



**AIIHPC**

All Ireland Institute of  
Hospice and Palliative Care

## **Palliative Care Week 2020 Report**



***Palliative Care: In This Together***

December 2020

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### 'Palliative care doesn't mean you're going to die soon'

Palliative care is an often misunderstood specialty - while it does encompass end-of-life care - it is so much more. Emily Hourican talks to Joe McCann (63), who was diagnosed with Stage 4 cancer and received support and pain management strategies from St Francis Hospice



Joe McCann (63) with his daughter Vivienne at his home in Dublin's North Wall. Joe has Stage 4 cancer and had been attending St Francis Hospice until the pandemic and continues to receive their support. Picture: Frank McGrath

Emily Hourican

September 14 2020 02:30 AM



Joe and Vivienne McCann interviewed for Palliative Care Week

## 'It's like a comfort blanket knowing they are there all the time'

For parents of a child with Aicardi syndrome, palliative care works wonders

© Wed, Sep 9, 2020, 06:01

Sheila Wrayman



Derm and Francesca Villena with their daughter Isabella (11) and son Alica (12). Photograph: Nick Brodhanne

The Villena family featured in The Irish Times for Palliative Care Week

### **Palliative Care Week 2020 At A Glance**

- 1** President's Message
- 2** Health Ministers involved
- 7** Ambassadors supported
- 7** Videos of personal experiences of palliative care
- 9** Service users and carers featured in videos
- 29** Radio bulletin broadcasts on launch day
- 46** Voices4Care members consulted
- 48** Radio items broadcast
- 94** Media interactions in total
- 511** Posters distributed
- 1,500** People took part in survey
- 1,657** Palliative Hub sessions
- 2,600** Twitter posts
- 3,000** Leaflets in Coffee Morning packs
- 5,600** Leaflets distributed

## 1. Introduction

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. As a leading organisation with national and international influence driving excellence in palliative care, AIHPC advances education, research, and policy and practice to improve the palliative care experience of people with life-limiting conditions and their families.

Through its involvement with its 26 partners, with the National Clinical Programme for Palliative Care in the Republic of Ireland, and Palliative Care in Partnership in Northern Ireland, AIHPC supports the delivery of high quality palliative care.

Working with colleagues across these sectors, AIHPC has facilitated an annual Palliative Care Week since 2014. This is a dedicated campaign to raise public awareness and increase understanding of palliative care.

Palliative care has a role to play in promoting health and wellbeing. Serious illness, death, dying, loss and grief are universal experiences. The seventh annual Palliative Care Week campaign comes under the broad understanding of public health approaches to palliative care and is in line with key palliative care policy direction across both jurisdictions on the island of Ireland.<sup>1</sup>

## 2. Planning for Palliative Care Week 2020 – the year of COVID-19

Planning for Palliative Care Week 2020 began in late 2019. By March 2020, our plans were being reconsidered in light of the developing COVID-19 pandemic. As the devastating impact of COVID-19 became clear, Palliative Care Week needed to be relevant in the ongoing pandemic context. AIHPC wanted Palliative Care Week to be an opportunity to promote the quality of life benefits of palliative care. Quality of life is improved where all supports for a person with palliative care needs are in place, including the wider community alongside health and social care services. This was a feature of the outstanding community response to COVID-19, which we wanted to connect with for Palliative Care Week 2020.

### **AIHPC's objectives for Palliative Care Week 2020 were to:**

- Deliver a palliative care awareness-raising campaign across the island of Ireland
- Increase awareness and understanding of palliative care among the public and among health and social care professionals
- Deliver a campaign informed by service user experiences
- Position AIHPC as a facilitator for the campaign, supporting integration of messaging and activities with the needs of AIHPC partners and the palliative care sector, the wider health and social care system, and wider society
- In addition to our original planning objectives, it was decided that the campaign needed to be relevant in the context of the COVID-19 pandemic.

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<sup>1</sup>Republic of Ireland: Report of the National Advisory Committee on Palliative Care (2001); Palliative Care Services: Three Year Development Framework (2017-2019), HSE Primary Care Division; Northern Ireland: Living Matters: Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland (2010); Review of the Implementation of the Palliative and End of Life Care Strategy NI RQIA (2016)



*Robin Swann MLA, Health Minister, Northern Ireland, helps to launch Palliative Care Week 2020. Minister Swann is pictured with Karen Charnley, AllHPC Director, and Brendan O'Hara, AllHPC Programme Manager.*

### **3. Key Developments**

#### **Theme - Palliative Care: In This Together**

Having consulted with Voices4Care members, with the Palliative Care Week Reference Group (Appendix A) and considering the context of the Coronavirus pandemic, the theme for 2020 was confirmed as: Palliative Care: In This Together.

#### **Palliative Care Experience Videos**

For the fourth year, AllHPC supported by the Health Service Executive (HSE) Quality Improvement Division (Republic of Ireland), collaborated to produce seven videos released during Palliative Care Week. The videos reflect a range of experiences, including what it was like living with palliative care needs during the COVID-19 pandemic. AllHPC is grateful to the participants for sharing their stories which include experiences from children's palliative care through to palliative care for adults. Filming took place remotely with participants from Donegal, Down, Dublin, Fermanagh and Mayo. The videos, along with a transcript of each film, are available on [www.thepalliativehub.com](http://www.thepalliativehub.com)

#### **Survey**

To inform Palliative Care Week 2020, AllHPC commissioned iReach to carry out a survey of public understanding of palliative care and palliative care in the context of COVID-19. In July 2020, a survey of a sample population of 1000 people in the Republic of Ireland and 500 people in Northern Ireland was carried out. The survey results are available [here](#) The questions for the survey are included in Appendix B.





“ I am delighted to have this opportunity to express my gratitude to all those who work in palliative care for the spirit of solidarity and deep concern for others that is so central to all you do. Your dedication and your great generosity is deserving of our deepest admiration. I wish you every success during this important awareness raising week, and I thank you all for your vital and inspiring work. ”



**President Michael D Higgins**

### **Launch – Support from President Higgins, and Health Ministers north and south**

AIIHPC was delighted to receive a message for Palliative Care Week 2020 from President Michael D. Higgins, President of Ireland, which can be viewed [here](#)

Press releases to launch the week were issued on Sunday 13 September and were tailored for both jurisdictions on the island. Robin Swann MLA, Health Minister, Northern Ireland endorsed the week. Minister Swann also released a video message for the week indicating his awareness of the leadership shown by the palliative care community. Minister Swann’s video can be viewed [here](#)

Stephen Donnelly TD, Health Minister, Republic of Ireland, endorsed the campaign in the press release for the Republic. To mark the beginning of the week, Minister Donnelly also issued a Government press release endorsing the work of AIIHPC and commending the efforts of hospices, health and social care organisations and universities, north and south of the border, to deliver a better experience for patients and their families. Minister Donnelly’s statement can be viewed [here](#)



**Stephen Donnelly TD,  
Minister for Health**

(Photo courtesy of flannafail.ie)

“ Much like the national effort against Covid-19, Palliative Care Week reminds us that we are all in this together when it comes to caring for people with life-limiting conditions in our society. We stand in solidarity with all those receiving palliative care, and I am delighted to support Palliative Care Week. ”

## Media

The results from the population survey informed key messaging in press releases issued for Palliative Care Week, and they were accompanied by infographics highlighting key statistics from the survey. (See Appendix C for press releases and Appendix D for the infographics)

A press release issued well ahead of Palliative Care Week, on 6 August, urging people to find out more about palliative care and to get involved in the week, generated significant media coverage. The launch press releases on Sunday 13 September resulted in news items across a range of radio, print, and online media. A soundbite of AIHPC Director Karen Charnley was broadcast across news bulletins on 29 radio station on 13 September. Messaging addressed misconceptions about palliative care and included comment from service users involved in the videos, health ministers, and colleagues from the health programmes north and south.



A sample of print media coverage for Palliative Care Week 2020

## Events

AIHPC is delighted at the number of events held to coincide with Palliative Care Week. Although curtailed from physical gathering due to COVID-19 restrictions, there were 10 virtual 'gatherings' at online events, with more than 2,000 registering to attend.

