



Mapping Public Engagement on Palliative Care, Death, Dying, Loss and Care

July 2018

Background and Introduction

A range of public engagement activities regarding dying, death and bereavement, and raising awareness of palliative care have been taking place across Ireland for a number of years.

All Ireland Institute of Hospice and Palliative Care (AIHPC) and the Irish Hospice Foundation (IHF) have been key agents in this work. Over the past decade, the IHF has been involved in initiatives associated with public health/health promoting/public engagement on dying, death and bereavement. AIHPC has led Palliative Care Week across the island of Ireland since 2014 – the Institute’s annual awareness-raising campaign, which is supported by all of the Institute’s partners, including the IHF, and other palliative care stakeholders.

With a view to continuing involvement in, and development of, public engagement and a public health approach to palliative care, the IHF provided funding to AIHPC to assist mapping out activities relating to initiatives in Ireland and internationally. This Mapping Public Engagement on Palliative Care, Death, Dying, Loss and Care document is the result of this work.

The mapping exercise was carried out in the spring/summer of 2018 and it gives an overview of public engagement activities on the island of Ireland, Scotland, England and Wales, Australia, Canada, New Zealand, and internationally. The document includes web links to a variety of organisations, initiatives and resources.

By its nature this overview is on activities at country, national and regional levels. For these activities to be successful there is a requirement for communities to be involved, a view shared by AIHPC and IHF.

It is suggested that this mapping document is complemented by a briefing paper on [‘Public Health Approaches to Palliative Care’](#) produced by AIHPC in November 2017. A high level introduction to the concept of public health approaches to palliative care, examples of a range of initiatives, including at community level, and links to resources are included in Appendix A in the Public Health Approaches to Palliative Care briefing paper.

It is hoped that this mapping document will be a helpful contribution to increasing understanding, to stimulating ideas, and to supporting the development of public engagement and public health, so that people are supported when they are living with illness; death and dying is not hidden away; and grief is addressed and not avoided. It is acknowledged that this is a developing field and the information provided in this document will be reviewed and added to.

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Document for Review December 2019

Initiative	Location (geographic)	Lead organisation	Key people	Key information
Forum on End of Life Council and Forum conference	Ireland (Republic)	Irish Hospice Foundation	Sharon Foley, chief executive officer Angela Edghill, advocacy manager	<p>In 2009, the Irish Hospice Foundation launched the Forum on End-of-Life in Ireland. The initiative was launched by President Mary McAleese. This started with a year-long listening exercise aimed at gathering people’s views and opening dialogue on a very broad range of issues, through public meetings, workshops, presentations and invitations for submissions.</p> <p>The work and vision of the Forum was then carried on by the National Council of the Forum on End of Life, established in July 2010 and chaired by Mrs Justice Catherine McGuinness. Membership of the National Council reflected a wide range of stakeholders and diversity in relation to end-of-life issues. The Council of the Forum on End of Life was stood down in 2016 and will be reviewed again in 2019. See also Forum on End-of-life – About</p> <p>Alongside the activities of the Council of the Forum on End of Life, the Irish Hospice Foundation co-ordinates and funds a biennial Forum on End of Life conference in Dublin Castle. The IHF has committed to running this event in the future and the next Forum conference will be in October 2019.</p> <p>Twitter: @Irish Hospice</p>
Think Ahead	Ireland (Republic)	Irish Hospice Foundation	Sharon Foley, chief executive officer	<p>Think Ahead – Planning for death and dying</p> <p>Think Ahead is the flagship project of the Forum on End of Life in Ireland</p> <p>It comprises of a form to guide planning for end of life. The form aims to assist and guide a person’s thoughts on planning for their end of life and protect those close to them from the additional stress from having to guess what they would have wanted in the case of death or a lack of capacity.</p> <p>The purpose of Think Ahead is to help members of the public talk about and record their preferences in the event of emergency, serious illness or death.</p> <p>Input from all groups helped to produce the final version of the Think Ahead form which enables a</p>

