



End of Life Care: Helping people to be cared for and die at home

“A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one’s story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone’s lives.”

Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

“End of Life Care does not start with palliative care. It starts with community.”

Julian Abel, *Life & Death Matters*

This briefing is for people working in housing, public health, care and support. Recognising a gap in information on this topic, Public Health England commissioned the Housing LIN (Learning and Improvement Network), the leading voice of expert advice and support in the field of housing, care and support services, to produce this briefing.

Drawing on the Housing LIN’s knowledge of the sector and with input from its network members, it looks at the importance of end of life care delivered at home, describing the context, inequalities in end of life care, and examples of good or emerging practice. It is intended to be a practical guide for those working in mainstream and/or specialist housing, care and support, and public health to understand their respective roles, and how they may work with each other and with the wider health care system, to help people to have their end of life care wishes met.

Written by **Dr Alison Giles** for the Housing Learning & Improvement Network

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Introduction

It is vital that we get end of life care at home right. Whilst Clinical Commissioning Groups, healthcare providers and GPs take the lead on end of life care, combining their resources more effectively with those of housing, public health, and social care and support will enable us to meet more people's aspirations and needs, and to reduce health inequalities.

It is important to remember that end of life care applies to all ages. Some people entering their last year of life will be relatively young, for example those with advanced, progressive incurable disease or people with life-threatening acute conditions caused by catastrophic events such as accidents. Therefore plans need to be age-appropriate.

The framework is in place to enable a fully integrated approach to end of life care that draws in the expertise of all sectors, including the voluntary sector, to deliver the services that people want, and more importantly, where and when they want them.

Why does the home matter to end of life care?

The home and people's living arrangements are integral to people's wellbeing. This is particularly true at the end of life, where people wish to be in a familiar place, surrounded by their personal possessions and their memories. Around 75% of people say they would prefer to die at their usual place of residence but only 45.6% of people actually do. About 47% of people die in a hospital.¹ However, a recent paper questions the robustness of research into preferences and suggests that the quality and place of care may be more important to the public than the place of actual death.²

Enabling choice at the end of life is as much about the preparation during the last year of life as it is about providing the necessary services and response in the final few days. Without early recognition and support it is less likely that the preferred choice regarding place of care and of death will be realised.

Cohort modelling undertaken by the National End of Life Care Programme using tools developed by the National End of Life Care Intelligence Network has identified that in a typical population of 200,000 people:

- There will be about 1,700 adult deaths from all causes each year;
- It should be possible for early recognition of the needs of 1,000 of the adults who will die, in particular those with cancer, frailty (including dementia, Alzheimers), organ failure (e.g. COPD) or other terminal illnesses (MS, Parkinsons);
- However, currently only 470 out of the 1,700 adults who die each year will have their needs recognised before their last days – and just over half of these will be people with cancer;
- As a result, currently about 1,000 of the 1,700 adult deaths will occur in hospital at a cost of £3 million.

www.endoflifecare-intelligence.org.uk/end_of_life_care_models/reducing_deaths_in_hospital

A study by Nuffield Trust³ estimated the average cost of local authority-funded social care (specifically home care, nursing care, residential care, day care, direct payments, and respite care) in the last three months of life was £1,010 per person who died. This cost increased slightly when only non-cancer patients were included, and significantly decreased for cancer patients (who tend not to access social care). The study also examined the cost of secondary (acute hospital) care in the last three months of life and estimated it at £4,500 per person, explained by emergency hospital admissions. Effective community-based provision of end of life care (EoLC) therefore has cost benefits in the context of integrated care.

Recognising this, a number of the Vanguard Sites announced in the NHS Five Year Forward View⁴ are focused on the theme of Enhanced Health in Care Homes. These are looking at new models of care, including the integration of health and social care, telehealth, telecare and staff training, so that people, including those approaching the end of their life, can be cared for *wherever possible and appropriate*, in their usual place of residence, if that is their preference, and avoid hospital admissions.

www.england.nhs.uk/ourwork/futurenhs/5yfv-ch3/new-care-models/care-homes-sites/

It may be necessary to provide home adaptations to ensure that someone can remain in their usual place of residence as they approach the end of their life. The Department of Health has recently announced the 2015/2016 Better Care Fund allocation by local authority area. This includes information on the capital funding set aside for Disabled Facilities Grants (DFGs).