## **Ambassadors**

We are grateful to our partners who supported the engagement of high profile personalities as ambassadors for the week, among whom were [Nicola Coughlan](#), from 'Derry Girls', [Brian and Una](#) from RTE's Fair City, [Garry Ringrose](#) Leinster and Ireland rugby player, Kilkenny hurler [Eoin Murphy](#), and TV personalities [Nuala Carey](#), and [Celia Holman Lee](#)

## **4. Campaign Planning**

### **Audiences**

Primary audiences included those who could benefit from palliative care, health and social care professionals, the public and communities across the island of Ireland. Secondary audiences included politicians, policy makers, both health departments, the HSE, the Public Health Agency (NI), and opinion leaders. AllHPC's partners and the wider sector with an interest were key to reaching these audiences.

### **Reference Group**

The Palliative Care Week Reference Group, with updated membership, was a key channel for communication and raising awareness of the campaign itself; and for testing thinking for 2020. Reference Group membership, terms of reference and details of engagement are in Appendix A.

There were ongoing briefings with, and support from, communications colleagues from AllHPC's partners, from the Health Service Executive (Republic of Ireland) and the Public Health Agency/Health and Social Care Board (Northern Ireland).

There was ongoing contact with Reference Group members throughout campaign planning and delivery. Two Zoom briefings, which had large attendances, were hosted on 29 July and on 2 September. They were a valuable opportunity for sharing information on plans for the week and for answering any questions. The attendance of PR/Communications colleagues at these two briefings was helpful.

### **Key messages**

In the promotional materials to accompany the campaign, messaging was built around these points. Palliative care:

- 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 closest 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.



The style and format of the promotional leaflet was changed this year. We presented the bulk of our messaging through a mnemonic of IN THIS TOGETHER, and through an interactive 'Test your knowledge of palliative care' format of nine statements with a true/false choice for each statement.

### **Voices4Care**

For 2020, AIHPC had hoped to support members of Voices4Care to be more involved in bringing Palliative Care Week to their communities. Voices4Care is the voluntary panel of people with palliative care needs, carers and interested citizens who work with AIHPC to improve palliative care. Colleagues in Quality Improvement in the Health Service Executive (Republic of Ireland) had indicated potential support for a programme to involve Voices4Care in Palliative Care Week. Given public health advice in relation to the COVID-19 pandemic, and physical distancing requirements, this project was not practicable in 2020.

Nonetheless, Voices4Care members informed the campaign throughout. Members were consulted at a Voice4Care meeting in January. As we had to change our plans in light of COVID-19, we asked members for their suggestions on our focus and messaging, in light of the pandemic. This feedback, in May, informed our thinking and messaging for Palliative Care Week. The draft content of the Palliative Care Week leaflet was sent to members for comment in early July, and the content was revised, taking account of members' feedback. On 31 August, the Institute Director wrote to all Voices4Care members and included Palliative Care Week leaflets, the poster, and social media frames with this letter. A number of Voices4Care members supported the campaign in various ways including through the distribution of promotional materials in their communities, through social media activity and in media engagement.

## **5. Resources**

We were mindful of the potential impact of COVID-19 restrictions on event planning this year, and that this would have an impact on the distribution of printed promotional materials. We decided it was still important to produce smaller quantities of printed materials. The campaign included a suite of promotional materials, media engagement, the use of social media and supporting online partner events. As well as printed copies of materials being available, people were directed to [www.thepalliativehub.com](http://www.thepalliativehub.com) where a range of resources could be viewed/downloaded.

### **Promotional Materials**

The following materials were designed (see Appendix D):

- Campaign logo
- Leaflet (A5 size)
- A poster
- A screensaver & email signature
- Twitter header and Facebook cover
- Social media campaign picture frame
- Two infographics highlighting key statistics from population survey (ROI and NI)

## Videos

The seven palliative care experience videos were released during the week and were available on the Palliative Hub. Shorter clips from videos were also used on social media.

The videos, all recorded remotely, feature:

- Sam and Isabella Villena, from Dublin, supported by LauraLynn Ireland's Children's Hospice
- John Joyce, from County Mayo, a Voices4Care member who had first been involved in Palliative Care Week in 2017
- Louise Smith, from Dublin, supported by St Francis Hospice at home during COVID-19
- Pat Keenan, from County Fermanagh, who with his wife Carmel was supported by the Western Health and Social Care Trust
- Joe McCann and his daughter Vivienne, supported by St Francis Hospice at home during COVID-19
- Barry Hession, from County Down, supported by Northern Ireland Hospice
- Tim Kelly, County Donegal, who with his wife Kathleen, was supported by Donegal Hospice

The support of LauraLynn Ireland's Children's Hospice, St Francis Hospice, Dublin, Northern Ireland Hospice, the Western Health and Social Care Trust, and Donegal Hospice are gratefully acknowledged for their support in involving participants in the videos.

## Social Media Plan

A social media plan was developed with prepared material for Twitter and Facebook around key video clips and other material each day. The social media plan was shared with communication colleagues so that opportunities to share/repost material could be used. The hashtag **#pallcareweek** was used in 2020, as with previous campaigns.





## Website

A direct link was provided to Palliative Care Week 2020 on [www.thepalliativehub.com](http://www.thepalliativehub.com) home page where there was a wide range of information including:

- Video stories
- All of the promotional materials
- Details of events
- Explanations about palliative care

## Media planning

AIHPC commissioned The Communications Clinic for media communications support for Palliative Care Week 2020. Planning began in June 2020.

In addition to the support with the press releases in August and September, and achieving coverage for same, this professional communications support was vital for securing the level and quality of media coverage obtained for Palliative Care Week.

With the support of the communications professionals, some video participants took part in media interviews for features which appeared in daily and weekly newspapers with a large circulation, and the participants also took part in radio programmes with a wide listening public.

A 'Palliative Care Week – Key messaging' document was shared with key communications contacts and the Reference Group members, which everyone was free to tailor for local use. These messages could be adapted for social media channels, including Facebook and Twitter, and for media engagement.

We are also grateful to AIHPC partners who supported media interviews locally, involving people who had experience of their services.

## 6. Costs

The total campaign cost for 2020 was €23,000.

Costs included the population survey, design, printing and distribution of promotional materials, including postage etc, communications/PR services including media monitoring. Overall costs for Palliative Care Week were kept to a minimum. These costs do not include the significant time and support provided by AllHPC staff, which was absorbed within the Institute's running costs.

## 7. Reach and Impact

### Promotional materials

As we anticipated, there was a significant decrease in the volume of promotional materials distributed this year. This was an expected impact of the COVID-19 pandemic. Nonetheless, 5,600 leaflets, 511 posters and 405 social media frames were distributed. They were requested by 28 contacts including service users, interested individuals, health and social care professionals and civic society organisations.

Promotional Materials	2017	2018	2019	2020
Leaflet	10,300	13,500	18,200	5,600
Poster	550	538	814	511
Social Media Sheet	Not available	928	771	405

**Coffee Morning 2020:** For the fourth year, the date for Palliative Care Week was set to fall a week ahead of Ireland's Biggest Coffee Morning for Hospice which was held on Thursday 24 September 2020. The Coffee Morning team facilitated the distribution of 3,000 leaflets through Coffee Morning packs (the number of leaflets distributed through Coffee Morning packs was also significantly reduced).

On 17 August, just under a month ahead of the campaign, AllHPC emailed more than 500 contacts in its database alerting them to the campaign, inviting them to take part and offering to send promotional materials.

