South East London Integrated Care System

NHS South East London

South East London LeDeR Programme

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Overview:

- Introduction to the LeDeR programme.
- Overview of the process of LeDeR Reviews.
- Key LeDeR findings: National, South East London and Southwark.
- Annual Health Checks.
- Reasonable Adjustments.
- The Mental Capacity Act.
- Learning from Southwark cases.
- How LeDeR and Primary Care can work together.

"…we cannot sugar-coat the stark truth that people with learning disabilities still die several decades earlier than the general population, and that many of these deaths are avoidable."

Professor Irene Tuffrey-Wijne

Leader of the *Staying Alive and Well* co-production group

Professor of Intellectual Disability and Palliative Care at Kingston University 2022

What is LeDeR?

- LeDeR: Learning from lives and deaths – People with a learning disability and autistic people.
- Previously known as the Learning Disability Mortality Review Programme, which was set up in 2015 in response to significant ongoing concerns about the likelihood of premature deaths of people with learning disabilities.
- LeDeR is a service improvement programme led by NHS England.
- LeDeR aims to improve health and social care, reduce health inequalities and prevent premature mortality.
- LeDeR reviews look at the health and social care a person received to identify areas of good practice and areas that need improvement.

What LeDeR isn’t

- A LeDeR review is not a mortality review. It does not restrict itself to the last episode of care before the person’s death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes.
- LeDeR reviews are not investigations or part of a complaints process. Any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission (CQC) or other appropriate body.
- Where a death might be subject to a statutory review or other investigation, the LeDeR review will be placed on hold until that process has been completed. For example, a coroner's inquest or Police investigation.

The LeDeR Process

Notifications

- A notification should be sent to LeDeR whenever a person with a learning disability and/or autistic person aged 18 years or over dies. This can be done by anyone: health and social care staff, administrative staff, family members or anyone who knew the person via the LeDeR website. https://leder.nhs.uk/
- It does not matter if more than one notification is made for the same person.
- The person must have a formal diagnosis of Learning Disability and/or Autism in their clinical records in order to be accepted into the LeDeR process.
- The notification is then allocated to the appropriate LeDeR Team based on the location of their GP practice.

Type of LeDeR review- Initial vs focused

- All notified deaths are subject to an initial review, which includes:
    - a guided conversation with the family member or someone close to the person who died
    - a detailed conversation with the GP or a review of GP records
    - a conversation with at least one other person involved in the care (e.g., healthcare professional, hospital mortality reviewer etc).
- A more detailed, focused review will be carried out in certain circumstances. This will automatically take place where the person who died is from a group of people known to experience significant health inequalities:
    - from a minority ethnic community
    - subject to mental health or criminal justice restrictions in the five years prior to death
    - autistic with no learning disability
- A focused review will also be carried out where:
    - in the reviewer's professional judgement, there is likely to be learning from a focused review
    - there are concerns about the quality of care provided or evidence of a lack of coordinated care
    - a family member has requested a focused review
    - there is a local area of focus on a particular issue, for example cancer related deaths.

