



PHE Board Paper

Title of meeting	PHE Board
Date	Wednesday 24 February 2016
Sponsor	Kevin Fenton
Title of paper	Public health approaches to end of life care

1. Purpose of the paper

- 1.1 The purpose of the paper is to provide the Board with background information on the concept of public health approaches to end of life care, and the current and planned future work of PHE in this area.
- 1.2 The board meeting to which this paper relates is a direct result of a meeting between Duncan Selbie (Chief Executive of PHE), Elaine Rashbrook (National Lead for Older People, PHE) and Claire Henry (Chief Executive of the National Council for Palliative Care) in September 2015.

2. Recommendation

- 2.1 The Board is asked to **NOTE**:
 - a) The concept of public health approaches to end of life care
 - b) PHE's work to date to promote, facilitate and evaluate these approaches
 - c) Future actions PHE is planning to undertake in this area

3. Background

- 3.1 The impact of a single death affects a wide network of carers, family, friends, employers and communities. Approximately 460,000 people die in England every year, many of whom have family, friends and co-workers caring for them and later grieving for them.
- 3.2 Despite recent progress, dying and death remain significant social taboos in society. Our inability to engage in these topics as individuals, communities and wider society can leave many people unprepared, unsupported and isolated in dying, caring and bereavement.
- 3.3 Though pockets of good practice exist throughout the country, many communities across the country are ill equipped to provide holistic care and support to people who are dying, caring and are bereaved in their communities.

Impact on health and wellbeing

- 3.4 Inadequate care and support for death dying affects not only the health and wellbeing of those at the end of life, but those around them too. Caring has long been associated with negative health impactsⁱ, and caring for a loved one at the end of life provides further emotional challenges.
- 3.5 Further, grief and bereavement can be trigger factors associated with social isolation, mental ill health, substance misuse and suicide.ⁱⁱ
- 3.6 Given the number of people dying in England every year, the potential annual health and social impact of these deaths can be conservatively estimated to affect millions of people. In this epidemiological context, end of life care is a major public health issue.

The role of public health in end of life care

- 3.7 There is extensive evidence to suggest that communities that are involved in planning and decision-making about the services in their area, are well networked and supportive and where neighbours look out for each other, have a positive impact on people's health and wellbeingⁱⁱⁱ.
- 3.8 A community focused approach can also be applied to end of life care, given that dying and death do not happen in isolation from the rest of life. Many people who are dying do not wish to be disconnected from the communities in which they live, and their families and friends require local support to cope with caring and their eventual loss.
- 3.9 Public health approaches to end of life care focus on developing partnerships between healthcare services and communities, and building community capacity and resilience in recognition that death, dying, loss and care take place in everyday life within families and communities.^{iv}
- 3.10 Public health activities to facilitate this community development approach involve engagement of a range of local actors including schools, workplaces and museums, as well as traditional end of life care actors, to break down the taboo around death and acknowledge that responsibility for care and support at end of life goes beyond palliative services.
- 3.11 A great number of end of life care community development activities and projects already exist in pockets across England.^v These may be explicitly focused on the end of life, such as hospice bereavement services and death cafes*, or may be interventions focused in other areas which enhance the experiences of dying people, their carers or the bereaved, such as befriending services and intergenerational projects
- 3.12 In recent years this approach has garnered interest in England from national bodies recognising that a public health approach has much to offer in this area. PHE has been working closely with the National Council for Palliative Care to promote a systematic adoption of this approach across the country. Close links have been made to similar work being under taken in the Cabinet Office through its funding of social action projects that support people at the end of life^{vi}.

* Death Cafes are social events hosted in community settings in which people from all walks of life are invited to gather to discuss death. The aim of these events is to increase awareness of death within the community and help tackle the social taboo around talking about death and dying.

4. PHE's work on public health approaches to end of life care

4.1 Work on public health approaches to end of life care has been undertaken jointly between the Older Adults team in the Health and Wellbeing Directorate and the National End of Life Care Intelligence Network (NEoLCIN) in the Chief Knowledge Office Directorate.

4.2 The Health and Wellbeing Directorate in PHE aims to save lives, promote wellbeing and create environments that enable individuals, families and communities to be informed, empowered, healthier and more productive. The Older Adults team focuses on this objective in relation to the health and wellbeing needs of older people.

4.3 NEoLCIN was established in May 2010 with the aim to bring together diverse strands of nationally available data on end of life care and to transform it into intelligence which will drive service improvement, better experience for people approaching the end of life and their families and to support development of cost-effective services. On 1st April 2013, NEoLCIN became part of PHE.

This work has included representing PHE on the Leadership Alliance for the Care of Dying People and the Choice Review, as well as supporting the Acute Hospital Transform Programme, the National Hospital Audit of the Care of Dying Patients. NEoLCIN works closely with partners across the system, in particular with the National Clinical Director for End of Life Care for NHS England.