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/444302/SC_capital_grant_determination_2015-16.pdf

For more on DFGs, Public Health England commissioned Care & Repair England to produce a useful briefing that explains the changes to the provision of national government funding for home adaptations and the outcomes that can be delivered.

http://careandrepair-england.org.uk/?page_id=98

What is the national framework for improving end of life care?

The government published a national strategy in 2008⁵ and in 2015 the National Palliative and End of Life Care Partnership published [Ambitions for Palliative and End of Life Care: A National Framework for Local Action](#) that proposed six ambitions:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help.

Responsibility for the end of life care strategy passed over to NHS England in 2013.⁶ In 2014, the Government set up a Programme Board to consider how quality and experience of care for adults at the end of life and those close to them could be improved by expanding choice. The Board published its report to government in February 2015⁷, recommending that each person who may be in need of end of life care is offered choices in their care focused on what is important to them.

In order to enable choices to be achieved, the report set out some key recommendations including that:

- 24/7 end of life care for people being cared for outside hospital should be in place across England by 2019;
- The Government should implement a clear policy to make access to social care for people at the end of life fast and free.

In response, the Government said it will work with organisations in the health and care system to consider the Programme Board's advice. In October 2015, the Government also published

its response to a Health Select Committee's report on end of life care in England, setting out what has been done recently to improve end of life care.

<https://www.gov.uk/government/publications/end-of-life-care-response-to-health-select-committees-report>

From a public health perspective, Public Health England has announced plans for a new national data collection from specialist palliative care provider services. This patient-level data will include activity, demographic and patient and carer outcomes. The new data collection is due to start in July 2016 from all NHS and non-NHS hospital, hospice and community specialist palliative care services with full implementation scheduled for April 2017.⁸ The purpose of the data collection is to improve outcomes for patients, carers and their families and support the development of a new specialist palliative care funding model by NHS England.

In 2011, NICE defined 16 quality statements for end of life care that when applied collectively should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers.⁹ In December 2015, NICE published a guideline¹⁰ to help NHS staff and others recognise when someone is nearing death and made evidence-based recommendations on how people should be cared for in their final two to three days of life.

End of Life Care should be included in every local authority's Joint Strategic Needs Assessment (JSNA) and Health and Wellbeing strategy.* The National Council for Palliative Care (NCPC) has produced a *What about end of life care?* Action Sheet to help Health and Wellbeing Boards consider end of life care and support.

www.ncpc.org.uk/influencing-toolkit

There is also a growing movement around the concept of 'Compassionate Cities'. This recognises that the prevailing focus of attention on hospital care is inadequate for meeting the wider social, psychological and spiritual needs of those who are dying. Compassionate Cities promotes the themes of public health, community involvement and development, partnerships, and education as central to end of life care, making dying 'everyone's business'.

A Compassionate Charter

A Compassionate Cities Charter has been developed that sets out 13 social changes for implementation locally, across settings such as education, workplaces, places of worship, museums, and through civic activities, to 'address the negative health impacts of social inequality and marginalization attributable to dying, death and loss'.

[Click here for the link to the Compassionate Cities Charter](#)

The NCPC was commissioned by Public Health England to produce a Dying Well Community Charter that sets out the principles of care and support that should be adopted by individuals, communities and organisations so that those affected by death and dying do not feel abandoned or isolated. On page 9 we highlight eight pathfinders that are exploring the effective implementation of the Charter.

www.ncpc.org.uk/sites/default/files/Dying_Well_Community_Charter.pdf

* JSNAs analyse the health needs of populations to inform and guide commissioning of health, wellbeing and social care services within local authority areas. The local health and wellbeing strategy is informed by the JSNA and sets the priorities for collective action

Based on the concept of Compassionate Cities, Public Health England and the NCPH have jointly published the *Public Health Approaches to End of Life Care* toolkit. The toolkit sets out community development approaches to end of life care to help address the problems of access to end of life care services, and also in recognition that experiences of dying, care giving and bereavement can occur over long time periods and across a diversity of institutional life– workplaces, schools, places of worship, the high streets and recreational venues. “Health promotion and community development activities complement service goals often beginning their work where direct professional work ends.”

