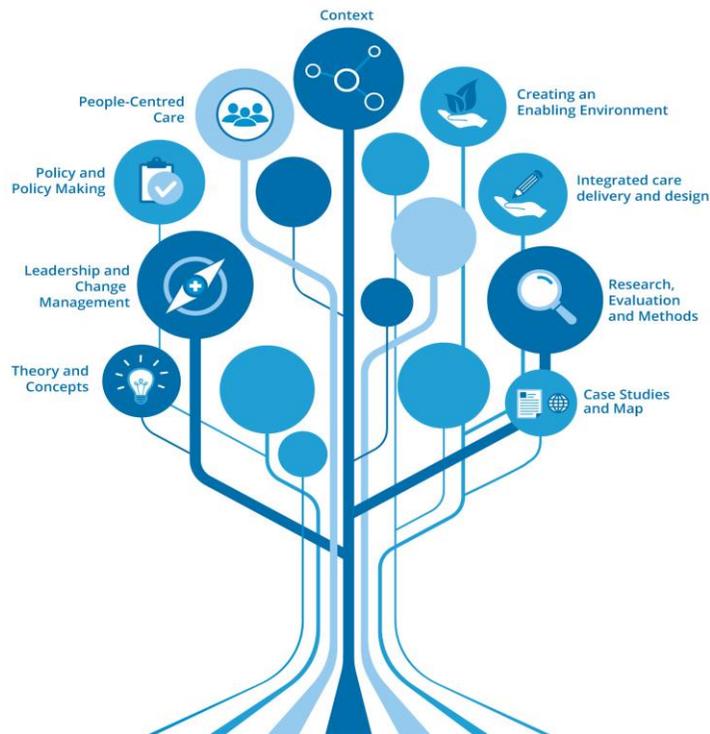# Integrated Care Matters

Compassionate Communities

Knowledge Resource

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

Developed in partnership

Compassionate Communities

Abel, J. (2018) [Compassionate communities and end of life care](#). **Clinical Medicine Feb 2018, 18 (1) 6-8 (open access)**

Development of compassionate communities is part of the broader initiative of the public health approach to palliative and end of life care. Ambition 6 of the national guidance document for end of life care - communities are prepared to help - can be used by hospital teams to make best use of community support.

Aoun, SM. et al. (2018). [What sources of bereavement support are perceived helpful by bereaved people and why? Empirical evidence for the compassionate communities approach](#). **Palliat Med. 2018 Sep; 32(8): 1378–1388 (open access)**

A study to determine who provides bereavement support in the community, what are the most or least helpful, and to identify elements for support in developing future compassionate communities approaches.

[Compassionate Communities Hub](#) **(website)**

Compassionate Communities is a global movement for whole community engagement, a way to shift the dialogue and encourage communities to reconsider how care is provided to people who are dying. Includes [resources and toolkits](#).

Good Life God Death Good Grief. [The Scottish Compassionate Communities Toolkit](#) **(website)**

Collection of resources for people wishing to make their local community more supportive of people going through difficult times that come with death and dying.

Hasson, N. et al. (2018). [Building a narrative for compassionate communities: the case of Getxo Zurekin](#). **International Journal of Integrated Care. 2018;18(s2):321 (open access)**

Poster abstract: This study aims to identify the needs of those in need of palliative care and get relevant insight into the perceptions and improvement opportunities; identify an underlying narrative of change, aligned with the sociocultural characteristics of the community; make communities become more involved in palliative and end of life care.

Health and Social Care Alliance Scotland (2013) [In Good Faith: Building Compassionate Communities](#) **(pdf)**

Identifies key messages and good practice from projects that can be shared and adapted to local needs and interests, to encourage models that will further tap into resilience and build community capacity.

Kellehear, A (2013) [Compassionate communities: end-of-life care as everyone's responsibility](). **QJM: An International Journal of Medicine, Volume 106, Issue 12, December 2013, Pages 1071–1075 (open access)**

Examines compassionate communities policy and practice development in British end-of-life care, explaining its conceptual origins and describing its policy importance to current practice.

Librada Flores, S. (2018). [All with You: a new method for developing compassionate communities - experiences in Spain and Latin-America](). **Ann Palliat Med. 2018 Apr;7(Suppl 2):S15-S31 (open access)**

A systematic approach that enables anyone interested in building compassionate communities or cities to include all of the elements outlined in the Compassionate City Charter.

McLoughlin, K. (2013). [Compassionate Communities Project Evaluation Report]() **(pdf)**

Looks at The Milford Care Centre's Compassionate Communities pilot to demonstrate and evaluate the process of developing a compassionate community model in an Irish context.

Mills, J. & Rosenberg, JP (2019). [Compassionate communities](). **International Journal of Palliative Nursing 2019, Vol 25, No 3 (paywall)**

Editorial asking where nurses fit into the compassionate communities approach, and what contributions can be made through palliative nursing.