				<p>person to record their preferences for emergency or end-of-life care, funeral services, key information about legal and financial affairs, and more. A number of prompts and background explanations are also provided for advice on making a will, power of attorney, rights of succession (Succession Act) and financial affairs.</p> <p>A wide range of information and prompts for planning for end of life including Advance Care Planning and Advance Healthcare Directives is provided alongside Think Ahead.</p> <p>See also this link to Think Ahead</p> <p>Twitter: @Irish Hospice</p>
<p>Living with Loss</p> <p>November annually</p>	<p>Ireland (Republic)</p>	<p>Irish Hospice Foundation</p>	<p>Orla Keegan, head of education and bereavement</p>	<p>An annual evening for the general public, people who are bereaved or those who are working with bereaved people, hosted in Dublin by the Irish Hospice Foundation.</p> <p>The format includes a guest speaker, information on an aspect of bereavement/bereavement care delivered by IHF staff and an opportunity to meet organisations (voluntary and statutory) who are involved in delivering support and information to the bereaved who are invited by the IHF to take an information stand at the event.</p>
<p>Limerick Compassionate Communities Project</p>	<p>Limerick (Ireland)</p>	<p>Milford Care Centre</p>	<p>Pat Quinlan, chief executive</p>	<p>The first phase of the project (2010-11) took place in North West Limerick with communities, exploring the complexities of living with death, dying, loss and care. Central to the development of the project since 2010 was the development of Bill, first through Bill United and now more strategically through the inspirational series of 'Let's Talk' films.</p> <p>In 2012, following an extension of project funding, the Compassionate Communities Project expanded to cover the whole of Limerick City and Newcastle West.</p> <p>The project based on health promoting palliative care and community development principles had three strands:</p> <p>Strand One: A Whole Population Approach</p> <p>Compassionate Communities website revised and updated.</p> <p>Agree and develop a Triple Call to Action: Think Ahead (personal and family) ... Talk Together</p>

				<p>(family, friends, neighbours and colleagues) ... Lend A Hand (wider community). Communication/Marketing/PR strategy developed and implemented; partnership work with others on joint initiatives e.g. Think Ahead, targeted awareness raising initiatives e.g. beer-mat campaign.</p> <p>Strand Two: Community Engagement Community organisations and statutory and voluntary groups within the pilot area identified and engaged with re: Project purpose and aims, and elicited as community partners. Café conversations on issues related to death, loss and care organised in conjunction with community partners. A matched seed grant scheme provided to communities within the pilot area to engage in projects related to death, dying, loss and care. A community education project around death, dying, loss and care developed and delivered.</p> <p>Strand Three: Community Mentors/Social Model of Care A model of the Community Mentor Project as part of a Social Model of Care agreed. Voluntary Community Mentors recruited and trained in two areas.</p> <p>The project ceased in 2017. An evaluation report on the project is available.</p>
Compassionate Communities 'Reach Out' project	Northern Ireland (Derry/Londonderry)	Foyle Hospice Leading the project which is supported by statutory and voluntary organisations in the locality	Donall Henderson, chief executive officer	<p>The Compassionate Communities 'Reach Out' project provides social support to frail and vulnerable people through a befriending service. Trained volunteer befrienders provide weekly contact with people who have palliative care needs and who have become isolated at home as a result of illness, bereavement or other circumstance.</p> <p>Social contact offered with a trusted companion.</p> <p>A leaflet for people wishing to avail of the service provides more information.</p>
Palliative Care Week 9-15 September 2018	Ireland (Republic & Northern Ireland)	All Ireland Institute of Hospice and Palliative Care	Karen Charnley, director	<p>A dedicated annual campaign to raise public awareness and understanding of palliative care</p> <p>The theme for the 2018 campaign is: Palliative Care, Because Every Moment Matters</p>

