A communication aid helped initiate discussions around care at the end of life

Think about it: a prompt to discuss end of life choices

In this article...

- Why effective communication skills are crucial in end-of-life care
- How a tool to improve communication was developed and implemented
- An evaluation of the tool and how it can help improve end-of-life care

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A team of nurses in East Lancashire developed a communication tool to help initiate end-of-life discussions and support advance care planning. This article describes the development, implementation and evaluation of the "Think about it" communication prompt.

In line with national developments and the Department of Health’s (2008) end-of-life care strategy, a number of end-of-life projects have been implemented across Blackburn with Darwen. Tools such as the Gold Standards Framework (www.goldstandardsframework.nhs.uk), the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute, 2009) and preferred priorities for care (www.endoflifeicareforadults.nhs.uk) are accepted best practice, and their use is supported by service providers and commissioners.

Research from the King’s Fund identifies two broad challenges in end-of-life communication: difficulty predicting prognosis; and communicating with patients to plan care. Conversations at the end of life may be avoided because they are difficult, and health professionals may have concerns that they will not be able to meet patients’ preferences (Addicott, 2010).

Health professionals across Blackburn and Darwen were developing end-of-life communication skills by accessing communication training. However, it became clear that discussions around end of life to support advanced care planning were at times avoided or delayed. The main reason for this was staff had limited confidence in their communication skills and concerns about discussing perceived negative topics such as late-stage management and practical elements at the end of life.

Preferred priorities for care

PPC is a patient-held document designed to facilitate patient choice. Monitoring of the numbers of PPC documents completed locally identified they were not being routinely used. The PPC document should be patient-led, reflecting conversations around the patient’s end-of-life care agenda. However, most of those audited recorded discussions about where the patient wanted to be cared for at the end of life. This could be because the PPC was initially implemented in its original version – preferred place of care – or because of outcome measures to monitor where someone dies. This is one of the end-of-life care quality markers that measures numbers of patients who died in their preferred place (DH, 2009).

During training sessions groups of professionals were asked the question: “If you were given a two-year prognosis, what would be your priority?” Those with clinical experience of palliative care gave answers relating to symptom management and where they would want to be cared for, but those with little palliative care experience talked about goals and ambitions. This emphasises the broad range of subjects patients may prioritise, highlighting the need for discussions to be patient-led.

Keywords: Communication prompt/Advance care planning/End-of-life care

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**Project development**
Following a successful bid from North West NHS Regional Innovations Fund, the “Think about it” tool was developed to prompt patient-led communication (Fig 1). The tool was developed to initiate earlier discussions about advance care planning and determine patients’ priorities for care. It was developed, implemented and evaluated by professionals from East Lancashire Hospice and NHS Blackburn with Darwen community nursing services. The project was led by the end-of-life care lead and clinical practice lead for community nursing.

After feedback from hospice professionals, community nurses, primary healthcare teams and allied health professionals, we showed the tool to East Lancashire Hospice day therapy patients, and presented at a GP patient forum meeting.

Around 20% of the 145,000 people living in Blackburn with Darwen are Asian, so the tool was also shown to Asian carers. It was then translated into Urdu and a design company was recruited to improve its appearance. The final “Think about it” prompt incorporated 12 topics.

**Implementation**
Principles for implementation were agreed (Box 1), and the tool was piloted across Blackburn with Darwen between March and August 2010. We also provided copies of the tool to mental health and motor neuron disease services, and care homes.

The communication prompt was displayed at a palliative care conference and promoted at local events for the National Dying Matters coalition (www.dyingmatters.org). We also sent information to the Lancashire and Cumbria end-of-life network team and PPC development team to inform them of the pilot.

**Evaluation**
A questionnaire was sent to all health workers who used the prompt over the five-month pilot. Of the 50 questionnaires sent out, just under half (22) were returned. The evaluation included questions about the number of times the prompt had been used, and whether it increased the professionals’ awareness and confidence to support discussions with patients.

The completed evaluations showed the topics discussed by patients included family, friends and pets, medical care and support, and legal issues (see Fig 1).

Feedback from hospice day therapy professionals suggested the tool triggered discussions with patients. One patient said the tool’s subtle and indirect approach meant he felt more able to consider topics that concerned him. Discussions at the GP patient forum meeting also suggested people wanted to discuss important issues and the prompt helped them to do this.

The number of completed PPC documents and advance care planning discussions increased during the pilot phase, although this cannot be attributed solely to the prompt as “quality in healthcare is a multifaceted concept” (Sutherland and Coyle 2009). We also identified ways to improve implementation, such as leaving a paper copy with patients after discussion. The tool also received positive feedback from NHS Blackburn with Darwen Patient Advice and Liaison Service Readers Group.

**Conclusion**
Effective communication is vital to delivering high-quality care at the end of life, but professionals need training and support to maintain confidence and develop their skills. A team approach was vital to the success of the communication prompt, and partnership working across the region has improved the overall implementation of end-of-life care initiatives, improving outcomes for patients and their families.

**References**


Marie Curie Palliative Care Institute (2009) Liverpool Care Pathway for the Dying Patient. Liverpool: MCPCI. tinyurl.com/Marie-Curie-LCP


**BOX 1. IMPLEMENTATION**
- Only introduce the tool when there is an established relationship between the patient and professional
- Use as part of supported discussion
- Respect a patient’s choice to decline discussion
- Use to prompt further discussion, which may lead to advanced decisions to refuse treatment when appropriate
- Each community nurse, clinical nurse specialist and community matron to have own laminated copy
- Hospice teams, motor neuron disease service, care homes and mental health care teams to have copies
- Each team to have an Urdu copy
- Written introductory information to be provided for each team

**FIG 1. “THINK ABOUT IT” PROMPT**

Choose what is discussed
- Family, friends and pets (7)
- Medical care and support (5)
- Home and finances (5)
- Hobbies and interests (2)
- Memory boxes and letters (3)
- Organ donation (1)
- Funeral preferences (5)
- Food likes and dislikes (3)
- Will and legal issues (3)
- Spiritual care and religion (2)
- Goals and ambitions (5)

**Think about it!**

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