www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

Understanding end of life care needs locally

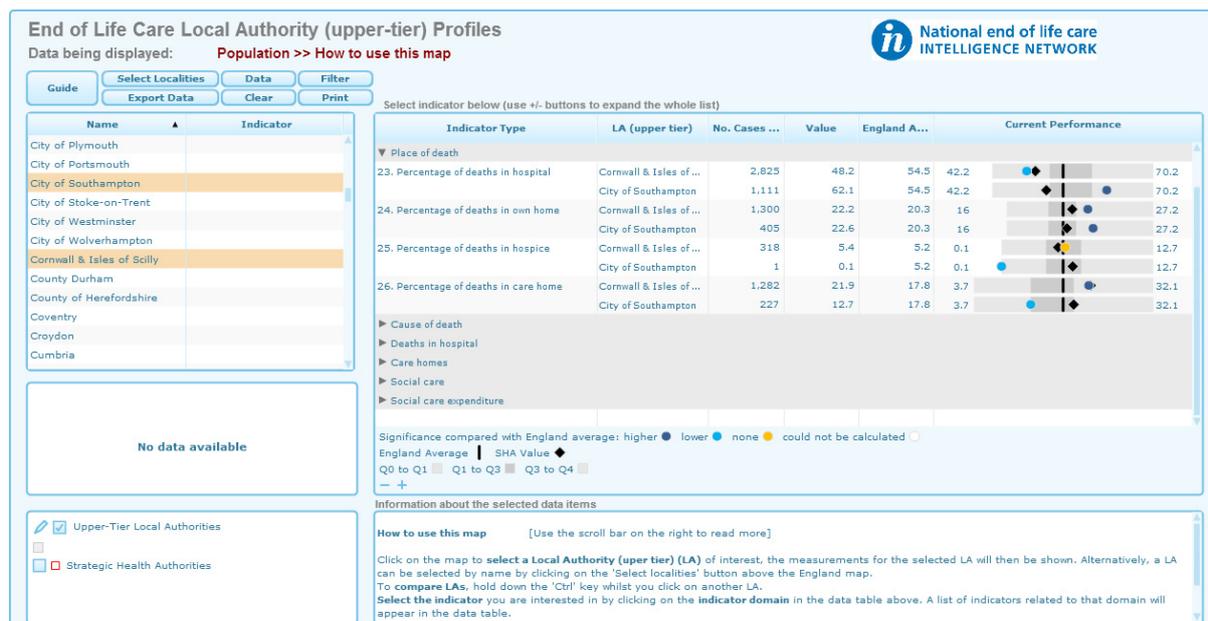
Public Health England publishes End of Life Local Authority Profiles that you can access to understand how your area is doing in terms of:

- place of death
- cause of death
- deaths in hospital
- care homes
- social care.

The data are presented in table, chart and map formats so that one local authority can be compared against another. PDFs for each local authority can be downloaded giving a snapshot of each local authority’s position compared to England.

www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012

The example below compares the place of death indicators for two localities and also shows the England average.



In addition, end of life care profiles are provided in an alternative format that allows users to select reporting geographies.

<http://fingertips.phe.org.uk/profile/end-of-life>

It is important to recognise that not everyone will experience the same end of life care. The Marmot Review¹¹ demonstrated that health inequalities flow from social inequalities. Socio-economic deprivation is a major determinant of where, when and how people die.

- Nationally people living in the most deprived quintile (the poorest 20% of areas) are more likely to die in hospital (61%) than any other quintile (54-58%).¹²
- People living in the most deprived quintile are less likely to die in care or nursing homes (11%) than any other quintile (16-20%).¹²
- Amongst the black and minority ethnic population, there is a lower uptake of palliative and end of life care services compared to white/majority groups and evidence of poorer outcomes.¹³
- People with learning disabilities are less likely to have access to specialist palliative care services, receive inadequate pain control in their final illness and are more likely to have their deaths described as not being planned for, uncoordinated and poorly managed.⁵
- Approximately one third of people aged over 60 years will die with dementia, many with complex physical and psychological needs. Yet many receive poor quality care towards the end of life.⁵
- Older people are less likely to die at their usual place of residence.
- Homeless people die at more than three times the rate of aged matched controls in the general population. The average age of death in the UK for single homeless people is between 40 and 44 years.⁵

While cause of death and the pace of disease progression play their part, there are equity of access issues that need to be taken into account when services are commissioned and also underlying social factors; for example, housing quality, financial resources and family support that need to be considered and addressed.

What is the role of public health professionals in end of life care?