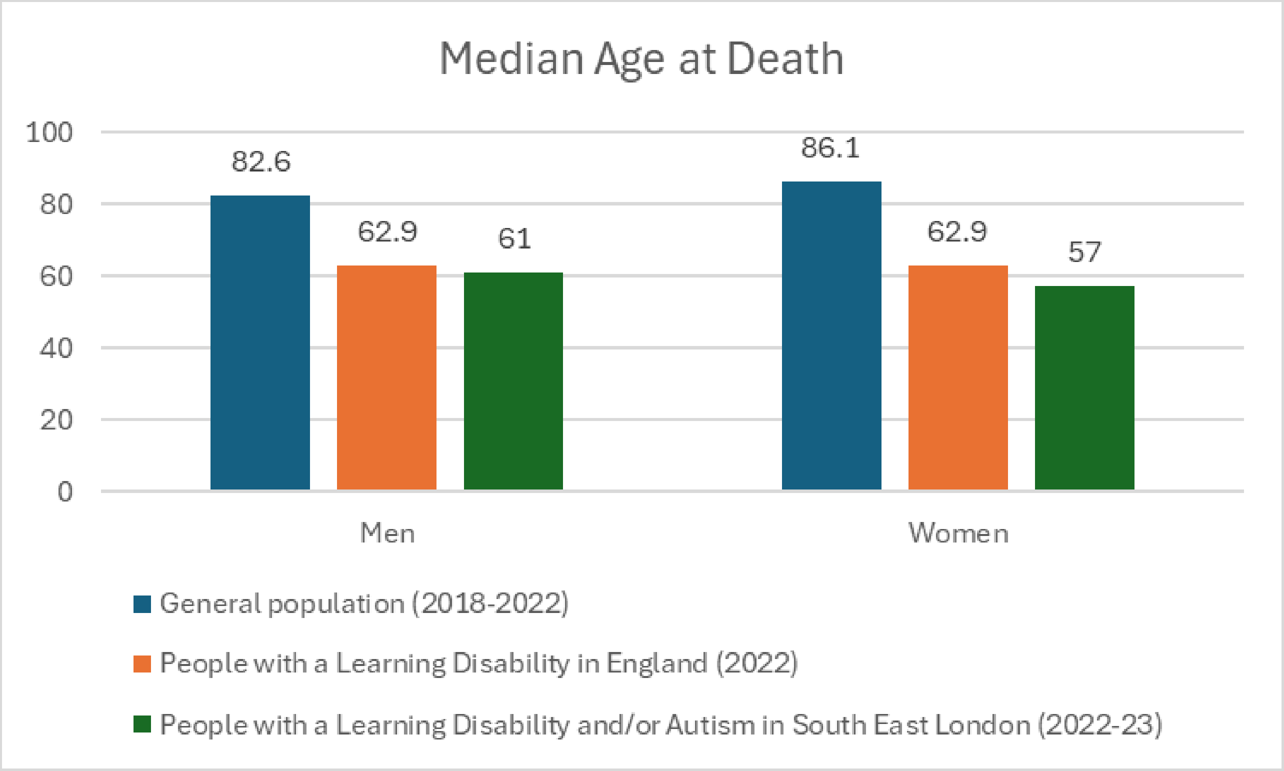
Sharing and accessing confidential information

- LeDeR has approval from the Secretary of State for Health and Social Care to process confidential patient information without consent. Section 251 of the NHS Act 2006 (ref: 20/CAG/0067) is the legal basis that allows identifiable information about people with a learning disability and autistic people to be shared with the LeDeR programme after their deaths, as well as limited information about their living relatives. More information can be found on the LeDeR website https://leder.nhs.uk/
- There is no expectation or requirement for information to be redacted for the purposes of LeDeR, but the UK GDPR and Data Protection Act 2018 are applicable in relation to records of living persons (e.g. family members).

SEL LeDeR Governance structure

- Both initial and focused reviews identify areas of good practice as well as issues with the care and treatment that the person received. The learning from these reviews is then disseminated at a local, regional and national level.
- **Focused Review Panels:**
- The findings from focused reviews are presented to a monthly focused review panel attended by a variety of professionals from key health and social care stakeholders across south east London.
- At this panel, key issues from each review, are discussed and actions agreed to promote service improvement.
- **Borough Specific Steering Groups:**
- Each of the 6 Boroughs across south east London have a Steering Group, chaired by a local LeDeR lead.
- These usually take place quarterly and are used to lead changes needed across the borough in both health and social care. These groups also address learning from initial reviews relating to that Borough.
- **LeDeR Strategic Group:**
- This meeting discusses recurrent themes and significant issues across all 6 Boroughs. It also monitors ongoing or planned actions on how learning and recommendations will be applied to improve care provision.

