Integrated Care Matters
A Community Approach to Palliative and End of Life Care
Knowledge Tree Branch May 2018
Resources

Scotland

The Scottish Government set out its 5-year vision to improve palliative care in its Strategic Framework for Action 2016–2021. This includes a commitment to strengthening research and evidence based knowledge exchange across Scotland. A comprehensive scoping review of Scottish palliative care research was considered an important first step. The aim of the review was to quantify and map palliative care research in Scotland over the ten-year period preceding the new strategy (2006–15). Concludes that there was a steady increase in Scottish palliative care research during the decade under review. Research output was strong compared with that reported in an earlier Scottish review (1990–2005) and a similar review of Irish palliative care research (2002–2012). A large amount of descriptive evidence exists on living and dying with chronic progressive illness in Scotland; intervention studies now need to be prioritised. Areas highlighted for future research include palliative interventions for people with non-malignant illness and multi-morbidity; physical and psychological symptom assessment and management; interventions to support carers; and bereavement support. Knowledge exchange activities are required to disseminate research findings to research users and a follow-up review to examine future research progress is recommended.

Inbadas, J et al. (2017) The level of provision of specialist palliative care services in Scotland: an international benchmarking study. *BMJ Support and Palliative Care* [link]
Comparative benchmarking of specialist palliative care (SPC) services across jurisdictions can be used to assess the adequacy of provision. Published in 2016, the Scottish Atlas of Palliative Care unlocks the possibility of benchmarking Scotland’s provision against other European Union (EU) countries. Objectives were to describe the provision of SPC services in Scotland and compare this with other EU countries, assessing coverage against European norms. Concludes that Scotland is positioned among the top 10 EU countries for the level of provision of SPC services. National policy in Scotland has focused on the delivery of palliative care at home or in a homely setting. These data support a focus on developing services in community settings to meet Scotland’s policy ambitions.

This evidence summary seeks to address the following question relating to palliative and end of life care for people with alcohol related brain damage (ARBD): What is considered good practice in providing end of life and palliative care for people with ARBD? It draws on evidence from academic research, health and social care guidelines and recommendations from specialist organisations to identify examples of good practice in palliative and end of life care, in terms of general recommendations, dementia-specific guidance and ARBD-specific considerations.

Palliative and End of Life Care Aims

- Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.
- Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.

Palliative and End of Life Care Outcomes

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

The Strategic Framework for Action sets out a vision for the next five years, outcomes and ten commitments to support improvements in the delivery of palliative and end of life care across Scotland.

Watson, A et al. (2016) Development of the NHS Education for Scotland Online Palliative Care Training Package for Health and Social Care Staff: Final Report [link]
The aim of this project is to develop an online Palliative Care Training Resource for Health and Social Care Staff. The objectives are:

- To review current Scottish strategies and initiatives for delivering palliative care services
- To review current (palliative) medicine-specific training and education on offer to healthcare staff in Scotland and identify gaps in content.
- Improved identification of people who may benefit from palliative and end of life care.
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland.
- Recognition of the wider sources of support within communities that enable people to live and die well.
• Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.

• To amalgamate the contents of pre-existing NHS GG&C and Highland (palliative care) training packages so that the new training meets the aims outlined in the aforementioned education, training and strategic documents.

• To design and deliver the above (amalgamated) resource in an interactive e-learning format.

• To pilot the new training resource on a selection of staff from both health boards, (thereby providing an opportunity for feedback to help shape the final version of the training).


Telehealth technologies are an emerging resource opening up the possibility of greater support if they have utility for patients, carers and clinicians. They may also help to meet health systems’ imperatives for improved service delivery within current budgets. Clinicians’ experiences and attitudes play a key role in the implementation of any innovation in service delivery. This paper explores clinicians’ perspectives on and experiences of the utilisation of a pilot telehealth model and its integration into a specialist community palliative care programme.