				<p>Palliative Care Week was initiated in 2014 by All Ireland Institute of Hospice and Palliative Care with the following themes:</p> <p>Palliative Care, Making the most of life (2014) Palliative Care, Quality Care – where it’s needed, when it’s needed (2015) Palliative Care, Enabling Living (2016) Palliative Care, What have you heard? (2017) Palliative Care, Because Every Moment Matters (2018)</p> <p>Key messaging</p> <p>Palliative care...</p> <ul style="list-style-type: none"> • Ensures that a person with a serious and progressive condition, regardless of age or condition, can have the best possible quality of life • Involves the person and those close to them • Supports planning for the future • May be appropriate for a number of years, not just the weeks and days at the end of life • Puts the person at the centre of care whether it is provided at home, in a nursing home, hospital or hospice. <p>The Palliative Care Week 2017 Report is available.</p> <p>A range of resources are provided to support the campaign, including leaflets and posters</p> <p>Videos and stories of Personal experiences featured prominently in the 2017 campaign</p> <p>Other promotional materials included a logo, screensavers, myth-busting video scribes Events are held across the island of Ireland during the week. There is extensive use of traditional, on-line and social media.</p> <p>Twitter: @aiihpc Hashtag: #pallcareweek</p>
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<p>Finite Lives A study in how the State deals with issues relating to end of life Part One</p>	<p>Ireland (Republic)</p>	<p>Invitation from An Taoiseach</p> <p>Part One - details of the internal procedures relating to dying, death and bereavement as they affect staff of Government Departments and Agencies.</p>	<p>Senator Marie Louise O'Donnell</p>	<p>This study's origins were a series of public hearings on palliative care, end-of-life care and bereavement care before the Oireachtas Joint Committee on Health and Children, from 24 October to 14 November 2013.</p> <p>PART 1: Finite Lives: A Report on how the Civil Service deals with dying, death and bereavement among its own members was published in 2015.</p> <p>The study from which the report arises was initiated by the Taoiseach. Senator O'Donnell aimed to establish how the civil service deals with in-service death, bereaved colleagues, serious illness and people facing loss and challenges in their lives. Senator O'Donnell's survey found that 75 civil servants died in service in two years covered by the study and almost 7,000 were bereaved in the same period. The report points to a need across Departments and Agencies to put in place a range of measures to better support bereaved staff including having a comprehensive bereavement policy including staff training, protocols for a return to work following a bereavement and provision of ongoing support to bereaved staff.</p>
<p>Finite Lives Dying Death and Bereavement An examination of State Services in Ireland Part Two</p>	<p>Ireland (Republic)</p>	<p>Invitation from An Taoiseach</p> <p>Part Two - examines end-of-life issues in policy and practice as they relate to each Department's role in their interaction with and services to the public</p>	<p>Senator Marie Louise O'Donnell</p>	<p>PART 2: Finite Lives: Published in 2017, this report is the second in a programme of Senator O'Donnell's research into end-of-life care in Ireland (Republic) and how the State supports people who are facing dying, death and bereavement. Government Departments, the Office of Public Works and the Office of the Revenue Commissioners were involved in this study. The Department of Health was not included.</p> <p>The report makes 16 key recommendations among which are:</p> <ul style="list-style-type: none"> 2. Conduct a national dialogue on end of life issues 4. Develop a dedicated website on end of life services offered by the State 6. Reduce the administrative burden by developing a 'call us once' service and a bereavement service helpline 11. Adopt Think Ahead planning tool and encourage people to plan ahead (<i>the Irish Hospice Foundation tool which helps people plan, discuss and record their wishes in the event of serious illness or death</i>) 15. Recognise and promote the role of the arts particularly at end of life

<p>The People's Charter on Dying, Death and Bereavement in Ireland</p>	<p>Ireland (Republic)</p>	<p>Irish Hospice Foundation</p>	<p>Sharon Foley, chief executive officer</p>	<p>In 2016 the Irish Hospice Foundation asked the people of Ireland (Republic) what is needed for a good death and for healthy grieving. The <i>haveyoursay</i> survey was launched in September 2016 and remained open for an active eleven weeks. In this time period, nearly 3,000 responses were received.</p> <p>An initial report on the data gathered to inform the development of the charter on dying, death and bereavement in Ireland has been produced.</p> <p>IHF has developed the People's Charter on Dying, Death and Bereavement in Ireland based on the views of those people who participated through <i>haveyoursay</i>. This Charter is now being communicated to NGOs and civic society groups working with people all across Ireland.</p>
<p>Bereaved Children's Awareness Week</p>	<p>Ireland (Republic)</p>	<p>Irish Childhood Bereavement Network (hosted at Irish Hospice Foundation and sponsored by Tusla Child and Family Agency)</p>	<p>Maura Keating, coordinator</p>	<p>The Irish Childhood Bereavement Network convenes an annual Bereaved Children's Awareness Week to coincide with UN Universal Children's Day which is held on 20 November. Building on the success of a Bereaved Children's Day in 2015 a week-long initiative has been held since 2016.</p> <p>Local and national events, talks and media engagement are convened throughout the week aiming to help people understand how grieving impacts children, and to ensure they are included, listened to and talked with.</p> <p>Twitter @ICBNirl</p>
<p>Good Life, Good Death, Good Grief</p> <p>As well as ongoing communication to members, two flagship activities:</p>	<p>Scotland</p>	<p>Scottish Partnership for Palliative Care</p>	<p>Mark Hazelwood, chief executive</p>	<p>Good Life, Good Death, Good Grief is an Alliance of organisations and individuals that want to work together to:</p> <ul style="list-style-type: none"> ▪ Raise public awareness of ways of dealing with death, dying and bereavement ▪ Promote community involvement in death, dying and bereavement <p>Context</p> <p>A stakeholder group provides overall strategy, planning, priorities and direction for the Alliance. It aims to engage with Alliance Members to explore approaches and support the development by Scottish Partnership for Palliative Care staff of more detailed plans to take forward recommendations 2-10 as outlined within the <i>Addressing palliative and end of life care from a</i></p>

