



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

Palliative Care Week 2019 Report

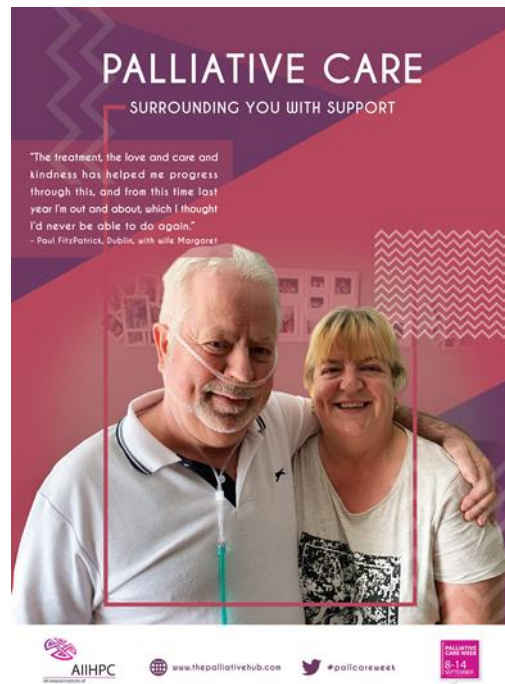
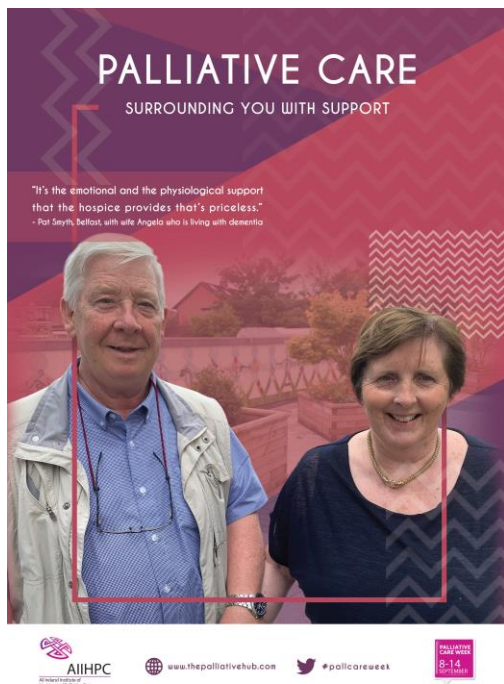


Palliative Care: Surrounding You With Support

January 2020

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Palliative Care Week 2019 at a glance

- 1** Minister launch
- 1** Permanent Secretary launch
- 7** Service users and carers involved in media
- 7** Videos of personal experiences of palliative care
- 11** Service users and carers featured in videos
- 13** AIHPC Partners featured in VIEW Magazine
- 16** Voices4Care members distributing materials
- 21** TV and Radio Palliative Care Week interviews
- 78** Recipients of promotional materials for distribution
- 126** Media interactions in total
- 1,400** Leaflets to Hospice Friendly Hospitals Network
- 1,896** Palliative Hub sessions
- 2,677** Twitter posts
- 6,000** Leaflets in Coffee Morning packs
- 18,200** Leaflets distributed in total
- 67,000** Viewers of one media story
- 300,000** Estimated listenership to radio interviews

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 practice to improve the palliative care experience of people with life-limiting conditions and their families.

Through its involvement with its 25 partners, with the Regional Palliative Care Programme in Northern Ireland - Palliative Care in Partnership, and with the National Clinical Programme for Palliative Care in the Republic of Ireland, AIHPC supports the delivery of high quality palliative care.

Palliative care has a role to play in promoting health and wellbeing. Serious illness, death, dying, loss and grief are universal experiences.

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 understanding of palliative care. The sixth 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.¹

2. Planning for Palliative Care Week 2019

Planning for Palliative Care Week 2019 began in late 2018. Notification of the dates was issued to key contacts in late November 2018 and published in the AIHPC newsletter in February 2019 to enable scheduling and planning of activities.

AIHPC was delighted that, for a third year, the Health Service Executive (Republic of Ireland) funded a Palliative Care Experience Video Project and agreed that the videos could be featured in the campaign. The project was also supported by the Public Health Agency (Northern Ireland). Promotion of the opportunity to take part in the video project got underway in March.

AIHPC's objectives for Palliative Care Week 2019 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.

¹Republic 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)

3. Key Developments

Theme - Palliative Care: Surrounding You With Support

Having consulted with the Palliative Care Week Reference Group (Appendix A) and considered previous Palliative Care Week themes (Appendix E) and other campaigns, the theme for 2019 was confirmed as: Palliative Care: Surrounding You With Support.

