Supporting People with Learning Disabilities at end of life: A summary report of a training programme to increase staff skills to enable people to meet their wishes at end of life

Summary report prepared by

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Background

The project was developed in response to a patient's experience shared by a local hospice service and the Learning Disability Service. A gentleman with learning disabilities had been admitted to the hospice for symptom control at end of life (EOL) by a Residential Care Home, where he had lived for many years. Staff at the Care Home were struggling to support him as he was coming to end of life and with managing the symptoms that he was presenting.

When the gentleman was first admitted to the Hospice, he was clearly distressed by the change of environment in addition to his presenting symptoms. Hospice staff found it difficult to establish clear communication with him because it was challenging to understand how to plan his care needs and ascertain what his wishes were. This was compounded by not having a communication passport, which is a resource to support vulnerable people with communication difficulties, drawing together complex information. In addition, there was not the availability of a key worker who could share important information and history. Future care planning became compromised due to lack of engagement with the care home. The hospice staff discovered by using “Dr Who” as a point of reference; his favourite TV programme, they developed an effective way to communicate with him. This allowed some barriers to be overcome which enabled better planning and improved care. This gentleman continued to ask to go home but the residential home felt they were unable to support him. This was following his symptom control needs becoming stable, however he was continuing to deteriorate physically. Therefore, he remained at the Hospice until his end of life. This story illustrated that there was a gap in the confidence, advance care-planning, understanding for end of life care and palliative care issues in homes who support people with learning disabilities.

Reflecting on this situation, the following points were noted:
A) An appropriate referral was made to a local hospice for end of life support
B) The gentleman’s placement broke down due to the support staff not being able to manage and understand the deterioration in his health and feeling they were unable to cope with a dying person
C) Although the hospice seemed like the best place to support a person dying this was not the person’s first choice
D) Effective communication and sharing of information is key in planning for end of life care
E) Specialist Nursing Learning Disability Team were not involved appropriately, due to the team being unaware of when to make a referral to establish a multi-disciplinary approach to end of life care.
Development- Ambitions for Palliative and End of Life Care [2014]

As part of the pre-development of the training programme and resources the project team held 2 x ½ day multi-agency workshops [services invited to attend were private organisations, charities, hospices, NHS acute and community and social care] to prioritise topics which they would like included in the training. Group work produced discussion about areas of end of life care for people with learning disability which attendees felt staff needed to develop skills and confidence in. These were mapped against the six ambitions for end of life care to demonstrate congruence for all services and multi-agency involvement.

These are the six ambitions for end of life care:

01. Each person is seen as an individual
02. Each person gets fair access to care
03. Maximising comfort and wellbeing
04. Care is coordinated
05. All staff are prepared to care
06. Each community is prepared to help

Additionally, the evaluation partner undertook a literature review, which supported the output from the workshops as to the identified topics to be included in a 2-day training programme.

The output from the workshop and literature review indicated that there was congruence with the project team’s initial thoughts for the topics to be included in the programme.

Sustainability/dissemination

As part of the project development and implementation a workbook, as shown in Appendix 1, was produced to include many of the resources available, provide signposting to supporting information and materials for those attending the course dates. Participants were all given a workbook to enable them to take the information back to their teams to assist in dissemination and act as general resource.
The training also focused on learning disability awareness, reasonable adjustments, mental capacity and breaking bad news, which was delivered by the learning disability nurses.

At the end of each training course, all participants were asked to complete an evaluation form confirming the knowledge and skills gained and what they will do differently in the future. Appendix 2 details all responses received.

The comments within the evaluation forms showed that staff learnt about the importance of communication and the different ways and resources, which enable communication (i.e. advanced care planning and the use of easy read materials.) Many shared that after the training they felt confident to talk about end of life with people with a learning disability. Appendix 4 shows some words, which were commonly found within the evaluation forms:

Appendix 5 is an example of care planning within a group for end of life care and what to consider if the person has a learning disability, including tools and resources.

The presentations delivered at the End of life care training can be found in appendix 3. However, during the training other group work was completed and supported by the trainers using an assortment of resources.

A Survey Monkey review of participants was undertaken 6 months after the programmes completion; comments made demonstrated that there had been a continued impact from attending the course. Some of the responses from the Survey Monkey were:

‘This course was very well thought out and enjoyable. I found it particularly useful, especially regarding communication styles/ tools.’

‘The training was very good and I took a lot away from it. Thank you’

Using this information, Canterbury Christ Church University was commissioned to evaluate the impact of the training course on the knowledge, skills, competence and confidence of the course participants. This report can be found in Appendix 6.
After the delivery of the training, the project team has taken opportunities to share their experience and promote the work that has been undertaken as part of the project both within their employing organisations and externally; this is detailed as follows:

- Community of practice June 15 2017 KSS Poster 1 was displayed to illustrate development of the training programme in advance of the delivery.
- KCHFT Champions meeting presentation by Tracey Rose on End of Life Care for People with learning Disabilities
- PCPLD conference June 2018 displayed Poster 1 and this has been added to the PCPLD website
- KCHFT Quality Improvement Network presentation to staff on the project
- AHSN KSS End of Life Network Presentation November 2018
- Hospice UK annual conference November 2018 Poster 2 illustrating the overall project was presented
- The Specialist Learning Disabilities Nurses involved in this project were nominated for one of the trust annual awards and were awarded as runners up.

**Recommendations**

From the project team discussions, our recommendations to consider are:

1. If the programme is repeated, the survey should be for completion by all participants administered by the delivery partner at the start and end of the programme. The evaluation tool would require a review and a simpler online survey to enable a more detailed analysis of data for comparative purposes.

2. Themes from the evaluation illustrations show core EOL training needs which staff can link in with future projects such as Advanced care planning and communication skills.

3. To add general Learning Disability awareness training to all courses.

4. Identify ways to improve the promotion of the course to external organisations, increasing the courses uptake.
5. The training to be disseminated to KCC staff and added as a requirement to the KCC care contract.

6. To hold a two-day consecutive training course for social care and other qualified staff and a one-day introductory course for support workers.

7. Post-centre focus group interviews with supporting managers would enable insight into the impacts of the training.

8. A formal evaluation to be written by a partner with more experience in Learning Disabilities.

9. As a result of the evaluation responses, appendix 2, we would recommend that the PCPLD local group restarted and the EOL training provides a more in-depth session on breaking bad news for people with a Learning Disability.
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