

Geriatric Palliative/End of Life Care - UK experience

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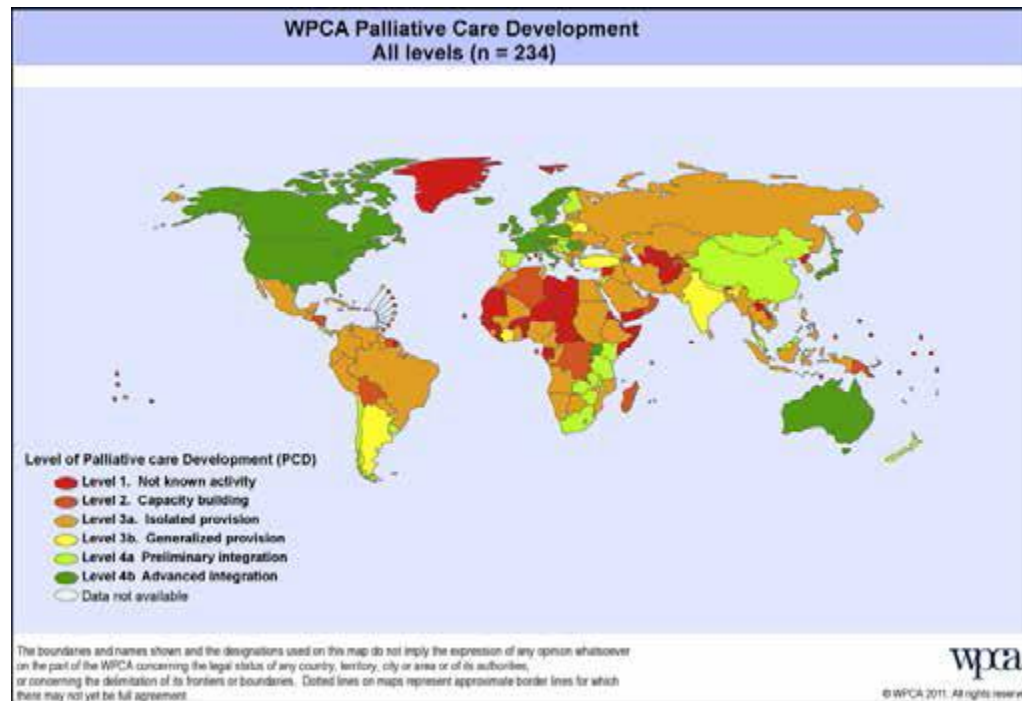
Introduction

Understanding palliative and end of life care

End-of-life care “helps all those with advanced, progressive, incurable illness to live as well as possible until they die”

- It enables the supportive care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.
- It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support ¹
- The “end-of-life” is generally understood as the last year of life ^{1a 1b}
- **Palliative care** may start earlier and is advocated by the World Health Organization to begin alongside potentially curative care when an individual is diagnosed with a life-limiting condition.

Worldwide palliative care development



Crucial Facts About Dying

- Human mortality remains 100 percent; we all eventually die. HOW we die should be up to us.
- 100 million people need palliative care each year – only 8 million people have access to it.
- 90 percent of the world's morphine is used by 16 percent
- Only 20 (8.5 percent) countries have integrated their palliative care effectively into the wider health care system to enable greater access to all citizens. This clearly leaves much room for improvement in making palliative and end-of-life care accessible to all who need it.
- This is a global tragedy and that access to palliative and end-of life care is a human right for every person and a benchmark for the development of a nation.

A Roadmap for Action

- **World Innovation Summit for Health in December 2013** called to improve palliative and end of life care for all patients who need it.
- Recognising there is no time to waste, as ending unnecessary suffering is an achievable goal.
- A series of recommendations in five steps as follows, backed by innovations that can dramatically improve end of life care.⁴

Recommendation 1

Make care of the dying a priority for all

- Produce a national strategy for end-of-life care.
- Include palliative and end-of-life care as part of healthcare for all diseases.
- Monitor the scale and need for end-of-life care locally.
- Sign the **Prague Charter** and recognize that access to palliative and end-of-life care is a human right.
- Set up a national initiative using online tools and innovative campaigns to encourage people to learn and communicate more about death and dying.
- Encourage the use of advance care directives, so that patients can make their own end-of-life wishes and expectations known beforehand, rather than under pressure at a time of crisis. ¹¹

Adopt Policies that Prioritise End of Life Care and National Strategy



The Prague Charter urges governments to relieve suffering and ensure the right to palliative care. In recognizing and celebrating palliative care as a human right, the Prague Charter maintains that palliative care should be part of all governments' fundamental health policy and should be available to everyone

The Prague Charter

Governments should:

- develop health policies that address the needs of patients with life-limiting or terminal illnesses.
- ensure access to essential medicines, including controlled medications, to all who need them.
- make sure that healthcare workers receive adequate training on palliative care and pain management at undergraduate and subsequent levels.
- design and develop the integration of palliative care into healthcare systems at all levels.³

Recommendation 2

Reduce unnecessary suffering

- Adopt the WHO Model List of Essential Medicines and eliminate overly-restrictive regulations banning the use of opioids for palliative and end-of-life care.
- Ensure essential medicines are nationally available in central medical stores, licensed appropriately, and distributed effectively through existing distribution channels where possible.
- Ensure the appropriate use of opioids and other essential medicines.

