Conclusion In collaboration with others and several different approaches, the hospice is able to offer choice and access to care for the homeless population it serves; therefore transforming experience for this marginalised group.

HOMELESSNESS AND END OF LIFE CARE: IMPROVING PARTNERSHIP WORKING

Catherine Thompson, Janet Hawksworth, Jayne Bargh, Sadaf Adnan. Kirkwood Hospice, Huddersfield, UK

The aim of this project has been to engage with services who have traditionally not worked in partnership with the hospice, in order to jointly identify ways of integrating services to better support vulnerable adults. By up-skilling and increasing confidence for multi-disciplinary professionals both internally and externally, we hope to both widen access to our services but also to develop compassionate communities, in line with the Ambitions guidance.

Aims
- Improving reach
- Challenge pre-conceived ideas surrounding end of life care and dispel myths
- Identify opportunites to work in partnership to support hidden and isolated carers
- Increase awareness of the interconnections between end of life care and agencies supporting those who are more likely to be faced with health and social inequality.
- Develop practical guidance to improve earlier identification and signposting.

A workshop was held in February 2018, within the hospice, with attendance from 11 local organisations supporting those who are homeless within Kirklees. This was an engaging and thought provoking event, with many attendees acknowledging the gaps in promoting holistic end of life care.

There was recognition of the value of working together to understand and share each other’s specialism and skills but also the need for external improvement in professionals’ confidence in end of life conversations. Another area of focus was the need to improve bereavement support and skills.

A training and education plan is currently in development, with the initial focus on developing and piloting self-management sessions for those with liver failure. A clinical ambassador programme is also planned to be launched, with input from organisations attending workshop.

Considerations The role of the hospice in offering ‘outreach’. Importance of advocacy for individuals less likely to actively engage with end of life care services. Person-centred care and respecting people’s decisions, especially if other priorities come before seeking healthcare.

LEARNING DISABILITY COMMUNITY COLLABORATION PROJECT FOR PEOPLE WITH PALLIATIVE CARE NEEDS

Gemma Allen. The Mary Stevens Hospice, Stourbridge, UK

Background People with a learning disability (LD) are three times more likely to die at a younger age than the overall population (Heslop, Blair, Fleming, et al., 2013). Furthermore, they may experience inadequate end of life care through providers not recognising or considering individual needs (Care Quality Commission, 2016).

Two LD champions were appointed, to examine how we support more people in the community from this marginalised group.

Aim(s) Increase accessibility for people with LD to receive coordinated, personalised, end of life care. Identify gaps in knowledge of hospice staff.

Methods Hospice peer review conducted by LD self-advocacy group. Opinions of LD providers and professionals canvassed. Presentations delivered through community engagement emphasising objectives.

Outcomes
- Information pack produced, and training developed for hospice staff and volunteers. End of life care education scheduled for LD professionals.
- Easy-read literature review, funds granted to adapt hospice information.
- 24 LD care home staff accessed ‘Palliative Care Champions’ training.
- Interactive Dying Matters event for people with profound, multiple LD.
- Staff trained in Makaton.
- University partnership creating diversity/inclusion initiatives and research proposals.
- Development of regional LD palliative care network.
- Recognised as a ‘Safe Place.’

Feedback from people with learning disabilities: ‘...they are true learning disability champions, passionate and committed to getting the service right for everyone.’ ‘The hospice is already a friendly place and I can see it getting more disability friendly.’

Conclusions The project has addressed inequalities from this marginalised group’s experience. The programme is ongoing, ensuring people with a LD receive fair, accessible, inclusive end of life care, now and in the future.

SUPPORTING PEOPLE WITH LEARNING DISABILITIES AT END OF LIFE: A TRAINING PROGRAMME

Nicola Le Prevost, Tracey Rise, Rosalyn Chapman. Kent Community Health NHS Foundation Trust, Maidstone, UK

Background The project arose from personal experience/reflection resulting from caring for someone with a learning disability (LD) at the hospice. Lack of support and knowledge from the involved services contributed to an outcome in not meeting the person’s wishes to be cared for at ‘home’, which should have been possible.

Reports and enquiries indicate the inequity in health and need for end of life care: health care is not equitable (Confidential Inquiry into Premature Deaths of People with Learning Disabilities, 2013); staff caring for people with LD require development of end of life care knowledge and skills (Palliative Care for People with Learning Disabilities Network, 2017/18; Care Quality Commission, 2016; NHS National End of Life Care Programme, 2011).
Aim The project aimed to improve awareness and knowledge of end of life care needs for people with LD; increase confidence and skills of staff providing end of life care for people with LD.

Methods A partnership group met to make a funding bid; development and delivery of an education project across sectors and professionals, successfully submitted to HEE regionally. Held consensus curriculum development workshops to inform the training programme. Literature review and evaluation commissioned from university (report due September 2018). A two-day training programme with support materials, e.g. resource book. Programme delivered by utilising both specialist LD and end of life care knowledge and practice. 6×two-day courses were delivered between October 2017 and April 2018.

Results The delivery of the project has been beset with personnel issues such as staff sickness and changes in roles which was a challenge for project management. Training day evaluations were positive about the learning, presentation and gaining knowledge for practice. Practitioners provided examples of learning use in practice as feedback illustrating their increased confidence. Collaboration between specialist LD practitioners and the hospice Education Team has been a positive experience.

Conclusions De-brief project meeting recommended further development of advance care planning and skills and confidence in end of life care for people with LD locally. A multi-professional attendance was achieved. Collaborative hospice/LD team working contributed to the overall experience.

Background The CIPOLD (Heslop, Blair, Fleming, et al., 2013) study found that people with learning disabilities (PWLD) died on average 13 years (men) or 20 years (women) sooner than the average UK population. Despite 57% of studied deaths being ‘expected’, only 20% received support from specialist palliative care services (Heslop, Blair, Fleming et al., 2013). Initial consultations with PWLD, their families, and professionals in Cardiff and the Vale found limited knowledge of palliative care services and this lack of awareness limited access to services.

Aims The Big Lottery funded Improving Access project aimed to identify barriers to PWLD accessing palliative care services and implement activities to reduce these.

Methods 12 organisations and 54 individuals consulted, including PWLD, families/carers, health and social care professionals. Project advisory group includes a PWLD and inclusion of PWLD and professionals in Cardiff and the Vale found limited knowledge of palliative care services and this lack of awareness limited access to services.

Results Consultations identified the following needs:
- Improved community engagement and education to increase awareness of services.
- Opportunities for PWLD to be supported to talk about end of life
- Varied formats of accessible information.

Project delivering the following activities:
- Education and workshops to professionals, PWLD, and carers on topics including bereavement and advance care planning. Audiences included learning disability teams, attendees of the Learning Disability Wales annual conference, and bereavement teams.
- Promoting Marie Curie Easy Read materials.
- Working with PWLD to develop ‘what to expect’ videos that can be used to educate PWLD about hospice and palliative care.

145 people reached through face-to-face events.

Conclusion The project has increased internal staff awareness of the challenges PWLD face in accessing services so that these needs can be considered in shaping and delivering services. It has improved awareness of palliative care services for PWLD, carers, and professionals and created opportunities for PWLD to talk about end of life. Involvement of PWLD is vital in reaching more people and ensuring the voices of PWLD are heard and included.