Mogan, C. et al. (2018). [The facilitators and challenges of dying at home with dementia: A narrative synthesis](). **Palliative Medicine 2018, Vol. 32(6) 1042 –1054 (open access)**

Research to identify and understand the provision of end-of-life care at home for people with dementia, including how community development approaches to palliative care such as compassionate communities, can support families.

Murray Hall Community Trust / National Council for Palliative Care Dying Matters Coalition (2013). [An Overview of Compassionate Communities in England]() **(pdf)**

Scoping exercise, helping to give an overview of the development of Compassionate Communities in England.

NOUS (2018) [Compassionate communities: An implementation guide for community approaches to end of life care](#) (pdf)

An information resource on how to initiate, grow and sustain compassionate communities approaches.

Pereira, SM. et al. (2018). [Towards a public health approach for palliative care: an action-research study focused on engaging a local community and educating teenagers](#). BMC Palliative Care (2018) 17:89 (open access)

An education program about palliative care among teenagers and study of the impact on participants. One conclusion was that compassionate communities should be promoted to enhance the health and wellbeing of all citizens at the end of their life.

Pesut, B. (2017). [Volunteer navigation partnerships: Piloting a compassionate community approach to early palliative care](#). BMC Palliat Care 17, 2 (2018) (open access)

Pilot of a capacity-building model in which volunteers and a nurse partnered to provide navigation support in the early palliative phase for adults living in community.

Public Health England (2016). [Public Perceptions and Experiences of Community-Based End of Life Care Initiatives: A Qualitative Research Report](#) (pdf)

Report aimed at commissioners of end of life care services, to support new ways of commissioning through using public health approaches to build compassionate communities.

Russell, C. (2017). [Compassionate Communities and Their Role in End-of-Life Care](#). UOJM Epub Jan 23, 2017 (pdf)

Commentary: Given the need for support throughout all aspects of end-of-life care, an emerging paradigm shift shows Compassionate Communities as a new standard for placing responsibility back in the community and promoting respectful and compassionate care.

Scottish Partnership for Palliative Care (2018). [A Road Less Lonely: Moving Forward with Public Health Approaches to Death, Dying and Bereavement in Scotland](#) (pdf)

Explores what action might be taken at a national level to encourage and support open and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland. Includes a chapter on encouraging Compassionate Communities in Scotland.

Tasmanian Government (2017). [Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017–21](#) **(pdf)**

Compassionate Communities is an initiative of the Better Access to Palliative Care Program, which has been working within the Department of Health and Human Services to improve access to community-based palliative care for people in Tasmania.

Tompkins, B. (2018). [Compassionate Communities in Canada: it is everyone's responsibility](#). **Vol 7, Supplement 2 (April 2018): Annals of Palliative Medicine (open access)**

Presents historical development of the public health approach to end-of-life care in Canada. Draws from examples of regional, provincial, and national initiatives to discuss future directions for community engagement as a public health approach to palliative care.

Case Studies

Abel, J. et al. (2018). [Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities](#). **British Journal of General Practice 2018; 68 (676): e803-e810 (open access)**

Report on the impact of a complex intervention over a 44-month period in Frome, Somerset on unplanned admissions to hospital.

Compassionate Inverclyde (2018). [Compassionate Inverclyde: Evaluation Summary Report](#) **(pdf)**

An overview of Compassionate Inverclyde, how it evolved, and differences and similarities to other compassionate communities. It presents key messages about enablers and barriers, and offers advice to those considering how they may take this approach forward in their own area.

Compassionate Inverclyde (2018). [Compassionate Inverclyde Evaluation Report: A Deeper Dive](#) **(pdf)**

Insights on various aspects of Compassionate Inverclyde - the outcomes achieved, the policy fit, leadership considerations and the approach to community engagement.

Compassionate Inverclyde (2018). [Compassionate Inverclyde Voices: The Narrative from a local perspective](#) (pdf)

Learning from the evaluation of Compassionate Inverclyde from a local perspective. It describes the approach taken, reasons for presenting learning in narrative form and tells the story of Compassionate Inverclyde as a living entity.

Connecting Communities. [Highland Compassionate Communities](#) (website)

Highland Compassionate Communities used their Helmsdale Circle of Support to roll out a socially inclusive model to 4 other rural communities across the Highlands with the ultimate aim of taking the learning across Scotland.

Ferguson, Z. (2017). [The Place of Kindness: Combating loneliness and building stronger communities](#). Carnegie Trust & Joseph Rowntree Foundation (pdf)

Project working with seven different organisations to test what could be done to encourage kinder communities, to explore new ideas around the importance of places and opportunities to connect, and the intrinsic values underpinning our interactions and relationships.

Gómez-Batiste, X. et al. (2018). [Compassionate communities: design and preliminary results of the experience of Vic (Barcelona, Spain) caring city](#). Ann Palliat Med 2018;7(Suppl 2):S32-S41 (open access)

Describes the principles, aims, initial phases, activities, and preliminary results of the Vic caring city project in the context of the Compassionate / Caring Community program.