Key findings- the LeDeR Report for England 2022 and the South East London LeDeR Annual Report 2022-23



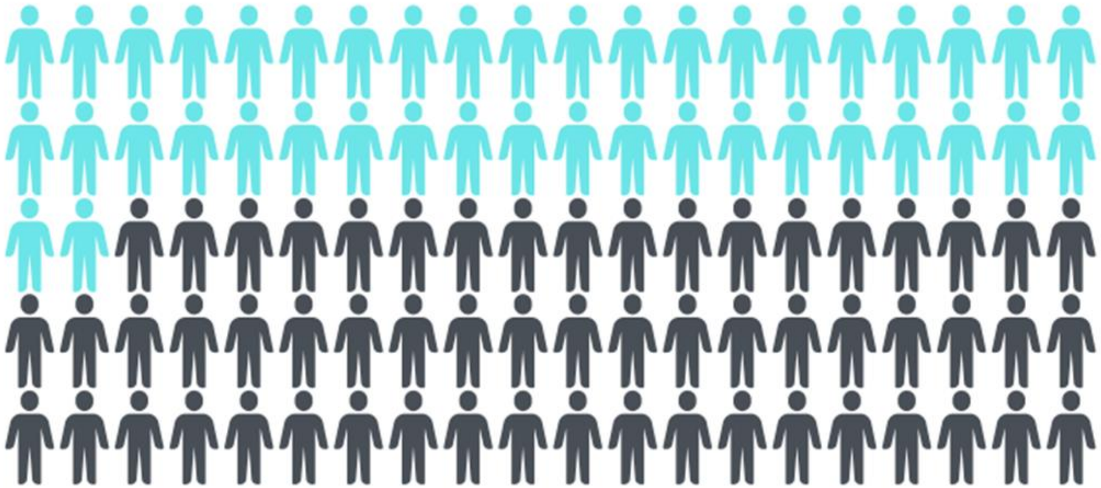
Men with a learning disability and/or Autism in South East London are dying on average **21.6** years earlier than the general population in England. For women, the difference is even greater at **29.1** years.

https://www.kcl.ac.uk/research/leder

National life tables – life expectancy in the UK - Office for National Statistics (ons.gov.uk)

South East London Annual Report 2022-23

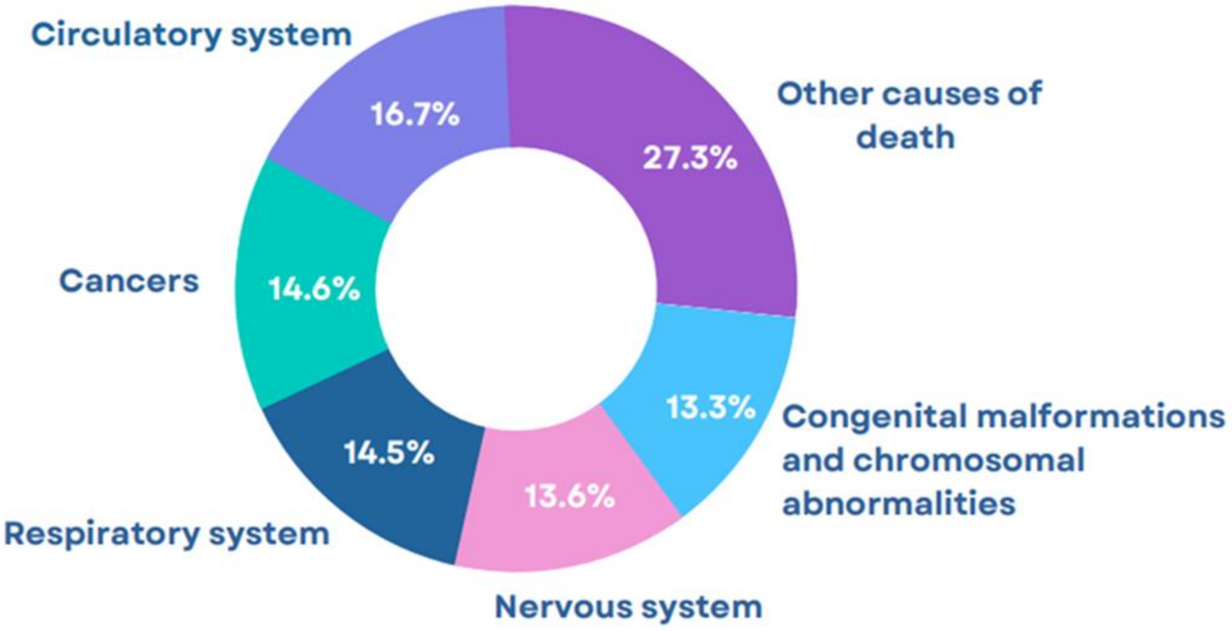
- 42% of deaths were deemed ‘avoidable’ for people with a learning disability in England, compared to 22% for the general population.



