Southend-On-Sea Health and Wellbeing Board

SET LeDeR (Learning from Lives and Deaths) 2023-24 Annual Report

Introduction

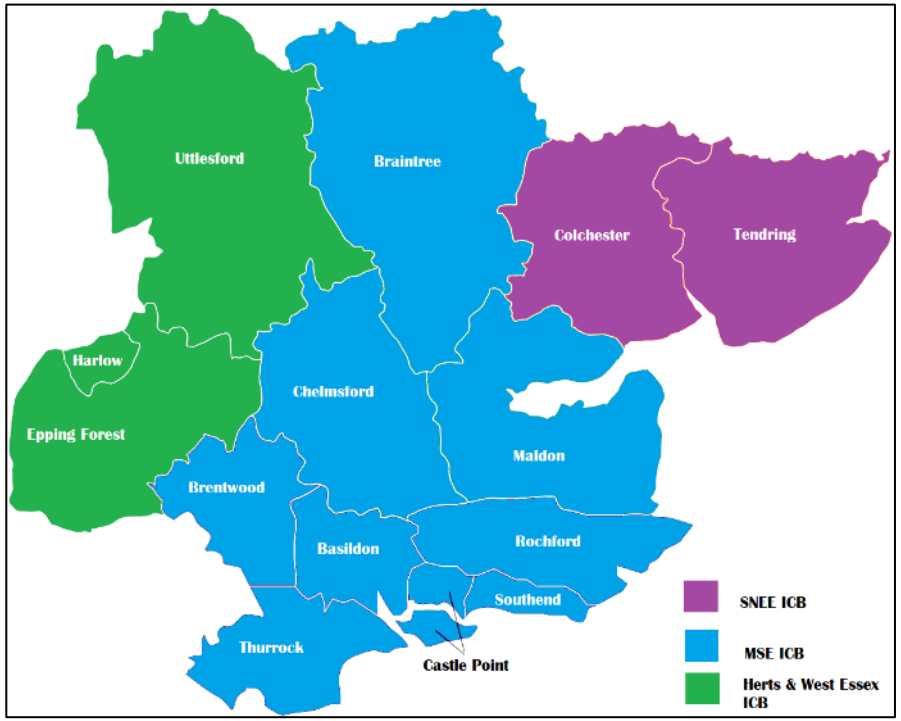
The Learning from Lives and Deaths (LeDeR) Programme started in 2017 with the aim to reduce the health inequalities faced by people who have a learning disability (LD) it later expanded to review autistic people without a learning disability also.

When somebody with a learning disability or an autistic person dies, their death should be notified to LeDeR. As of July 2023, LeDeR reports only reports on deaths of people with a Learning Disability and or Autistic people aged 18 and above.

LeDeR is a review of all aspects of the care and support a person received in their life and death. This is done to improve quality of care and support by learning from what went well and making recommendations for changes where there are opportunities for better outcomes.

The Southend, Essex and Thurrock (SET) LeDeR programme works alongside other quality improvement measures currently in place to reform services and improve health outcomes. If other reviews and enquiry processes need to take place then the LeDeR review will be put on hold until after these are completed, to ensure we capture the learning from the findings in our reviews.

This annual report provides an update on the achievements of the three Integrated Care Boards (ICBs) and SET Local Authorities and transforming care partnerships, and highlights the changes already being seen.



SET LeDeR Programme

We remain compliant with the revised LeDeR policy in terms of team structure. We are committed to maintaining good performance in respect of allocation and completion of reviews other key performance indicators.

Due to the historically lower numbers of notifications made in Suffolk County, the Senior Reviewer role is shared across SET and Suffolk. This began in 2023 and has been agreed to continue in 2024.

We now have a new SET 3 Year LeDeR Deliverable Plan 2024 - 2027 which identifies where we need to progress. The plan has twelve priorities and covers four priorities each financial year (24/25, 25/26, 26/27).

This plan reflects the commitment of all organisations, including public health. This is monitored by the SET LeDeR Steering Group and the success or not of each of the four priorities will be reported in future SET LeDeR Annual Reports.

SET Trends: Notifications

Notifications

The deaths of 120 people with a learning disability and/or Autistic people who were notified to us between April 2023 and March 2024.

