Evaluation of Learning Resources for End of Life Care in Extra Care Settings

Executive Summary

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The National End of Life Care Strategy (2008) aims to assist with the development of high quality end of life care that can enable people to die in a range of settings, including their own homes. In 2009, in line with these aims, the National End of Life Care Programme (NEoLCP) in partnership with Housing 21 (one of the leading providers of extra care housing) and with some funding from Skills for Care\(^1\), developed a learning resource pack and accompanying DVD for end of life care in extra care housing settings. The resources were intended to develop end of life care skills and highlight other end of life care resources that might be utilised. In 2010, researchers at the Centre for Housing Policy at the University of York were commissioned to evaluate how widely the resources had been disseminated in extra care settings, and whether they had assisted with changing attitudes and developing practice. Key findings from the study indicate that:

- The learning resources have considerable potential to assist with improving end of life care practice in extra care housing. This potential could be enhanced if the resources could be more widely disseminated.
- Dissemination strategies need to be ‘broad brush’, although senior managers have a key role to play in cascading information down to frontline staff.
- The learning resources had impacted on practice in extra care in a number of positive ways including: establishing new contacts or links with other service providers to improve end of life care; initiating discussions with extra care residents and their families about their preferences for end of life care; and introducing specific end of life care training for frontline staff.
- The learning resources were rated highly by people working in extra care settings and residents. They felt the written document was accessible and easy to read; and provided sufficient detail on key topics with directions to additional resources and sources of information if required.
- The DVD was felt to be particularly useful as an introduction and starting point for discussions about end of life care with frontline staff and, in some cases, residents.
- Barriers to providing end of life care included: training for front line staff; poor inter-agency working in some cases; and difficulties in breaking the taboo of talking about death and dying with staff and residents.

\(^1\) More information about Skills for Care can be found at: [www.skillsforcare.org.uk/home/home.aspx](http://www.skillsforcare.org.uk/home/home.aspx)
Provider organisations and service commissioners need to be proactive in making end of life care a priority, and to invest in end of life care training and staff development.

Introduction

The End of Life Care Strategy (DH, 2008) is a comprehensive framework aimed at promoting high quality care for adults approaching the end of life. Central to the Strategy is the intention to develop high quality care that can allow people to die in a range of settings, including their own homes. Much investment has been directed to developing the skills and competences of both health and social care staff, particularly in care homes. However, there has also been interest in developing practice in extra care housing which is often promoted as an alternative to residential care. Extra care housing schemes allow independent living to be combined with relatively high levels of care. In addition, communal facilities are provided to help reduce social isolation.

A small number of studies have shown that residents living in extra care housing often move to nursing homes or hospital at the end of their lives, suggesting that practice in end of life care in these settings could be further developed. More recently, two studies indentified the need to improve the knowledge base and skills of staff. Consequently the resource pack\(^2\), and accompanying DVD, were developed by a partnership between Housing 21 (one of the leading providers of extra care housing), and the National End of Life Care Programme, and were partly funded by Skills for Care. The resource pack is designed for anyone who is caring for, or giving support to, someone with a life limiting condition in an extra care setting. It is intended to be a practical tool giving guidance and information on a range of topics including:

- Important local contacts that can help in the delivery of end of life care
- Medication issues
- Common symptoms that may occur at the end of life
- Mobility issues
- Religious, cultural and spiritual needs
- Assistance and care in the last days and hours of life
- Care after death – supporting families and residents

\(^2\) The resource pack is available on line at:
A range of different strategies was used for dissemination: including presentations at national and regional events, and publicising the availability of the resources through professional networks and websites.

**Methods**

The evaluation was undertaken in two phases between August 2010 and March 2011. The first phase comprised a postal survey of extra care housing managers, utilising the Elderly Accommodations Counsel’s database of housing with care schemes. Survey forms were sent to 1,392 housing with care schemes across the UK. A total of 337 responses were received – a response rate of 27% which is a typical response rate for postal surveys in general. The second phase comprised a series of 14 in-depth interviews with a range of key informants, including strategic and operational managers, and front-line care staff. Topics included in the survey and explored in more depth during the interviews included: how people had found out about the resource, how the resources had been used, and how the respondents rated the usefulness of the material.