- Of avoidable deaths:
  - 26.4% were linked to cardiovascular conditions,
  - 23.8% to respiratory conditions (excluding COVID-19), and
  - 15.7% to cancers.

Causes of Death in England

5 MOST COMMON CAUSES OF DEATH (ICD-10 CHAPTER)



Causes of death in South East London

Cause of death	Percentage
Pneumonia (Aspiration, Broncho and Pneumococcal)	37.5%
Heart disease	12.5%
Cancer (Duodenal tumour, Oesophageal cancer, Metastatic renal cell carcinoma and malignancy of unknown origin)	12.5%
Sepsis	7.5%
COVID 19	5%
Respiratory Failure	5%
Frailty, old age	5%
Chest Infection	2.5%
Brain Stem Death	2.5%
Hypoxic Brain Injury	2.5%
Bowel Ischaemia	2.5%
Alzheimer's	2.5%
Postural Asphyxia associated with Epilepsy	2.5%

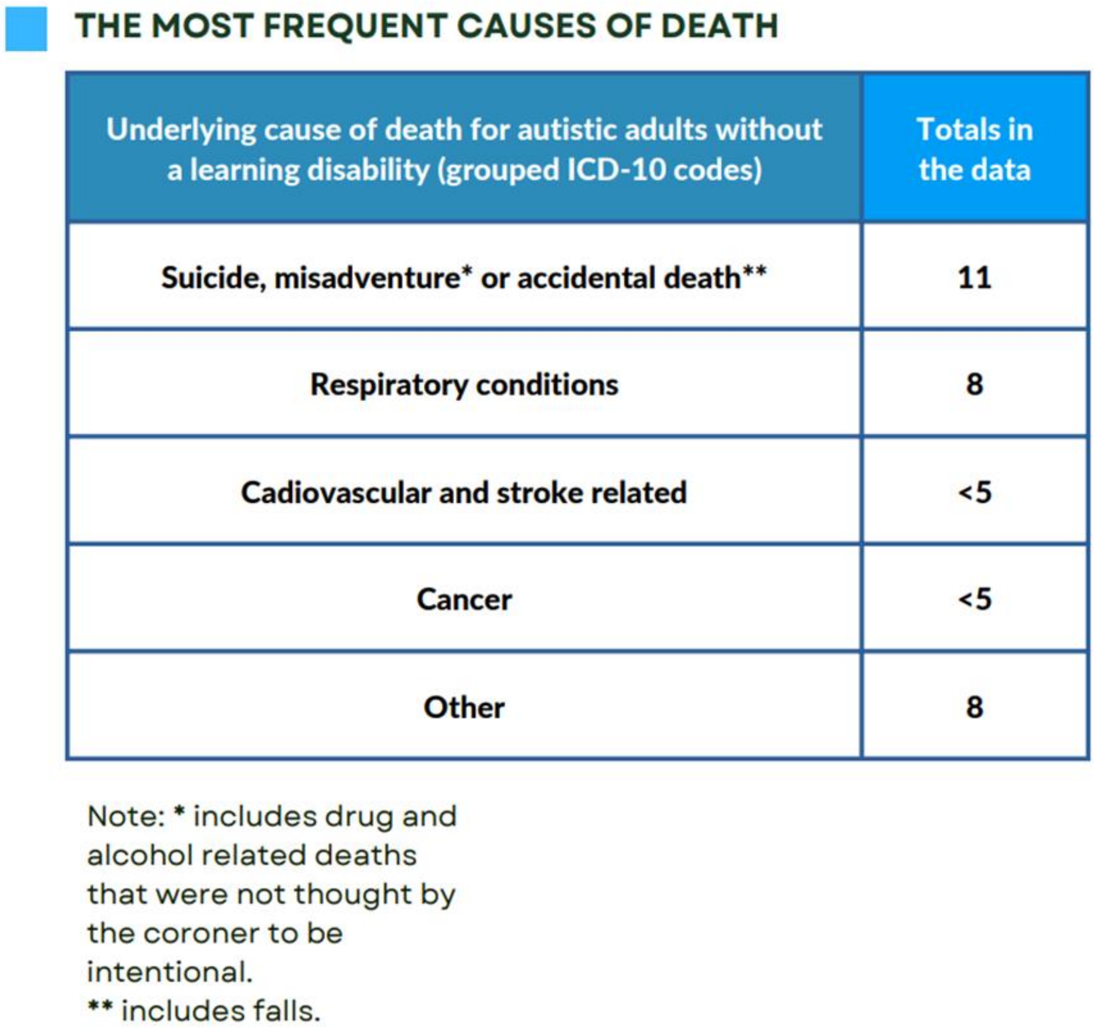
Long term conditions

Of the reviews completed in 2022-23 in Southeast London, the table below shows the percentage which included a diagnosis of various long term health conditions.

Long Term Health Conditions	Percentage
Mobility Difficulties (Including mobility aids and frequent falls)	63%
Continence (Including Urinary Tract Infection (UTI) and Incontinence)	53%
Epilepsy	50%
Dysphagia	43%
Gastro-intestinal (Including Constipation)	38%
Asthma/Chronic Obstructive Pulmonary Disease (COPD)	30%
Cardiovascular Disease (excluding Hypertension/Stroke)	30%
Diabetes	28%
Hypertension	28%
Sensory Difficulties	28%
Mental Health Condition	25%
Dementia	23%
Cancer	18%
Chronic Kidney Disease (Renal)	15%
Body Mass Index (BMI) over 30	10%
Stroke	10%
Body Massa Index (BMI) Under 18	8%
Deep Vein Thrombosis (DVT)	3%

Autism Only

- 2022 was the first year that the LeDeR programme reviewed the deaths of autistic adults without a learning disability. However, only 34 were completed.
