

C. Public Health Approach to Palliative Care in the United Kingdom

Overview

In the UK, there has been a growing interest over the past decade in embedding the public health approach and community compassion in end-of-life care. This interest was prompted by the socio-demographic changes, brought about by the ageing population in the UK, and diminishing resources of the health care system.¹²⁶ The proportion of people aged 65+ is projected to rise from 17.7% currently (11 million) to 23.5% in 2034. Around 70% of people would prefer to die at home, yet around 60% of the 500,000 people who die each year in England die in hospitals.¹²⁷

UK National End-of-life Care Strategy

To address these challenges, the 2008 National End-of-life Care Strategy supported a public health partnership approach to improve the quality of care at the end of patients' lives and enable more patients to live and die in the place of their choice.¹²⁸ It is important to note that a combination of the National Health Services resources and the voluntary sector in the UK funds and provides palliative care free of user fees at all care settings.

The strategy sets out key areas with related actions:

- **Raise profile of end-of-life care:** Partner with local communities to increase awareness of end-of-life care;
- **Strategic commissioning:** involving all relevant provider organizations;
- **Early identification of patients:** training health care professionals in identifying people reaching the end-of-life and in communication skills;
- **Enhance capacity of all staff groups:** end-of-life care to be embedded in all training curricula;
- **Patient-centred care:** involving all people reaching the end-of-life in care planning;
- **Coordination of Care:** establishing a central coordinating facility as a single point of access through which services can be coordinated as well as locality-wide registers;
- **Rapid access to care:** all health care and support services to be available in the community, 24 hours a day, 7 days a week;
- **Delivery of high-quality services in all settings;**
- **The last days of life and death:** the Liverpool Care Pathway, or equivalent tool, is recommended;
- **Involving caregivers/family in decision-making** and providing them with all the information they require;

¹²⁶ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

¹²⁷ http://www.ageuk.org.uk/Documents/ENGB/Factsheets/Later_Life_UK_factsheet.pdf?dtrk=true

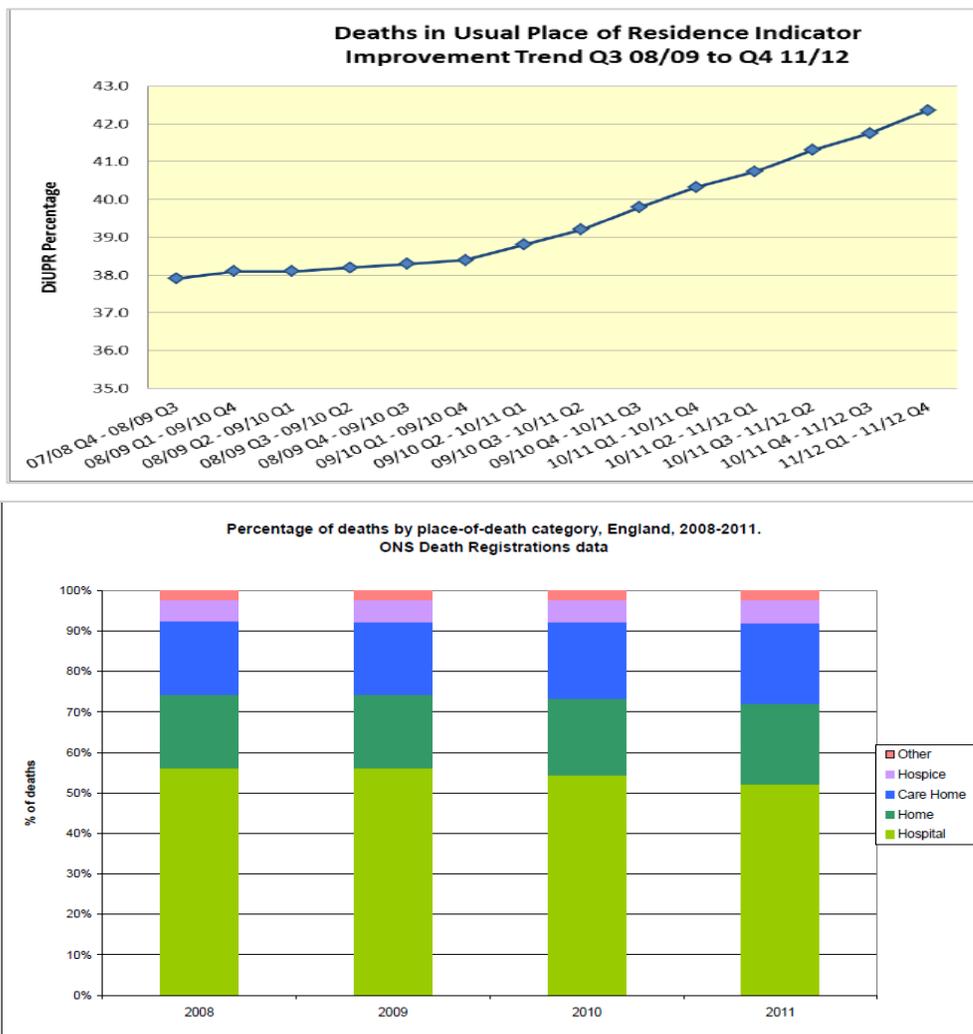
¹²⁸ End-of-life Care Strategy: promoting high quality care for all adults at the end-of-life. London, Department of Health, 2008