### Events

The fact that Palliative Care Week related events had to be hosted online meant people could attend from across the island of Ireland and from further afield. More than 2000 people registered for these range of events:

**Social justice, minority groups and palliative care in Northern Ireland**, organised by Marie Curie, Monday 14 September

**Managing Breathlessness in Primary Care – Why? Who? How?** webinar hosted by the Royal College of General Practice, Northern Ireland, Southern Health and Social Care Trust and AllHPC, Tuesday 15 September

**Palliative Care in a Pandemic: Lessons and Insights from Practice and Poetry**, the Institute for Life Course and Society, the Irish Centre for Social Gerontology, the Centre for Economic and Social Research on Dementia, and PPI Ignite at NUI Galway, Tuesday 15 September

**Showcasing Palliative Care Research in Northern Ireland Webinar**, Palliative Care Research Forum for Northern Ireland (PCRF NI), supported by AIIHPC, Wednesday 16 September

**Advance Care Planning Webinar**, Southern Health and Social Care Trust, supported by AIIHPC, Wednesday 16 September

**Primary Palliative Care for GPs – Webinar for GPs**, organised by the Irish College of General Practice and the Irish Hospice Foundation, Wednesday 16 September

**Palliative Care: Making the Difference**, Galway Mayo Institute of Technology, Mayo Campus Thursday 17 September

**Palliative Care Week 2020 Webinar: Palliative Care: Future Challenges for Ireland**, AIIHPC and Professor Charles Normand, Trinity College, Dublin, Thursday 17 September

**Project ECHO AIIHPC Webinar – ‘Palliative Care Week 2020 – The impact of COVID-19 on care services for vulnerable adults – learning as we go’**, Thursday 17 September

**Grief & Bereavement during COVID 19 – Supporting Nursing Home Staff Webinar**, The Irish Hospice Foundation – Thursday 17 September

A number of the events were recorded and the recordings can be viewed on the AIIHPC YouTube channel [here](#)

### **Media – Broadcast, Print and Online**

A total of 94 items of media coverage were identified referencing Palliative Care Week 2020 across national, regional, local and online media outlets, including RTE Radio, Today FM, Newstalk, Sunday Independent, The Irish Times, The News Letter (Belfast), The Echo (Cork), TheJournal.ie and The Irish Farmers’ Journal. Although there were slightly fewer media items compared to 2019 (126 in 2019) there was a higher volume of radio opportunities - 48 - in 2020, more than half of the total media items.

As well as 10 radio interviews facilitated with national and local media, a soundbite of AIIHPC Director Karen Charnley was featured in news bulletins across 29 radio stations on launch day on 13 September.

Radio interviews featured Joe and Vivienne McCann, who were being supported by St Francis Hospice, Voices4Care member John Joyce, Dr Brian Creedon, Clinical Director for the National Clinical Programme (ROI), Karen Charnley, AIIHPC Director, Brendan O’Hara, AIIHPC Programme Manager. Joe and Vivienne McCann also took part in media interviews for print media, as did Sam and Isabella Villena, supported by LauraLynn Ireland’s Children’s Hospice, and Linda O’Neill, whose parents were supported by Our Lady’s Hospice & Care Services, Dublin. An opinion piece by Dr Brian Creedon was carried in the Sunday Independent and an opinion piece by Dr Bridget Johnston, Trinity College Dublin, was published in The Echo



(Cork). All those who engaged with media were supported by AIHPC and by media communications experts in the process.

AIHPC is grateful to these interview participants, to its partners, other organisations and colleagues who supported raising the profile of palliative care through media interview opportunities arranged locally across the island. A full list of media coverage is available at Appendix E.

### Other promotion opportunities

An email was issued to Northern Ireland Civil Service colleagues promoting awareness of palliative care during the week.

Palliative Care Week was featured in the Patient and Client Council (Northern Ireland) Updates on Friday 11 September and Friday 18 September.

A broadcast email was issued to all HSE staff (Republic of Ireland) on 16 September featuring a brief explanation of Palliative Care Week with a link to the palliative care experience videos, a project supported by the HSE.

Palliative Care Week was also promoted in the regular update from the HSC R&D Division (Northern Ireland).

We appreciate all the content developed by our partners and other organisations which was shared through staff communication networks and through print, online and social media for Palliative Care Week.

### Website and Social Media

There were variations in traffic to social media over the campaign this year.

### The Palliative Hub

There was a small decrease in the number of visits to [www.thepalliativehub.com](http://www.thepalliativehub.com) compared to 2019 but 85% of these were new visitors. Details of activity on the Palliative Hub is presented below:

	Sessions	Users	Page views	Pages per Session	Avg. Session Duration	% New Visitors
2020 Sept 11 – Sept 21	1,657	1,339	3,452	2.08	02:04	85.04%
2019 Sept 6 – Sept 16	1,896	1,555	3,048	1.61	01:36	85.7%
2018 Sept 7 – Sept 17	2,164	1,807	4,187	1.93	01:45	86.9%
2017 Sept 1 - Sept 10	2,571	2,269	4,349	1.69	01:30	84.52%
2016 Oct 1 - Oct 10	1,141	925	2,108	1.85	02:02	76.77%

Details on the source of the traffic to the [www.thepalliativehub.com](http://www.thepalliativehub.com) is presented below for the past five years

	Direct	Social (redirected from social media)	Referral (link from another website/ newsletter)	Organic Search
<b>2020 Sept 11 – Sept 21</b>	509	473	116	279
<b>2019 Sept 6 – Sept 16</b>	642	291	135	511
<b>2018 Sept 7 – Sept 17</b>	776	782	135	471
<b>2017 Sept 1 - Sept 10</b>	1033	798	512	228
<b>2016 Oct 1 - Oct 10</b>	372	344	301	124

## Twitter

While the number of individual posts was maintained close to the 2019 level, and there was a slight reduction in the number of contributors, our reach was down from last year to a similar level to 2018. Twitter activity figures for the past five years are presented in the table below:

Twitter	Individual Posts	Contributors	Reach	Impressions
<b>2020 Sept 11 – Sept 21</b>	2,600	697	1.4m	5.17m
<b>2019 Sept 6 – Sept 16</b>	2,677	773	2.2m	6.67m
<b>2018 Sept 7 – Sept 17</b>	3,128	799	1.6m	6.4m
<b>2017 Sept 1 - Sept 10</b>	856	1,090	1.7m	5.7m
<b>2016 Oct 1 - Oct 10</b>	720	255	535,000	4.2m

## YouTube

As in 2019, there were seven videos of personal experiences for the 2020 campaign. Although there was a decrease in the viewing numbers, given the overall impact of the pandemic on the campaign it is encouraging that more than 3,000 views of the videos are reported.

YouTube	Watch Time (minutes)	Views	Average View Duration
<b>2020 Sept 11 – Sept 21</b>	6,384	3,008	01:59
<b>2019 Sept 6 – Sept 16</b>	8,600	3,700	02:18
<b>2018 Sept 7 - Sept 17</b>	7,600	3,200	02:25
<b>2017 Sept 1 - Sept 10</b>	2,200	1,100	02:02

## 8. Commentary

Palliative Care Week was delivered in a very different context in 2020 due to the ongoing COVID-19 pandemic. Key points to note from this year's campaign:

- Planning for the campaign was difficult in the evolving COVID-19 context. The decision to place Palliative Care Week within the societal response to the pandemic was the correct one, and an ever more important context to promote the quality of life benefits of palliative care.
- The population survey providing an insight into general understanding of palliative care and palliative care in the context of COVID-19 was invaluable in forming our messaging and contributed to media pick up on our press releases.
- The opportunity to involve personal experiences in the campaign was invaluable, and despite the physical distancing we were able to work with GK Media to produce seven high quality videos which were all recorded remotely.
- Personal experiences continue to enable the public to connect with the campaign and are of particular interest to media organisations when we try to engage the media to bring Palliative Care Week to a wider public audience.
- Consultation with Voices4Care members and with the Palliative Care Week Reference Group was very helpful in refining our messaging and developing our promotional materials.
- Palliative Care Week was an opportunity to keep palliative care on the government and policy agenda. The campaign was an opportunity to involve both Health Ministers on the island of Ireland, and it was an opportunity for the Ministers to endorse the work of AIHPC and the palliative care sector.
- Communications support from the PR company was vital to securing media coverage in newspapers with large circulation and on radio. Although there were slightly fewer media items compared to 2019 there was a higher volume of radio opportunities - 48 - in 2020, more than half of the total media items, including a soundbite from AIHPC Director Karen Charnley on 29 radio stations on launch day on 13 September.
- While no events in person could be held this year, the success of having 10 events marketed with an association with Palliative Care Week, with more than 2,000 registering to attend, should not be underestimated. The fact that events were online meant that many joined who may not otherwise have attended in person.
- There was a significant negative impact on the number of printed promotional materials distributed this year. We did anticipate this and reduced our print run accordingly. There was a slight reduction in expense for printing and distribution, but the costs of material design etc remains the same, regardless of the print run.