- We therefore cannot draw conclusions based on this information and more work is needed to increase the number of death notifications that LeDeR receives in order to determine areas for improvement in the care and treatment of autistic adults.



THE MOST FREQUENT CAUSES OF DEATH

Underlying cause of death for autistic adults without a learning disability (grouped ICD-10 codes)	Totals in the data
Suicide, misadventure* or accidental death**	11
Respiratory conditions	8
Cadiovascular and stroke related	<5
Cancer	<5
Other	8

Note: * includes drug and alcohol related deaths that were not thought by the coroner to be intentional.
** includes falls.

Ethnicity

AGE AND ETHNICITY

People from all ethnic minority groups died at a **younger age** in comparison to people of white ethnicity, when adjusting for sex, region of England, deprivation, place of death, and type of accommodation.

% increased risk of dying earlier by ethnic minority group, in comparison with people from white ethnicity backgrounds, when adjusting for other demographic factors

The National LeDeR Report- Annual Health Checks

- In reviews where AHC data was available, 72% of people with a learning disability were found to have had an annual health check in the 12 months before they died.
- The report stated that:
  - ‘In primary and community care, the learning disability annual health check was sometimes reported to be “limited” and “brief” and a “missed opportunity” for promoting health and exploring long-term health conditions. There was a concern that not all annual health checks resulted in the development of health action plans or clinically indicated actions being undertaken.’
- However, it also recognised:
  - ‘there were examples of “high-quality learning disability health checks” and comprehensive health action plans.’