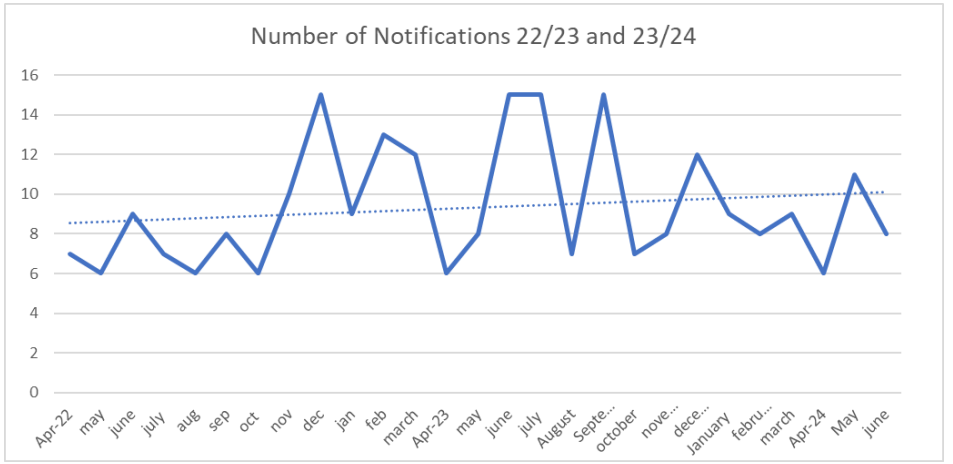
ICB	April	May	June	July	August	September	October	November	December	January	February	March	Total
MSE	3	5	9	7	5	8	4	5	7	10	4	5	72
WE	1	0	0	2	0	0	1	0	0	0	1	1	6
NEE	2	3	6	6	2	7	2	3	5	0*	3	3	42
SET Total	6	8	15	15	7	15	7	8	12	10	8	6	120

This is an increase on the previous year when 113 deaths were notified. Since January 2022, the scope of LeDeR has been broadened to include reviews for people with Autism only (without a Learning Disability) and we are starting to see notifications for this group of people. Also since July 2023 LeDeR reports only on deaths of adults with a learning disability or autistic adults.

Notifications 22/23 and 23/24

Since most notifications are made close to the day when the person died, this data is helpful for us to understand some of the trends around deaths as they occur.

When analysing the data there is a clear indication of not only the winter impact on health, but also shows the potential impact of a very hot summer in 2023, which has caused us to consider the impact of heat and hydration on health.

