



End of Life Care: Information for housing & care providers

The independent 'Choices Review' of End of Life Care sets out how more choice and control can help improve the quality of end of life care, specifically through identifying and delivering individual's choices and preferences about their care, including those who want to die at home.

This factsheet is written for those managing housing with care so that you can demonstrate and/or develop your role improving the experience of people approaching the end of life locally within a housing setting. It updates Action Sheet 6 in the National Council for Palliative Care's 'Influencing Toolkit' and now also includes useful examples of where housing organisations have improved the way they deliver their services for people at end of life and their carers.

Produced by the Housing Learning and Improvement Network, in partnership with the **National Council for Palliative Care**, the **National Care Forum** and **NHS Improving Quality**

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**THE
NATIONAL
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PALLIATIVE
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1. Introduction

Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035. England has one of the highest rates of hospital death for older people in England. However, the majority of people express a wish to die at home.¹ People's home and their living arrangements are integral to their wellbeing, especially at the end of life.

- ➔ 21% people die at home, including sheltered and extra care housing
- ➔ 18.5% people die in a care home
- ➔ While most people would prefer to die in their usual place of residence, older people are less likely to die at home



TIP: Find out the precise statistics on the cause and place of death for your area at: www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_and_Cause_of_Death/atlas.html

Whether you manage purpose-built specialist accommodation (such as extra care housing) or provide housing related care and support to people (home care, aids and adaptations services or community alarm/telecare), understand the part you play, or could play, in supporting more people approaching the end of life, so that you can make a strong case to local commissioners and decision-makers.

A good death: Home Group's end of life care

Home Group's vision is to provide homes for life and its 'good death' pilot supports this. The pilot aims to give people a positive experience in the last years of life by providing community-based services. It was launched in September 2011 after Home learned that many people were unable to access the support they needed to die in their own home.

Working with family and wider support networks, the service helps people to plan and prepare for their death. It also supports those with a terminal illness. It enables people to make a choice about where they will die and offers emotional and practical support.

At any time the service can support up to 30 people who live in the most disadvantaged areas of Tyne and Wear. It is targeted at people over 75 but it does not exclude the over 55s. Referrals come from Macmillan Cancer Support, hospital social workers, Cancer Connections (a local third sector organisation) and self-referral.

More at:

www.homegroup.org.uk/careandsupport/stonhamservices/Pages/a-good-death.aspx

¹ The Choice of End of Life Care Review Programme Board (2015), *What's important to me. A Review of Choice in End of Life Care*



TIP: Consider the 16 statements laid out in the NICE End of Life Care Quality Standard <http://guidance.nice.org.uk/QS13>. Which ones touch on housing?

How can housing:

- ➔ Enable more people to die in their usual place of residence or a dignified homely setting of their choice?
- ➔ Improve people's quality of life towards the end of life?
- ➔ Reduce costly unnecessary / unwanted hospital admissions at the end of life?

My Home Support: a Collaboration between Housing and Hospice Care

My Home Support is a joint project between St Giles Hospice and Bromford (a local housing association) in Lichfield. The aim of the service is to support independence and resilience for patients who are referred to St Giles who either do not need specialist clinical intervention, or whose hospice care would be enhanced by the supportive care skills that Bromford offers. This included the following indicators:

Support people to remain at home for as long as possible at the end of life if it is their wish.	Analysis concluded that the service has a positive impact on this outcome.
Reduction in inappropriate use of clinical time.	Analysis concluded that the service has in all likelihood had a positive impact on this outcome.
Reduction in accidental falls / injuries.	Analysis concluded that the service in all likelihood has a positive impact on this outcome.
Improved quality of life.	Analysis concluded that the service has had a positive impact on this outcome.
Reduction in social isolation.	Analysis concluded that the service has in all likelihood had a positive impact on this outcome.
Reduction in unplanned admissions / readmissions to hospital.	Detailed analysis of five specific cases where avoidance of admission was judged likely undertaken and accepted by commissioners. Concluded that the service has been important in avoiding admissions, reducing length of stay and supporting home death in each case.

More at: www.bromfordlab.com/mindyourlanguage

2. Leading by example

Do you currently offer high-quality hospice at home, palliative care or end of life care to the people using your service(s) (either yourself or in partnership with others)?



TIP: Make links with other local services who are in contact with people approaching the end of life and their carers, to see what they're providing, where the gaps are and ways of working together.

For example, visit the Find me website: <http://get.findmehelp.org.uk>



TIP: Find training and support, for example the Care to Learn programme: www.ncpc.org.uk/care-learn-training-0

End of life care in extra care housing: a learning resource pack

This pack provides practical information and advice for managers and support staff working in extra care housing schemes. Published by the then National End of Life Care Programme at the Department of Health and the Housing Learning & Improvement Network, and prepared by the International Longevity Centre (ILC-UK), the pack includes case studies and top tips on topics ranging from initial conversations and end of life care planning through to the things staff might be expected to do after a resident's death.

More at:

www.housinglin.org.uk/library/Resources/Housing/Support_materials/Other_reports_and_guidance/EoLC_Learning_Resource_Pack_Housing.pdf

3. Getting connected with health and social care

As recognised by the Care Act 2014, suitable housing is a vital part of well-being and well-designed specialised housing can be instrumental in improving the health and wellbeing of many people at all stages of life.

