

Conversations for Life: Implementation of a pilot public awareness campaign about end of life issues

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"It's my life so it can be my death too."
- Participant Quote

Background

The critical need for family, carer, and community conversations about end of life issues has never been more significant. Although most adults would prefer to die in their own homes, only 22% of people in the UK currently do (1). Caring for patients outside of their preferred place incurs significant costs to the NHS and recently published national statistics cite 54% of NHS complaints are around end of life care (2). Yet as is pointed out in the national End of Life Strategy, "In the absence of open discussions, it is difficult or impossible to elicit people's needs and preferences for care and to plan accordingly". (3:23). In one English health region (NHS Cumbria) a 12 month pilot project was launched in collaboration with the Conversations for Life Programme to develop and deliver the first phase of a county (Cumbria) wide community based public and professional engagement campaign around end of life conversations and care.

Project Aims

To improve awareness about, and increase, advance care conversations amongst the general population using an public health campaign. This sought to:

- Break the taboo of talking about death and dying while healthy,
- Help the public to consider options and access resources,
- Support people to have a say in their future care (advance care planning)

"I need to think and talk about it now not later with parents and children so if anything happens we are all on the same page.."
- Participant Quote

Methods

Personal stories are at the core of this campaign as they are a powerful tool for communication around sensitive issues such as end of life care. The public awareness campaign comprised three elements:

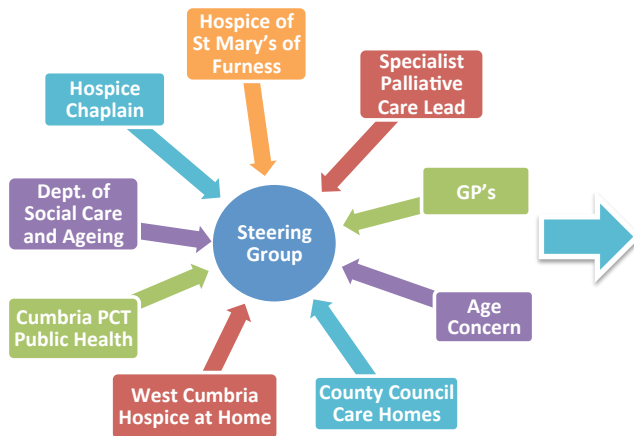
1. A DVD was produced presenting stories by local people of their personal experiences
2. Development of promotional and resource materials (web and print) , signposting information and resources.
3. Facilitated workshops about end of life conversations and care

An evaluation of each workshop was undertaken using a short survey form and analysed using descriptive statistics and a coding of responses to open questions.

The Facilitated Process



"89% of delegates said they were likely to implement their new knowledge"



12 month pilot outcomes

(9 months planning & production; 3 month launch)
• 200,000 positive media impressions via newspapers & radio due to interest in the film and focus on local stories.

Within 3 months

- Website in this rural community had 3645 visitors, averaging 22.6/day (with 17,771 to date)
- 93 people attended 11 workshops in 6 locations across the region.
- Delegates ranged in age from 26-88 years old.
- 84% of respondents stated they had learned how to hold end of life conversations, make informed choices, access local resources and received materials to begin documenting their own future plans.
- 98% would recommend the workshops to others.

Evaluation

Did you feel you learned something useful about how to:	
1	Open these conversations?
2	Explore what matters most to you?
3	Make informed choices?
4	Let people know your wishes?
5	Access resources over time?
6	Begin to create a plan for your future care?
On a scale of 1-5 (5 being high)	
86% of delegates responded with a 4 or 5 out of 5	

Conclusion

This pilot has demonstrated that a community-based public awareness campaign on end-of-life issues can reach the public and achieve greater awareness/ educational outcomes. The trademarked campaign is now being introduced in more regions and (inter)nationally under a not-for-profit social enterprise.

The Conversations for Life approach and programme is now available under an independent, not for profit social enterprise.

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References

(1) Office of National Statistics (2004). Mortality Statistics General Series DH1 No.33. London, Office for National Statistics.

(2) Healthcare Commission (2009) Spotlight on Complaints. London, Healthcare Commission.

(3) Department of Health (2008). End of Life Care Strategy - promoting high quality care for all adults at the end of life. London, Department of Health.