

Aims

- To understand and identify the needs of those supporting people with learning disabilities from a hospice and learning disability perspective.
- Explore levels of confidence of varying health and social care professionals when talking about death, dying and bereavement to someone with a learning disability.
- Compare and contrast experiences and gaps in knowledge and experiences between hospice and learning disability carers.
- Inform the content and process of the training programme.

Actions

- The project steering group collaboratively developed a survey to establish baseline data and increase knowledge.
- The survey shared with hospice staff and local learning disability organisations.
- Survey thematically analysed outcomes to illustrate similarities and differences within and across data sets.
- The data directly informed the three-session training programme.

Outcomes

- Over 100 responses received, with a near equal split of hospice/non-hospice.
- The replies are being thematically analysed.
- The data directly informed the content and process of the training programme.
- The project is currently being prepared as a paper for publication in a peer reviewed journal to maximise dissemination of outcomes.

Conclusion Learning is key in any project. By conducting the survey, we have learnt much about people's levels of confidence, their understanding, and their training needs. The results of the survey have already influenced the project and when shared more widely, will help us develop a more compassionate community around people with learning disabilities.

P-10 STEPPINGSTONES TO BETTER PRACTICE: LIVING, DYING AND REMEMBERING WITH A LEARNING DISABILITY

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10.1136/spcare-2021-Hospice.31

Background We are committed to remaining an inclusive hospice and have adopted a community development approach to respond to national reports and research (LeDeR programme, 2018; Hunt et al., 2019; Heslop, Blair, Fleming et al., 2013; Oliver, 2017) that highlight the need to improve end-of-life care and bereavement support for people with learning disabilities in England.

Aims

- To enable the hospice to effectively monitor patients with learning disabilities accessing services, providing a more patient centred service.
- Develop and support a network of local learning disability champions.
- Deliver targeted, multidisciplinary training on best practice when supporting people with learning disabilities at end-of-life and through bereavement.

Actions

- A local learning disability partner was sourced.

- A steering group, including two members with a learning disability, oversaw the project.
- A survey was developed and distributed.
- Building on the survey outcomes, a focused programme around supporting people with a learning disability at end-of-life was developed and delivered by experienced trainers, in conjunction with two people with a learning disability.
- Champions were recruited to develop and drive the work forward.

Outcomes

- Better hospice systems of recording patients with learning disabilities.
- New relationships with learning disability organisations developed.
- Created a network of learning disability champions who will meet regularly to develop their knowledge; share good practice; and act as a conduit to inform future aspects of end-of-life care with this marginalised group.
- Delivered a three-part training programme (informed by the responses from the survey).

Conclusion Bringing together local learning disability organisations has strengthened our ongoing commitment to develop compassionate communities. By adopting a community development approach to better understand the issues faced by people with learning disabilities at end-of-life and through bereavement, we have already identified issues and changed practice and there is real passion and determination to take this work forward through the network of local learning disability champions.

P-11 'MIND THE GAP' – WIDENING ACCESS TO HOSPICE CARE FOR PEOPLE WITH A LEARNING DISABILITY

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10.1136/spcare-2021-Hospice.32

Background It is recognised that people with a learning disability do not access specialist palliative care services in the same way as their peers without learning disabilities; and that people with a learning disability may need significant reasonable adjustments to enable them to fully access all aspects of end-of-life care. To address this need, our hospice is currently undertaking a year-long project running until early 2022. A grant funded role of Learning Disability Nurse as End of Life Care Facilitator has been established.

The key aims are to:

- Work across hospice and learning disabilities services, to understand and challenge gaps in knowledge and access for people with a learning disability.
- Use the skills of both sets of teams, to support learning, and build sustainable resources, knowledge and relationships across all stages of palliative and end-of-life care – from early identification through to last days and bereavement.
- Engage with local communities, to start conversations about death and dying– to ensure the right support is available for people with a learning disability, their families and carers.

Outcomes

- Gap analysis across hospice and learning disabilities statutory provision to identify training skills and deficits indicates

variance in confidence and knowledge about working with people with a learning disability at end-of-life.

- Shared teaching programme commenced.
- New resources available for hospice staff, and patients.
- Engagement within the hospice environment – inpatient and community.
- Engagement with community services, experts by experience, care providers, community groups to plan events and start the conversation about death and dying.
- Increased recognition of the needs of relatives with a learning disability when caring for a parent, sibling, co-resident etc.