<p>Good Death Week 14-20 May 2018</p> <p>Called Death Awareness Week in 2016 & 2017</p> <p>To Absent Friends 1-7 November each year</p>				<p><i>public health and health promotion perspective: facilitating wider discussion of death, dying and bereavement across society</i> report</p> <p>This report was the product of a short life working group set up under the Living and Dying Well (2008) Scottish Government’s action plan on palliative and end of life care. The working group’s remit was to develop recommendations regarding appropriate initiatives to:</p> <ul style="list-style-type: none"> • address current low levels of awareness of palliative and end of life care • address existing societal taboos around discussion of death and dying and • enable people (patients, families, professionals and the general public) to feel more comfortable in speaking about such issues.” <p>Activities – ‘bottom up and locally relevant’ Good Life, Good Death, Good Grief can act as a support, a sounding board, and a network of like-minded people, to help individuals and organisations undertake the change they think needs to happen. With the hope of providing inspiration and ideas for these members, they have produced resources and a list of activities that members can consider undertaking.</p> <p>Regular newsletter – emailed to members</p> <p>Good Death Week - 14-20 May 2018 - promoted the positives of living in a society where people can be open about dying, death and bereavement. In previous years events included death cafes, conferences, art exhibitions, information sessions, film screenings, craft workshops and before I die walls. Link to 2018 resources has Advance Care Planning (origami game) prominent.</p> <p>To Absent Friends - 1-7 November each year - a people's festival of storytelling and remembrance</p> <p><i>Good Life, Good Death, Good Grief</i> currently has over 1000 members. You can join by filling in online form. Members include organisations and individuals.</p> <p>Twitter: @GoodGriefProj @Palliative_Scot</p>
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<p>Everyday Compassion Conference</p> <p>25 April 2018</p>	<p>Glasgow, Scotland</p>	<p>Organised by: Scottish Partnership for Palliative Care</p> <p>Good Life, Good Death, Good Grief</p> <p>In association with Public Health Palliative Care UK branch</p>		<p>Everyday Compassion: Supportive responses to dying and bereavement by schools, neighbourhoods and workplaces</p> <p>This conference was aimed at exploring how to encourage open and supportive attitudes and behaviours relating to death, dying and bereavement in Scotland. Information about the conference and the presentations made are available here</p> <p>The conference launched A Road Less Lonely - a new report by Good Life, Good Death, Good Grief and the Scottish Partnership for Palliative Care, looking at practical next steps for Public Health Palliative Care in Scotland.</p> <p>The report includes chapters exploring:</p> <ul style="list-style-type: none"> Compassionate Workplaces Death Literacy Funeral Poverty Scaling up Good Life, Good Death, Good Grief work Death education and bereavement support in schools Compassionate Communities Wills, Power of Attorney, Advance Directives Media Awareness Campaigns Supporting socio-economically disadvantaged communities.
<p>Mapping the progress and impacts of public health approaches to palliative care: a scoping review</p>		<p>Being supported by Scottish Partnership for Palliative Care</p>		<p>A group from the University of Edinburgh, Strathclyde University, La Trobe University, Scottish Partnership for Palliative Care and St Columba's Hospice Edinburgh, are undertaking a scoping review relating to public health palliative care.</p> <p>The scoping review aims to:</p> <ul style="list-style-type: none"> Map the wide variety of activities and programmes that could be classified as 'public health palliative care' Explore the impact of these activities where impact has been measured.

