About the information

The information provided in this document is intended to support the Integrated Care Matters webinar series.

Where possible, we select evidence that is published open access, and provided links to the materials referenced. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

If you found this resource useful and would like to use the free Evidence Search and Summary Service (ESSS) to help you find and use evidence please get in touch to discuss your needs: esss@iriss.org.uk

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Development of compassionate communities is part of the broader initiative of the public health approach to palliative and end of life care. Hospital teams can participate in this approach, making best use of the enormous resource of community support, which is in keeping with principles of good care and efficient patient flow.

Abel, J (2018) *Palliative care - the new essentials* Vol 7, Supplement 2 (April 2018): Annals of Palliative Medicine (Public Health Approaches to Palliative Care) (open access)

Describes 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.

Aoun, SM (2020) *The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia* Palliative Care and Social Practice. January 2020 (open access)

This feasibility project aims to develop, implement and evaluate a model of community volunteers, identified as Compassionate Communities Connectors, to support people living with advanced life limiting illnesses / palliative care needs.

British Geriatrics Society (2020) *End of Life Care in Frailty: Community settings* (open access)

Looks at how good end of life care in frail older people can be achieved in the community.

Care Quality Commission (2017) *The state of hospice services in England 2014 to 2017* (open access)

Findings from CQC’s initial programme of comprehensive inspections of hospice services.

CEBM (2020) *The role and response of primary care and community nursing in the delivery of palliative care in epidemics and pandemics: a rapid review to inform practice and service delivery during the COVID-19 pandemic* (open access)

This review looks at the role and response of primary care and community nursing services in the delivery of palliative care in epidemics and pandemics.


The role of community nurses in end of life care.
Galiana, J (2019) **Home-Based Palliative Care and Aging in Place and Community** In: Aging Well. Palgrave Macmillan, Singapore (open access)

Makes the case for home-based palliative care and aging in place and community as alternatives to assisted living and hospitalized end-of-life care.

Grindrod, A (2018) **Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia** Vol 7, Supplement 2 (April 2018): Annals of Palliative Medicine (Public Health Approaches to Palliative Care) (open access)

Outlines a comprehensive community development project that identifies local end of life needs and meets them through the efficient use of community resources.

Hilbers, J (2018) “**We are all in this together**: Building capacity for a community-centred approach to caring, dying and grieving in Australia” European Journal for Person Centered Healthcare. 6. 685 (open access)

Explores in-home caring networks to understand if and how network centred care supports carers of the dying while developing a whole of community approach.

Hoare, S (2019) **Home care and end-of-life hospital admissions: a retrospective interview study in English primary and secondary care** British Journal of General Practice 2019; 69 (685): e561-e569 (open access)

Aims to understand problems in professional and lay care provision that discourage death at home and lead to hospital admissions at the end of life.

Hospice UK (2018) **Hospice Care in Scotland 2018** (open access)

This briefing presents an overview of the care and support provided by charitable hospice services in Scotland in 2017-18.

Hospice UK (2018) **Providing comprehensive, person-centred assessment and support for family carers towards the end of life** (open access)

A summary report of a project examining organisational structures and procedures needed to identify, assess and support carers during end of life care.
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.

IPPR (2018) End Of Life Care In England (open access)

This briefing paper lays some of the foundations for a programme of work to better understand trajectories of patients at the end of life and assess variation in health care use, costs and care quality.


This study provides insights to the value of Hospice at Home care where Hospice Nurses are helping to bring Hospice care into the home, helping to support older people who are dying and their caregivers, to live as well as possible and facilitate their wish to be cared for and die in their own home.

Knights, D (2020) Upside down solutions: palliative care and COVID-19 BMJ Supportive & Palliative Care Published Online First: 17 July 2020 (open access)

This article explores how palliative care principles and practices can be woven into everyday healthcare practice, explores alternative ways of providing care, and discusses three areas of learning from resource-limited settings: (1) integration of palliative medicine into everyday practice, (2) simplification of biomedical management plus multidisciplinary teamwork and (3) effective use of volunteers.

Marie Curie (2016) Dying to care: A report into social care at the end of life (open access)

This report looks at the role social care services play in supporting people with palliative care needs or at the end of life in Scotland. It explains how social care can help people to remain at home, get out of hospital, stay connected to their communities and live as well as possible before they die.
Murray, SA (2015) Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care Palliative Medicine. 2015;29(2):101-111 (open access)

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 could use to facilitate the development of palliative care.

NHS Health Scotland (2018) Coordination of palliative care in community settings: Summary report (open access)

Rapid evidence review of the components of palliative care models.


Project piloting a capacity-building model in which volunteers and a nurse partnered to provide navigation support beginning in the early palliative phase for adults living in community. The goal was to improve quality of life by developing independence, engagement, and community connections.

Public Health England (2016) Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: A Qualitative Research Report (open access)

This report is for commissioners of end of life care services, to support new ways of commissioning through using public health approaches to build compassionate communities.


A 2017 national survey aiming to describe and compare the features of HAH services and understand key enablers to service provision.

Gabrielle, R (2020) Palliative Care: Changing Paradigms to Face New Challenges Medical Research Archives, [S.l.], v. 8, n. 5, may 2020 (open access)

Looks at the Compassionate Community model as a viable alternative to the current approach to palliative care.
Sallnow, L (2015) *The impact of a new public health approach to end-of-life care: A systematic review* *Palliative medicine.* 30 (open access)

Reviews the evidence relating to the impact of a new public health approach to end-of-life care, specifically as this applies to efforts to strengthen community action.


The aim of this study was to appraise available research on the impact of inpatient palliative care consultations on transitions from hospital to community settings.

Scottish Government (2018) *Strategic Commissioning of Palliative and End of Life Care by Integration Authorities* (open access)

An advice note to support the strategic commissioning of Palliative and End of Life Care by Integration Authorities.

Stein, D (2017) *Delivering Palliative Care in a Community Hospital: Experiences and Lessons Learned from the Front Lines* *JCOM Vol. 24, No. 10 October 2017* (open access)

This paper aims to describe an approach to develop a community-centric palliative care program in a rural community health system and to review data collected over the program’s first year.


This study aimed to examine the effectiveness of a holistic capacity-building program for volunteers in community-based EoLC.

Western Sydney University (2015) *End of Life at home: Co-creating an ecology of care* (open access)

This report documents 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.
Whitfield, KY (2016) *Community Capacity in End of Life Care: Can a Community Development Model Address Suffering and Enhance Well-Being?* *Handbook of Community Well-Being Research* pp 275-289 (paywall)

Focuses on community development principles and actions that are necessary to address suffering and enhance well-being in hospice palliative care.

Whitfield, KY (2018) *A case study exploring the implications of one Alberta rural community’s experience with planning their own hospice care* *The Journal of Rural and Community Development, 13*(1), 1–12 (open access)

There are major implications for rural health care when citizens are organizing themselves to plan and address their own community health care needs. This article describes how one community in rural Alberta, Canada, worked to plan for their rapidly increasing hospice care needs.