient deterioration tools.
- Use of a patient deterioration tool may have led to a more joined up approach across community and acute sectors to manage the person's physical health needs as they got older.
- Lack of GP and carer awareness regarding the use patient deterioration tools in supported living and residential homes.

Conclusion

It is useful to note that the common themes identified above are also picked up in other reviews and are not specific to respiratory deaths. There is ongoing work looking at these areas currently. Therefore, going forward Focused Reviews for respiratory deaths will only be carried out where there will be significant learning.

Learning into Action

- There is an EOL Learning Disability Practitioner in post carrying out work regarding Advanced Care Planning (ACP) and TEPs. This is currently only a fixed term post however evidence from the review of respiratory deaths would support the need for this to become a permanent post.
- There has been a pilot of 'No Barriers Here' which is a creative approach to ACP with people with learning disabilities living in residential care in Somerset. This has led to an increased number of ACPs and TEPs being completed. There may be funding available to train more people in this approach and increase availability.
- Further work is needed to raise awareness and use of appropriate patient deterioration tools in a consistent way.
- We will work with our vaccination team to increase the uptake of influenza and pneumococcal vaccines in high-risk groups within the learning disability population.
- We will share information across the system about the importance of MDT working and a holistic approach regarding the risk factors and management of respiratory health.

References:

Truesdale, M., Melville, C., Barlow, F., Dunn, K., Henderson, A., Hughes-McCormack. LA., McGarty. A., Rydzewska. E., Smith. G., Symonds. J., Jani. B. and Kinnear. D. (2021) Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. *BMJ Open* 2021;11:e043658.

Gover. G. and Ayub. M. (2010) How people with a learning disability die. *IHAL: Learning Disabilities Observatory*

Brown. L. and Burman. J. (2021) The role of dysphagia in hospital admissions among people with learning disabilities. *RCSLT Bulletin*, January 2021, Pp 16-17 www.rcslt.org

Ashford. J,R. (2005) Pneumonia: Factors Beyond Aspiration. *American Speech-Language-Hearing Association*, March 2005, pp 10-16

LeDeR - Respiratory

NHS England » RightCare learning disability and aspiration pneumonia scenario

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