<p>Dying Matters</p> <p>Dying Matters Awareness Week – 14-20 May 2018 ‘What Can You Do ... in your community?’</p>	<p>United Kingdom (mainly England and Wales)</p>	<p>Initially set up by the National Council for Palliative Care (NCPC) – NCPC merged with Hospice UK in July 2017</p>	<p>Tracey Bleakley, chief executive</p>	<p>In 2009, the National Council for Palliative Care (NCPC) set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement.</p> <p>Dying Matters is a coalition of 32,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.</p> <p>Activities</p> <p>Wide range of resources to help people start conversations about dying, death and bereavement. Information Section area of the website has been created primarily for people approaching the end of their life, and their carers, relatives and friends, including information on Planning Ahead Find Me Help, described as the UK's most comprehensive directory of services for people in the last years of life, their families, carers and friends.</p> <p>Dying Matters Awareness Week – annual campaign Focus on discussion about death and bereavement</p> <p>Twitter: @DyingMatters</p>
<p>Hospice Care Week</p> <p>8-14 October 2018</p>	<p>United Kingdom</p>	<p>Hospice UK</p>	<p>Tracey Bleakley, chief executive</p>	<p>Hospice Care Week is an annual week of activity to raise the profile of hospice care across the UK. Promoted as a week of celebration and action each year, which helps to change people’s perceptions of hospice care.</p> <p>In 2017, the seventh Hospice Care Week for Hospice UK and its members was held - in recent years at least 80 per cent of Hospice UK members participated.</p> <p>Held on 9-15 October in 2017 with the theme ‘We are hospice care’ it is a ‘hook’ for hospices to hold their own events around the week.</p> <p>‘We are hospice care’ is an opportunity to show the many faces of hospice care and to share their inspiring stories.</p> <p>The overall aims of the week are to:</p> <ol style="list-style-type: none"> 1. boost engagement with existing volunteers, donors and supporters;

				<p>2. attract new volunteers, donors, supporters; and 3. build a sense of togetherness within the hospice care community.</p> <p>The target audience for the week is:</p> <ol style="list-style-type: none"> existing networks of staff, volunteers, patients, families, donors, corporate partners – and their networks; and prospective staff, volunteers, patients, families, donors etc -- and their networks. <p>Hospice Care Week incorporates: Fundraising: ‘Go Yellow’ for Hospice UK.</p> <p>Hospice Shop Challenge: Dress your hospice shop to impress during Hospice Care Week, and win a great prize!</p> <p>Provides a range of resources to support the week, mainly for events such as posters, bunting etc Focus is primarily on hospices (place of care) #WeAreHospiceCare</p> <p>Twitter: @hospiceuk</p>
Compassionate Communities UK	United Kingdom	Charity set up to implement the Compassionate City programme	Allan Kellehear Julian Abel Catherine Millington Sanders	<p>Compassionate Communities UK has been developed to work the 95% of time when there is no professional or health service contact. Provide a variety of different services relating to the public health approach to the spectrum of chronic disease management into end of life care including bereavement.</p> <p>An online resource on an earlier Compassionate Communities initiative developed by Murray Hall Community Trust, the National Council for Palliative Care and the Dying Matters Coalition published an Overview of Compassionate Communities in England in 2103 report</p>
Children’s Hospice Week 21-27 May 2018	United Kingdom	Together for Short Lives		<p>Children’s Hospice Week 2018 – Life’s Short Children’s Hospice Week is the UK's only awareness and fundraising week for children with life-limiting conditions and their families, and the hospice and palliative care services that support them.</p>

				<p>The campaign's combined purpose of raising awareness of children's palliative care and fundraising seems to have been a consistent approach to the week which has been held in May for several years (campaign supported by the Duchess of Cambridge since 2013)</p> <p>For 2018, Royal Mail created a Children's Hospice Week postmark for the week to reach 30 million people.</p> <p>The 2017 Campaign was billed as 'Let's Turn Up the Volume' with a poster stating Help #UpTheVolume on children's palliative care and raise money for seriously ill children and their families</p> <p>Resources are provided to support events</p> <p>Children's stories are a feature of the campaign</p> <p>The results of a survey were released to support the 2017 campaign which showed that 1 in 3 people would not feel comfortable talking to a friend whose child had been diagnosed with a life-limiting or life-threatening condition. The survey also revealed the lack of awareness surrounding children's palliative care.</p> <p>Twitter: @Tog4ShortLives</p>
<p>National Palliative Care Week 20-26 May 2018</p>	Australia	<p>Palliative Care Australia</p>	Liz Callaghan, chief executive officer	<p>National Palliative Care Week is an annual awareness raising week organised by Palliative Care Australia. The CEO of Palliative Care Australia describes this as 'our feature event for the year' in the organisation's 2016/2017 Annual Report</p> <p>The theme for National Palliative Care Week 20-26 May 2018 was 'What matters most?' National Palliative Care Week is a national week supported by the Department of Health to raise awareness and understanding about palliative care in the Australian community.</p> <p>The theme addresses the need for Australians to plan ahead for their end-of-life care and discuss it with their loved ones and health professionals. Palliative Care Australia highlights how palliative care can help people with a life-limiting illness to have a high quality of life, right to the end of life.</p>