Public health's role is to protect and improve health and wellbeing and reduce health inequalities and as such has been identified by NHS England as a key strategic partner in the delivery of high quality end of life care.

As outlined by the Department of Health⁵, public health should be the champion of end of life care locally and could play the following roles:

- Supporting inclusion of EoLC in the JSNA and in local health and wellbeing (HWB) strategies;
- Ensuring that data is captured and informs strategy and practice, including socioeconomic and geographical variations;
- Gathering evidence and promoting effective interventions;
- Engaging communities, and promoting and assessing the impact of the Dying Well Community Charter, Compassionate Communities, and the *Public Health Approaches to End of Life Care* toolkit;

- Making the case for allocating Better Care Fund[†] resources to fund aids and adaptations;
- Championing the role of social housing and supporting the development of frontline housing staff to respond to this agenda. For example:
 - avoiding the harms for those affected by death and dying- increased mental health issues, physical illnesses;
 - Reducing risk of increased mortality & morbidity for bereaved;
 - Maximising quality of remaining life, and;
 - Developing healthy environment- and infrastructures.

What is the role of social landlords in end of life care?

Identifying people's future needs and putting in place a care plan can make the difference between people being cared for and treated at home (whatever tenure and dwelling type), and people being admitted to hospital as emergency cases that could have been prevented.

However, in a survey undertaken by LGIU¹⁴, less than a quarter of respondents agreed that housing departments, and by extension social landlords, work closely with the NHS and social care on end of life provision, despite their often crucial role in supporting quality of life outcomes.

In addition, although the importance of the home environment is recognised, social landlords are rarely mentioned in EoLC strategies. For an example of a strategy that does cite housing providers among the wealth of partners needed to deliver patient care see Cumbria's joint commissioning strategy for EoLC.¹⁵

Social landlords could play a significant role in identifying and supporting people to die at home. For example, two thirds of deaths each year occur among people aged over 75 and almost 20% of people aged over 75 live in social housing.¹⁶ Social landlords also house the groups experiencing the most inequalities in end of life care, as well as some of our most vulnerable and low income citizens. Social landlords have regular contact with their customers and are already engaged in crucial support activities such as reducing loneliness and social isolation. Frontline staff are therefore well-placed to:

- Identify people approaching the end of life
- Discuss their end of life care wishes and help them draw up a living will
- Be their advocates
- Organise adaptations where appropriate
- Alert other agencies and services.

They can also ensure that tenants are accessing the right benefits and other support services to enable them to continue paying rent and maintain their home.

[†] The Better Care Fund creates a local single pooled budget to incentivise the NHS and local government to work more closely together around people, placing their well-being as the focus of health and care services

What can be achieved by working together?

Analyse

The local public health team will be able to help identify and make sense of local data, including the End of Life Local Authority Profiles, the place of death statistics, and may be interested in applying the Cohort Modelling tools to the local area. Social landlords may have surveyed residents about their wellbeing and health or have other useful intelligence that can inform end of life care planning.

1. Look at the data that exists and understand which of your populations are at risk and in which of your populations inequalities in end of life care exist.

Plan

2. Work together to ensure the role of social landlords in end of life care in the home is understood by the wider health and social care system and reflected in key documents e.g. the Joint Health and Wellbeing Strategy.
3. Use the data to co-design approaches that will better meet the needs and aspirations of different population groups and reduce inequalities.
4. Develop working partnerships with the staff and services that will take the lead on EoLC; for example, local community/primary health and social care services, voluntary organisations such as Marie Curie and Macmillan, hospices, funeral directors, and community transport, to coordinate services around the needs of social housing tenants, in particular if they lose mobility, or become cognitively or sensory impaired.

Do

5. Collaborate on funding applications for schemes to provide affordable warmth, insulation, energy efficiency, aids and adaptations.
6. Establish an EoLC protocol for social landlords across the locality, identify the training needs of frontline housing staff and create partnerships with the other professionals and services who will need to be involved (see point 4 above). Activities to consider include:
 - Training for housing staff in how to approach the subject of end of life with tenants;
 - Providing home adaptations and/or community equipment;
 - Arranging access to HIA and/or handyman services;
 - Providing Telecare and community alarms;
 - Providing home assessments e.g. health promotion, falls prevention;
 - Moving residents to extra care housing or sheltered housing. The local allocations and letting policy should facilitate this. However, in some cases it may be more appropriate to move residents to a hospice.
7. Establish public health training opportunities for staff e.g. extra care managers, sheltered housing scheme managers, tenancy support officers, home improvement agency (HIA) staff, handymen etc to recognise when a tenant's health is deteriorating and to trigger the end of life care protocol.