**International Examples**


If global palliative care is to successfully address challenges of unequal access, continuity of care, and health services reductionism, new practice models to address these issues need to be identified, debated and tested. This paper offers one such practice model based on a public health approach to palliative care that has so far shown promising evidence of effectiveness. The authors describe how four essential elements within a public health model can work together to address quality and continuity of care as well as addressing the numerous barriers of access. These elements are: (I) specialist, and (II) generalist palliative care services working with (III) communities and neighbourhoods, working in their turn with their (IV) key civic institutions. A solely clinical model of palliative care is inadequate to addressing the multiple co-morbidities and access issues characteristic of modern palliative care. A public health approach based on a close partnership between clinical services and communities/civic institutions is the optimal practice model.

*Annals of Palliative Care* [link]

Annals of Palliative Medicine publishes articles in the field of palliative medicine, specific fields related to symptoms management (pain, fatigue, vomiting, delirium, etc.), palliative medicine in different diseases (cancer, AIDS, and other diseases), palliative care in elderly and young, and end-of-life health care, etc., and provides current and practical information on palliative medicine. Contributions pertinent to palliative medicine are also included from related disciplines of oncology, psychology, surgery, nursing, public health, education,
nutrition, sociology, ethics and policy, and others. It publishes article types including Original Articles, Review Articles, Case Reports, Clinical Guidelines, Technical Notes, Perspectives, Editorials, and Commentaries. It also publishes special issues focusing on selected topics of palliative medicine.

Provision of effective palliative care is a globally important issue. This article describes the journey of cancer, specialist providers of oncology education, from developing an e-learning course in palliative care to recognizing the importance of palliative care education on a long-term basis and striving to create a comprehensive library of resources.

Early integration of pediatric palliative care (PPC) for children with life-threatening conditions and their families enhances the provision of holistic care, addressing psychological, social, spiritual, and physical concerns, without precluding treatment with the goal of cure. PPC involvement ideally extends throughout the illness trajectory to improve continuity of care for patients and families. Although current PPC models focus primarily on the hospital setting, community-based PPC (CBPPC) programs are increasingly integral to the coordination, continuity, and provision of quality care. In this review, the authors examine the purpose, design, and infrastructure of CBPPC in the United States, highlighting eligibility criteria, optimal referral models to enhance early involvement, and fundamental tenets of CBPPC. This article also appraises the role of CBPPC in promoting family-centered care. This model strives to enhance shared decision making, facilitate seamless handoffs of care, maintain desired locations of care, and ease the end of life for children who die at home. The effect of legislation on the advent and evolution of CBPPC also is discussed, as is an assessment of the current status of state-specific CBPPC programs and barriers to implementation of CBPPC. Finally, strategies and resources for designing, implementing, and maintaining quality standards in CBPPC programs are reviewed.

Kelly, ML (2015) AB014. The evolution of the Kelley community capacity development model for palliative care. *Annals of Palliative Care, 7*(1) [link]
Describes the conceptual evolution of the Kelley model for Community Capacity Development [2000–2016]. Illustrates how and why the model changed to become a powerful Canadian example of a public health approach to developing community based palliative care programs.

Continuous monitoring and management of a person’s symptoms and performance status are critical for the delivery of effective palliative care. This monitoring occurs routinely in inpatient settings; however, such close evaluation in the community has remained elusive. Patient self-reporting using telehealth offers opportunities to identify symptom escalation and functional decline in real time, and facilitate timely proactive management. We report the case of a 57- year-old man with advanced non-small cell lung cancer who participated in a telehealth trial run by a community palliative care service.

A multidisciplinary European Association of Palliative Care Taskforce was established to scope the extent of and learn what facilitates and hinders the development of palliative care in the community across Europe. This paper aims to document the barriers and facilitators for palliative care in the community and to produce a resource toolkit that palliative care specialists, primary care health professionals or policymakers, service developers, educationalists and national groups more generally could use to facilitate the development of palliative care in their own country. Many barriers and facilitators were identified. The primary palliative care toolkit can help community-based palliative care services to be established nationally.


**Objective:**
To describe patterns in the use of hospital emergency departments in the last year of life by people who died with dementia and whether this was modified by use of community-based palliative care.

**Design:**
Retrospective population-based cohort study of people in their last year of life. Time-to-event analyses were performed using cumulative hazard functions and flexible parametric proportional hazards regression models.