4.2 PHE's role in end of life care is to support local Health and Wellbeing boards and their key strategic partners to:

- a) Recognise death and dying as an area for strategic action in Joint Strategic Needs Assessments and Health and Wellbeing strategies, including the recognition of the needs of carers and the bereaved.
- b) Support community based public health approaches to end of life care, such as volunteer networks, support groups and befriending services, which maximise the potential of social and community assets in supporting individuals and their families and carers at the end of life.
- c) Provide a national hub for intelligence, evidence, tools and guidance relating to end of life issues through the NEoLCIN.
- d) Support local government public health teams in their role providing advice to clinical commissioning groups regarding commissioning of palliative and end of life care services.
- e) Develop the understanding of inequalities and equality issues at end of life.
- f) Support the integration of end of life issues across the PHE corporate priority programmes.
- g) Provide national public health leadership on end of life issues.
- h) Support the work of NHS England to implement national policy on end of life care including Actions for end of life care^{vii} and implementation of relevant NICE guidance on End of Life^{viii}.

4.3 The Health and Wellbeing Older Adults team and NEOCLIN are working in partnership with the National Council for Palliative Care (NCPCC) to promote, facilitate and evaluate public health approaches to end of life care.

Dying Well Community Charter

- 4.2 Commissioned by PHE, NCPC produced and launched the Dying Well Community Charter^{ix} in September 2014. The Charter sets out a series of commitments for individuals, organisations and communities to work together to ensure that people are well supported and cared for through dying, death, grief and bereavement.

Public Health Approaches to End of Life Care: A Toolkit

- 4.3 A toolkit^x, commissioned by PHE and produced by Professor Allan Kellehear and Dr Aiki Karapliagkou at Middlesex University, was released alongside the Charter to support its practical implementation in local areas.

Implementation of the Charter and Toolkit: 'Pathfinder' pilot

- 4.4 To facilitate implementation of this approach PHE and NCPC sought applications from local actors (including local authorities, CCGs, Health and Wellbeing Boards and NHS or voluntary sector providers of health and social care) interested in implementing the aforementioned Charter and Toolkit in their areas. Twenty-three applications were received from partnerships across England. Eight areas already begun undertaking work in this area were selected as Pathfinders^{xi} to pioneer this approach in practice, and six were 'buddied' with surrounding areas in earlier stages of development.
- 4.5 Provided with advice and non-financial support from PHE and NCPC, the Pathfinders have each launched the Charter in their areas and are now working to raise awareness of good end of life care in their areas, develop local partnerships to improve local provision and share good practice among other parts of the country.
- 4.6 To support this local implementation PHE is currently in the process of producing a guide about the role of faith at end of life for those providing community care and support, to help address inequalities in end of life care.

Promotion of this approach to end of life care

- 4.7 PHE promoted this approach to end of life care at conferences and events between September 2014 and March 2015. This approach was also presented to Strategic Clinical Networks across England as part of NEoLCIN workshops. The concept and its application in practice have generated much interest across a range of stakeholders throughout the year.
- 4.8 This work on public health approaches to end of life care was showcased at PHE's annual conference in September 2015 as part of the healthy places and communities work stream.
- 4.9 In September 2015 representatives from PHE met with Baroness Finley in relation to the Access to Palliative Care Bill, and provided updates in relation to aforementioned work on compassionate communities and data collection undertaken by NEoLCIN.

Evaluation of this approach to end of life care

- 4.10 Implementation of this approach has not been tried at this scale previously in England. As such, PHE commissioned NCPC to develop an evaluation approach and use it to measure the impact of the Pathfinders' activities in their communities. This evaluation is due to report in early 2016.

4.11 PHE has commissioned two pieces of research to gain insight into existing work on community end of life care, from which build on and monitor future progress. This includes a survey of Directors of Public Health about end of life care priorities, opportunities and challenges, and social marketing research with the public about their awareness, understanding and experiences of these public health approaches. It is expected that findings from these activities will be used to inform local implementation of these approaches and supplement intelligence NEOLCIN already provides to develop a richer understanding of end of life care and drive improvement.

5. Future PHE actions

5.1 PHE and NCPC have agreed to coordinate on end of life care communications, co-badging events on end of life care and providing personal quotes from Chief Executives in support of work, when appropriate. NEOLCIN will lead on PHE's future engagement with NCPC post April 2016.

5.3 Three current pieces of work led by NEOLCIN plan have relevance to this agenda:

- a) Evaluation of the Dying Matters Coalition, which was set up by the National Council in 2009 and is the first example of a nationally funded long-term awareness and behaviour change campaign in end of life care.
- b) Project to apply existing evidence and information on the health economics of end of life care to service delivery models, identify where further information is needed, and propose cash releasing options for service delivery. This would include a focus on the provision of palliative care in the community and the overall associated cost burden.
- c) Project to bring together the evidence, examples of good practice, experiences and knowledge of care home provision in England to better understand their role in end of life care, care integration with NHS and social care services, issues and the incentives for place of care.
- d) Integration of public health approaches to end of life care work with the Variations and Value Programme and work with NHS Right Care on introducing end of life care to their Optimal Pathways Programme.

5.4 Further work is being undertaken by Occupational Health to explore PHE's support for staff caring for someone who is dying or post bereavement. NCPC will present their Compassionate Employers scheme to PHE's Wellbeing Champions in February 2015 to explore these ideas further.

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http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Car_e_Toolkit_WEB.pdf
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