Health and social care commissioners and decision-makers in your area will be in touch with a range of providers wanting to make sure their particular service is funded. Articulate your offer clearly to your local:

Health & Wellbeing Board (HWB) - established to improve integration between health, social care and public health. You see the interplay of services through the experiences of people you support, including at the end of their lives when integration is often lacking; for example, how housing can ensure a level of choice and independence at home even for those who are chronically ill and approaching the end of their lives. You are therefore well-placed to offer solutions.



TIP: What are local people saying about end of life care in your area? Use the latest local findings from the national bereaved carers survey to make the case for change to members of the HWB: www.dh.gov.uk/health/2012/07/voices



TIP: Find out who is on your local HWB and use Action Sheet 4 (in the NCPIC Influencing Toolkit) to support meetings you have about end of life care.

Local Authority (LA) commissioners - End of life care is bigger than health. People approaching the end of life spend the majority of their time at home, and many have social care along with continuing care needs.



TIP: Consider ways you are uniquely placed to support people at home end of life care on a 24/7 basis. Put yourself in the commissioner's perspective. For example: think prevention, integrated care, telecare, personal budgets, respite care, hospice at home, unnecessary admissions.

Is it that time already? Extra Care Housing at the End of Life

Housing & Care 21 were awarded a contract by Lancashire County Council and NHS Central Lancashire to pilot an end of life care service for people. The pilot project's aims included:

- enabling tenants to die at home if this was their choice;
- putting processes in place to ascertain tenants' wishes and preferences;
- developing an integrated approach to work within the community in accessing supportive care for tenants, their families and staff;
- to explore the challenges of end of life care in extra care housing settings;
- to improve the skills and knowledge base of staff.

It found that housing with care staff need to engage with other professional groups, and raise awareness of what housing with care can do.

More at:

www.housingandcare21.co.uk/news/news-archive/2012-news-archive/lancashire-end-life-care-pilot-contract



TIP: As personalisation is rolled out, LAs will have an increasing role as market shapers. Consider your role in this changing context: What will people approaching the end of life choose to commission to make their lives comfortable at home? How can you best design person-centred accommodation?

Getting the design right

Consider the following regarding the built environment:

- Does the built environment support and enable people, giving choice and independence?
- Does the built environment enhance dignity, well-being and a sense of control?
- Do space standards, private and shared spaces, colours, finishes to surfaces and access to outdoor space enable the above?
- Consider your procedures and the built environment when a person dies and how dignity and respect is maintained:
- What happens if someone dies in their private space or if they die in a shared space?
- Is there private space for relatives and friends to pay their respects and to discuss matters with housing staff?
- How will the person finally leave? Will they go through the front door for others to pay respects, or a back door so as not to upset others?

More at:

www.housinglin.org.uk/Topics/browse/Design_building

Clinical Commissioning Group (CCGs) - responsible for NHS commissioning, including continuing care and end of life care.



TIP: Find out who your CCG is at www.commissioningboard.nhs.uk or at www.england.nhs.uk/resources/ccg-maps/ and use Action Sheet 3 (in the NCPC Influencing Toolkit) to support meetings you have about end of life care.



TIP: CCGs are encouraged to set up an area-wide end of life care group and invite statutory, voluntary and independent services. However, there is a risk that housing and care will get overlooked if you don't make contact with them. For example, the benefits of extra care housing, making best use of sheltered housing, the role of home improvement agencies or handyman services, community equipment, community alarms and/or telecare to support at home end of life care.

HealthWatch - These bodies will act as the voice of local service users. Find out about your local HealthWatch at www.healthwatch.co.uk.



TIP: Make contact with your local HealthWatch and provide opportunities for the people using your service(s) to engage with its work. Action Sheet 2 (in the NCPC Influencing Toolkit) can help.

4. Sharing your learning

Tell us what you did to try to engage with the new decision-makers and what you learnt so we can share amongst our respective networks. Email: info@housinglin.org.uk

5. Useful contacts:

Dying Matters www.dyingmatters.org

Hospice UK www.hospiceuk.org

MacMillan Cancer Support www.macmillan.org.uk

Marie Curie Care www.mariecurie.org.uk

National Care Forum www.nationalcareforum.org.uk

National Council for Palliative Care www.ncpc.org.uk

NHS England www.england.nhs.uk

NHS Improving Quality www.nhsiq.nhs.uk

Sue Ryder www.sueryder.org

6. Useful resources:

- ➔ The Choice of End of Life Care Review Programme Board (2015), *What's important to me. A Review of Choice in End of Life Care*
- ➔ To view the NCPC Influencing Toolkit, *What about end of life?*, and the other Action Sheets in this series, visit: www.ncpc.org.uk/influencing-toolkit
- ➔ To find out more about the NHS Improving Quality End of life care programme, visit: www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx
- ➔ For a comprehensive range of learning and improvement tools and resources on housing and end of life care, visit the dedicated Housing Learning and Improvement Network pages at: www.housinglin.org.uk/Topics/browse/Housing/EndOfLifeCare

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About the Housing LIN

Previously responsible for managing the Department of Health's Extra Care Housing Fund, the Housing Learning and Improvement Network (LIN) is the leading 'learning lab' for a growing network of housing, health and social care professionals in England and Wales involved in planning, commissioning, designing, funding, building and managing housing, care and support services for older people and vulnerable adults with long term conditions.

For further information about the Housing LIN's comprehensive list of online resources on end of life care and to participate in our shared learning and service improvement networking opportunities, including 'look and learn' site visits and network meetings in your region, visit: www.housinglin.org.uk

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