- There was a slight decrease in website and social media activity. While individual tweets were only down slightly on 2019, there was a significant reduction in reach across Twitter on the previous year, with it being close to 2018 levels. Where organisations post material without using the #pallcareweek hashtag this activity cannot be captured through monitoring. An increase in participants and in the number of tweets will be required to improve social media reach. Tracking of the #pallcareweek hashtag indicates that a significant number of organisations and individuals appear to have sent only one tweet during the campaign.
- It must be acknowledged that 2020 was not a normal year for anyone. As many of our partners continued to respond to the ongoing COVID-19 pandemic this may have reduced the capacity and the energy to get involved in Palliative Care Week. AllHPC is a facilitator of Palliative Care Week and needs its partners to bring the campaign to each of the local communities where they are working. We are grateful to all those who got involved this year to bring the Palliative Care: In This Together message to the communities we all serve.

## 9. Planning for 2021

As AllHPC begins planning for 2021, key considerations for the Institute and its partners include:

- Consideration of the ongoing impact of COVID-19 and its potential impact
- Consideration of theme in light of the evolving context and/or ongoing policy development across the island
- Additional resources are required to maintain and build the reach of this annual campaign
- Buy in from AllHPC partners, maximising partnership opportunities, is essential for success
- Buy in from government, health agencies, community and voluntary sector and wider interest is essential for increased reach of the campaign
- Regional and local efforts using the hook of the all-island campaign is essential for increasing the reach of Palliative Care Week
- While personal experiences will be a central feature of the campaign, and AllHPC partners are essential to sourcing these narratives, opportunities for fresh ideas on format, presentation and focus would be welcome, e.g. a different video project
- To increase social media profile and reach, there is a need for more engagement by AllHPC partners and a focus on involving new audiences/agents for activity.

## APPENDIX A – Palliative Care Week Reference Group

Member	Organisation
Alex McGreevey	Northern Ireland Hospice
Alice Coffey	University of Limerick
Anne-Marie Hayes	Milford Care Centre
Audrey Allen	Marymount University Hospital & Hospice
Audrey Houlihan	Our Lady's Hospice & Care Services
Bernie Michaelides	Foyle Hospice
Bob Brown	Western Health and Social Care Trust
Brian Beattie	Southern Health and Social Care Trust
Brian Creedon	National Clinical Prog. for Palliative Care (ROI)
Carina O'Neill	Our Lady's Hospice & Care Services
Carmel Doyle	The Jack & Jill Children's Foundation
Caroline Dalton	University College Cork
Caroline McIlwain	Marie Curie Belfast
Charlene Hurley	Galway Hospice Foundation
Charles Normand	Trinity College Dublin
Ciara Cunningham	Southern Area Hospice Services, Newry
Claire McFall	Northern Health and Social Care Trust
Claire Sheeran	The Jack & Jill Children's Foundation
Corrina Grimes	Department of Health (NI)
Craig Harrison	Marie Curie Belfast
David Calvin	Southern Health and Social Care Trust
Dee Kinane	St Francis Hospice, Dublin
Diane Walker	Palliative Care in Partnership (NI)
Eamon O'Kane	Marie Curie Belfast
Eileen Courtney	Dublin City University
Eleanor Flew	Our Lady's Hospice & Care Services
Emma King	Western Health and Social Care Trust
Felicity Hasson	Ulster University
Fintan Fagan	St Francis Hospice, Dublin
Fiona Gilmour	Northern Health and Social Care Trust
Georgina Gethin	National University of Ireland Galway
Geraldine Tracey	Our Lady's Hospice & Care Services
Gillian Traub	Belfast Health and Social Care Trust
Greg Price	Health Service Executive
Hazel O'Shea	Ireland's Biggest Coffee Morning for Hospice
Heather Weir	Northern Ireland Hospice
Joan McEwan	Marie Curie Belfast
Joanne Reid	Queen's University Belfast
John Joyce	Voices4Care
Karen Dawson	Department of Health (NI)
Kathleen MacLellan	Department of Health (ROI)



Kerry	McLavery	LauraLynn Ireland's Children's Hospice
Kim	Elliott	Voices4Care
Kiran	Kaur	South Eastern Health and Social Care Trust
Lisa	McGirr	St Francis Hospice, Dublin
Loretta	Gribben	Public Health Agency
Louise	Hagan	Belfast Health and Social Care Trust
Lucy	McGettigan	Donegal Hospice
Lynn	Coulson	Macmillan Cancer Support
Mari	O'Connell	Kerry Specialist Palliative Care Services
Mary	Nash	Galway Hospice Foundation
Megan	Mason	Public Health Agency
Michael	Connolly	University College Dublin
Mila	Whelan	Health Service Executive
Nicki	Patterson	South Eastern Health and Social Care Trust
Pamela	Yeh	Health and Social Care Board
Pat	Quinlan	Milford Care Centre, Limerick
Paul	Turley	Health and Social Care Board
Paula	McGovern	Marymount University Hospital & Hospice
Pauline	Meskell	University of Limerick
Ray	Elder	South Eastern Health and Social Care Trust
Rebecca	Lloyd	The Irish Hospice Foundation
Roy	Hamill	Northern Health and Social Care Trust
Sally	Downing	Health Service Executive
Sarah	O'Callaghan	LauraLynn Ireland's Children's Hospice
Sarah	Meagher	LauraLynn Ireland's Children's Hospice
Sarah	McCloskey	Marymount University Hospital & Hospice
Sharon	Foley	The Irish Hospice Foundation
Sheilagh	Reaper-Reynolds	Health Service Executive
Shirley	Oguz	Northern Ireland Hospice
Siobhan	McCarthy	Royal College of Surgeons in Ireland
Tina	Priestly	The Jack & Jill Children's Foundation

The role of the reference group members are to advise on a campaign which:

- Identifies messages and content which are representative of thinking across the sector
- Is reflective of the perspectives of people with palliative care needs and carers
- Integrates harmoniously with messages and activities of other stakeholders in the sector
- Has members as links and champions of Palliative Care Week within their organisation, where appropriate, and across the health system.

AllHPC engaged with the reference group at key points in the planning and delivery of Palliative Care Week 2020. Engagement was two-way, with reference group members invited to make suggestions/propose ideas throughout the process, including consultation on the theme and tag line, involving participants in the palliative care experience video project, and consultation on draft promotional materials. Briefings for Reference Group members (by Zoom) in July and September were well attended and helped to keep members informed and engaged.

## APPENDIX B

### Questions for Palliative Care Survey, July 2020

#### Your understanding of palliative care

**Q1. Please state how much you agree or disagree with each of the following statements about palliative care** *Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, Strongly Disagree*

- I know how palliative care could help me or someone important to me
- Palliative care should be considered as early as possible when diagnosed with any life-limiting illness
- Palliative care is only for people with advanced cancer
- If a person is receiving palliative care, they must give up their other treatments
- I am comfortable to think or talk about palliative care
- I would feel confident to discuss palliative care with a hospital consultant, GP, community nurse or other health and social care professional
- I would like to be supported to discuss and write down my wishes and preferences for care at the end of life
- Palliative care is a last resort

#### COVID-19 Coronavirus pandemic and palliative care

**Q2. In terms of Covid-19, how has it affected your thoughts on palliative care?**

- The COVID-19 Coronavirus pandemic has made me more reluctant to think or talk about palliative care than before - **Yes or No**
- The COVID-19 Coronavirus pandemic has made me think more about death and dying than before - **Yes or No**
- The COVID-19 Coronavirus pandemic has increased the importance of discussing my wishes and preferences for care at the end of life - **Yes or No**
- The COVID-19 Coronavirus pandemic has increased the importance of discussing palliative care if I or someone important to me has a life-limiting illness - **Yes or No**
- COVID-19 Coronavirus pandemic infection control measures have changed the delivery of palliative care – **Yes/No/Don't know**

## APPENDIX C – Press Releases

### Press Release (tailored to locality/county)

6th August 2020

#### **People in [localised to each county] urged to get better informed about palliative care and tell others**

The All Ireland Institute of Hospice and Palliative Care (AIHPC) is calling on people in [county] to learn more about the benefits of palliative care as part of Palliative Care Week. Now in its seventh year, Palliative Care Week takes place from the 13<sup>th</sup> to 19<sup>th</sup> September.