The Southeast London LeDeR Annual Report 2022/23- Annual Health Checks

- Of the LeDeR reviews completed in South East London, 78% of people had received an annual health check. In Southwark 84% of people eligible for an annual health check received one.
- Within SEL reviews, Annual Health Checks were identified both as areas of good practice and as areas in need of change.
- For example, a review noted that a GP offered annual health check virtually and in person to promote engagement, and liaised with carers over the phone to ensure the right support was offered.
- However, as with the National report, reviews identified that improvements in the quality of some Annual Health Checks is needed in order for them to pick up on unidentified problems. Reviews also highlighted the need for increased use of reasonable adjustments for appointments, especially Annual Health Checks.
- Another related issue is that sometimes the wrong people are identified for an Annual Health Check due to inaccuracies in the LD register- both people not invited when they should be and invited when they don’t actually have a learning disability.

Reasonable Adjustments

- The LeDeR 2022 report and 23/24 SEL report highlighted a lack of reasonable adjustments in primary and community care, as a reoccurring theme from reviews.
- NHS England defines ‘reasonable adjustments’ as ‘to make it as easy for disabled people to use health services as it is for people who are not disabled’. https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/
- Data showed that reasonable adjustments were not made where they should have been in roughly **in one-quarter of deaths** occurring in 2022 in England.
- This included:
  - a lack of accessible communication and information which, in some cases, could limit individuals’ access to healthcare: ‘X received text messages from the GP which their mother states they would be unable to read’.
  - Primary and community care settings sometimes had inadequate equipment to cater to people with additional needs; a lack of hoisting facilities or of wheelchair scales was mentioned in reviews: ‘The GP surgery could not accommodate X having a full examination due to not having a hoist or high low bed’.

- As well as the concerns with lack of reasonable adjustments, the LeDeR report also highlighted examples of positive practice in this area and the importance of personalised reasonable adjustments as crucial tools to support people to access healthcare.
- For example;
  - longer appointment times
  - giving someone a priority appointment if they find it difficult waiting in their GP surgery
  - adjustments to the sensory environment
  - acclimatisation visits to clinical spaces or home visits if preferred
  - providing photos of waiting areas/treatment rooms to allow social stories to be developed
  - delivering information in adapted formats
  - welcoming family and carers to support the person.

Use of the Mental Capacity Act

- The National LeDeR report showed that the Mental Capacity Act was correctly followed in three quarters of reviews in 2022 where it was deemed relevant.
- Application of the Mental Capacity Act is a highly frequently raised issue across South East London including:
  - Use of blanket capacity statements, eg X lacks capacity to make decisions. No decision specific capacity assessments completed/documented.
  - Lack of reference to considering capacity issues within notes, eg I have no reason to doubt X's capacity to make this decision.
  - Confusion of when someone should be referred to an IMCA.
  - No reference to Best Interest meetings or discussions. Lack of documentation on how and why decisions are made on another person's behalf.
  - Lack of understanding of the role of family members in the Best Interest decision making process and the legal powers needed for a family member to be entitled to make a decision on their loved one's behalf.
  - Clinician's taking at face-value when family members describe themselves as having Lasting Power of Attorney or Deputyship, rather than asking for evidence.
  - Lack of follow up when a person who lacks capacity to make decisions about their medical treatment does not attend health appointments.

Lasting Power of Attorney vs Deputyship vs Appointeeship

- The need to improve professionals' legal literacy is an increasingly common theme across LeDeR reviews in South East London, particularly in relation to the Mental Capacity Act.
- A concerning number of reviews show that a family member’s description of themselves as having Power of Attorney can be taken at face value without clinicians being shown the paperwork to back this up.

