

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.

### P-12 COLLABORATIVE WORKING WITH LEARNING DISABILITIES PATIENT EXPERIENCE GROUP

Joanne Schofield. *The Prince of Wales Hospice, Pontefract, UK*

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.

### P-13 THE LEARNING DISABILITY DEATH REVIEW (LEDER) PROGRAMME IN A UK HOSPICE

Nick Dando. *Phyllis Tuckwell Hospice Care, Farnham, UK*

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**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.

### P-14 THE CASCADE PROJECT: PROMOTING AGE-ATTUNED PALLIATIVE CARE

<sup>1</sup>Helen King, <sup>1</sup>Heather Richardson, <sup>2</sup>Caroline Nicholson. <sup>1</sup>*St Christopher's Hospice, London, UK;* <sup>2</sup>*University of Surrey, Guildford, UK*

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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