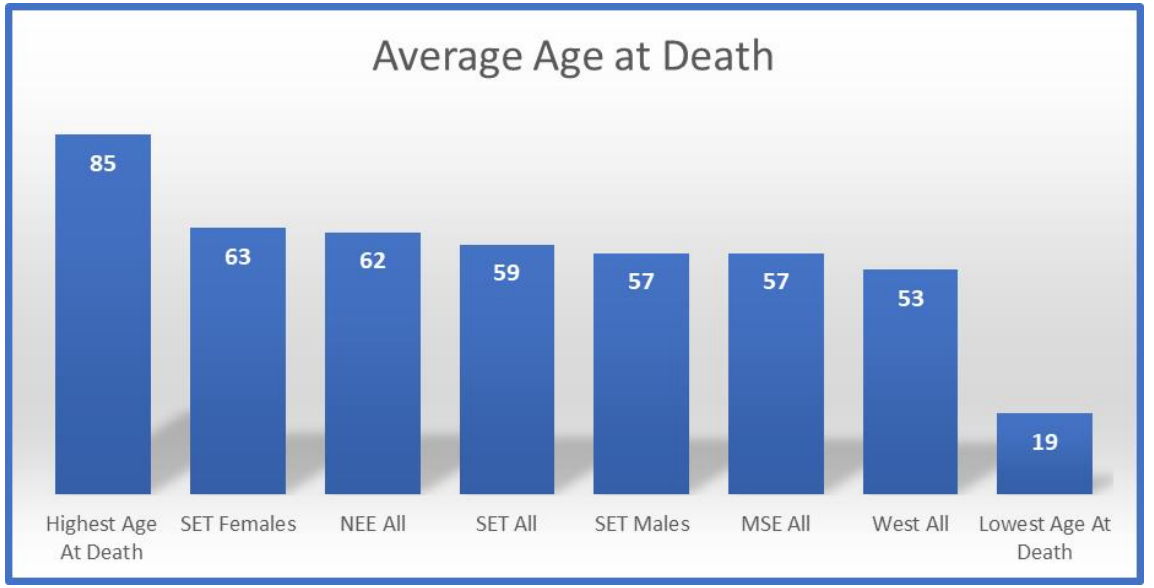


SET Trends: Age Of Death Of Those Reviewed

Deaths Of Those Reviewed

This has resulted in the average age of death going up slightly this year, but not raising as sharply as we hoped. We believe that we are still seeing some impact of Covid-19 on our notifications and we are seeing significantly more notifications for men. With men passing away younger.

The impact of Covid-19 throughout 2020 and 2021 had a significant impact on the number of deaths of older people reported and the average age at death.



Average Age Of Death

The median average age at death for adults across SET in 2023/24 was 59.3. This up from last years median average age of death across SET for 2022/23 which was 57. But it is down from 2021/22 when the median average age of death across SET was 65.5 years.

- **In West Essex the average median age is lower at 53,** but this is impacted by the small sample size and narrow range of notifications**.**
- **In North East Essex the average age is higher at 62.1**, which is very close to the national average (from the LeDeR national report for 2022).
- **The average age of death in MSE is 57.2**, which is slightly lower that the SET average.
- **The average age of death in Southend is 66.** This is higher than the SET average and based on 20 notifications.

SET Trends: Primary Cause Of Death Completed Reviews

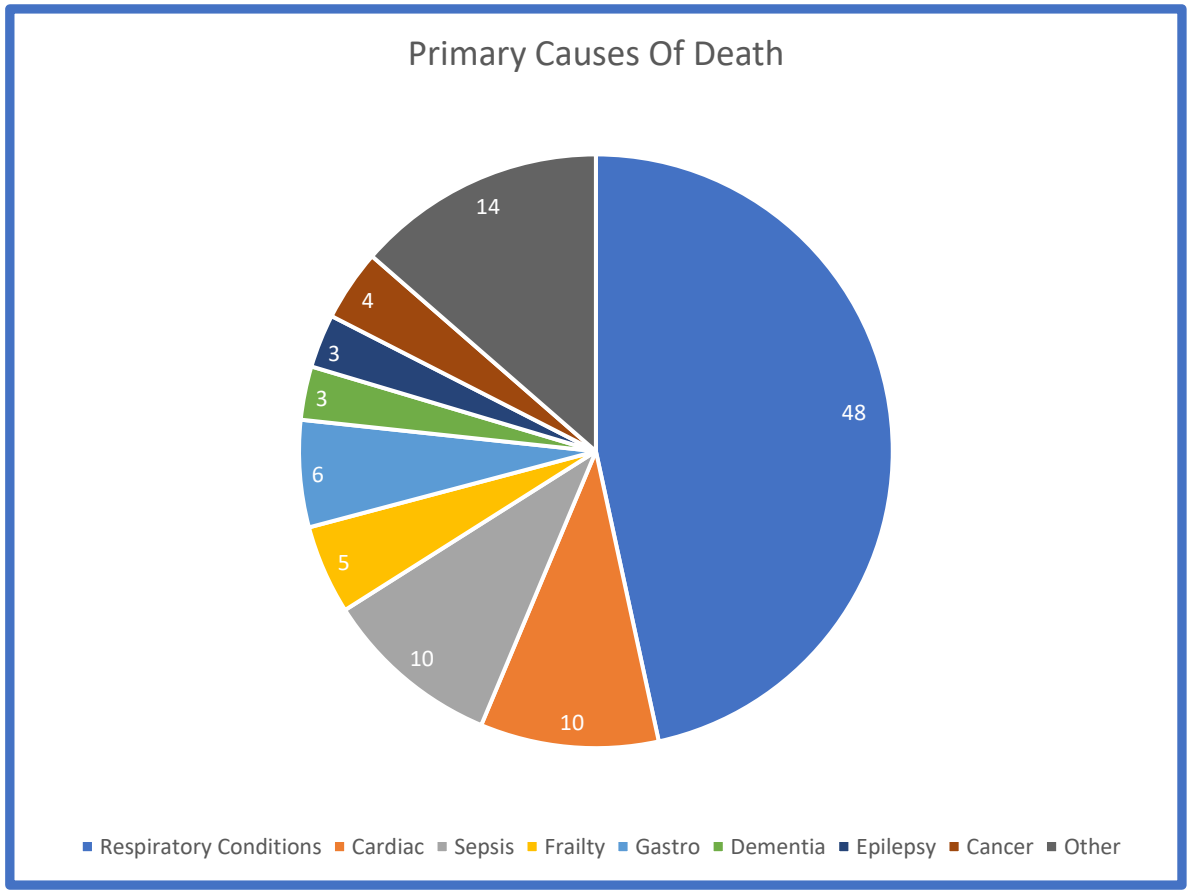
From those reviewed respiratory conditions are by far the leading primary cause of death for people with a Learning Disability totalling (48), followed by Cardiac deaths (10) and Sepsis (10).

