

P-33 A COMMUNITY DEVELOPMENT APPROACH TO TRANSFORMING PALLIATIVE CARE – HARNESSING THE ‘POWER OF PEOPLE’

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Background Common headlines and perceptions: Death is a taboo subject (Dying Matters, 2011); Hospices are a place to go and die (National Hospice and Palliative Care Organization); Isolation is an increasing factor to illness (Age UK, 2018; Iliffe, Kharicha, Harari *et al.*, 2007).

These have been the catalyst for hospices to explore beyond clinical intervention and engage resources to help create a world where communities talk openly about death and dying, everyone lives life to the full and dies with dignity in the place of their choice, knowing their loved ones are supported.

Aims To increase awareness of services earlier, facilitate conversations about death and dying, increase wellbeing, and decrease isolation by establishing regular community cafés/coffee mornings and a network of trained Compassionate Neighbours.

Methods Employ a Community Development Manager to:

- Establish volunteer-led community cafés/coffee mornings in target areas
- Lead Compassionate Neighbours Project equipping them with knowledge of hospice services and confidence to engage in end of life conversations
- Facilitate regular Dying Matters conversations using interactive activities and ‘What’s the Plan’ card prompts at coffee mornings; host Death Café
- Develop partnership and collaborations with community organisations e.g. Dementia Action Alliance.
- Establish regular monitoring and evaluation using questionnaires, peer evaluators and user forums.

Results

- Community Café open three days a week at Living Well Centres
- Established two satellite coffee mornings/Pop up cafés
- 64 Compassionate Neighbours/24 matches by Jan 2019
- Increased participation in services by wider community.

Conclusions Early results are showing increased confidence and cohesion between Compassionate Neighbours, and successful matches with community members who otherwise might face dying in isolation. There is a willingness to explore end of life, including interest in Advance Care Plans with attendees to the café. Regular visits to coffee mornings/cafés will increase awareness of hospice services.

P-34 DYING ON THE STREETS: PALLIATIVE CARE FOR PEOPLE WHO ARE HOMELESS OR VULNERABLY HOUSED

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Background People who are homeless or vulnerably housed are likely to die young, with an average age of death of 45 years. Many experience life-limiting illnesses, further complicated by dependence on alcohol or drugs. These illnesses can

cause significant problems in the last year of life, however, access to palliative care is severely limited.

Aim To develop a co-ordinated approach to palliative and end of life care for people who are homeless and vulnerably housed across the city of York.

Approach The project began with research undertaken at the University of York (Hudson, Flemming, Shulman & *et al.*, 2016; Skelton, 2017) informing education in end of life care for Changing Lives hostel staff, delivered by St Leonard’s Hospice. The education programme had a positive impact on care, however, joint working across organisations highlighted that vulnerable individuals were falling through ‘gaps’ in end of life care provision. This was the catalyst to bring together health professionals working with the homeless population of York and palliative care specialists to develop: processes of identification of individuals nearing the end of life, guidelines for symptom management, advance care planning and palliative care education.

Next steps Drawing on best practice nationally, we aim to develop a responsive service relevant to the needs of service users at the end of life.

P-35 HOSPICE AND HOMELESS – A NATURAL COLLABORATION

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Background Many people who are homeless experience poor health. 41% have long term health issues, including a mix of mental and physical poor health and substance misuse (Homeless Link, 2014). Death often occurs early and symptom burden at end of life is heavy. Access to palliative care is limited (Shulman, Hudson, Low *et al.*, 2018). Those least able to advocate for themselves are most often overlooked (Care Quality Commission, 2017).

Aims By working in collaboration with others, to bring choice and access to palliative and end of life care for local people who are homeless. To ensure barriers to care are removed and homeless individuals and their supporters are not overlooked.

Methods Monies obtained from the Rayne Foundation. One homelessness lead employed one day a week and two experienced counsellors for three hours a week each. Education to local hostels and ongoing support maintained by visits, phone calls and referrals. Collaboration with housing and social care, local voluntary organisations, hospitals and discharge team. Teaching around homeless health and end of life care to final year nursing students. Hospice provides bed at end of life and Day Hospice welcomes people who are homeless in to services. Links with other hospices setting up similar projects. Dissemination of learning through conferences, presentations and engaging with media (e.g. Radio 4). Individual case work, and counsellors provide emotional and psychological support around loss and grief flexibly across the geographical footprint.

Results Excellent relationships with local hostels which are better able to support residents. Less secondary and more primary care. Individuals now accessing Day Hospice, Macmillan nurses and planning for their future care. Place of death honoured for three individuals (two in hospice and one in hostel). Hospice supporting other hospices with similar projects.

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.

P-36 HOMELESSNESS AND END OF LIFE CARE: IMPROVING PARTNERSHIP WORKING

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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 opportunities 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.

P-37 LEARNING DISABILITY COMMUNITY COLLABORATION PROJECT FOR PEOPLE WITH PALLIATIVE CARE NEEDS

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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.

P-38 SUPPORTING PEOPLE WITH LEARNING DISABILITIES AT END OF LIFE: A TRAINING PROGRAMME

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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).