8. Empower and support staff (whether in mainstream or specialist housing) to join local palliative care networks and be tenant advocates –discussing and championing their end of life care needs and ensuring they access the benefits they are entitled to.‡
9. Work together to support, plan and deliver social awareness campaigns to get communities talking about end of life care, dying, death and bereavement. For example, encourage community conversations through art projects, activities in public spaces and via extra care, sheltered or supported housing schemes.
10. Partner with hospices and other end of life and bereavement support services e.g. Marie Curie and Macmillan, to support the provision of effective services in the home, and to train residents as peer support volunteers to help meet the social and emotional needs of people approaching the end of their lives, and their carers.

Review

11. Jointly review social landlords' end of life care strategies and procedures and confirm that they meet best practice standards for staff training and meeting the needs of customers.
12. Adopt a continuous improvement approach and seek feedback from carers and relatives about the end of life care that people received.
13. Review palliative and end of life care services available in the locality to confirm that they are able to support people of different ages, ethnicity and social background to die well at home.
14. Ensure that networks and coordination arrangements are in place to enable health, housing, care and support professionals (including those responsible for arranging and delivering the care) to work together, share their knowledge and review their practice.

Emerging practice, case studies and resources

This section provides links to online resources and highlights a number of examples of existing or emerging practice to help you plan your local end of life care approach.

The Housing LIN has a dedicated page on relevant housing and EoLC practice.

www.housinglin.org.uk/Topics/browse/Housing/EndOfLifeCare/

The Dying Well Community Charter mentioned on page 3 will help social landlords to think about an approach from the perspective of their tenants.

‡ Most people who need care towards the end of their lives qualify for Personal Independence Payment (PIP) (which is gradually replacing the Disability Living Allowance), if under the age of 65, or Attendance Allowance (AA), if over the age of 65. These benefits are not means-tested and anyone who isn't expected to live longer than six months because of an illness can apply for PIP/DLA or AA under special rules which mean the claim will be given priority and dealt with more quickly than the 16 week timeframe given for other claimants.

Emerging practice: Dying Well Community Charter Pathfinders

NCPC and Public Health England are supporting eight 'Pathfinder' organisations and groups across England, including CCGs, local authorities, and voluntary sector organisations, to engage in a range of activities to involve their local communities in implementation of the Dying Well Community Charter. Public Health England has commissioned NCPC to work with Pathfinders to develop a method for evaluating the impact that Pathfinders are having on awareness and activities around dying, death and bereavement in their local areas.

www.ncpc.org.uk/pathfinders-and-buddies-dying-well-community-charter

In one pathfinder, staff from the three main housing associations have attended brief intervention training courses, "the purpose of which is to enable and empower residents to engage in future life planning activity (including End of Life Planning) and to increase awareness of end of life issues."

www.eolp.org.uk

Case Study: Compassionate Neighbours

Compassionate Neighbours is a partnership between St Joseph's Hospice and Social Action for Health, funded by Hackney CCG and the Cabinet Office. This approach could be adopted by housing associations working in partnership with a local hospice.

The partnership aims to create a network of volunteers who will offer their time and support to those in their community who have been diagnosed with a life limiting illness, those looking after people with a life limiting illness, and people in the later stages of life who are socially isolated. Community outreach, in this case by Social Action for Health, recruits potential compassionate neighbours who attend a selection day and then participate in an eight week training programme. Monthly practice development meetings are held in order for the neighbours to share, support, learn and develop their practice.

Key learning:

- Face to face contact by people who know the communities is key for recruitment;
- Build in time during recruitment to explain the concept of supporting people who are dying – death can be a scary thing - allow space for challenging conversations;
- Ensure that volunteers in this capacity understand that this is not a service to provide personal care – many start the training thinking that they may be asked to change bed pans etc;
- More women than men are likely to come forward and so invest heavily in promoting to networks that support men; and
- A key reason for some people becoming compassionate neighbours is that they themselves are socially isolated and elderly and it is therefore an important intervention for increasing inclusion and connectivity.