**Setting/participants:**
All people living in Western Australia who died with dementia in the 2-year period 1 January 2009 to 31 December 2010 (dementia cohort; N = 5261). A comparative cohort of decedents without dementia who died from other conditions amenable to palliative care (N = 2685).

**Results:**
More than 70% of both the dementia and comparative cohorts attended hospital emergency departments in the last year of life. Only 6% of the dementia cohort used community-based palliative care compared to 26% of the comparative cohort. Decedents with dementia who were not receiving community-based palliative care attended hospital emergency departments more frequently than people receiving community-based palliative care. The magnitude of the increased rate of emergency department visits varied over the last year of life from 1.4 (95% confidence interval: 1.1–1.9) times more often in the first 3 months of follow-up to 6.7 (95% confidence interval: 4.7–9.6) times more frequently in the weeks immediately preceding death.

**Conclusions:**
Community-based palliative care of people who die with or of dementia is relatively infrequent but associated with significant reductions in hospital emergency department use in the last year of life.


Objective: To determine the pooled effect of exposure to one of 11 specialist palliative care teams providing services in patients’ homes.
Design: Pooled analysis of a retrospective cohort study. Setting: Ontario, Canada. Participants: 3109 patients who received care from specialist palliative care teams in 2009-11 (exposed) matched by propensity score to 3109 patients who received usual care (unexposed).

Intervention: The palliative care teams studied served different geographies and varied in team composition and size but had the same core team members and role: a core group of palliative care physicians, nurses, and family physicians who provide integrated palliative care to patients in their homes. The teams’ role was to manage symptoms, provide care and education, coordinate services, and be available without interruption at all times.

Main outcome measures: Patients (a) being in hospital in the last two weeks of life; (b) having an emergency department visit in the last two weeks of life; or (c) dying in hospital.

Results: In both exposed and unexposed groups, about 80% had cancer and 78% received end of life homecare services for the same average duration. Across all palliative care teams, 970 (31.2%) of the exposed group were in hospital and 896 (28.9%) had an emergency department visit in the last two weeks of life respectively, compared with 1219 (39.3%) and 1070 (34.5%) of the unexposed group (P<0.001). The pooled relative risks of being in hospital and having an emergency department visit in late life comparing exposed versus unexposed were 0.68 (95% confidence interval 0.61 to 0.76) and 0.77 (0.69 to 0.86) respectively. Fewer exposed than unexposed patients died in hospital (503 (16.2%) v 887 (28.6%), P<0.001), and the pooled relative risk of dying in hospital was 0.46 (0.40 to 0.52).

Conclusions: Community based specialist palliative care teams, despite variation in team composition and geographies, were effective at reducing acute care use and hospital deaths at the end of life.


In January 2017, the National Coalition for Hospice and Palliative Care received funding from the Gordon and Betty Moore Foundation to develop and disseminate national practice guidelines that formalize and delineate provision of quality community-based palliative care delivery for adults, children, and families living with serious and/or chronic progressive illness to safely and reliably meet their supportive care needs where they live.


With the growing public demand for access to critical health data across care settings, it is essential that advance care planning (ACP) information be included in the electronic health record (EHR) so that multiple clinicians can access it and understand individuals’ preferences for end-of-life care. Community-based palliative care programs often incorporate ACP services. This study examined whether a community-based palliative care program is associated with digitally extractable ACP documentation in the EHR.

Palliative care for slum populations: A case from Bangladesh: [link]
Further References

Public Health Palliative Care International website  http://www.phpci.info/

The New Health Foundation: Compassionate Cities.
The NewHealth Foundation, a Spanish non-for-profit organisation, is leading the project Compassionate Cities. "We are all one”. The project aims to involve citizens in creating communities of care to help people at the end of life phase.[link]

Impact of a home-based social welfare program on care for palliative patients in the Basque Country (SAIATU Program)
SAIATU is a program of specially trained in-home social assistance and companionship which, since February 2011, has provided support to end-of-life patients, enabling the delivery of better clinical care by healthcare professionals in Osakidetza (Basque Health Service), in Guipúzcoa (Autonomous Community of the Basque Country).[link]