Palliative Care Week 2020 aims to raise awareness throughout the island of Ireland about the positive difference palliative care can make to people with life-limiting conditions, their carers and their families.

This year's theme is 'Palliative Care: In This Together'. In these extraordinary times, this reflects the community response to Covid-19 but also the range of supports mobilized by health and social care professionals, and the wider community, to help people with palliative care needs and their loved ones to live as well as possible.

This personalised network of support can involve a broad range of professionals from primary care (such as GP's and public health nurses/district nurses), support from family and friends and the wider community, and support at home, in hospitals, nursing homes and hospices. The support is for all ages and life-limiting conditions and can be for days, weeks or years.

**Karen Charnley, AIHPC Director**, said;

*"Palliative care improves the lives of those living with a life-limiting illness and those who matter to them. It puts the individual at the centre of care and supports their physical, social, psychological and spiritual health needs. We've all seen this year how something like Covid-19 has brought out the best in people, especially in our communities, and while we can't hold events to mark Palliative Care Week 2020 we hope we can reignite some of that community spirit to help those closest to us to get better informed about palliative care and its benefits.*

*"Ultimately, we want as many people as possible in [county] to have a greater understanding of palliative care. So if people can help by sharing this knowledge or the Palliative Care Week leaflet, or even by sharing their story on social media, together we can help to remove any stigmas or misconceptions about palliative care.*

*"We might need to remain socially distant for some time to come but we can still feel close to our family and friends by having conversations about things like palliative care and understanding each other's future care wishes."*

To get informed:

- Visit [www.thepalliativehub.com/public-awareness](http://www.thepalliativehub.com/public-awareness) to find out more about palliative care and Palliative Care Week 2020 and test your knowledge of palliative care by taking a short True or False quiz
- Talk to your GP or any healthcare or social care professional about palliative care and its benefits.

For those with an interest in promoting a better understanding of palliative care:

- Download the leaflet from [www.thepalliativehub.com/public-awareness](http://www.thepalliativehub.com/public-awareness) and share it with your family, friends, colleagues, fellow members of local groups, or your online community
- Talk to your family and share your wishes in the event that you have palliative care needs in the future, and encourage others to do the same
- Share your own palliative care experience story on social media during Palliative Care Week 2020 using *#pallcareweek*.

AIHPC is encouraging people to get informed and to share this information with their family and friends, and any local groups they are in, during Palliative Care Week 2020.

Any groups or individuals wishing to obtain leaflets and/or posters can contact AIHPC by calling +353 1 4912948 or by emailing [info@aiihpc.org](mailto:info@aiihpc.org)

**-ENDS-**

**For further information or to request an interview contact:**

Robyn Keleghan on +353 87 136 8975 or [robyn@cclinic.ie](mailto:robyn@cclinic.ie)

Sarah Dunne on +353 85 853 5647 or [sarahd@cclinic.ie](mailto:sarahd@cclinic.ie)

#### **Notes to Editors:**

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AIHPC advances education, research and practice to improve the palliative care experience of people with life-limiting conditions and their families.

AIHPC works with a group of visionary partners who recognise the value of working together to achieve a better, richer experience of palliative care for people with life-limiting conditions. The organisation's 26 partners (15 Republic of Ireland / 11 Northern Ireland) are:

An Roinn Sláinte / Department of Health  
Belfast Health and Social Care Trust  
Dublin City University  
Dublin University Trinity College  
Galway Hospice Foundation  
Irish Hospice Foundation  
Lauralynn Children's Hospice  
Macmillan Cancer Support NI  
Marie Curie  
Marymount University Hospital & Hospice  
Milford Care Centre  
National University of Ireland Galway  
Northern Health and Social Care Trust  
Northern Ireland Hospice  
Our Lady's Hospice & Care Services  
Public Health Agency  
Queen's University Belfast

Royal College of Surgeons in Ireland  
South Eastern Health and Social Care Trust  
Southern Health and Social Care Trust  
St. Francis Hospice  
Ulster University  
University College Cork  
University College Dublin  
University of Limerick  
Western Health and Social Care Trust



**Press Release**

13<sup>th</sup> September 2020 (embargoed to 12 noon)

**Six in Ten People Believe Discussing Palliative Care is More Important Because of Covid-19**

Six in ten people think Covid-19 has increased the importance of discussing palliative care. The finding is from a new survey of perceptions of palliative care commissioned by the All Ireland Institute of Hospice and Palliative Care (AIHPC) to highlight Palliative Care Week (13th to 19th September). The tagline and theme for the seventh annual Palliative Care Week is 'Palliative Care: In This Together'.

The survey of people in Northern Ireland, carried out in July 2020, also found that 3 in 4 people would like to be supported to discuss and write down their wishes and preferences for care at the end of life.

The findings also demonstrate that misconceptions exist about palliative care. The survey found that 1 in 3 people think palliative care is a last resort, whereas palliative care may be appropriate for a number of years, not just for weeks and days at the end of life. It also found that nearly 1 in 3 people think that palliative care is only for people with advanced cancer, whereas everyone living with a life-limiting illness can benefit from palliative care.

Palliative Care Week, facilitated by AIHPC, aims to raise awareness across the island of Ireland about the positive difference palliative care can make to people with life-limiting conditions and their carers and families. The focus of the week is for people to get better informed about palliative care and its benefits while helping to remove any stigmas or misconceptions about palliative care.

Marking Palliative Care Week 2020, **Minister for Health, Robin Swann**, said: *"I am supporting this year's Palliative Care Week to encourage a broader public discussion on this important issue. Good palliative care can support people living with life-limiting conditions to live well, making a real difference both for them and those who are important to them. We all need to be part of this wider conversation to help raise awareness and dispel the misconceptions around palliative care. That includes, at an individual level, thinking about the things that matter to us and having conversations with our loved ones about our preferences and wishes for our future care."*

Palliative care puts the individual at the centre of care and supports their physical, social, psychological and spiritual health needs. It requires a broad range of professionals, family carers and communities working together to support the person with a serious health condition and those closest to them. Palliative care is provided at home, in hospitals, nursing homes and hospices and it can improve a person's quality of life throughout the course of their illness.

**AIHPC Director Karen Charnley** said the aim of Palliative Care Week is for people to have a better understanding of palliative care and its benefits: *"This week we would like people to think about palliative care and how it could help them. We encourage people to talk about palliative care and its benefits with their GP or other health and social care professionals, and with those who are important to them. It's clear from our findings that Covid-19 has increased the importance of discussing palliative care, and its quality of life benefits for those with life-limiting illnesses and for their family carers."*

**Macmillan Clinical Nurse Specialist in Altnagelvin Hospital, Patricia O'Connor** said: *“The palliative care focus is to maintain sight of the whole person in all of this; getting to know what it is they want, where they want to be, to support the patient and their loved ones through this time, and to work with the multi-disciplinary team to make sure an effective symptom management plan is implemented.*

*“Covid-19 has changed everything and it has meant a new way of working. The understandable restrictions placed on visiting has been the most difficult, particularly for patients who were at the end of their lives. However, the deep connections made with patients and those closest to them by phone during this period have enriched these experiences. Whether Palliative Care is the hand that holds yours or the voice at the other end of the phone, it’s there for you as a person - a person who is valued and matters.”*

**Rodney Morton, Director of Nursing and Allied Health Professionals at the Public Health Agency** said: *“The theme of this year’s Palliative Care week, ‘In this together’, highlights what palliative care is all about. The ethos of our regional palliative care programme - Palliative Care in Partnership - recognises the importance of collaboration between our health and social care system, voluntary organisations and local communities in working together to meet the holistic needs of people and those important to them as they approach the end of their lives.*

*“The Palliative Care in Partnership programme is committed to ongoing engagement with our partners and stakeholders across care settings to ensure the delivery of safe, effective and compassionate end of life care for the population of Northern Ireland.”*

Visit [www.thepalliativehub.com/public-awareness](http://www.thepalliativehub.com/public-awareness) to find out more. #pallcareweek

Watch the AIHPC short In This Together video [here](#).