Lasting Power of Attorney (LPA)- A person can only become an LPA for financial affairs and/or health and welfare decisions if the appropriate legal paperwork has been completed and registered with the Office of the Public Guardian when the person concerned has capacity to make their own decisions. They can then only make decisions on that person’s behalf if they subsequently lose capacity.

Deputyship- If a person loses capacity to make decisions or has never had capacity, then in order for someone to be able to make financial or welfare decisions on their behalf, an application for Deputyship must be made to the Court of Protection. The Court of Protection makes a formal ‘order’ detailing what the deputy may do in each case and there are restrictions on what a deputy can do under the terms of the Mental Capacity Act

Appointeeship- if a person lacks capacity to manage their benefits, someone else can apply to the Department for Work and Pensions to become their appointee. Appointeeship only gives the power to claim and manage the person’s benefits on their behalf, however families can often confuse this power with the ability to make other decisions.

Safeguarding Issues

- Concerns about self-neglect, neglect by paid support workers, family or friends, acts of omission not being raised with social services.
- Concerns about the quality of care being provided to someone with a learning disability or autistic person not being raised with social services.
- Lack of communication between services, particularly what they are doing to highlight to other professionals when the person is not attending medical appointments, particularly if they require support to attend appointments or don’t have capacity to make decisions about their medical care.

Case Study

- X was a 77 year old man with mild learning disabilities who hadn't been known to services for much of his adult life.
- X lived in his own flat with his cousin, who provided him with day-to-day support for tasks of daily living at increasing levels as X's health deteriorated. His brother lived in Kent but visited X regular and supported with the management of X's finances.
- X had type 2 diabetes, hypertension, and left-sided hemiparesis. In the last year of his life his health deteriorated significantly, his mobility reduced to the extent that he was housebound, he became doubly incontinent and had recurrent UTIs which required hospital treatment on 3 occasions. X also had pressure sores on his sacrum.

- Several GP entries noted safeguarding concerns regarding neglect and self-neglect, as well as concerns that X needed more support. For example, poor living conditions and X sitting in soiled trousers, which appeared to have been that way for a long period of time. However, these concerns were not raised with social services.
- The London Ambulance Service did raise safeguarding concerns regarding 'Neglect and acts of omission' after they took X to hospital for a UTI infection. They reported that X's cousin was unaware of how to manage X's diabetes and monitor blood sugar levels and that he had not sought help for 2 weeks after X had a fall and was stuck in an armchair.
- This safeguarding concern was not responded to appropriately by social services or the GP.

- Social Care notes state that X had the capacity ‘to make decisions for himself’ but that he did not have the capacity to manage his finances. However, there was no documentation of any formal, decision specific capacity assessments in relation to key decisions about X’s care and treatment in his last months of life.
- Whilst there should always be a presumption of capacity, from the notes reviewed it seems X's cognitive state in the last years of his life did indicate that there was reason to doubt his capacity to make some key decisions. For example, a hospital discharge summary 2 months before X’s death stated ‘gradual worsening of memory over the last few months, has been acutely confused in the last couple of weeks, poor short-term memory’.
- It was widely reported in both health and social care notes that X's brother had Power of Attorney, however when this was checked with the Office of the Public Guardian by social care, it was found that no such arrangements were in place.

Capacity to consent to care and support arrangements.

- X’s cousin requested that X’s care package was reduced on two occasions, stating that he would provide the care instead. It appears this was because he didn’t like other people being in the flat.
- However, X’s views on this or his capacity to consent to the proposed support arrangements was never considered.
- This is of importance as there were concerns about the cousin’s ability to provide adequate care, particularly in relation to diabetes management, personal care and continence care. X and his cousin were reported to live in ‘very unkempt, poor living conditions’.
- Similarly, X’s cousin refused to allow District Nursing into the flat at times, stating that it was upsetting for X but it was unclear if X shared this opinion and if he had capacity to decline the medical treatment that was being offered to him.
- If X’s capacity had been assessed and his views sought, we would know if he was making an informed choice to accept the nature of the support his cousin could provide, or if consideration needed to be given to what level of support would be in X’s best interest.