			<p>The use of two resources was promoted: The Dying to Talk discussion starter launched by the Minister for Health in 2017 and the Dying to Talk card game to help people work out what matters most to them There is also an Aboriginal and Torres Strait Islander Discussion Starter.</p> <p>A toolkit was provided for the campaign which includes: National Palliative Care Week theme and key messages Communication materials Ideas for holding an event Tips on engaging audiences through traditional and online media</p> <p>The 2016 campaign focussed on Living Well with Chronic Illness</p> <p>In 2017 the focus was on aged care and the results of a survey published to coincide with National Palliative Care Week showed 85 per cent of Australians believe that it is important to have a conversation with family about the care one would like to receive at end-of-life, but only a third of those surveyed have actually had the discussion.</p> <p>An online art competition 'Connection with Community' was incorporated for the second time in the 2017 campaign</p> <p>During the 2017 week, a joint position statement developed by Palliative Care Australia and Meaningful Ageing Australia call for the universal acceptance of the importance of spirituality and spiritual care for people receiving palliative and end-of-life care in aged care.</p> <p>Twitter: @Pall_Care_Aus</p>
National Advance Care Planning Week 16-22 April 2018	Australia	Advance Care Planning Australia Austin Health – major provider of tertiary health	National Advance Care Planning Week 16-22 April 2018 – Plan for tomorrow Live for today In an October 2017 statement Health Minister Greg Hunt MP allocated Austin Health for Advance Care Planning Australia (\$4.1 million) to increase awareness and uptake of advance care planning nationally.

		services and health professional education & research in the north-east of Melbourne.		<p>This supersedes the Decision Assist program</p> <p>Be Open Be Ready Be Heard.</p> <p>Advance Care Planning Week runs from the 16 - 22 April to raise awareness of advance care planning across Australia. The campaign encourages all Australians to start a conversation with their friends and family about what's important to them. People can take part by hosting or attending an event, or simply help raise awareness of advance care planning by sharing their values and conversations on social media during National Advance Care Planning Week using #acpweek18.</p> <p>Hashtag: #acpweek18</p>
<p>The GroundSwell Project</p> <p>Dying to Know Day – D2KDay 8 August</p>	Australia	<p>Set up by clinical psychologist Kerrie Noonan, and playwright Peta Murray in late 2009</p> <p>Not-for-profit organisation, incorporated in New South Wales</p>	<p>Kerrie Noonan, co-founder, director, executive officer</p>	<p>Organisation's vision is that when someone is dying, caring or grieving, everyone knows what to do.</p> <p>The organisation states that: 'Our purpose is to create a more death literate society, one where people and communities have the practical know-how needed to plan well for end of life. This means shifting focus from 'talking about it' to transforming this 'difficult' conversation into one of deep community engagement, social action and empowerment.'</p> <p>In early 2018, the GroundSwell Project announced their contribution to the Compassionate Communities movement in Australia, by launching the first Compassionate Communities Practice Forum and Digital Hub with the support of Bupa.</p> <p>The practice forum will comprise of eight communities around the country, engaging in the compassionate communities model in their local area. The GroundSwell Project plans to support these communities by offering on-the-ground community development expertise, a digital resource hub plus access to a national and international network of leading Compassionate Communities practitioners and researchers. Project commenced in February 2018.</p> <p>Dying To Know Day (8 August) is an annual day of action dedicated to bringing to life conversations and community actions around death, dying and bereavement.</p>

				<p>The organisers want to encourage all Australians to:</p> <ul style="list-style-type: none"> develop their death literacy make their end of life plans such as a will and advance care plans share these wishes with their families get informed about end of life and death care options such as dying at home, home and community led funerals and natural burial be better equipped to support family and friends experiencing death, dying and bereavement <p>A range of D2KDay Resources are available, some which can be downloaded and others which must be ordered and paid for.</p> <p>Previous GroundSwell projects included a number involving various art media</p> <p>Twitter: @GroundSwellAus Hashtag: #D2KDay</p>
<p>National Hospice Palliative Care Week 6-12 May 2018</p>	Canada	<p>Canadian Hospice Palliative Care Association</p> <p>Funding for the Week is provided by GlaxoSmithKline, Purdue, CBI Health Care and Innovative Medicines Canada</p>	Sharon Baxter, executive director	<p>Theme for 2018: Towards a more compassionate Canada, Eh? - encouraging Canadians to consider ways community involvement can support the dying and bereavement process.</p> <p>For National Hospice Palliative Care Week 2018, the Canadian Hospice Palliative Care Association called on Canadians to answer these questions:</p> <ul style="list-style-type: none"> What makes a compassionate community? How can compassionate communities support end of life care? <p>Theme for previous National Hospice Palliative Care Week 7-13 May 2017: Hospice Palliative Care is about living well. Right to the end.</p> <p>The 2017 campaign was endorsed by Minister of Health Jane Philpott</p> <p>For National Hospice Palliative Care Week 2017, CHPCA called on Canadians to conquer their fear and commit to two actions:</p>