Two consultations were also held with residents living in two extra care schemes in order to gain some understanding of residents’ impressions of the content and format of a resource that was specifically designed to improve their experience. These consultations were planned with considerable care given the sensitive nature of the topic and involved careful liaison with staff and residents within the two schemes.

**Survey findings**

Only a small proportion, (16%) of survey respondents was aware of the learning resource. Of these: 56% had heard of the resource from a senior manager in their organisation; 24% had heard about it at a training event or conference. The learning resource had been promoted and disseminated in a wide range of ways but this finding highlights the importance of the role of senior professionals and those who have the opportunity to attend events and conferences in disseminating learning resources throughout their organisation. Sources such as newsletters and websites appear to be less useful in dissemination. However, a substantial proportion of respondents came across the resource through their own searches for information on end of life care.

With regard to the potential of the resource to develop practice, the results of the survey are encouraging. Of those respondents who had heard of the resource:

- 65% had established new contacts or made links with other services, most usually general practitioners and community nurses;
- 34% had provided additional support for staff within their schemes, (note 56% reported they were doing this already);
• 53% had initiated discussion with individual residents about their preferences for end of life care;
• 48% had initiated a system of record keeping of individuals’ stated preferences.

More than 80% reported that the resources had made “some” or “a lot” of difference to the way their staff approached end of life care with residents and their families, and the way their organisations approached end of life care more generally.

**Key Informant interviews and consultation with residents**

Interviews and consultation with residents offered the opportunity to explore some of the survey questions in more depth. Overall, the respondents found the learning resource useful, and thought it was most relevant to frontline care workers. The DVD was felt to be a valuable means of opening discussion. People felt the resource was written in an accessible way, was the right length, and easy to navigate, which was felt to be particularly important for care workers. The topics were all relevant and covered in sufficient depth, with directions to other sources of more detailed information if required. Knowledge about end of life care varied. Some informants felt they had not learned anything new, but were reassured that they were “doing the right thing”. Others however had learned a great deal and felt this had a very positive impact on the care they were able to provide. Residents felt that the learning resource would be helpful to informal carers. Both residents and those working in extra care felt that the resource might be too optimistic, and that the necessary resources might not always be available. Many felt that good end of life care often depending on undervalued care workers “going the extra mile”. In some cases, respondents felt people’s needs, for example management of pain, would be better met in a more specialist setting such as a hospice or nursing home.

A small number of topics were identified that respondents felt might usefully be covered. These included, advance care planning; the need for specialist support for people with dementia; advice about supporting formal and informal carers and neighbours. Residents also felt there should be more about helping people to enjoy life as well as care in the latter stages of life.

**Challenges and barriers to providing end of life care**

Respondents described a number of barriers to providing end of life care. In particular, respondents raised the problem of ensuring that front line staff received adequate training – some reported that care workers did not even have time to attend in-house training sessions held on site or to read the learning resource pack. Most stressed that whilst a learning resource pack could make a valuable contribution to the improvement of end of life care, it could not replace face-to-face training. Another barrier to effective end of life care provision was poor inter-agency working. Many schemes had developed good working relationships with the various
agencies and professionals in their area and others reported that these relationships were improving; however, in some areas it appeared that poor working relations were still a significant barrier. Finally, almost every respondent raised the point that many people still find it difficult to talk about death which makes it extremely difficult to plan end of life care.

**Conclusions**

The evaluation has shown that the learning resource pack has been well received, and has promoted changes in practice. Dissemination needs to be broad brush and on-going to ensure that the learning resource achieves its potential. The National End of Life Care Programme is limited to what it can achieve on its own, and needs to continue working in partnership with extra care housing providers and other organisations that can support people approaching the end of life in extra care settings. Provider organisations and commissioners also need to be proactive in making end of life care a priority within their organisations, and investing in training and support for front line staff.

An electronic copy of the full report *Evaluation of Learning Resources for End of Life Care in Extra Care Settings* is available on request by emailing information@eolc.nhs.uk

The NEoLCP website also provides a range of resources and information for health and social care staff working in any capacity to support people at their end of lives.

http://www.endoflifecareforadults.nhs.uk/publications