Learning Disabilities Mortality Review (LeDeR) Programme

NHS England

Roll out of the Learning Disabilities Mortality Review Programme (LeDeR)

Important information for families and friends

The purpose of this communication is to advise you about the LeDeR programme and how you might be asked to contribute to it. The programme values the contribution of families of people with learning disabilities to all aspects of the work.

The LeDeR programme has been set up to improve the quality of health and social care for people with learning disabilities. It is doing this by supporting local areas to carry out reviews of the deaths of all people with learning disabilities. The process will draw attention both to good practice and to potentially avoidable aspects of care and treatment which contributed to a death. Any resulting recommendations will be put into practice.

There are two specific ways in which you could help with the reviews of deaths:

I. By notifying the LeDeR programme about the death of any person with learning disabilities. The details you provide will remain confidential throughout the process. You can report a death by calling a secure number: 0300 777 4774* or via the LeDeR website: www.bristol.ac.uk/sps/leder/notify-a-death.

*(Calls cost no more than a local cheap rate land line call)

II. By contributing to the review into the circumstances leading to the death of a relative of yours with learning disabilities over 4 years of age. The LeDeR progamme encourages reviewers to involve families throughout the whole review process, or as much as families feel able or want to be involved. As a family member you are likely to have the greatest knowledge of the person who has died, to know a great deal about their care and support, and be able to help the reviewers understand the sequence of events leading to your relative's death. Your unique perspective can tell us what could make a difference to the lives of other people with learning disabilities

Important: The programme aims to complete a national roll out by December 2017.

The LeDeR programme strives to ensure that reviews of deaths lead to learning which will result in improved health and social care services for people with learning disabilities. It is not an investigation nor is it aimed at holding any individual or organisation to account. If individuals and organisations are to be able to learn lessons from the past it is important that the reviews are trusted and safe experiences that encourage honesty, transparency and the sharing of information in order to obtain maximum benefit from them.

Reviews to date have highlighted good practice such as:-

i) staff being able to stay with patients with a learning disability during their hospital stay
ii) service improvements such as better communication training for A&E staff

Anita, a LeDeR reviewer commented "this feels like we are doing something really proactive to make a difference to people with Learning Disability".

NHS England's 'Commitment to Carers' guidance places family carers centrally in any consideration of a person's care. It sets out the need to review existing processes to gather bereaved carers' views on the quality of care provided to their relative in the last months of life in order to help address gaps in evidence.

Robina, a family carer who is part of the National Valuing Families Forum, and who also sits on LeDeR's National Steering Group says "this is a really important chance to use the knowledge family and friends have about the lives of people with learning disabilities…. If we all share our expertise it must be possible to improve people's lives and cut down on early deaths".

For FAQs and further information about the programme, please contact the LeDeR team :

: leder-team@bristol.ac.uk ☎: 0117 331 0686 💻: www.bristol.ac.uk/sps/leder