Learning Disabilities Mortality Review (LeDeR) Programme

Key programme aim: to support local areas to review the deaths of people with learning disabilities, and take forward the findings into service improvements.

All deaths of people with learning disabilities are now being reviewed throughout England.

Each death of a person aged 4 years and over, receives an initial review. If indicated a multiagency review is completed. Learning and recommendations should lead to service improvements.
Findings

- Median age at death 58 years (range 4-97 years)
  - males – 59 years
  - females – 56 years

- Most common individual causes of death
  - Pneumonia 16%
  - Sepsis 11%
  - Aspiration pneumonia 9%
Key recommendations

✓ Identify reasonable adjustments in Summary Care Record and regularly audit their provision.

✓ There should be a national focus on pneumonia and sepsis in people with learning disabilities.

✓ There is a need to strengthen inter-agency collaboration, information sharing, and effective communication.

✓ Need to strengthen adherence to the Mental Capacity Act.

✓ Mandatory learning disability awareness training should be provided to all staff.
All deaths of people with learning disabilities are now being reviewed throughout England.

Priority themes
There is a fuller review of each death that meets the criteria for the current priority theme.
In 2018 the priority themes are:
- deaths of young people aged 18-24 (inclusive)
- deaths of people from Black and Minority Ethnic (BME) communities
All deaths receive a full multi-agency review, and are independently scrutinised by specialist panels.

Findings:
Age at death (n=1,131)
- Median age of death: 58 years (range 4-97)
- For males it was 59; for females 56.
- More than a quarter (28%) of deaths were of people aged under 50 years.
Cause of death (n=576)
- Underlying cause: respiratory system: 31%
- Underlying cause: circulatory system: 16%
- Most common individual causes of death
  - Pneumonia: 16%
  - Sepsis: 11%
  - Aspiration pneumonia: 9%

From 'learning' to action
Acting on the findings of mortality reviews is vital. Examples of actions resulting from LeDeR reviews of deaths of people with learning disabilities include:
- Review of safeguarding procedures in relation to discharge planning.
- Introduction of ‘reasonable adjustment care plans’ for patients with learning disabilities.
- Discussions with Clinical Commissioning Group about funding specialist support for people with learning disabilities when admitted to hospital in an emergency.
- Review of joint working arrangements.
- Delivery of learning disability awareness training.
- Introduction of learning disability and autism ‘champions’.

Recommendations
- Strengthen collaboration and information sharing, and effective communication, between different care providers and agencies.
- Push forward the electronic integration (with appropriate security controls) of health and social care records.
- Health Action Plans should be shared with relevant health and social care agencies involved in supporting the person.
- All people with learning disabilities with two or more long-term conditions should have a local, named health care coordinator.
- Providers should clearly identify people requiring the provision of reasonable adjustments on the Summary Care Record, record the adjustments that are required, and regularly audit their provision.
- Mandatory learning disability awareness training should be provided to all staff.
- There should be a national focus on pneumonia and sepsis in people with learning disabilities.
- Local services to strengthen their governance in relation to adherence to the Mental Capacity Act.
- A strategic approach is required nationally for mortality reviews or investigations.

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