• Evaluation and research

Numerous programs were established by a wide range of organizations in the statutory, voluntary and private sectors to support the strategy objectives. Table 5 presents examples of current end-of-life care initiatives and programs mapped to the ten essential elements of the public health approach.

The fourth annual report on the 2008 Strategy revealed a steady improvement in the proportion of people who died in their usual place of residence which combines people’s homes and care homes. 2011 data showed a drop in hospital deaths to 51%, while the percentage of deaths at home and in care homes increased to 21.8% and 19.4% respectively.¹²⁹

Figure 12 UK data shows steady increase in the proportion of people who died at home or in home like settings.



¹²⁹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf

Table 5 UK National Palliative Care Programs Mapped to the Essential Public Health Approach Elements

Public Health Approach <i>Essential Elements</i>		Corresponding UK Palliative Care Programs <i>Examples</i>
1	Monitor health status	- National End-of-life Care Intelligence Network-Data Repository - National Council for Palliative Care- Data (England)
2	Diagnose and investigate health problems	- Marie Curie Cancer Care End-of-life Care Atlas (Scotland) - Electronic Palliative Care Coordination Systems (locality end-of-life care registers)
3	Inform, educate, and empower people about health issues.	England -Dying Matters- website/events/campaign -Together for Short Lives - e-hospice UK-website/mobile application Scotland -Palliative Care Zone- on NHS website -Good Life, Good Death, Good Grief- website/events/campaign. -To Absent Friend-People’s Festival of Storytelling & Remembrance -Death on the Fringe- shows/events
4	Mobilize community partnerships and action	-Dying Matters- a national coalition led by National Council for Palliative Care in England -Hospice UK – alliance of organisations advocating and raising awareness of EOL/Hospice care across the UK. -Good Life, Good Death, Good Grief- Alliance Stakeholder Group led by the Scottish Partnership for Palliative Care - Cheshire Living Well, Dying Well Public Health Partnership
5	Develop policies/standards/regulations and community-wide plans	- NHS end-of-life care program [including: The Gold Standards Framework for Care Homes; the Liverpool Care Pathway for the Dying Patient; and Preferred Priorities for Care (advance care planning)]. - A new palliative care funding system is under development. -Quality Standard for end-of-life care by NICE (2011) Scotland -National Statement on caring for people in the last days and hours of life (2014) -Living and Dying Well- Government’s action plan on palliative and end-of-life care. (2014) -Palliative Care Guidelines (2014) -A Framework for the Delivery of Palliative Care for Children and Young People (2012)
6	Enforce laws and regulations that protect health and ensure safety.	- National Audit Office (NAO)
7	Link people to needed personal health services and assure the provision of health care when otherwise unavailable.	-Dying Matters- website providing information to the public. -Good Life, Good Death, Good Grief- website. - e-hospice UK-website/mobile application -Together for Short Lives-website

