



Meeting a growing need

Housing 21, End of Life Care Learning Resource Pack

Housing 21 worked with the End of Life Care Programme to produce a learning resource pack. It has practical information and advice for managers and support staff working in extra care housing schemes. It covers a range of issues relating to the care of residents with a life-limiting or progressive condition.





Background

The number of people over 65 is expected to double, from 8 to 16 million, by the year 2030. Housing associations are working more closely with health and social care to provide care and support to enable people to live well at home. Furthermore, recent policies that affect older people are focused on ensuring that older people have more choice and control over their lives including over the place they die. Most people would prefer to die at home, but many end their lives in hospital.

The National End of Life Care Strategy (2008) identified that staff working in health and social care need access to education and training to improve their skills in delivering end of life care. The Department of Health, Skills for Health and Skills for Care End of Life Care Programme developed common core competences for all staff delivering end of life care. Staff working in extra care settings could provide a home for individuals right up until the end of their life, but they needed more information and support to enable them to do this.

Extra care housing is specially designed housing with flexible on site care. In some situations it can provide an alternative to hospital. Many schemes have 24 hour on site care cover. There are over 1,000 extra care schemes across England and more are being developed. Housing 21 is the largest extra care operator in England.

Housing 21, in partnership with the National End of Life Care Programme, conducted a service improvement project in 2008 to promote dignity and choice at the end of life for older people who live in extra care housing. The project enabled tenants to die at home if they wished. The evaluation of this project pointed to the need for more skills development and learning resources for care and support staff working in extra care (Easterbrook, 2008).

Aims

The aims of the project were to develop, pilot, roll out and evaluate an end of life care learning resource pack for care and support staff working with older people in extra care housing settings. The pack would also include a DVD to capture good practice from the perspective of staff, service users and external stakeholders.



What was done?

The following key activities took place:

- a project steering group was set up, with representation from Housing 21, The End of Life Care Programme and palliative care education staff
- a project lead was commissioned to design and write up the materials
- the resource was designed and edited, in close consultation with care staff working in extra care housing
- tenants and carers were also consulted about the content of the guide
- a national launch event was planned in association with the Housing Learning Improvement Network
- the resources were circulated to all extra care settings and general sheltered housing schemes across the organisation
- the resource was also shared at a range of national health and social care events (over 4500 hard copies and several hundred downloads from the End of Life Care website)
- an independent evaluation was commissioned to assess the impact of the pack.

Outcomes

Feedback about the resource showed that it would help relatives, informal carers and care service recipients. Some of the basic advice on topics like mobility and nutrition would be useful for staff working across a range of care settings. Staff at the National End of Life Care Programme were very enthusiastic about the resource pack and felt it could be tailored to other sectors and settings.

An independent evaluation by the University of York reported that some respondents had established contact with relevant community services, such as district nursing services and GPs, as a direct consequence of the learning resource. Further, staff said they were able to initiate discussions with tenants about their end of life care preferences, leading to recording these decisions in the form of an advance care plan. Some organisations went on to provide additional support for staff (Jones et al, 2011).

“Filming the DVD has been a rewarding experience. Residents and staff have talked openly and often movingly about end of life care. One staff member said ‘When people come into the world they are surrounded by love and care, and that’s how it should be when they leave this world too’. It was inspiring for the film crew to hear how committed staff are to ‘going the extra mile’ to support people at end of life. In some ways it was surprising how many residents and staff were keen to be involved in the filming given the sometimes difficult subject matter.” Sarah Vallyelly, Research Manager.

The response from the launch event was very positive. The Department of Health Housing Learning and Information Network report that they had some of the best feedback from any event they had been involved with. Over 120 delegates attended the launch from housing and care sectors.



Impact

Key impacts include:

- **individual benefits – personalisation:** staff improved their knowledge of managing symptoms and worked more effectively with GPs, District Nurses, Community Matrons and Macmillan nurses to assess and manage tenants who experienced distressing symptoms. This enabled tenants to stay in their own homes for longer
- **prevent hospital admissions:** the proactive planning and management of tenants with end of life care needs has reduced the number of crises admissions. The increased use of advance care planning as a result of this resource can support people to remain in their place of choice and empowers staff to act as the tenants' advocate when this has been recorded
- **timely hospital discharge:** one extra care scheme manager reported that as a consequence of this resource she has shared information about the services that can be provided by extra care housing with local discharge planning teams. She now attends discharge planning meetings for tenants with complex needs
- **more effective transitions:** this service helps support people for longer in their place of choice. Ongoing assessment of needs can be carried out by staff who know the individual and can quickly recognise and report any changes
- **more effective use of resources:** a significant benefit of this initiative has been the development of links with a range of support services in the community to ensure that individual needs are met and people are supported to be cared for at the end of life.

The project helped health, housing and social care professionals to become more proactive in working with extra care schemes to support end of life care.

“It has become much easier for staff and tenants to talk about death and dying without stigma. Staff are becoming much more confident in ‘having difficult conversations’ with residents and in providing support to people who are dying.” **Sarah Vallyelly, Research Manager.**



Learning

Key learning points include:

- the expertise and backing of the National End of Life Care Programme and support from senior operational managers were crucial to the success of the project
- many older people think about end of life care and they, and some staff, want to talk about it
- managers need to give staff time to increase their confidence on end of life issues and reinforce the value of the resource pack and encourage them to refer to it often
- a 'one size fits' all approach is not appropriate
- care must be sensitive and person centred, for example, not everyone will want to complete an advance care plan, even if they have opportunity to do so
- staff need to be able to take what they know and apply it to each person differently.

Next steps

The resource has been updated by the National End of Life Care Programme and the Housing Learning and Improvement Network to include further information on advance care planning and other key areas.

Housing 21 continues to be involved in developing initiatives aimed at reducing hospital admissions and length of stay when residents are admitted to hospital. Examples of one of the pilots, along with details of the cost savings can be found in the National Housing Federation report *On the Pulse* (Leng, 2012).

References

- Department of Health, 2008 *End of life care strategy*. DH, 2008.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- Easterbrook, 2008 Easterbrook, Lorna with Valleley Sarah; *Is it that time already? Extra Care Housing at the End of Life: A policy-into-practice evaluation*. Housing 21, 2008.
http://www.housing21.co.uk/files/2412/4827/0303/Is_it_that_time_already.pdf
- Jones et al, 2011 Jones, Anwen; Croucher, Karen and Rhodes, David; *Evaluation of Learning Resources for End of Life Care in Extra Care Settings, Executive Summary*, Centre for Housing Policy, The University of York, 2011.
<http://www.york.ac.uk/media/chp/documents/2011/eolcaresum.pdf>
- Leng, 2012 Leng, Gill; *On the Pulse: Housing routes to better health outcomes for older people*. National Housing Federation, 2012
http://www.housing.org.uk/publications/find_a_publication/care_and_support/on_the_pulse.aspx



Links

NToW41 - project report

NToW41 - Transforming end of life care

Updated End of Life Care Learning Resource Pack

<http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/end-of-life-care-learning-resource-pack.aspx>

End of Life Care Programme, <http://www.endoflifecare.nhs.uk/>

Skills for Care, End of Life Care Programme http://www.skillsforcare.org.uk/developing_skills/endoflifecare/endoflifecare.aspx

http://www.skillsforcare.org.uk/workforce_strategy/workforce_innovation_programme/prevention/NToW41.aspx (includes video)

Contacts

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Further information

For further information about the health and social care integration work between Skills for Health and Skills for Care please contact:

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