End of Life at Home: Co-creating an Ecology of Care.
This report documents Stages 2–4 of the Caring at End of Life Study, which identified the end-of-life care arrangements that allowed 20% of terminally ill people to be cared for at home. We wanted to know how ordinary people supported each other to care for someone dying at home, how their wider community supported the carer, what formal support was available to carers and how those formal and informal networks interacted with each other.[link]

Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities
The main aims of the research were to illuminate the quality and effect of informal caring networks that are established, or strengthened, as a result of caring for a person dying at home and to understand how being involved in such a caring network impacts family, friends and the wider community.  [link]

Equity in the Provision of Palliative Care in the UK: Review of Evidence
A team from the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE) was commissioned by Marie Curie to explore the evidence on equity in palliative care and to consider the economic implications of extending palliative care to those currently under-served. This report presents the findings from a wide-ranging and comprehensive review of research literature and nationally available data, and new multivariate analyses of data from the National Survey of Bereaved People in England, 2013.[link]

Midhurst Macmillan Community Specialist Palliative Care Service Delivering end-of-life care in the community
This case study is part of a research project undertaken by The King’s Fund and funded by Aetna and the Aetna Foundation in the USA to compare five successful UK-based models of care co-ordination (see Appendix 1 for methods used to collect the study data). The aim of
each case study has been to understand the strategies used to deliver care co-ordination effectively; examine barriers and facilitators to successful care co-ordination; isolate key markers for success for the practical application of the tools and techniques of care co-ordination; and to identify lessons in how care co-ordination can best be supported in terms of planning, organisation and leadership. [link]

Public Health Palliative Care International: Creating Compassionate Communities
A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life. All members of this association hold this principle to be true and commit their respective organizations to this value and vision of end of life care [link]

All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America
New Health Foundation, Sevilla, Spain; 2Palliative Care Team, Hospital Virgen Macarena, Sevilla, Spain; 3Spanish Society of Palliative Care SECPAL, Spain; 4Hospital Arnau de Vilanova, Lérida, Spain Contributions: (I) Conception and design: S Librada Flores; (II) Administrative support: M Nabal Vicuña; (III) Provision of study materials or patients: S Librada Flores; (IV) Collection and assembly of data: S Librada Flores; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors. Correspondence to: Silvia Librada Flores, MSc. New Health Foundation, Sevilla, Spain. Email: silvia.librada@newhealthfoundation.org.

The impact of a new public health approach to end-of-life care: A systematic review: Libby Sallnow, Heather Richardson, Scott Murray, Allan Kellehear:
Communities play an increasingly significant role in their own health and social care, and evidence demonstrates the positive impact of this work on a range of health outcomes. Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities [link].

Palliative care reimagined: a needed shift: Julian Abel, Allan Kellehear
Palliative care, since its inception over 60 years ago, has set the standard of how to care for people who are dying. Key features among these standards have been the professional development of clinical specialisms such as palliative medicine and palliative nursing; the essential addition of the multidisciplinary team to these two new specialisms that included social, spiritual and allied health workers—an outgrowth of the recognition that routine work with the dying, their carers, and the bereaved required more than solely clinical skills; and the unique partnership with communities that yielded the volunteer movement within palliative care. Professional, evidence-based symptom management and the importance of supportive care in its widest possible sense were and remain the cornerstones of the modern palliative care approach. However, the majority of people with terminal illnesses do not have access to palliative care teams, whose main focus of care remains patients with cancer. In the context outlined above this paper therefore poses two key questions: how can we provide an equitable level of care for all people irrespective of diagnosis and how can we increase the range and quality of non-medical/nursing supportive care in a context of diminishing resources? We argue that an important opportunity and solution can be found by adopting the principles of a public health approach to end-of-life care [link].
Palliative care—the new essentials: Julian Abel, Allan Kellehear, Aliki Karapliagou.
If global palliative care is to successfully address challenges of unequal access, continuity of care, and health services reductionism, new practice models to address these issues need to be identified, debated and tested. This paper offers one such practice model based on a public health approach to palliative care that has so far shown promising evidence of effectiveness [link].

Fighting talk’ can leave people living with cancer unable to talk about death and dying.
Reluctance to talk honestly about death is preventing people with cancer from dying ‘well’, leading charity warns [link].