Public Health Approach <i>Essential Elements</i>		Corresponding UK Palliative Care Programs <i>Examples</i>
8	Assure competent public and personal health care workforce.	<ul style="list-style-type: none"> -The National Council for Palliative Care-Training programs and toolkits, Conferences/forums. -Gold Standards Framework Centre for training primary care providers -End-of-life care for all (e-ELCA)- e-learning to enhance training and education of health and social care staff in England -Palliative & End-of-life Care Work-Based Learning Resource-by NHS Scotland -Quality End-of-life Care for All (QELCA) training program - Securing end-of-life care modules in social work qualifying programmes.
9	Evaluate effectiveness, accessibility, and quality of personal and population-based health services.	<ul style="list-style-type: none"> -National Quality Indicators for Palliative Care by-Healthcare improvement Scotland -Annual Reports on Palliative Care Strategy Implementation (NHS Board Update Reports) - Gold Standard Framework Accreditation Program
10	Research for new insights and innovative solutions to health problems.	<ul style="list-style-type: none"> -National End-of-life Care Intelligence Network- research - Marie Curie Palliative Care Research Centre - Palliative Care Research Society -The Cancer, Palliative and End-of-life Care Research Group at the University of Southampton -Bath University, The Centre for Death and Society

UK Providers prioritize public health approaches to death, dying, and loss

In 2013, the National Council for Palliative Care (NCPC), the umbrella charity for all palliative and hospice care providers reported an increasing uptake of compassionate communities by palliative care services in England. In the same year, an online survey of 220 palliative care providers across the four UK countries reported that most of the providers were prioritizing public health approaches to death, dying and loss, most commonly adopting a 'compassionate community' model. Respondents to the survey identified working with schools and working directly with local community groups to be their most successful work. The findings confirmed the relevance of a public health approach for palliative care services.¹³⁰

To further promote this trend, the NCPC partnered with Public Health England to provide technical advice and support to community organizations interested in pioneering a public

¹³⁰ Paul S. and Sallnow L. Public health approaches to end-of-life care in the UK: an online survey of palliative care services. *BMJ Supportive & Palliative Care* 2013;3:196–199.

health partnership approach to end-of-life care in line with the “Dying Well Community Charter” and the public health approach to end-of-life Toolkit.^{131 132}

The following are examples of UK palliative care providers using the public health/health promoting approach to palliative care, and compassionate communities model.

Dying Matters¹³³

Dying Matters is a broad based and inclusive national coalition of almost 30,000 members. It aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement.

Approach

- Raising awareness and promote conversation about death and end-of-life issues:
 - Annual National Dying Matters Awareness Week (in May)
 - Community outreach events in partnership with other community organizations
 - A community forum and blog on website to share stories and thoughts about death and dying
 - Building compassionate schools and workplaces through onsite educational sessions and promoting activities
- Providing information to patients and carers and link them to services that exist in their local community
- Training and education of health care professionals, carers, and volunteers
 - A volunteer training program about Advance Care Planning
 - Information on website for all types of carers
 - Sponsoring demonstration projects such as **Find Your 1% Project**, which aims to engage GPs in identifying the individuals on their lists who might be in their last year of life, so that they can undertake end-of-life care planning with them. The Project showed that the confidence of GPs in talking about dying with patients improves end-of-life care.

The Cheshire Living Well, Dying Well (CLWDW) Public Health Program

The Cheshire Living Well, Dying Well (CLWDW) Public Health Program aims to improve health and wellbeing of the people of Cheshire by breaking down taboos and supporting a change in public knowledge, attitude and behaviour so that people consider, discuss and plan for end-of-life throughout their lives. The Program model has been presented at the House of Lords and consequently referred to as a model of good practice in Parliament.

