



Hertfordshire Community Learning Disability Nursing Service

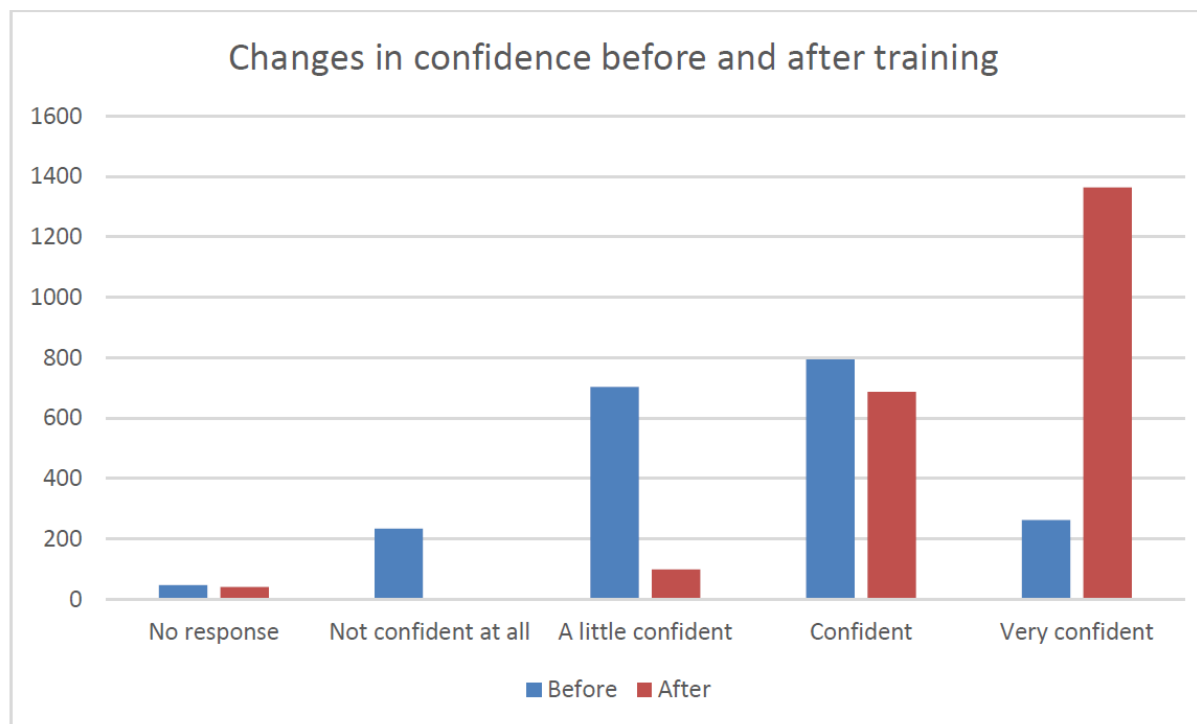
Implementing a Workforce Training Programme to Improve End of Life Care for Adults with Learning Disabilities

What did we do?

- Identified that there was a gap in social care staff knowledge of how to recognise and manage end of life care for people with learning disabilities.
- Initial Pilot with 2 care settings to test out adapted ABC Palliative care programme delivered over 2 ½ days to the whole team over 3 months.
- Graham Rowlandson Fund provided £26,250 towards the aim of delivering an End of Life education programme to up to 250 social care staff in 10 learning disability care settings across Hertfordshire.
- Delivered education to 107 staff across 16 residential and supported living settings across 48 sessions. Sessions delivered jointly by Palliative care Educator/Practitioner and Community Learning Disability Nurses.
- Due to savings during the delivery we were also able to deliver 6 education sessions to social care staff working in local authority Day Opportunities projects and colleagues working in Adult Disability Social Care Teams. An additional 2 care settings also requested to receive this 2 ½ day training due to hearing other care staff talk about the impact.
- Evaluated the learning and outcomes of delivering this education.