The pie chart on the right shows the split between the eight categories of primary causes of death which impacts 89 out of the 103 completed reviews. With 14 other causes of death grouped together in dark grey.

For comparison, if we had reviewed a sample of deaths of people from the general population, we would expect to find the leading cause of death to be Dementia and Alzheimers (around 12 people), followed by Ischaemic Heart Diseases (10 people) and chronic lower respiratory diseases (around 6 people).

Clearly there is a very great difference in the leading causes of death for people in the general population compared with people with a learning disability.

This continues to inform the work of the SET Health Equalities team and partners. We have had a focus on respiratory illness throughout 2023/24 and into the 2024/2025 reporting period.



Southend Specific Insights: Completed Reviews

Completed reviews

- There was a total of 14 reviews completed for Southend comprising of 9 initial reviews and 5 focused reviews.
- The reviews consisted of 4 females and 10 males, with an average age of 59.
- Ethnicity: All 14 individuals involved in the review identified as White British.

Vaccination

- 10 individuals received their Covid vaccine, 9 were administered their Flu vaccine. No individuals received their Pneumococcal vaccine.

Learning Disability Annual Health Checks

- Learning Disability Annual Health Checks were completed for 9 individuals, out of which 5 received a Health Action Plan.

DNACPR (Do not attempt cardiopulmonary resuscitation)

- 9 reviews had a DNACPR in place, and 7 were correctly followed according to the reviewer's professional opinion.

Mental Capacity Assessment (MCA)

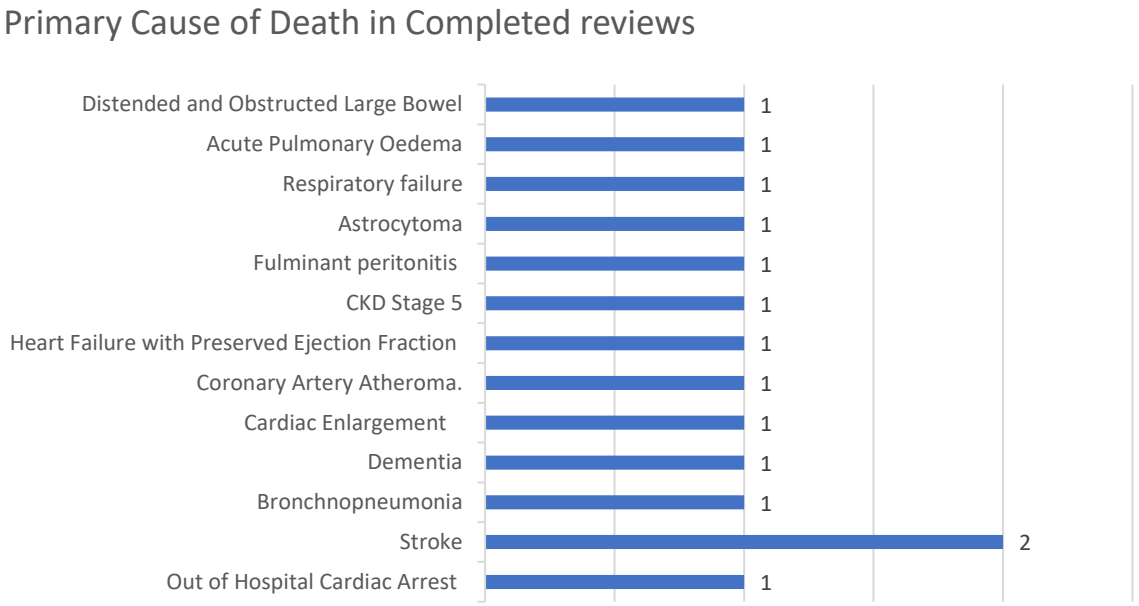
- 10 reviews had an MCA in place ,9 of which were correctly followed.