¹³¹ http://www.ncpc.org.uk/sites/default/files/Dying_Well_Community_Charter.pdf

¹³² http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

¹³³ <http://www.dyingmatters.org/overview/about-us>

Approach

During 2010, Cheshire Hospice consulted with the local community about end-of-life issues and concerns. The community groups and organisations supported a broad public health approach to death, dying and loss. To bring this strategic direction to reality, a partnership was established to enable and support the implementation of the CLWDW Public Health Program.¹³⁴

Highlights of the Program

1. The Program was referred to as a model of good practice in Parliament
2. Appointed a Public Health Lead for the Program
3. Identified a Champion for the Program at Health and Wellbeing Board Level
4. Co-ordinated activity for National Dying Matters Week
5. A range of awareness and training sessions for the community and public health workforce
6. Compassionate Communities established to date:
 - ‘Good Neighbour Scheme’ in Middlewich, using a timebanking model ¹³⁵
 - ‘Vintage Blacon’ a faith based bereavement group
 - St. Luke’s Community Support –A satellite group in Alsager have set up palliative day care support with hospice support. This includes home visits and support for people with life limiting illness, families, carers, and early dementia
7. External evaluation has been commissioned to evaluate the impact of the program

Severn Hospice

Severn Hospice in Shropshire, England, aims to raise awareness that the end-of-life care is everyone’s responsibility.¹³⁶

Approach

Through public forums and discussions Severn Hospice called for volunteers who are able to dedicate a portion of their week to the care of the frail and vulnerable in their own local community. A growing number of volunteers responded to this message. Before they are allocated to care for people, the volunteers are subjected to a short training session on how to reduce anxiety and panic and alleviate feelings of isolation and loneliness. Severn Hospice has now a wide and diverse network of volunteers drawn from all walks of life—retired as well as employed.

¹³⁴ <http://www.cheshire-epaige.nhs.uk/Stages/Cheshire%20Living%20Well,%20Dying%20Well%20Partnership.aspx>

¹³⁵ <http://www.middlewichgoodneighbours.org.uk/>

¹³⁶ <http://www.severnhospice.org.uk/>

Evaluation

The evaluations of Severn Hospice model revealed a consistent decrease in the need for out-of-hours and emergency support from the health system. The volunteer support also reduced isolation and anxiety, and supported people in the self-manage of their condition.

St Christopher's Hospice

St Christopher's Hospice in South London uses a health promoting approach to palliative care by engaging local schools to achieve a greater understanding about dying, death, practical care, and grief and loss among school students, teachers, and parents.¹³⁷ The aim of such knowledge was not only to reduce the community's fear and anxiety about these topics but also to prevent harms related to isolation, loneliness, and stigma among the patients at the hospice.

Approach

St Christopher's Hospice discussed the idea of engaging school students with the head teachers, and with the patients, families, and staff in the hospice to ensure that the idea and approach were acceptable to both sides. According to the plan, the students attended four sessions (1 – 3 hours each) at the hospice, meeting with patients and asking them questions that address their fears and curiosities. When the students returned to school, they discussed their experiences with the teachers and often produced artwork or performances which in turn, helped to raise awareness in the larger community. The age group of the students who have participated in this process so far ranges from 9 to 16 years old.

Evaluation

The evaluations of the student–teacher–parent engagement showed a change in attitudes from uncertainty and fears to understanding and confidence, normalizing the idea of death and dying. The engagement helped as well in alleviating social isolation and feeling of loneliness among patients at the hospice.