Capacity to decline medical treatment and end of life planning

- During the final month of X's life when X had very limited food and drink intake, a meeting was held in his flat with the GP, Social Worker and Physiotherapist. It was reported that X said that he didn't want to go to hospital, however there was no mention of consideration of his capacity to make this decision, despite it being reported that X only spoke a few words during the meeting and that his cousin did most of the talking. There was no discussion of what should happen if X's health was to deteriorate further.
- The social worker later reflected that she thought X's decision not to go to hospital for treatment should not have been taken at face value as there had been reason to doubt his capacity to make this decision, and that she had concerns about the influence of the cousin's views on X.

- 4 days on from this meeting, in a phone call with X's social worker, X's cousin reported that X was very unwell, that he wasn't eating or drinking, couldn't get out of bed and was having difficulty breathing. The cousin said that they thought X would die that day, however he refused to call X's GP, 111 or an ambulance stating that this was not what X wanted.
- X's brother was then called who said that he didn't think X could make informed decisions about his health and that he was concerned about the influence of the cousin.
- Whilst the social worker and support workers then made attempts to seek medical assistance for X via the GP and 111, X died later that day without any pain relief or other palliative care.

Examples of Learning from Southwark Reviews

LeDeR ID: 24112

- **Issue:** Recommendation for GP to consider medication changes on discharge from hospital (reduction of Duloxetine due to renal function and prescribe an alternative to Tetrabenazide following inpatient diagnosis of tardive dyskinesia). No mention of either of review of medications in GP notes or any changes made to doses/medications prescribed.

LeDeR ID: 21707

- **Issue:** Referrals were not made to the services that could have supported to reduce the effects of X’s self-neglect. e.g. Mental Health/Learning Disability Community Teams.

LeDeR ID: 21437

- **Issue:** GP Practice focus on treating the presenting symptoms rather than a consideration or investigation of wider causes.

LeDeR and Primary Care

- It is vital that GPs and other Primary Care practitioners are aware of the health inequalities and risks faced by people with a learning disability and autistic people. That they proactively offer high quality preventative care and treatment, to reduce the risk of premature, avoidable mortality.
- Ensure that meaningful annual health checks are offered, and health action plans are followed.
- Ensure that any safeguarding concerns are reported to social services, including if you feel that a person's medical needs are not being met by their care provider or family.
- Offer reasonable adjustments to remove any barriers that could make it difficult for people with a learning disability or autistic people to use your service and make use of the reasonable adjustments flag.
- Avoid diagnostic overshadowing, by assuming that behaviours, symptoms or skill deficits are attributable to the learning disability or to autism.
- Regularly review medications; reduce and stop the use of any inappropriate medications, to reduce adverse side effects and potential drug interactions.
- Use the Mental Capacity Act and best interests processes where relevant.
- Offer proactive management and support for long-term conditions and ensure that patients and carers understand what they need to do and look out for.
- Look out for soft signs of health deterioration and encourage patients and carers to do the same.

LeDeR and Primary Care- how you can support our work

- Please continue to notify LeDeR of the death of anyone with a Learning Disability and/or Autism over the age of 18.
- We are receiving very few notifications for autistic adults who do not also have a diagnosis of Learning Disability and so want to raise awareness of the need to make a notification for this cohort of people.
- Please continue to respond to requests for records as soon as possible to enable us to complete timely reviews.
- Please share information generated by LeDeR, discuss it in your practices, make links with the Southwark Steering Group when it reforms, and feel free to get in touch with the LeDeR team.

Contact Us

- LeDeR Team: lederteam@selondonics.nhs.uk
- Tolu Olaniyan: LeDeR Programme Lead, tolu.olaniyan@selondonics.nhs.uk
- Megan McClintock: Senior LeDeR Reviewer, megan.mcclintock@selondonics.nhs.uk

- To report a death to LeDeR/Complete a notification: https://leder.nhs.uk/report