

Looking at differences in people's care at the end of their lives

For people with a learning disability

Easy read report (May 2016)



This is an easy read version of the report called ‘A different ending: Addressing inequalities in end of life care – People with a learning disability.’ It looks at what special care is like for people with a learning disability at the end of their lives.

It is written by the Care Quality Commission (CQC). We check services like hospitals, doctors’ surgeries and care homes to make sure they are giving good health and social care to people.



In the United Kingdom, people with a learning disability live a shorter life than other people. Often, their deaths could have been avoided.

People with a learning disability are more likely to have their health needs missed by health and care staff. This means it is harder to plan their care during the end of their lives and to give them support.

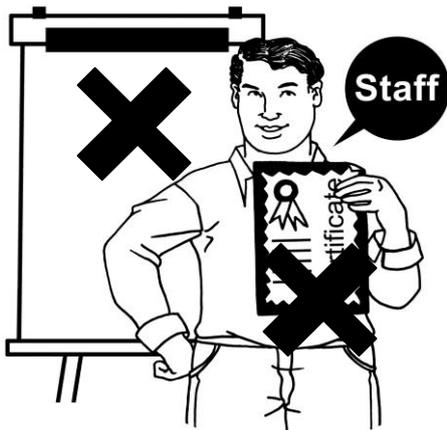
CQC asked a group of people with a learning disability about what was important to them for good care at the end of their lives. They said:

- having family and friends nearby
- having privacy, peace and quiet,
- to be at home (not in a hospital)
- to be able to go outside
- to have the support of a care coordinator when they needed help.



They also said care services should talk more to people who have a learning disability to get their views.

Knowing early on about a learning disability



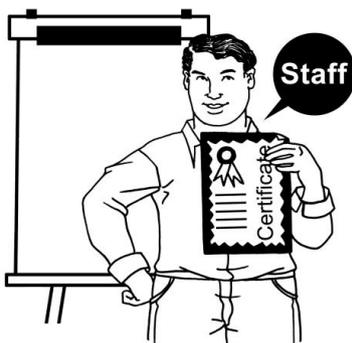
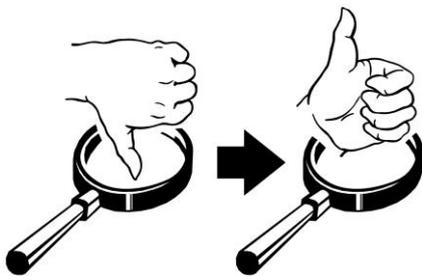
Health and care staff told CQC that they did not know enough about learning disabilities. This meant they may be too slow to know about someone's illness and they might not get the treatment they need.



An example:

One man lived in a care home for people with a learning disability for 17 years. When he became ill and could not swallow, he was sent to a learning disability service that supports people to talk. But he got worse so his GP told him to go to A&E. They found out that he had throat cancer.





A team of doctors and carers decided, with the man, to start his special care to make him comfortable at the end of his life. He went home for Christmas and then died in the local hospice with a member of staff from the care home looking after him.

Afterwards, health and care staff things they should have done differently were:

- the care home staff should have gone to the GP for help instead of thinking the man's illness was because of his learning disability
- they should be more able to support someone with a learning disability at the end of their life.

The care home has now improved its services because the staff now have the right training.



Health and care staff told CQC that sometimes it was hard to get the right care for people with a learning disability because other people did not understand the Mental Capacity Act 2005.

Explaining people's care



Some staff found it hard if they could not understand a person's pain or illness because they could not tell them with words. But people with a learning disability said that being able to explain or use picture cards with a nurse, or someone they knew, was helpful.



However, CQC found some good services that had organised the way they work to make sure everyone had a say about their care at the end of their lives.

Bringing together people's care



CQC found good examples where someone with a learning disability was looked after by one special nurse at the end of their life. The nurse was able to bring together all the areas of care, and build a friendship with the person.



An example:

A man with a learning disability, who lived in supported housing, was told he had cancer. His GP told the community learning disability team when he knew he would die from his cancer. The team got to know him and he shared his likes and dislikes with them. They also helped his family and housing staff to support him. There was one nurse in charge of bringing together the man's care.





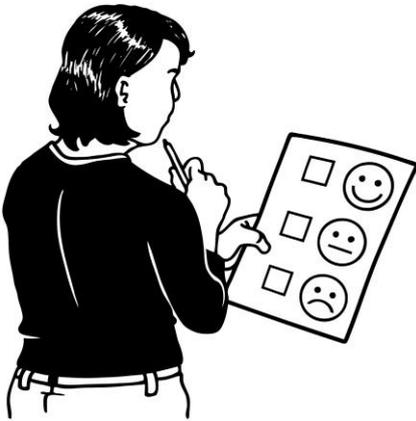
In the last days of his life, he lived in a hospice where his family could visit and stay with him. After he died, the hospice still supported his family. His mum said that knowing about all the help was really important and worked well.



The learning disability team said it was important that the GP told them about the man early, so they could build relationships and make plans. The team used a picture pain scale so they could know how much pain he was in, and kept him and his family at the centre of his care.



CQC would like to see



CQC would like to see all health and care staff:

- working together to find out early if people with a learning disability are near the end of life so they can get better care.
- making sure they have the skills to explain to people with a learning disability about their health and treatment, and that they are supported through things like easy read books.