

People with a learning disability



A DIFFERENT ENDING: ADDRESSING INEQUALITIES IN END OF LIFE CARE

Life expectancy for people with a learning disability is significantly lower than the UK average, and there is also a high incidence of premature and avoidable death.^{1,2} In addition, people with a learning disability are more likely to have unidentified health needs, which can make recognising the end of life phase difficult. This means that people are likely to be identified as approaching the end of life late, which affects their ability to plan and make choices. It can also lead to problems in coordinating end of life care and providing support to the person and their family.

We asked a group of people with a learning disability about what was important to them for good end of life care. They told us that it was important to have family and friends nearby, to have privacy, peace and quiet, preferably not to be in hospital, to be able to go outside, and to have the support of a care coordinator when needed. They thought that services should talk more to people who have a learning disability to get their views and check that they are improving and inclusive.

Lack of knowledge

The health and care staff we spoke to felt that a lack of knowledge around learning disabilities could result in late diagnosis of illness, which could

have an impact on the likely success of treatment. In addition, symptoms may not be investigated because they are thought to be related to the person's learning disability.

Staff also said they sometimes had to fight to get the right care for a person with a learning disability, and that it could be difficult to organise best interests decision meetings because other professionals did not understand the Mental Capacity Act 2005.

Communication

Communication was identified as a significant barrier to good care, with health and care staff sometimes making assumptions about an individual, for example, that they may not be able to 'cope' with discussions about end of life. In addition, not being able to communicate verbally or needing specific support to communicate, presented challenges for some people. For example, health and care professionals told us that it was difficult to assess the person's pain when they have limited verbal communication. This was also a concern for people with a learning disability, who said that being able to explain or use picture cards with a nurse when they were in pain was important. Knowing the person well helped staff to understand non-verbal communication, as did using assessment tools for pain or distress, for example DisDAT, the Disability Distress Assessment Tool.³

1 Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L, **Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), Final report**, 2013

2 Mencap, **Death by indifference**, 2007

3 St Oswald's Hospice, **Disability Distress Assessment Tool**

A MIXED EXPERIENCE OF END OF LIFE CARE

We heard of the case of one man who lived in a care home for people with a learning disability, run by the local authority, and was diagnosed with oesophageal cancer.

Staff had supported him for 17 years and provided care that responded to his needs because they knew him well. When he became ill, staff referred him to a learning disability service because of issues with swallowing, and he was referred from there for speech and language therapy. His symptoms worsened and the GP advised him to go to A&E, where he was sent for tests, which resulted in the diagnosis of cancer.

A multidisciplinary team including care home staff and his sister discussed the diagnosis with him present, and a decision was made that he should receive palliative care.

He went home for Christmas and then died in the local hospice. A member of staff from the care home stayed with him in the hospice day and night so that he was not afraid. Although it was felt that he experienced a good death, the local authority and hospice identified a number of lessons from his care. They identified that care home staff had referred him to a learning disability service rather than the GP initially, thinking his symptoms were due to his learning disability. They also felt that care home staff lacked confidence in supporting someone with a learning disability at the end of life.

Recommendations were made around training and development of staff, communication and decision-making, and person-centred approaches. As a result, the care home has developed and improved its services.

Local area fieldwork findings

We found some good examples of planning for end of life care for people with a learning disability in some local areas. Tools had been developed locally that supported staff to assess each person's communication needs to ensure they were given the right amount of information in the right way. The requirements of the Mental Capacity Act 2005, including assessing capacity and best interests discussions, were included in the tools. People with a learning disability were sometimes encouraged to have discussions and complete end of life care plans when they were well.

Coordination of care

Health and care staff told us about their experiences of caring for people with a learning disability who are approaching the end of life. They highlighted how important it is to know someone well to make sure they get the right care.

“We support 350 people with a learning disability and as the end of life link nurse I ensure I am in the home 24/7 to support the dying person, carers and family in the last days of life. Last year we supported a gentleman aged 18 to get married just three days before he passed away; he died a happily married gentleman in a local children's hospice, with his bride, myself and hospice staff at his side.”

We found several other examples of good practice for people with a learning disability where a learning disability nurse took on the care coordinator role. The following example demonstrates how this can make a difference to the care of a person with a learning disability.

UNDERSTANDING WHAT A GOOD DEATH MEANS FOR PEOPLE

In one case, a person with a learning disability who had a diagnosis of cancer was living in supported living accommodation, and referred to the community learning disability team by his GP when his cancer became terminal. The support requested included guidance for the supported living team and the person's family, liaison with health professionals, provision of materials to help with communication, and education and training about the needs of people with a learning disability. The team got to know him, and he shared his likes and dislikes with them. They developed a plan of action to reflect this, working closely with him and his family to understand what 'a good death' meant for them.

The care coordinator, a Community Learning Disability Nurse, was at the centre of his support network, which included his family as well as health and care professionals. He was cared for in the last days of his life in the local hospice, where his family could visit at any time, and stay overnight with him. The hospice has continued to support his family since his death. His mum said that she thought being made aware of all the help available to them was most important to good end of life care.

From the perspective of the learning disability team, what made a difference was early referral by the GP. This gave them time to build relationships and plan. The use of a visual pain scale to aid communication with him, keeping him and his family at the centre of his care, good communication, and individually tailored advance care planning were also important.

National Council of Palliative Care story

CQC ENCOURAGES:

- Commissioners and providers to support early identification of people with a learning disability who may be approaching the end of life, as part of improved health care.
- Commissioners and providers to make sure that health and care staff have the skills and support they need to communicate well with people with a learning disability who may be approaching the end of life. This includes access to appropriate communication aids and tools.

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GOOD PRACTICE CASE STUDIES

PEOPLE'S EXPERIENCE BRIEFINGS:

- People with conditions other than cancer
- Older people
- People with dementia
- People from Black and minority ethnic (BME) groups
- Lesbian, gay, bisexual or transgender people
- People with a mental health condition
- People who are homeless
- People who are in secure or detained settings
- Gypsies and Travellers