End Of Life.

- 6 individuals were referred onto an End of Life pathway.

Southend-On-Sea Specific Insights: Completed Reviews

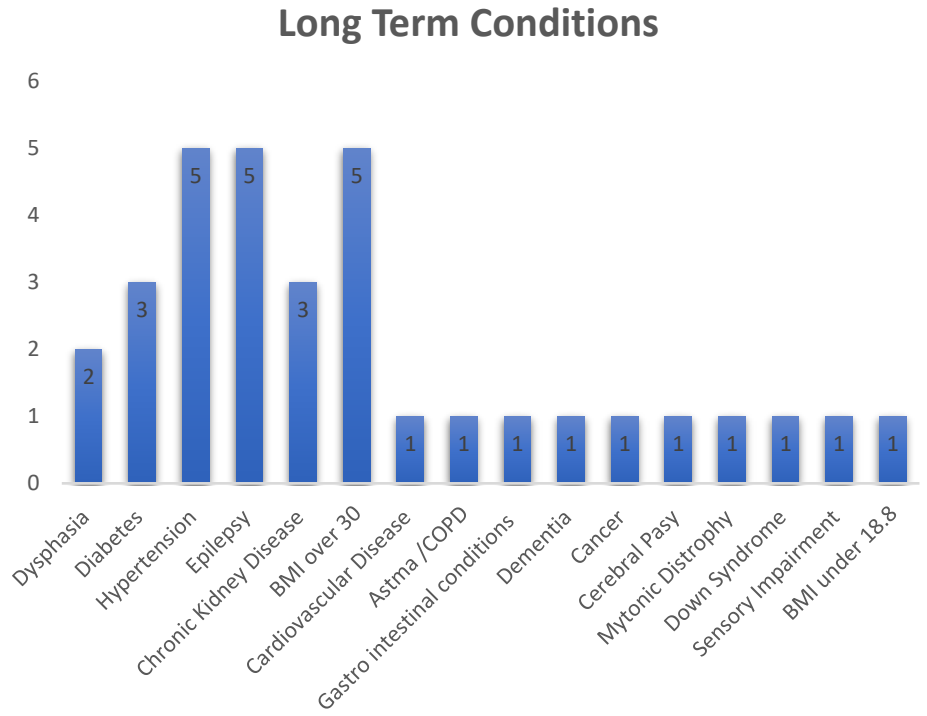
Primary Cause Of Death Completed Reviews



Place of Death Completed Reviews

- 7 individuals died at home, 7 died acutely in hospital (6 in Southend Hospital, and 1 in Basildon hospital).

Long Term Conditions



Psychotropic medication.
8 individuals were identified as being on psychotropic medication, 5 was on medication to control their epilepsy and 2 individuals had a serious mental health diagnosis. There were 0 people on a STOMP (Stopping Over Medication of People with a learning disability and autistic people) pathway

Highlights of Progress Since Last Year's Report

- Aspiration Pneumonia Conference – run by ECC's Provider Quality & Innovation Team and open to SET.
- Ageing Well Programmes by Local Authorities.
- Establishment Of All Age Dynamic Support Mental Health Register.
- ELDP Care Coordination, Physical Health Dynamic Support Register and Enhanced Physical Health Checks.
- Use Of Digital Hospital Passports.
- End Of Life Programme.
- Oliver McGowan Training / Equivalent Training Roll Out Began Across SET.
- LD/A Health Equalities Team Representation On Working Groups.
- Increase In Number Of Learning Disability AHCs and HAPs Delivered Across SET.
- Mid and South Essex NHS Foundation Trust Matrix For LeDeR Learning Established.
- Work Of Learning Disability and Autism Liaison Nurses and Health Care Assistants.
- GP Surgery In Southend On Sea Learning Disability Register Audit.