**-ENDS-**

**For further information or to request an interview/photos contact:**

Sarah Dunne, +353 85 853 5647 or [sarahd@cclinic.ie](mailto:sarahd@cclinic.ie)

Robyn Keleghan, +353 87 136 8975 or [robyn@cclinic.ie](mailto:robyn@cclinic.ie)

**Photo caption:**

(L to R) Brendan O’Hara, Programme Manager, All Ireland Institute of Hospice and Palliative Care (AIHPC), Minister for Health, Robin Swann, and Karen Charnley, AIHPC Director, launching Palliative Care Week 2020, with the aim of encouraging people to think about palliative care and how it can help them.

**Notes to Editors:**

- \*iReach survey of 500 people in Northern Ireland conducted in July 2020.
- Karen Charnley, AIHPC Director, is available for interview.
- Press Eye will issue images to photo desks today for reproduction free-of-charge.

**Additional Information on the Ageing Population and Palliative Care Requirements:**

- Evidence suggests that between 75% and 80% of people who die have conditions that would benefit from some palliative care services, with the potential to support their quality of life for weeks, months and years.
- Demands for palliative care services are expected to double by 2050.
- The need for palliative care is increasing across the island of Ireland. The number of people dying in Northern Ireland over a 25-year period from 2016 to 2041 is projected to increase by 32 per cent (from 15,300 to 20,300) - NISRA Statistical Bulletin (October 2017).
- The number of deaths in the Republic of Ireland (which is a good indicator of likely palliative care needs) is projected to rise to 54,000 by 2050, representing a rise of 74% since 2016.

### **About All Ireland Institute of Hospice and Palliative Care:**

All Ireland Institute of Hospice and Palliative Care (AIHPC) is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. AIHPC advances education, research and practice to improve the palliative care experience of people with life-limiting conditions and their families.

AIHPC works with a group of visionary partners who recognise the value of working together to achieve a better, richer experience of palliative care for people with life-limiting conditions. The organisation's 26 partners (15 Republic of Ireland / 11 Northern Ireland) are:

An Roinn Sláinte / Department of Health  
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 Macmillan Cancer Support NI  
 Marie Curie  
 Marymount University Hospital & Hospice  
 Milford Care Centre  
 National University of Ireland Galway  
 Northern Health and Social Care Trust  
 Northern Ireland Hospice  
 Our Lady's Hospice & Care Services  
 Public Health Agency  
 Queen's University Belfast  
 Royal College of Surgeons in Ireland  
 South Eastern Health and Social Care Trust  
 Southern Health and Social Care Trust  
 St. Francis Hospice  
 Ulster University  
 University College Cork  
 University College Dublin  
 University of Limerick  
 Western Health and Social Care Trust.

Press Release

13<sup>th</sup> September 2020 (embargoed to 12 noon)

**Half the Population Believe Discussing Palliative Care is More Important Because of Covid-19**

Half the population think Covid-19 has increased the importance of discussing palliative care. The finding is from a new survey of perceptions of palliative care commissioned by the All Ireland Institute of Hospice and Palliative Care (AIHPC) to highlight Palliative Care Week (13th to 19th September). The tagline and theme for the seventh annual Palliative Care Week is 'Palliative Care: In This Together'.

The survey of people in the Republic of Ireland, carried out in July 2020, also found that 4 in 5 people would like to be supported to discuss and write down their wishes and preferences for care at the end of life.

The findings also demonstrate that misconceptions exist about palliative care. The survey found that 1 in 3 people think palliative care is a last resort, whereas palliative care may be appropriate for a number of years, not just for weeks and days at the end of life.

Palliative Care Week, facilitated by AIHPC, aims to raise awareness across the island of Ireland about the positive difference palliative care can make to people with life-limiting conditions and their carers and families. The focus of the week is for people to get better informed about palliative care and its benefits while helping to remove any stigmas or misconceptions about palliative care.

Speaking ahead of Palliative Care Week 2020, **Minister for Health, Stephen Donnelly**, said: *"Palliative care plays a vital role in maintaining quality of life for people with life-limiting or life-threatening conditions. It is important that the public understands palliative care and the benefits of accessing such care when needed. Palliative Care Week helps to grow this awareness and understanding."*

Reflecting on this year's theme, Minister Donnelly added: *"Much like the national effort against Covid-19, Palliative Care Week reminds us that we are all in this together when it comes to caring for people with life-limiting conditions in our society. We stand in solidarity with all those receiving palliative care, and I am delighted to support Palliative Care Week."*

Palliative care puts the individual at the centre of care and supports their physical, social, psychological and spiritual health needs. It requires a broad range of professionals, family carers and communities working together to support the person with a serious health condition and those closest to them. Palliative care is provided at home, in hospitals, nursing homes and hospices and it can improve a person's quality of life throughout the course of their illness.

**AIHPC Director, Karen Charnley** said the aim of Palliative Care Week is for people to have a better understanding of palliative care and its benefits: *"This week we would like people to think about palliative care and how it could help them. We encourage people to talk about palliative care and its benefits with their GP or other health and social care professionals, and with those who are important to them. It's clear from our findings that Covid-19 has increased the importance of discussing palliative care, and its quality of life benefits for those with life-limiting illnesses and for their family carers."*

**Joe McCann** from Dublin is receiving palliative care from St Francis Hospice, Dublin. In 2018 Joe was diagnosed with prostate cancer that had spread into his bones and leg. Speaking to mark the launch of Palliative Care Week 2020, Joe said: *“It was a complete shock to myself and the family. They caught the cancer in time but there is nothing they could do with the bone. Then St Francis Hospice got in touch and I went there about once a month for relaxation therapy, occupational therapy and physiotherapy. They also gave me exercises to do at home, like breathing exercises; I found this very relaxing. The palliative care has been absolutely great.”*

Joe’s daughter, **Vivienne**, said: *“When you hear the word palliative care it knocks you back but we have seen a whole other side to it. It’s a support system – it’s being around people that are in the same position as you, and the support received has been amazing. I’d say the biggest improvement I’ve seen in him would be his mental health.”*

**Dr Brian Creedon**, Consultant Palliative Medicine Physician in University Hospital Waterford and Clinical Lead for the National Clinical Programme for Palliative Care, said: *“Much fear and misunderstanding persists about palliative care. The assumption that the role of palliative care professionals is limited to end-of-life risks denying vital care to patients. Palliative care enables those living with a life-limiting illness to be empowered to experience an improved quality of life – it is not dependent on prognosis, or disease, and can be delivered at the same time as curative treatment.*

*“As a community we have never been more ‘in this together’ and during Palliative Care Week I encourage you and your families to become informed about the role and place of palliative care, and reflect on your own future care preferences.”*

Visit [www.thepalliativehub.com/public-awareness](http://www.thepalliativehub.com/public-awareness) to find out more. #pallcareweek

Watch the AIHPC short In This Together video [here](#).

**-ENDS-**

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**Photo captions:**

*Photo 1:*

(L to R) Karen Charnley, Director, and Brendan O’Hara, Programme Manager, All Ireland Institute of Hospice and Palliative Care (AIHPC) launching Palliative Care Week 2020, with the aim of encouraging people to think about palliative care and how it can help them.

*Photo 2:*

Karen Charnley, Director, and Brendan O’Hara, Programme Manager, All Ireland Institute of Hospice and Palliative Care (AIHPC) launching Palliative Care Week 2020, with the aim of encouraging people to think about palliative care and how it can help them.