Recommendation 3

Improve knowledge and use data to drive innovation

- Invest in research and development in palliative and end-of-life care.
- Form partnerships between national, regional, and international palliative care organizations to carry out research and publish high-quality reports.
- Capitalize on knowledge gained from research outcomes to lower costs and improve care.
- In places where Western medicine has not been fully adopted, engage with traditional healers to improve end-of life care

Recommendation 4

Maximise resources

- Engage the local community in end-of-life care. Aim for better integrated services. For e.g. ‘National Voices’ in the UK helps people with shaping health and social care.
- Utilize telemedicine and technology-based innovations to improve access to end-of-life services, especially in rural and remote areas.
- Empower patients through better access to knowledge about end-of-life care choices and availability.

Recommendation 5

Improve skills

- Include palliative and end-of-life care training in all professional healthcare undergraduate and postgraduate programmes. See UK College of Physicians end of life training.¹⁰
- Include bereavement support in palliative and end-of-life care training programs.
- Share global learning to enable all countries to build palliative and end-of-life care services.
- Access or develop e-learning training modules for staff and volunteers.

UK experience

In the UK, although the palliative care movement created by Dame Cicely Saunders started in the 60's and end of life and palliative care has been reported to be good, it is still patchy for older people and there are still many challenges especially in acute and care home based settings.

One person dies every minute but most dying people are not diagnosed as being at the end of their life. The majority of people are dying in hospitals, with around a fifth dying in care homes and their own homes respectively⁶ with only 1% of patients stating that their choice would be to die in a hospital, with far higher numbers preferring to die at home⁷. The argument for change is clear.

Many who might benefit from palliative care are denied this opportunity and some professionals seem uneasy about discussing death with their patients let alone with their families.

With the publication of the **End of Life Care Strategy by the Department of Health, UK** in 2008⁸ a number of key areas of End of life Care were explored.

UK Department of Health

End of Life Care Strategy

- Identifying people approaching the end of life and ensuring that staff have appropriate training to communicate and deliver care to these individuals.
- Advanced care planning to be crucial, with all people approaching the end of life having an assessment of their needs, and a discussion of their wishes and preferences with agreed actions.
- Coordination of care across sectors, which should be able to continue regardless of the time of day or night Strategic commissioning, such as having an 'integrated approach to planning, contracting and monitoring of service delivery'.

Quality Standard on 'End of life care for adults'.

- Recent progress on this topic includes the introduction of a Quality Standard from the National Institute of Health and Care Excellence (NICE) (formerly the National Institute of Health and Clinical Excellence) on 'End of life care for adults'.
- The quality standard covers 'all settings and services in which care is provided by health and social care staff to all adults approaching the end of life', helping to move towards a more integrated model as prioritised in the End of Life strategy.

Recent UK initiatives to meet future challenges

National End of life Care Pathway (NEoLCP)

- To elicit the individuals wishes and preferences for care
- Advance care planning including best interests decisions
- Information sharing
- Care quality and continuity
- However, the Liverpool Pathway did have serious problems recently as there was a lack of family involvement in diagnosis and treatment.

Electronic Palliative and Care Co-ordination Systems (EPaCCS)

- EPaCCS support individuals approaching the end of life and their families by allowing advance care plans to be recorded, by facilitating instant access to crucial information about patients, and by providing a shared local electronic record for health and social care professionals.

Electronic Palliative and Care Coordination Systems) (EPaCCS)

- **Pilots and cost.** There has now been a fourfold increase in pilot sites. The pilots have seen some technology challenges though including synchronization between systems, consistency of information between localities and links with other care planning solutions. As of yet, it is unclear what the total national cost of the scheme has been, as the costs have been borne locally within their budgets.
- **Confidentiality and Training.** It is vital that as the scheme expands there is a consistency that confidentiality for patients must continue to be a top priority. With regard to an electronic record, there is a need to ensure that the system is as strong as it can be. This is a particular concern for videos and the possibility of manipulation or editing of footage. The system has an information governance framework covering who should be accessing the information. Before access to the system is granted, professionals must have signed up to this framework, in addition to receiving training.
- **Future.** Research is needed on benefit of local registers, impact on quality of care and avoidance of duplication and raising awareness amongst the population.