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COLLABORATIVE WORKING WITH LEARNING DISABILITIES PATIENT EXPERIENCE GROUP

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10.1136/spcare-2021-Hospice.33

In 2019 the hospice was contacted to provide easy-read literature explaining what hospice care is for a person with a learning disability. As an organisation we didn't have this kind of documentation and we couldn't source it from elsewhere. This set us on a journey of collaborative working and service co-design with our local Community Learning Disabilities Team and Learning Disabilities Patient Experience Group (LDPEG).

The first draft of the leaflet was utterly 'trashed' by the group; they were particularly critical of the images we had used as none of them were of our hospice building and none of them contained people with a learning disability. As a result, a number of the LDPEG visited the hospice and met with staff. They proved very insightful and challenging in their questioning of the work we do as well as about death and dying. We were in the process of finalising the leaflet, using members of the LDPEG in the photographs as well as piloting a wellbeing group when COVID-19 hit and everything had to be postponed.

We are now in a position to re-commence that work. We have an afternoon tea event scheduled for 23 June to celebrate Learning Disability Week and will hopefully be in a position to complete the easyread literature before Hospice UK's conference in November. In talking to professionals and carers we are aware how challenging advance care planning discussions can be, and we hope to pilot a group for people with learning disabilities and their families/carers to introduce hospice care and advance care planning discussions. This will hopefully address some of the shocking inequalities in end-of-life care people with a learning disability can experience.

We also plan to provide bereavement support, not only to families and informal carers, but also to paid carers who may have had a longstanding relationship with an individual prior to their death.

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THE LEARNING DISABILITY DEATH REVIEW (LEDER) PROGRAMME IN A UK HOSPICE

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10.1136/spcare-2021-Hospice.34

Background The Learning Disability Death Review (LeDeR) was commissioned by NHS England in 2015 in response to the 2013 Confidential Inquiry into the Premature Deaths of people with Learning Disability (CIPOLD) (Heslop, Blair, Fleming, et al., 2014). Phyllis Tuckwell Hospice Care (PTHC) integrated the LeDeR programme into our learning from deaths process in 2019.

Aims This report shares our experience of undertaking reviews of the care provided to patients with a learning disability and outlines the enhanced working relationships which have resulted from our engagement with the LeDeR programme.

Methods PTHC reported our first patient death to the LeDeR programme in October 2019 and conducted a Structured Judgement Review (SJR) in line with NHS (NHS Improvement, 2018) and Royal College of Physicians (2016) guidelines. We have subsequently reviewed the deaths of seven other patients with a learning disability between April 2019 and March 2021.

Results Of the eight cases reviewed, five patients were cared for at the end-of-life in their usual place of residence - considered a marker of good practice - with three supported on the inpatient unit. Other examples of good practice include documented mental capacity assessment and best-interests decision-making on admission or first community review and evidence of reasonable adjustments including adaptation to room lighting and supporting a pet to visit.

One case identified important areas for improvement with limited evidence of mental capacity assessment and delayed access to appropriately funded care. The case was reviewed at a multi-professional meeting with action points disseminated within the hospice and shared with the regional LeDeR team.

Conclusions Training on mental capacity assessment in learning disabilities has been included in educational meetings and incorporated into organisational mandatory training. PTHC is now a core member of the regional LeDeR team and has provided training in end-of-life care to the learning disabilities team in our local Community Mental Health Trust. These links help us reach and enhance the care for more patients with learning disabilities.

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THE CASCADE PROJECT: PROMOTING AGE-ATTUNED PALLIATIVE CARE

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Background It is now widely recognised that the palliative care needs of older people with frailty are poorly met compared to those of others at the end-of life (Hamaker, van den Bos, Rostoft, 2020). More people die of frailty and age related comorbidities than of cancer or heart disease and yet they are not the focus of end-of-life care. The COVID-19 pandemic has emphasised the difficulties in providing the right care at the right time for this particular disadvantaged group (Lebrasseur, Fortin-Bédard, Lettre, Raymond, et al., 2021).

Aim To improve confidence and capability in (a) hospice and (b) community sectors in understanding and delivering age-attuned palliative care.

Method We implemented the approach described in Age-attuned Hospice Care (Nicholson & Richardson, 2018). Three