### **Notes to Editors:**

- \*iReach survey of 1,000 people in the Republic of Ireland conducted in July 2020.
- A number of individuals in receipt of palliative care are willing to share their experience with the media including Joe McCann. Please see a video of Joe [here](#).
- Karen Charnley, AllHPC Director, is available for interview.
- To request an interview with Dr Brian Creedon, Clinical Lead for the National Clinical Programme for Palliative Care, use the contact details above.

### **Additional Information on the Ageing Population and Palliative Care Requirements:**

- Evidence suggests that between 75% and 80% of people who die have conditions that would benefit from some palliative care services, with the potential to support their quality of life for weeks, months and years.
- Demands for palliative care services are expected to double by 2050.
- The need for palliative care is increasing across the island of Ireland. The number of deaths in the Republic of Ireland (which is a good indicator of likely palliative care needs) is projected to rise to 54,000 by 2050, representing a rise of 74% since 2016.
- The number of people dying in Northern Ireland over a 25-year period from 2016 to 2041 is projected to increase by 32 per cent (from 15,300 to 20,300) - NISRA Statistical Bulletin (October 2017).

### **About All Ireland Institute of Hospice and Palliative Care:**

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AllHPC works with a group of visionary partners who recognise the value of working together to achieve a better, richer experience of palliative care for people with life-limiting conditions. The organisation's 26 partners (15 Republic of Ireland / 11 Northern Ireland) are:

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Marymount University Hospital & Hospice

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Public Health Agency  
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Southern Health and Social Care Trust  
St. Francis Hospice  
Ulster University  
University College Cork  
University College Dublin  
University of Limerick  
Western Health and Social Care Trust.

## APPENDIX D – Promotional Materials

### Information Leaflet



# PALLIATIVE CARE IN THIS TOGETHER



PALLIATIVE CARE WEEK  
 13-19 SEPTEMBER

### What do you know about palliative care?

Test your knowledge by choosing true or false for the following statements\*

- One goal of palliative care is to address any psychological issues brought up by serious illness. T / F
- Palliative care can help people manage the side effects of their medical treatments. T / F
- Palliative care is exclusively for people who are in the last six months of life. T / F
- Palliative care is specifically for people with cancer. T / F
- People must be in hospital to receive palliative care. T / F
- Palliative care applies only to adults and older people. T / F
- One aim of palliative care is to help people better understand their treatment options. T / F
- Palliative care encourages people to stop treatments aimed at curing their illness. T / F
- Palliative care helps the whole family cope with a serious and progressive illness. T / F

**Check out the answers on the bottom of the back page of this leaflet**

\* Adapted from Development and Validation of the Palliative Care Knowledge Scale (PKCS) - Kavanagh, Coakley, Rodhebaugh, Palliative and Supportive Care (2017), 15, S24-S24. Cambridge University Press. DOI: 10.1017/S1472262516000897

[www.thepalliativehub.com](http://www.thepalliativehub.com)

### Palliative Care Week

**Sunday 13 September to Saturday 19 September 2020**

Palliative Care Week aims to raise awareness of the difference palliative care can make to a person with a life-limiting illness, their family and carers, across the island of Ireland. Find out more about palliative care, and its benefits for you and those important to you.

Palliative care requires a broad range of professionals, family carers and communities working together to support the person with a serious health condition and those close to them.

### Palliative care

**I** I am a patient  
**N** Not an illness

**T** Time may be limited  
**H** Help for of ages, for days, weeks or years  
**I** Illness is difficult but my quality of life can be improved  
**S** Speaking openly and honestly will help

**T** Treatments for pain and other symptoms  
**O** Opportunities to plan ahead  
**G** Goal setting to help me live as well as possible  
**E** Emotional, spiritual and psychological support  
**T** Teamwork will help my care  
**H** Hospice is important  
**E** Embracing me as I am  
**R** Realising I am not entirely alone



### Palliative care needs community spirit

The starting point in palliative care is always the person. Palliative care improves the lives of people living with a life-limiting illness and of those who matter to them. Palliative care isn't just medical. It is about the person's physical, social, psychological and spiritual health, and can involve their friends and family.

Quality of life is improved where all supports for a person with palliative care needs are in place, including the wider community alongside health and social care services. This has been a feature of the outstanding community response to the COVID-19 pandemic, which has brought pain for many people as they face caring, death, dying, and bereavement.

This community response maintained and improved people's quality of life, including those living with serious and progressive illnesses. At all times people in our communities are living with a serious health problem. Let's apply our community spirit to supporting them, along with their friends and family, to live well until the end of their lives. We are in this together.

**Don't be afraid to ask**

If you think you or someone important to you could benefit from palliative care, talk to your GP, a community nurse, your consultant, social worker, or any health and social care professional.

**Get in touch or find out more about Palliative Care**

 [info@aaihpc.org](mailto:info@aaihpc.org)
 [www.thepalliativehub.com](http://www.thepalliativehub.com)
 @AIIHPC

All Ireland Institute of Hospice and Palliative Care  
 2nd Floor, Education and Research Centre  
 Our Lady's Hospital & Care Services  
 Harold's Cross, Drogheda  
 Tel: +353 (0) 25 22 22 22

#pallcareweek

1. True, 2. True, 3. False, 4. False, 5. False, 6. False, 7. True, 8. False, 9. True

## Poster



## Email signature



## Twitter Cover



Facebook Cover



Social Media Picture Frame



Infographics (based on key points from survey – ROI and NI)

**PALLIATIVE CARE WEEK 13-19 SEPTEMBER**

### Perceptions of Palliative Care

**1 IN 3 PEOPLE**

Think palliative care is a last resort\*

**FACT**

Palliative care may be appropriate for a number of years, not just for weeks and days at the end of life.

**50%\*** MORE THAN 50% OF PEOPLE\*

Think that COVID-19 has increased the importance of discussing palliative care

**4 IN 5 PEOPLE**

Would like to be supported to discuss and write down their wishes and preferences for care at the end of life\*

AIIHPC  
#pallcareweek  
www.thepalliativehub.com  
\* Survey of 1000 people in the Republic of Ireland July 2020

**PALLIATIVE CARE WEEK 13-19 SEPTEMBER**

### Perceptions of Palliative Care

**1 IN 3 PEOPLE**

Think palliative care is a last resort\*

**FACT**

Palliative care may be appropriate for a number of years, not just for weeks and days at the end of life.

**60%\*** MORE THAN 60% OF PEOPLE\*

Think that COVID-19 has increased the importance of discussing palliative care

**NEARLY 1 IN 3 PEOPLE\***

Think that palliative care is only for people with advanced cancer

**FACT**

Everyone living with a life-limiting illness can benefit from palliative care

**3 IN 4 PEOPLE**

Would like to be supported to discuss and write down their wishes and preferences for care at the end of life\*

AIIHPC  
#pallcareweek  
www.thepalliativehub.com  
\* Survey of 500 people in Northern Ireland July 2020

