



# Comprehensive end of life care training

## **Leicestershire Partnership NHS Trust**

The trust tested and developed a range of resources, training, pathways and support to create a consistent approach to end of life care for people with learning disabilities. They now implement this across the partnership.





## Background

Leicestershire Partnership NHS Trust delivered a Skills for Care funded end of life care (EoLC) project. The trust tested out a range of national resources for EoLC. It developed a comprehensive EoLC handbook for adults with learning disabilities and an effective EoLC pathway, to be used with the handbook.

The trust hosted a well-attended two day conference on EoLC in partnership with CHANGE, which works with health providers to support them to improve communication with people with learning disabilities and make their health information more accessible and inclusive. The event was targeted at a number of key stakeholders:

- staff from NHS learning disability services
- staff from generic NHS services, such as acute care and district nurses
- other NHS specialisms, such as palliative care
- people with learning disabilities
- staff from private, voluntary and local authority learning disability services.

## Aims

Key aims in relation to EoLC were to train a range of learning disability staff in good practice, enable service users to make their wishes known and signpost relevant information and evidence-based research. The focus was on raising awareness and bringing services together to support consistent best practice.

## What was done?

A successful two day conference was attended by 100 people. The conference was funded by the Department of Health National End of Life Project. A parallel workshop was run by CHANGE for a group of service users looking at advanced care planning.

The conference was significantly oversubscribed, with high demand from social care. There was a wide diversity of attendees: a palliative care doctor, nurses from community settings and learning disability services, social workers, social care staff from both Leicestershire County Council and Leicester City Council, nursing home managers, carers from care homes, domiciliary care workers, independent mental capacity advocates, NHS staff from both acute and community settings. Feedback from participants was extremely positive, with many commenting that such an event had been needed for years. Service users were also positive about the conference:

“Before today I was scared to die; now I am not afraid anymore.” **Service user.**

Two complementary training resource packs, demonstrated at the conference, were developed for:

- learning disability staff – palliative care: resources, academic research, books, signposting to further information
- generic district nurses – learning disability based: resources, books, articles, research, and signposting to further information.



The training resources were well-received at the conference, where the trust took the opportunity to test out the handbook with potential users and pinpointed parts of it that required further development work and increased scope. The packs have been further developed into resource boxes as a result of the feedback.

## Outcomes

In addition to the resource packs and the good practice shared at the conference, the trust delivers ongoing EoLC training. It benefits from having a dedicated EoLC trainer, who works equally across health and social care. One area of focus is staff from care homes. So far 285 staff from 100 care homes have attended a two day training course in palliative care covering the Liverpool Care Pathway, the Gold Standard, advanced care planning and care after death.

## Impact

There is already some evidence that the combination of the training and conference has had an impact. Staff make reference to the handbook and other training resources and try to follow the good practice guidance. More informed discussions take place about when it is appropriate for a service user to go into hospital. This means that the wishes of the service user are better taken into account and resources are used more effectively. The presence of service users at the conference made a real impact on staff and this was reflected in the feedback. The conference itself has helped to raise the profile of EoLC and increase its priority.

Staff now have access to good quality and up to date information and research about EoLC. Initial evidence suggests that they are more aware of the issues. Requests for further information and advice are increasing. The Liverpool Care Pathway is being implemented throughout inpatient care and care homes. There is a rolling process of identifying need.

## Learning

Useful learning points are:

- the need to work together – learning disability staff have to relate to district nurses and vice versa, this is essential to encourage individuals to think more widely
- it is important to use the Gold Standard and the Liverpool Care Pathway to make sure of the best care, do not try to reinvent the wheel and remember that there is only one chance to get it right
- it is easy to feel overwhelmed as so much priority is put on everything
- maintain the focus on the service user or patient throughout
- a central driving force is essential for success.

“It was really important to have people with learning disabilities at the conference and similar events, this is not an easy process, but the benefits flow from accepting the challenges—after all, communicating with people with learning disabilities is key to the whole process anyway.”

**Tracey Fynamore, Practice Learning Nurse.**



## Next steps

The trust is clear about the ongoing need for development:

- how to implement the Liverpool Care Pathway has been identified as a particular priority by learning disability homes
- further training for care homes in the future; making use of the learning resources and building on training that has already been provided
- a follow-up workshop conference. However, given resource constraints, funding will need to be identified for this
- a course specifically for people with learning disabilities in advanced care planning
- a review of the dementia and EoLC pathway
- further EoLC training is required for learning disability staff, occupational therapists and care home workers
- the possibility of a Liverpool Care Pathway audit, to gain a snapshot of progress in community hospitals.

## Contacts

[www.leicspart.nhs.uk](http://www.leicspart.nhs.uk)

### Further information

For further information about the health and social care integration work between Skills for Health and Skills for Care please contact:

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