The Cost of End of Life Care

- The Department of Health estimates that the cost of a hospital admission that ends in a palliative death is around £3,000 (based on a typical stay of 3 days). In 2010, an independent study modeled the costs of community staff care for patients in the last few days of life (typically 3-4 days): these costs were £1,200 for cancer, £1,400 for frailty and £1,800 for organ failure and other terminal conditions.
- In 2011, an independent commission reviewed the whole issue of palliative care, a per-patient funding mechanism for palliative care for adults and for children.⁵ The commission recommended a funding system that appears cost neutral to the state; this system could, by 2021, potentially reduce deaths in hospital by up to 60,000 a year by optimizing palliative care services outside hospitals.

Marie Curie Cancer Care (UK)

- **Marie Curie Cancer Care** supports patients, as well as their carers and families, delivering care to people in their own homes through its nursing service and in nine hospices across the UK. It funds one of the largest palliative care research programs in the UK and campaigns to make practical improvements to the quality of life and care that terminally ill people and their loved ones and carers experience.
- One such program is the Somerset Delivering Choice Project those receiving a Delivering Choice intervention were 80 percent less likely to die in hospital compared to those who did not receive care from Delivering Choice.
- Emergency admissions to hospital in the last month of life were 39 percent lower and A&E attendances were 34 percent lower for Delivering Choice service users in Somerset compared to people not in contact with the services.

ILC-UK Report on End of Life Care

A report of a recent debate of UK Stakeholders from Government Departments, Clinicians, Lawyers, NGOs and Academics⁹

Main aims

- Recording peoples desires
- Setting up registers to record and
- Communicating to medical professionals the details of these wishes, and
- Exploring the identification of good practice regarding End of life.

Further recommendations from the UK

- To use government guidance on advance care planning as core to any changes to end of life care systems.
- Using resources which already exist (such as e-ELCA, an e-learning programme for end of life care) to support professional education and skill training.
- The links between the medical and legal professions are key. Changes in behaviour and professional guidelines would help achieve more positive objectives.
- Improve the training of doctors and lawyers, including of each other's perspectives on this issue.
- Lawyers and doctors could work in a more co-ordinated fashion in discussing end of life issues with members of the public, for example, partnerships between them to offer advice on wills, advance decisions, and care options (and potentially also financial planning, perhaps including Independent Financial Advisers) in a more holistic fashion.⁹

References

- 1** *National Council for Palliative Care, www.ncpc.org.uk/* (2006).
- 1a** *National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care, www.consensus.nih.gov/2004/2004EndofLifeCareSOS024html.htm* (2004).
- 1b** Care provided by generalists at the end of life: scoping exercise on research priorities. (2007)
- 2** Lynch, T., Connor, S. & Clark, D. Mapping levels of palliative care development: a global update. *Journal of pain and symptom management* p45, 1094-1106, doi:10.1016/j.jpainsymman.2012.05.011 (2013).
- 3** The Prague Charter was published in 2013 at the Congress of Palliative Care by the EAPC, in collaboration with the International Association for Hospice & Palliative Care (IAHPC), the Worldwide Palliative Care Alliance (WPCA) and Human Rights Watch (WRW)
- 4** WISH End-of-Life Care Report 2013 www.wish-qatar.org

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- 5 Hughes-Hallett, T. C., A. and Davies, C. Funding the right care and support for everyone: creating a fair and transparent funding system; the final report of the palliative care funding
- 6 NHS End of Life Care Programme (2012) *What do we know now that we didn't know a year ago? New intelligence on end of life care in England*. Leicester: NHS End of Life Care Programme (Figures: 53% die in hospital, 18% die in care homes, 21% die in own home)
- 7 Ibid.
- 8 Department of Health (2008) *End of Life Care Strategy*.
<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-highquality-care-for-adults-at-the-end-of-their-life>.
- 9 'End of Life Care' Report www.ilcuk.org.uk
- 10 Royal College of Physicians with NHS National End of Life Care Programme 'Improving end of life care: professional development for physicians' March 2012
- 11 'Deciding Right' The Clinical Network report 6 April 2014

Useful organisations in the UK

- Help the Hospices www.helpthehospices.org.uk
- Dying Matters www.dyingmatters.org
- National Voices www.nationalvoices.org.uk
- The Clinical Network www.cnne.org.uk/end-of-life-care---the-clinical-network/Decidingright/plusdocument
- The National Association for End of Life Care www.goldstandardsframework.org.uk
- The National Council for Palliative Care (NCPC) www.ncpc.org.uk
- Dignity and Dying www.dignityindying.org.uk

Thank you

For more information

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