The Health and Social Care Alliance Scotland. [Compassionate Inverclyde: The creation of a Compassionate Community and Place of Kindness](#) (website)

Two-part case study covering the background of the programme, its implementation, how it is nurturing transformational change, the key factors of its success, and the main challenges it faces.

High, S. et al. (2018). [Living Right Up To The End: Strathcarron Hospice Final Report](#) (pdf)

The Strathcarron Hospice Community Development Team worked with people living with long term conditions and their carers to find what would help them live well through the challenges of declining health, and to develop community solutions.

Shift (2019). [Case Study: The Frome Model of Enhanced Primary Care](#) (website)

The Frome Model of Enhanced Primary Care - aka Compassionate Frome – is a project leveraging existing social networks to improve health outcomes.

Wegleitner, K. et al (2015). [Compassionate Communities Case Studies from Britain and Europe](#) (book)

Describes and examines compassionate community experiments in end of life care from a practical perspective. Focusing on community development initiatives and practice challenges, the book offers practitioners and policy makers practical discussions on the strengths and limitations of such initiatives.

Palliative Care & Community

Abel, J. & Kellehear, A (2015). [Palliative care reimagined: a needed shift](#). BMJ Supportive & Palliative Care 2016;6:21-26 (open access)

Asks how we can 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.

Abel, J. et al. (2018). [Palliative care - the new essentials](#). Ann Palliat Med. 2018 Apr;7(Suppl 2):S3-S14 (open access)

Offers a practice model based on a public health approach to palliative care that has so far shown promising evidence of effectiveness.

Mills, J. et al. (2015). [Building community capacity for end of life: an investigation of community capacity and its implications for health-promoting palliative care in the Australian Capital Territory](#). Critical Public Health, 25:2, 218-230

Identifies and examines community-based activities around death, dying and end-of-life care which might reflect a health-promoting palliative care philosophy.

The National Council for Palliative Care (2016) [Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six](#) (pdf)

Provides a theoretical framework and practical examples of how different health and social care organisations can use community development as a routine part of their provision of end of life care.

Sallnow, L. et al (2016). [The impact of a new public health approach to end-of-life care: A systematic review](#)**. Palliat Med. 2016 Mar;30(3):200-11 (open access)**

A review of the evidence relating to the impact of a new public health approach to end-of-life care, specifically around efforts to strengthen community action.

Care Networks

Horsfall, D. (2018). [Developing compassionate communities in Australia through collective caregiving: a qualitative study exploring network-centred care and the role of the end of life sector](#)**. Vol 7, Supplement 2 (April 2018): Annals of Palliative Medicine (Public Health Approaches to Palliative Care) (open access)**

Explores how network centred care supports carers of the dying while developing a whole of community approach.

Leonard, R. et al. (2018) [Carer experience of end-of-life service provision: a social network analysis](#)**. BMJ Supportive & Palliative Care Published Online First: 10 February 2018 (open access)**

Examines the nature and strength of relationships of informal caring networks with service providers.

Rosenberg, JP. et al. (2017). [Informal care networks' views of palliative care services: Help or hindrance?](#) **Death Studies (open access)**

Examines the ways health systems, services, and individual health care professionals influence care at home at the end of life.

Further Reading

Billig, G. et al. (2019). [Last Aid Course. An Education for All Citizens and an Ingredient of Compassionate Communities](#)**. Healthcare 2019, 7(1), 19 (open access)**

Last Aid courses have an enormous potential to spread information and discussion about palliative and end of life care throughout the public. A combination of the Last Aid and the compassionate community approach has the potential to improve palliative care at home for many people.

Public Health England (2015). [A guide to community-centred approaches for health and wellbeing](#) **(pdf)**

A guide for commissioning and practice that can be used to support delivery on the NHS Five Year Forward View and PHE's seven priorities for prevention.

Breen, LJ. et al. (2017). Building Community Capacity in Bereavement Support: Lessons Learnt from Bereaved Caregivers. American Journal of Hospice and Palliative Medicine®, 34(3), 275–281 (paywall)

This study aimed to inform bereavement support using the advice people bereaved through expected deaths in palliative care have for others in that situation.

Hospice Isle of Man (2018). Much More Than A Building (pdf)

2018-2023 Strategy for Hospice Isle of Man.

Hospice Isle of Man (2018). From Vision to Reality (pdf)

Island Plan for Integrated Palliative and End of Life Care 2018-2023

Isle of Man Government (2016). Delivering Longer Healthier Lives (pdf)

5 year vision for Health and Social Care in the Isle of Man.

NHS England (2015). A guide to community-centred approaches for health and wellbeing (pdf)

This guide outlines approaches for evidence-based community-centred approaches to health and wellbeing.

Realising the Value (2016). At the heart of health: Realising the value of people and communities (pdf)

Explores the value of people and communities at the heart of health, in support of the NHS Five Year Forward View vision.

Scottish Government (2018). A Connected Scotland: our strategy for tackling social isolation and loneliness and building stronger social connections (pdf)

The Scottish Government's first national strategy to tackle social isolation and loneliness and build stronger social connections.