				<p>Learn about Hospice Palliative Care and Advance Care Planning – what they mean, and what you think you may want (or know you won't want) when the time comes; and</p> <p>Make a "bucket list": Your top 5 things to do before you die, and share it on Twitter, Instagram and Facebook using #Top5WhileImAlive or #vivrebienjusqualafin.</p> <p>More information, and downloadable resources for National Hospice Palliative Care Week, are provided in this link to the 2018 campaign</p> <p>Twitter: @CanadianHPCAssn Hashtag 2018: #MyCompassionateCanada</p>
Let's Talk About Hospice Palliative Care First	Canada	Canadian Hospice Palliative Care Association	Sharon Baxter, executive director	<p>This appears to be an open-ended web-based campaign encompassing raising awareness of hospice palliative care prompted by the following:</p> <p>Let's talk about dying in Canada... What will I want or need at the end of life? Will I suffer pain and need medication to manage my symptoms? How can I let my family & friends know my wishes and preferences for end of life care? What help is available to me? Will I suffer from a chronic illness and feel like a burden to others? What decisions will I have to make?</p> <p>The initiative is supported by a range of resources including a poster, factsheet, brochure, getting stories in the media and a sheet of definitions which includes references to Palliative Sedation Therapy, Euthanasia and Physician Assisted Dying.</p> <p>It is noteworthy that the Canadian Hospice Palliative Care Association references the increasing debate around these issues as a reason for its campaign. Their stance is on promoting hospice palliative care.</p> <p>Twitter: @CanadianHPCAssn</p>

<p>ACP Planning Day 16 April, 2018</p> <p>Speak Up Campaign - Parlons-en</p>	<p>Canada</p>	<p>A project of the Canadian Hospice Palliative Care Association, but is being undertaken under the guidance of a Task Group which brings together a number of partners.</p>	<p>Sharon Baxter, executive director</p> <p>Chad Hammond, program manager, Advance Care Planning in Canada, Canadian Hospice Palliative Care Association</p>	<p>The Advance Care Planning in Canada: A National Framework and Implementation Project was initiated in 2008.</p> <p>April 16th is National Advance Care Planning Day, a day for people to think about and share their wishes for future health care with others. If a person has already made their advance care plan, April 16th is promoted as a great day to review it to make sure it still reflects the person's wishes.</p> <p>The long-term goal of the project is to raise the awareness of Canadians about the importance of advance care planning and to equip them with the tools they need to effectively engage in the process.</p> <p>The secondary goal is to prepare professionals/health care providers with the tools they need so they can facilitate and engage in the process of advance care planning with their clients.</p> <p>The Project has developed a National Framework to guide ACP programme and policy planning and implementation.</p> <p>The Project has its own website with a range of materials under the following headings: What Is Advance Care Planning?; What's Happening Across Canada, a Resource Library reflecting materials from across Canada's territories and cultures, for the public, health care professionals and researchers; and a Make My Plan facility for individuals to make their wishes known.</p> <p>The Advance Care Planning Task Group went through a planning process in spring 2013 to develop a 5-year plan. The plan includes goals, performance indicators and target audiences. An Advance Care Planning Day Campaign Kit is provided for the 2018 campaign</p> <p>Hashtag: #ACPD2018</p>
<p>Bereavement Day</p>	<p>Canada</p>	<p>Canadian Hospice Palliative Care Association</p>	<p>Sharon Baxter, executive director</p>	<p>Bereavement Day 2017 - November 21, 2017 was the first annual Bereavement Day in Canada. The Canadian Hospice Palliative Care Association (CHPCA) in its press release on the event links it to hospice palliative care and advance care planning as well as the need to talk about grief and bereavement.</p>

