



How social care staff can support palliative and end of life care for people with learning disabilities

Background

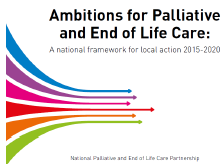


It can often be difficult for staff to recognise when people with learning disabilities are coming to the end of their lives. This means death is often not planned for and end-of-life care may be unco-ordinated. People with learning disabilities are less likely than others to have access to specialist palliative care services, like hospices. Often pain management for them is neglected or ineffective.



There are things that can be done to improve end of life care and the support given to people with learning disabilities and their families at this time.

Ambitions for palliative and end of life care



This is a **framework**¹ to help improve end of life care. There are six ambitions. Below we look at what social care staff can do in relation to each of these ambitions to improve the experience of people they support when they are coming to the end of their lives.

1

Each person is seen as an individual

Like everyone else, people with learning disabilities should have the chance to take part in conversations about death and dying. It is important to talk to the person about their end of life preferences and needs. This will take several conversations. Like others they are likely to be anxious and afraid. There are easy-read end of life plans² that can be used to help with this.

2

Each person gets fair access to care

It is important to identify when someone with learning disabilities is coming to the end of their life. If you would not be surprised if someone died in the next year this suggests it is time to start planning their end of life care.

Think about the reasonable adjustments the person might need. There is an information sheet about this.³

Maximising comfort and well-being

Give the person information about their illness and symptoms in a way they are best able to understand.

3

If the person is going to have treatment in hospital or in a hospice, help them to prepare. Visiting before they are admitted can be helpful. There are **easy-read resources** that may help with this.⁴

It is important to recognise if someone is in pain so this can be managed. There is an **information sheet** about this.⁵

Care is co-ordinated

There may be many people involved when supporting someone at the end of their life, particularly if they have several medical problems. There should be someone to take the role of co-ordinating this input so it works well for the person. This may be a GP or an end-of-life care nurse. Make sure you know who this person is.

4

Support workers can help by having good information about the individual so everyone knows things like how they communicate and their likes and dislikes. This might be a **hospital passport**⁶ or an **'All about Me'**⁷ document.

All staff are prepared to care

Supporting someone at the end of their life can be very challenging. Social care staff may need education and training around this. Mainstream palliative care services or community learning disability teams may be able to help. Staff may also need emotional support.

5

Each community is prepared to help

Think about what services there are in the community that could help. Local charities or voluntary organisations may be able to give advice, information or support. Care and support may also be needed by the person's family/friends. Local health, care and voluntary organisations may be able to help with this.

6

Further information



There is more detail about these six ambitions for people with learning disabilities in the NHS England report **'Delivering high quality end of life care for people who have a learning disability'**⁸

This also contains links to more resources and tools that may be helpful.

The Palliative Care for People with Learning Disabilities Network has lots of information and resources. It is free to join. Find out more at **www.pcpld.org**.

National Mortality Review



The Learning Disabilities Mortality Review (**LeDeR**)⁹ Programme supports local areas to review the deaths of people with learning disabilities and to use the lessons learned to make service improvements. Anyone can **notify** the death of a person with learning disabilities.

Key messages:

- it can be hard to recognise when someone with learning disabilities is approaching the end of their life
- this means sometimes their deaths are not well planned and they do not get the right support
- although it can be difficult, it is important to try to make sure the person understands what is happening and has a chance to express their wishes and needs
- it is important to recognise if they are in pain so this can be managed
- there is information and easy-read resources that can help social care staff when they are supporting someone at the end of their life

This is the 12th in a series of health factsheets for social care staff. You can find others and more [guidance](#) for social care providers.

There is a [supporting set of slides](#) for this document that can be used by social care staff as a training resource.

The pictures in this factsheet are from Photosymbols: www.photosymbols.co.uk

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¹ <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

² <http://webarchive.nationalarchives.gov.uk/20160704190619/https://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=340>

³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655373/Social_care_staff_supporting_reasonable_adjustments_in_learning_disabilities.pdf

⁴ <https://be.macmillan.org.uk/be/s-853-end-of-life-and-bereavement.aspx>

5
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/655386/Social_care_staff_supporting_pain_management_in_learning_disabilities.pdf

⁶ www.easyhealth.org.uk/listing/hospital-passports-%28leaflets%29

⁷ <http://www.uhs.nhs.uk/Media/Controlleddocuments/Patientinformation/Learningdisabilities/Hospitalpassport.pdf>

⁸ <https://www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/>

⁹ <http://www.bristol.ac.uk/sps/leder/>