

Understanding palliative and end-of-life care through stakeholder and community engagement

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Background/context

The pressures on palliative and end-of-life care, including the increasing elderly population; changes in illness and mortality trends; and public finances, have been well documented. Three Marie Curie palliative care service redesign initiatives in Argyll and Bute, Lanarkshire and Lothian are using a range of methods to effect improvements, including stakeholder and community engagement. Health promoting palliative care is an important concept within this changing environment.^{1,2} This poster highlights how stakeholder and community engagement are being used to address health promoting palliative care.

Method

Stakeholder workshops were held in Argyll & Bute, Lanarkshire and Lothian to identify innovative options for raising public awareness of, and promoting community involvement in death, dying and bereavement. In total, 155 people attended with representation from a wide range of stakeholder groups. Overall, around 125 ideas were generated by stakeholders, and were then themed, refined and assessed; 25 options have been shortlisted for further development.

Stakeholder groups - examples

- *Patients, carers, local public partnership forum.*
- *Health & social care: acute, community, occupational therapy*
- *Independent sector: Housing association, domiciliary services, care homes*
- *Other: Funeral services, Benefits agency, Community transport providers*

Qualitative themes from the workshops

At home:

- *Discussing as an extended family*
- *Build memory boxes and family trees together*

At school:

- *Include in curriculum e.g. personal social development classes*
- *Reflective essays*
- *Invite grandparents to school*

Health & Social Care

- *Ambassadors in hospitals, GP practices*
- *Mandatory CPD for staff*
- *Palliative care communication skills for non-clinical staff e.g. domestics, equipment staff*

Communities:

- *Film festival, death cafes,*
- *Celebrating different cultural perspectives*
- *Use volunteers to support awareness raising*



Funerals

- *Discuss "Affordable Funerals" as part of Funeral Planning*
- *Open days at funeral directors*
- *Benefits of early planning*

Legal/Financial institutions:

- *Key trigger points to start discussions e.g. mortgage applications, joint accounts*
- *Reduce legal costs through allowing paying up (as per bike or season ticket loans or through credit unions)*

Independent sector:

- *Recognising the contribution of care homes in supporting death, dying and bereavement.*
- *Training in bereavement for care home staff*

Private sector/businesses:

- *Build information on end-of-life care issues into HR standards re sudden death, absence management, medical checks, retirement, bereavement and carers leave*

Conclusion

By creating opportunities to discuss death, dying and bereavement, local stakeholders were able to engage with each other to develop innovative ideas to raise public awareness of, and promote community involvement in death, dying and bereavement.

1. Kellehar, A. Health promoting palliative care. Melbourne: Oxford University Press, 1999.

2. Haraldsdottir, E., Clark, P., Murray, SA. Health promoting palliative care arrives in Scotland. *European Journal of Palliative Care*, 2010; 17(3).