				<p>Purpose Throughout the month of November, culminating on November 21, CHPCA aimed to promote resources and tools to help Canadians throughout their grief journeys – for those dealing with anticipatory grief, as, for example, caregivers for loved ones at end-of-life, to those who have recently said goodbye to a loved one, and those who are experiencing complicated grief, even years after the death of a loved one.</p> <p>Invitation: to public/organisations to share their bereavement resources with CHPCA; to people to share their stories; to hold an awareness event; to write an article, to meet their elected representatives.</p> <p>Some Resource Documents are provided, including links to Bereavement Resources</p>
Mobilizing Compassionate Communities in Canada	Canada	Pallium Canada	<p>Jeffrey B Moat, chief executive officer</p> <p>Bonnie Tompkins, Compassionate Communities national lead</p>	<p>Pallium Canada has been supporting the building of capacity within the health care field since 2001. A significant element of the organisation’s work is facilitating the education programme Learning Essential Approaches to Palliative Care (LEAP).</p> <p>Pallium Canada is also focussing on mobilizing Compassionate Communities and Bonnie Tompkins, Pallium Canada’s Compassionate Communities National Lead presented on this work at the Everyday Compassion Conference in Scotland on 25 April 2018.</p> <p>Bonnie's work focuses on assisting Compassionate Community initiatives across Canada to help create supportive environments for death, dying, loss and caregiving.</p> <p>Pallium Canada’s role in mobilizing Compassionate Communities National support includes:</p> <ul style="list-style-type: none"> • Hubs for conversation and connection across Canada • Plant the seed of Compassionate Communities within LEAP courses • Sharing Tool Kits and Resources • Pan-Canadian Evaluation <p>Bonnie’s presentation in Scotland on 25 April 2018 can be viewed here</p>

<p>Hospice Awareness Week 14-20 May 2018</p>	<p>New Zealand</p>	<p>Hospice New Zealand</p>	<p>Mary Schumacher, chief executive</p>	<p>Hospice Awareness Week is an opportunity to profile and celebrate the services that hospices provide in their local communities, and address misconceptions that people may have around hospice care.</p> <p>According to Hospice New Zealand’s 2017 Annual Review, Hospice Awareness Week is an opportunity for hospices to profile and celebrate the services they provide in their local communities, to address misconceptions that people may have around hospice care, and to encourage the New Zealand public to support their local hospice.</p> <p>In 2017, Hospice New Zealand coordinated a national awareness week in conjunction with its members. It provided member hospices with a range of personalised materials to give a consistent look and feel to the overall campaign.</p>
<p>World Hospice & Palliative Care Day 13 October 2018</p> <p>Held on the second Saturday of October every year</p>	<p>Worldwide</p>	<p>Worldwide Hospice Palliative Care Alliance, a network of hospice and palliative care national and regional organisations that support the development of hospice and palliative care worldwide</p> <p>Office: 34-44 Britannia Street London WC1X 9JG United Kingdom</p>	<p>Dr Stephen R. Connor, executive director</p>	<p>World Hospice and Palliative Care Day is a unified day of action to celebrate and support hospice and palliative care around the world.</p> <p>Voices for Hospices is a wave of concerts taking place on World Hospice and Palliative Care Day every two years.</p> <p>World Hospice and Palliative Care Day takes place on the second Saturday of October every year and Voices for Hospices takes place on the same date every two years.</p> <p>The theme for World Hospice and Palliative Care Day 2018 is Palliative Care – Because I Matter</p> <p>Aims of World Hospice and Palliative Care Day:</p> <ul style="list-style-type: none"> • To share our vision to increase the availability of hospice and palliative care throughout the world by creating opportunities to speak out about the issues • To raise awareness and understanding of the needs – medical, social, practical, spiritual – of people living with a life limiting illness and their families • To raise funds to support and develop hospice and palliative care services around the world. <p>Previous themes include: ‘Universal Health Coverage and Palliative Care – Don’t leave those suffering behind!’ in 2017 Living and dying in pain – It doesn’t have to happen 2016</p>

				<p>Hidden Lives, Hidden Patients 2015</p> <p>Accompanying resources are provided by WHPCA to support the campaign</p> <p>The suggested themes for World Day 2019 & 2020 are Volunteers at the Heart of Palliative Care, and Palliative Care – Yes we can!</p> <p>Twitter: @whpca</p>
Death Café	Begun in UK - worldwide	Project begun by Jon Underwood who died suddenly in June 2017		<p>At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death.</p> <p>Objective is 'to increase awareness of death with a view to helping people make the most of their (finite) lives'.</p> <p>A Death Cafe is a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counselling session.</p> <p>Death Cafes are always offered:</p> <ul style="list-style-type: none"> On a not for profit basis In an accessible, respectful and confidential space With no intention of leading people to any conclusion, product or course of action Alongside refreshing drinks and nourishing food – and cake! <p>There is a how to guide provided for those interested in holding a Death Café</p>