Learning Disabilities Mortality Review (LeDeR) Programme

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Background

The national Learning Disabilities Mortality Review (LeDeR) Programme is the first of its kind in the world. It supports local areas in England to review the deaths of people with learning disabilities (aged 4 years and over), and take forward the findings from reviews into service improvements.

Values and Core Principles

We aim to effect change and make an identifiable difference to the lives of people with learning disabilities and their families.

We value the on-going contribution of people with learning disabilities and their families to all aspects of our work.

We take a holistic perspective when considering the circumstances leading to deaths of people with learning disabilities, and do not prioritise any one source of information over any other.

We want to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

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.

Review methodology

- ✓ All deaths of people with learning disabilities aged 4 years and older are **reported to the LeDeR programme** (http://www.bristol.ac.uk/sps/leder/notify-a-death/ or phone 0300 777 4774).
- ✓ An **initial review** is undertaken, which provides sufficient information to determine if there are any areas of concern in relation to the care of the person who has died, and if any further learning could be gained from a multi-agency review of the death that would contribute to improving practice. The reviewer speaks with family/ carers and consults available case-notes, including GP summary records.
- ✓ If indicated, a more in-depth, **multi-agency review** is conducted, or the death is referred for further investigation (e.g. to safeguarding or to the coroner) before the review is completed by the LeDeR programme.
- ✓ The local Steering Group follows up any learning or recommendations and translates these into **service improvements** as appropriate.

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%

Comments from reviewers:

Discharged home with a catheter, but care staff had never had any training about catheter care.
Nick* was later readmitted to hospital with likely urinary sepsis. The failure to liaise with carers about their knowledge and skills in catheter care contributed to an unsafe discharge, readmission and rapid decline in health.

The family actively participated in planning Jenny's* end of life care. This was facilitated by a high level of communication between the acute, critical care, palliative care and community professionals involved in her care, as well as by a clear and organised plan for managing her transfer back to the care home and her management there.

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.

Contact

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NHS England

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

* All names have been changed to protect confidentiality