Recommendations

1. **System to continue to promote overall awareness of LeDeR** to increase notifications for those who have died who had a Learning Disabilities and / or Autistic people.
2. **Reasonable adjustments should be explored to increase access to health care.** For the best outcomes we recommend reasonable adjustments for face to face appointments for those with a Learning Disability and / or Autism to enable early diagnosis of health issues and cancers.
3. **Health and Social Care to continue to support targeted work to address Aspiration Pneumonia and wider respiratory conditions.** Aspiration Pneumonia and wider respiratory conditions is by far the leading primary cause of death in LeDeR and has been for years, so perseverance is needed to help reduce the potential preventable death due to these conditions.
4. **Postural support should be considered by health and care professionals when supporting people with a learning disability and / or autistic people.** Good postural support can help to prevent against Aspiration Pneumonia and can also positively contribute to the person's quality of life.
5. **Raising Awareness Of Pneumococcal Vaccination eligibility for people with a Learning Disability and Autistic people** in preparation for Year Two priority in the SET 3 Year LeDeR Deliverable Plan 2024 – 2027.
6. **There should be increased access to dental services both mainstream and specialist.** This remains a persistent problem and so needs to remain as an action until this issue is resolved. Dentistry and its potential to help avoid aspiration is more important to people with a Learning Disability and / or Autistic people than the public. We will also ask that our cohort is prioritised over our wider population.
7. **Plans for ageing and end of life plans should be discussed with individuals and their carers.** To ensure there is a clear plan for a person's future as well as at the end of their life. To enhance the opportunity for individuals to die peacefully in their place of choosing.

Recommendations Continued (2/2)

8. **We recommend bereavement support for families / carers who lost their loved ones in the community be explored by health and social care.** This would enable people to die in their homes in accordance with their wishes without negatively impacting their family and / or carers support options.

9. **Continue to promote and support the training of the workforce across SET on Mental Capacity Assessments and promote the use of Mental Capacity Assessments (where appropriate)** along with best practice of how to record them.

10. **Promote and support the training of the workforce across SET on Do Not Attempt Cardiopulmonary Resuscitation (DNACPRs) and promote the review of DNACPRs at each new healthcare setting.** This to ensure best practice in appropriately completing DNACPRs and to ensure DNACPRs are reviewed. As there have been examples of some DNACPRs from the pandemic era are still seen as active on people's records.

11. **Continue to analyse and raise awareness of the most common genetic and long term conditions** that are experienced by those whose deaths were notified to LeDeR as well as how people with a Learning Disability and Autistic people access appropriate support for those conditions.

12. **Raise awareness of the signs of Sepsis again.** Previously work was completed to raise awareness of Sepsis and reduce the number of people dying of Sepsis. Unfortunately, this year there was a rise in the number of people dying of Sepsis, so this work needs to be recommenced. Issues related to urosepsis, and catheter care has emerged this year.

13. **Increase the representation on Focussed Review Quality Panels and the SET LeDeR Steering Group.** In the 2023/24 period the attendance of the SET LeDeR Steering Group and the Quality Panels has reduced.

14. **Significant Risk training to be explored for providers for health and social care to help people stay well in Winter and in Summer.** The training has been used in Southend, Essex and Thurrock and East of England in care home settings previously to prevent deterioration in residents and had good results. It also supports hydration which will be integral to stay well in Summer.

Asks For Southend-On-Sea Health and Wellbeing Board

1. **Note the Report and Action plan**.

2. **All Providers** - please make provision for Significant Risk training.

3. **Primary Care** – please help increase uptake of LD Health Checks.

4. **Help Improve attendance at the LeDeR Steering Group** so we can better roll out best practice.