Case Study: Home Group - A Good Death

Home Group has developed a service for adults who are coming to the end of their life, or have been diagnosed with a terminal illness, that helps them make practical arrangements and choices to enable them to remain in their own homes for as long as possible.

Staff and volunteers work with the individual and their family to help plan and prepare for the future, and support with practical considerations such as:

- organising aids and adaptations;
- applying for benefits
- putting affairs in order
- learning a new skill or hobby
- providing someone to talk to
- enabling IT or digital technology to keep people in touch with friends or family.

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

Case Study: Accord Group - Dementia support workers to improve end of life care in care homes

Pathways 4 Life, a Midlands based partnership between the Accord group and Age UK Walsall, have teamed up with St Giles hospice to provide an end of life care service in Walsall. The service has two dementia support workers who have been appointed to improve dementia and end of life care for people diagnosed with dementia living in care homes across the Borough.

Funded by NHS Walsall Clinical Commissioning Group and Walsall Council, the appointments are part of a year-long project. The support worker are using the Namaste Care approach by creating safe and relaxing spaces, while providing a broad spectrum of meaningful, person-centred activities that include sensory stimulation and advance a more holistic approach to dementia and end of life care.

http://accordgroup.org.uk/pathways_for_life

End of Life Care: Learning Resource Pack

Housing 21 (now Housing & Care 21) and the former National End of Life Care Programme developed a resource pack specifically for providers of extra care or similar housing, to provide guidance and information for anyone caring for someone with a life-limiting condition.

Use this resource to help develop your EoLC strategy and protocol.

In particular, the resource signposts to the different professional groups who should be involved in the care of the resident, including district nurses, advocates, and physiotherapists. It also sets out practical tips for making residents comfortable and for dealing with symptoms associated with the condition or with the medications.

www.housinglin.org.uk/pagefinder.cfm?cid=8155

A particular issue will be the confidence and skills of the housing sector workforce to provide end of life care and support. Training may be provided by local hospices, and community matrons may be able to offer support and advice with regards care planning and coping with certain situations that may arise.

And finally...

It is vital that we get end of life care right, not only to manage costs but also so that we can meet people's aspirations as well as needs. The time is right for housing, care and support, and public health to work together with the NHS, primary care and other healthcare providers to develop a fully integrated approach to end of life care that draws in the expertise of all sectors, including the voluntary sector, to deliver the services that people want, and more importantly, where and when they want them.

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16. English Housing Survey
<https://www.gov.uk/government/statistical-data-sets/tenure-trends-and-cross-tenure-analysis>

Useful websites and publications

The Social Care Institute for Excellence has published *Dying well at home: the case for integrated working*. The guide is aimed at practitioners and managers supporting people with end of life care needs across the health, social care and housing sectors:

www.scie.org.uk/publications/guides/guide48/files/guide48.pdf

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

The National Institute for Health and Care Excellence: www.nice.org.uk

Dying Matters: www.dyingmatters.org

Marie Curie: www.mariecurie.org.uk

Macmillan Cancer Support: www.macmillan.org.uk

Public Health England: www.phe.gov.uk

About the Author

This briefing was written by Dr Alison Giles. Following a PhD and two academic posts in cancer research Alison moved into public health policy, spending seven years as an Associate Director at the UK Health Forum (formerly National Heart Forum), a policy think tank devoted to the prevention of avoidable non-communicable disease. This was followed by a two-year secondment to the Department of Health to lead the cross-Government physical activity strategy before her appointment by the North West Strategic Health Authority in 2007 to set-up and run the social enterprise Our Life. During Alison's time at Our Life she helped bring the public health and social housing sectors closer together through a focus on their shared interests of wellbeing and community resilience and she currently works across these agendas in a freelance capacity.

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About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. Public Health England is an operationally autonomous executive agency of the Department of Health.

About the Housing LIN

The Housing 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.

Previously responsible for managing the Department of Health's Extra Care Housing Fund, the Housing LIN is called upon by a wide range of statutory and other organisations to provide expert advice and support regarding the implementation of policy and good practice in the field of housing, care and support services. Along with Public Health England, the Housing LIN is a signatory of the Health & Housing Memorandum of Understanding:

www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/A_Memorandum_of_Understanding_MoU_to_support_joint_action_on_improving_health_through_the_home.pdf

Further information about the Housing LIN's comprehensive list of online resources on end of life care can be found at: www.housinglin.org.uk/Topics/browse/Housing/EndOfLifeCare/

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