The National Gold Standards Framework (GSF) Centre

The GSF Centre in End-of-life Care is the national training and coordinating centre for the GSF programs in the UK, enabling generalists to provide a gold standard of care for people nearing the end-of-life.¹³⁸ Figure 13 presents a description of the GSF. The GSF is extensively used by primary care teams across the UK and has demonstrated its effectiveness in terms of improving consistency of care and improving the experience of care for patients, carers, and staff.¹³⁹ To ensure and celebrate sustained best practice in the different settings, the GSF Centre developed

¹³⁷ <http://www.stchristophers.org.uk/>

¹³⁸ <http://www.goldstandardsframework.org.uk/about-us>

¹³⁹ Shaw KL. et al. Improving end-of-life care: a critical review of the Gold Standards Framework in primary care. *Palliat Med.* 2010;24(3):317-29

Quality Hallmark Accreditation Programs: Primary Care Accreditation, Acute Hospital Accreditation, and Community Hospital Accreditation.¹⁴⁰ The home care organizations that received the GSF Quality Hallmark Award reported significant reduction in hospital admissions and hospital deaths, better integrated cross boundary coordination. (See below)¹⁴¹

Figure 13 The UK Gold Standards Framework- Overview

The Gold Standards Framework

One gold standard for all patients nearing the end-of-life to enable patients to die well

Three processes

1. Identify the key group of patients—using a register and agreed criteria
2. Assess patients’ main needs, both physical and psychosocial, and those of the carers
3. Plan ahead for problems—move from reactive to proactive care by anticipation and prevention

Five goals

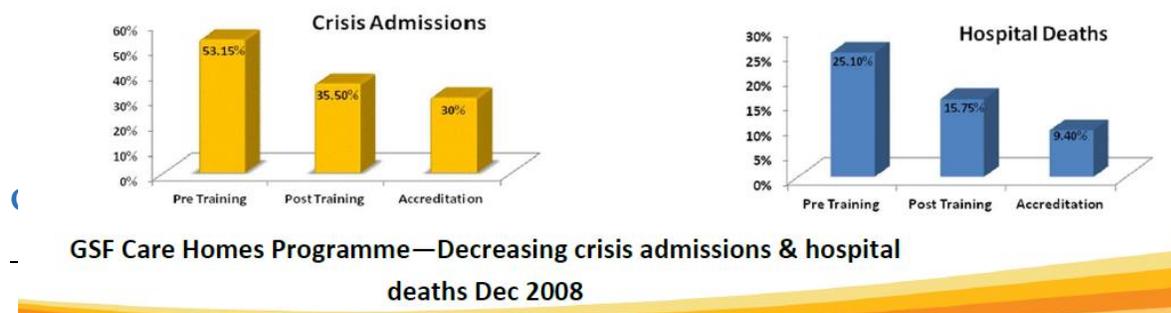
1. Symptoms controlled as much as possible
2. Living and dying where they choose
3. Better advanced care planning information, feeling safe and supported with fewer crises
4. Carers feeling supported, involved, empowered, and satisfied with care
5. Staff feeling confident, satisfied with good communication, and team working with specialists

Seven key tasks

Communication	Coordination
Control of symptoms	Continuity and out of hours
Continued learning	Cover support
Care in the dying phase	

Source: Goldstandardsframework.org.uk

Figure 14 UK Data: The GSF Home Care Program reduce crisis admissions and hospital deaths



¹⁴⁰ <http://www.goldstandardsframework.org.uk/accreditation>

¹⁴¹ <http://www.goldstandardsframework.org.uk/cdcontent/uploads/files/General%20Files/GSF%20Overview%20Autumn%202014%20-%20A4%20v1%20-%202013.11.2014.pdf>

A whole-system and care-pathway approach is a key feature of the End-of-life Care Strategy in the United Kingdom (UK).¹⁴² In 2008, the National Strategy recognized ‘raising national awareness’ as part of the whole-system approach. Since then a broad range of developments has been taking place under the banner of public health/health promoting end-of-life care across UK.¹⁴³ These developments serve a common vision: vulnerable and terminally ill people enjoy a high quality end-of-life in a supportive compassionate community. There is evidence that the UK’s public health palliative care model is effective and that individuals, families and communities can have the skills, knowledge and expertise to play key roles in their own end-of-life care.

¹⁴² End-of-life Care Strategy: promoting high quality care for all adults at the end-of-life. London, Department of Health, 2008

¹⁴³ Murray Hall Community Trust And National Council for Palliative Care. Dying Matters Coalition: An Overview of Compassionate Communities in England. July 2013