Feedback and outcomes;

1) Increased confidence to recognise and manage end of life care needs;



Feedback and outcomes;

2) Improvements in quality of care;

Pain control for non-verbal patients is an area covered by the training. A number of care homes reported that following the training they had begun to reflect on the non-verbal cues that might indicate a patient was in pain and adjust when pain relief was administered. For example, one service user was on regular doses of paracetamol for joint pain and stiffness and was agitated on waking and reluctant to get washed and dressed. Staff reflected that the resident might be in pain on waking, moved the first paracetamol dose forward to 30 minutes before the days routine started and saw a marked reduction in levels of agitation.

Advanced care planning for end of life with families is an essential part of the care staff role, and can often be difficult if families and carers have differing views about how much a service user can cope with. One home demonstrated how they had adopted new learning into their practice. During the training a resident with dementia's family made their annual visit from abroad. Staff were able to introduce the need for advanced care planning with the family, who compiled a large photo album with attached dialogue for each photo. There is now an Advance care plan, DNACPR documentation and funeral plans in place for this service user.

Feedback and outcomes;

3) Improved understanding of the end of life care needs of people with learning disabilities;

Improved communication with wider health partners. One care home is now working with a nearby GP practice pharmacist to review the medication of their end of life patients, another is sharing the care documentation with their linked GP practice. Another home reported changes in the way staff handover care of residents who are admitted to hospital, in which much more attention is now paid to ensuring hospital staff understand all communication cues, including non-verbal cues, of residents, so that hospital staff are better able to meet patient needs and provide appropriate care.

Community learning disability nurses who have been working alongside hospice educators to deliver the training have also reported increased understanding that has led to improvements in care. A nurse working with us in Dacorum reported an increased confidence in being able to recognise the signs of end of life and push for a referral to a hospice for one patient and to ensure that end of life plans, such as just in case medication was in place for another, that patient died four days later and benefited from the timely input from the community learning disability nurse.

Feedback and outcomes;

4) Improved bereavement support for residents, families and care staff in the service users home;

This was an unforeseen outcome of the training but one which has been consistently reported by many of the participating care settings as an area that staff felt they needed to make changes to improve the support offered to staff, residents and families. Particular focus has been on recognising bereavement distress in non-verbal residents or those who present with behavioural problems and developing strategies to support them. A number of homes have been developing remembrance materials about the deceased resident to help other residents manage their grief. The training has also prompted one home to reconsider a number of its practices and how they impact upon the bereavement process particularly to recognise that staff also experience grief when a resident dies and how to better support them. Examples of measures they are putting into place include, rethinking the immediate clearing of a room after a resident dies, introduction of more meaningful bereavement support for staff beyond a telephone support line, introduction of remembrance events to remember deceased residents.

Embedding it into practice;

Before the training had started there was an unexpected death one of the care settings of a service user who had lived there for many years. Even though a Do Not Resuscitate (DNACPR) was in place, staff panicked and called the emergency services and resuscitation was attempted, which was traumatic for staff and the service user. After the training they reflected on this patient's death and realised that there were signs in the last weeks of life that the resident was deteriorating and did not have long to live.

After the training, another service user at the care setting was admitted to hospital and then discharged back home for end of life care with support from the district nursing team. The management noted increased confidence and communication skills amongst the staff when co-ordinating and planning their care. The eventual death was very peaceful, staff stayed with her, holding her hand, playing her favourite classical music. A member of staff who had been present at both deaths reflected on the positive effect of knowing how to support a "good death" thanks to the training.

More to do;

- The changing expectations of role of social care staff in health surveillance tasks
- The need to engage wider health partners in discussions about Advance Care Planning and the complexities when working with people with learning disabilities
- How to support people with profound communication difficulties in loss and grief
- How to support a person with learning disabilities in meaningful DNACPR discussions
- How to support family/paid carers to recognise own desire to protect service users from things that may upset them and devising strategies that are right for that individual
- Recognising and managing the complexities of bereavement for residents, family and care staff
- How to respond to increasing complexity of need as resident's condition deteriorates and support staff anxiety in the service user remaining at home
- Improving understanding of pain control, postural support for feeding and when to engage speech and language therapists to support feeding and end of life conversations for people who receive PEG Feeding

Useful resources;

<https://www.pcpld.org/>

<https://www.dyingmatters.org/>

thank you