## APPENDIX E – Media Coverage

1. 6 August 2020, Carlow Live, 'Palliative care improves the lives of Carlow people living with a life-limiting illness' (ROI), Online
2. 6 August 2020, Waterford Live, 'Palliative care improves the lives of Carlow people living with a life-limiting illness' (ROI), Online
3. 6 August 2020, Connaught Telegraph, 'Get better informed about palliative care' (ROI), Online
4. 6 August 2020, Longford Leader, 'People in Longford urged to get better informed about palliative care and tell others' (ROI), Online
5. 10 August 2020, TheCork.IE, '#PallCareWeek – People in Cork urged to get better informed about palliative care' (ROI), Online
6. 10 August 2020, Carlow Nationalist, 'Palliative Care Information Week' (ROI) Online
7. 11 August 2020, Tipp Mid West Radio, Brendan O'Hara, Programme Manager AIIHPC, Morning Call, (ROI) Radio
8. 11 August 2020, The Argus, 'Palliative Care Week marked in Louth' (ROI)
9. 11 August 2020, Newry Democrat, 'Down people urged to get better informed about palliative care' (NI)
10. 12 August 2020, NEAR FM, interview with Karen Charnley, Director AIIHPC, (ROI), Radio
11. 13 August 2020, Ulster Gazette, 'People in Armagh are urged to get better informed about palliative care' (NI)
12. 13 August 2020, Banbridge Chronicle, 'People in Down asked to learn about palliative care' (NI)
13. 13 August 2020, Tyrone Constitution, 'People in Tyrone urged to get better informed about palliative care and tell others' (NI)
14. 13 August 2020, Newsletter, 'Marking Palliative Care Week 2020' (NI)
15. 13 August 2020, Laois Today, 'People in Laois urged to get better informed about palliative care' (ROI), Online
16. 13 August 2020, The Avondhu, 'People in the Avondhu area urged to get better informed about palliative care and tell others' (ROI)
17. 13 August 2020, Northern Standard, 'People in Monaghan urged to get better informed about palliative care' (ROI)
18. 13 August 2020, Mid-Ulster Mail, 'Benefits of Palliative care' (NI)
19. 14 August 2020, Dundalk FM – Town Talk (ROI), interview with Brendan O'Hara, Radio
20. 14 August 2020, Dungarvan Observer, 'People in Waterford urged to get better informed about palliative care and tell others' (ROI)
21. 14 August 2020, Connacht Tribune, 'Palliative Care Week' (ROI)
22. 14 August 2020, Clare Champion, 'In This Together' (ROI)
23. 19 August 2020, Northside People East, 'People are urged to get better informed about palliative care' (ROI)

24. 19 August 2020, Southside People East, 'People are urged to get better informed about palliative care' (ROI)
25. 19 August 2020, Londonderry & Roe Valley Sentinel, 'Marking Palliative Care Week 2020' (NI)
26. 20 August 2020, Athlone Advertiser, 'Become more pertinently informed during Palliative Care Week' (ROI)
27. 22 August 2020, Limerick Post, 'Palliative Care' (ROI)
28. 6 September 2020, Sunday Independent, 'How we can empower patients facing life-limiting illnesses', Opinion Piece, Dr Brian Creedon (ROI)
29. 8 September 2020, The Irish Times, 'It's like a comfort blanket knowing they are there', Sheila Wayman (parent of a child with Aicardi Syndrome) (ROI)
30. 9 September 2020, Cork ECHO, 'Palliative Care: We are in this together', Opinion Piece, Dr Bridget Johnson (ROI), Online
31. 10 September 2020, Irish Farmers Journal, 'Palliative Care: it's much more than you think' Interview with Dr Brian Creedon (ROI)
32. 10 September 2020, Kerry's Eye, '30% rise in palliative care referrals' Interview with Dr Patricia Sheehan (ROI)
33. 10 September 2020, TodayFM, The Last Word with Matt Cooper, interview with Joe McCann and daughter Vivienne, radio (ROI)

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13 September 2020, News Bulletins- Press release detail and soundbite from Karen Charnley featured on 29 radio stations bulletins – Radio

- 4fm
- 9FM
- Newstalk
- Today FM
- Spin 1028
- Spin South West
- Beat 102/103
- C103
- Q102
- Radio Nova
- Red FM
- Cork's 96fm
- East Coast Radio
- FM104
- Galway Bay FM
- KCLRFM
- KFM
- Limerick's 95FM
- Midlands 103

- Midwest Radio
  - Northern Sound Radio
  - Ocean FM
  - Q Radio
  - Radio Kerry
  - Shannon Side
  - South East Radio
  - Sunshine FM
  - Tipp FM
  - WLRFM
62. 13 September 2020, thejournal.ie, 'Half of Irish people think COVID-19 has increased the importance of discussing palliative care' (ROI) Online with Pic
  63. 13 September 2020, KFM Radio, 'Over half of people in Ireland believe the effect of Covid-19 has increased the importance of palliative care' (ROI) – Radio
  64. 14 September 2020, Irish Mirror, 'Covid-19 highlights importance of palliative care chat' (ROI) with pic
  65. 14 September 2020, Irish Independent, 'Palliative Care doesn't mean you're going to die soon' interview with Joe McCann, (ROI) with pic
  66. 14 September 2020, Dublin City FM 103.2, Aftering, (ROI), SoundCloud, interview with Karen Charnley – Radio
  67. 14 September 2020, KCLR 96FM, Palliative Care week featured in bulletins @ 7am, 8am, 9am and 11:30am (ROI) – Radio
  68. 14 September 2020, RTE Radio 1, A Living Word, (ROI), Brendan O'Hara, Radio
  69. 15 September 2020, RTE Radio 1, A Living Word, (ROI), Brendan O'Hara, Radio
  70. 16 September 2020, RTE Radio 1, A Living Word, (ROI), Brendan O'Hara, Radio
  71. 17 September 2020, RTE Radio 1, A Living Word, (ROI), Brendan O'Hara, Radio
  72. 18 September 2020, RTE Radio 1, A Living Word, (ROI), Brendan O'Hara, Radio
  73. 14 September 2020, The Ryan Tubridy Show, RTE Radio 1, 'Mention of Palliative Care Week in interview' (ROI) – Radio
  74. 14 September 2020, CRY104FM, Karen Charnley interviewed on Drivetime Show, (ROI) - Radio
  75. 14 September 2020, Radio na Gaeltachta, interview with Aine Moriarty, Kerry Specialist Palliative Care Services (ROI) - Radio
  76. 15 September 2020, Highland Radio, Nine til Noon Show, Donegal, Karen Charnley interviewed, Radio
  77. 15 September 2020, Midwest Radio, 96.1fm, (ROI), Interview with John Joyce, Radio
  78. 15 September 2020, WLRFM Interview with Dr Brian Creedon, Radio
  79. 15 September 2020, Derry Journal, 'Local people urged to discuss end of life car' (NI) with pic
  80. 16 September 2020, The Herald, 'Palliative Care doesn't mean you're going to die soon' interview with Joe McCann, (ROI) with pic
  81. 16 September 2020, Weekly Observer, Killeedy – Palliative Care, (ROI)



82. 17 September, Radio Kerry, interview with Deirdre Walsh Talkabout show, Dr Margaret Clifford Consultant and Geraldine Topham speaking about her daughter Rachel who was cared for by Kerry Specialist Palliative Care Services (ROI) - Radio
83. 17 September 2020, Derry News, Palliative Care Week events, (NI)
84. 17 September 2020, Impartial Reporter, 'Palliative Care Week shines a light on helping people' (NI) interview with Dr Conn Haughey
85. 17 September 2020, Kerry's Eye, 'Providing the personal touch in palliative care' (ROI) with pic
86. 17 September 2020, Ulster Herald, 'We can't thank them enough for providing the best care' (NI)
87. 17 September 2020, Ulster Herald, Much more than end of life support (NI)
88. 18 September 2020, Derry Journal, The Covid-19 crisis has raised awareness of palliative care (NI) with pic
89. 19 September 2020, Limerick Post, 'Palliative Care' (ROI)
90. 21 September 2020, Pat Kenny Show – Newstalk, Ask the Expert session with Dr Brian Creedon (ROI)
91. 24 September 2020, Limavady Northern Constitution, 'Palliative Care and Covid' (NI) with pic
92. 24 September 2020, Ballycastle Chronicle, 'Palliative Care and Covid' (NI) with pic
93. 24 September 2020, Ballymoney Chronicle, 'Palliative Care and Covid' (NI)
94. 24 September 2020, Coleraine Chronicle, 'Palliative Care and Covid' (NI)

#### **APPENDIX F – Themes**

Palliative Care Week 2020 was the seventh annual campaign facilitated by All Ireland Institute of Hospice and Palliative Care.

The tag lines for the seven campaigns are:

- 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)
- Palliative Care: Surrounding You With Support (2019)
- Palliative Care: In This Together (2020)

T: +353 (0)1 491 2948

E: [info@aiihpc.org](mailto:info@aiihpc.org)

**AIHPC, Second Floor, Education & Research Centre, Our  
Lady's Hospice, Harold's Cross, Dublin 6W, D6W RY72**

<http://www.aiihpc.org> | [www.thepalliativehub.com](http://www.thepalliativehub.com)



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