In 2019 we decided to focus on how people with palliative care needs are being supported in the community. Experiences could have involved support from primary care (GP, Public Health Nursing, District Nursing), from hospice, hospital, nursing home, and wider community support beyond formal health and social care services.

Palliative Care Experience Videos

For the third year, AIIHPC supported by the Health Service Executive (HSE) Quality Improvement Division (Republic of Ireland) collaborated to produce seven videos highlighting a wide range of palliative care experiences. The project was also supported by the Public Health Agency (Northern Ireland). We are indebted to the participants in the video project who were so generous in sharing their personal palliative care experiences; which were central to the campaign. The seven videos were released during the week and were available on the Palliative Hub. The support of AIIHPC partners, particularly voluntary hospices, in involving participants in the video project in 2019 was vital.

Faces of the Campaign

A number of participants in the videos agreed to be involved in the Palliative Care Week campaign through having their photographs and comments included in promotional materials, including the campaign leaflet and poster (Appendix B). The two couples who were the faces of the campaign posters – Paul and Margaret FitzPatrick from Dublin, and Pat and Angela Smyth from Belfast – were very generous with their engagement in the campaign, including attending events held during Palliative Care Week.



Paul and Margaret FitzPatrick with Health Minister Simon Harris in Dublin.



Pat and Angela Smyth in Belfast with Richard Pengelly, Permanent Secretary, Department of Health, and Karen Charnley, AIIHPC Director.

Launch – Support from Minister and Permanent Secretary

Health Minister Simon Harris in Dublin and Richard Pengelly, Permanent Secretary at the Department of Health in Belfast, supported the campaign and facilitated photocalls to formally launch the campaign. AllHPC is pleased to have facilitated these opportunities where Minister Harris was able to hear directly from Paul and Margaret; and Pat and Angela who were able to talk to Mr Pengelly from their living palliative care experience.

Media

There was a significant increase in media activity for Palliative Care Week 2019. Several participants who were involved in the videos agreed to involvement in media interviews and were supported by AllHPC and media communications experts in this process. Among media opportunities which were secured was a feature on RTE TV Six One News and U105 Radio in Belfast.



Kate Cameron, from Galway, interviewed for RTE Six One News on 12 September

Events

AIHPC is delighted at the number of events held to coincide with Palliative Care Week. A major event organised by the Palliative Care in Partnership Programme was addressed by Richard Pengelly, Permanent Secretary at the Department of Health, Northern Ireland, at the beginning of Palliative Care Week.

Other events were organised to link into strategic initiatives, for example Making Life Better, which considered where public health meets palliative care.

The Irish Centre for Social Gerontology at NUI Galway hosted well-known author Dr Kathryn Mannix at an event in Galway during the week.



Pictured left, Karen Charnley, AIHPC Director, with Richard Pengelly, Permanent Secretary, Department of Health, and Mary Hinds, Director, Public Health Agency and colleagues at the Transforming Palliative Care event in Belfast. Pictured above is Voices4Care member Janet Moffett who spoke at the event.



Dr Kathryn Mannix was featured in the Big Interview in the VIEW edition which focussed on palliative care. AIHPC Programme Manager Brendan O'Hara caught up with Dr Mannix when she spoke in Galway during Palliative Care Week.



Pictured at the Making Life Better Seminar in Lisburn are (from left) Ed McClean, Public Health Agency, Corrina Grimes, Public Health Agency, Professor Sonja McIlfatrick, Ulster University, Brendan O'Hara, AIHPC, Karen Charnley, AIHPC, Chris Matthews, Department of Health.



Pictured at the launch of the British Heart Foundation (NI) Guidelines at Stormont are colleagues from BHF NI, the Public Health Agency, Health and Social Care Board and AllHPC.



Fintan Fagan, AllHPC Chair (second from right) at the launch of VIEW magazine. Included are Paul and Margaret FitzPatrick, VIEW editor Brian Pelan and Brendan O'Hara, AllHPC Programme Manager and guest editor for VIEW.

VIEW Magazine

AllHPC sponsored what was the first all-Ireland edition of the VIEW social affairs magazine with a view to palliative care looking to the future. The 'Insight Into Palliative Care' edition had a broad range of contributions, including articles involving 13 of AllHPC's 25 partners, along with contributions from colleagues in the HSE. It also featured perspectives from beyond the island of Ireland, from England, from the USA and from New Zealand. The magazine can be viewed [here](#)

Hospice Friendly Hospitals

Palliative Care Week promotional packs, including posters and leaflets, were distributed to the 47 hospitals in the Hospice Friendly Hospitals Programme, an initiative of AllHPC partner The Irish Hospice Foundation.

Champions

AllHPC positioned itself as a supportive facilitator for Palliative Care Week with the aim that key stakeholders, including Institute partners and funders, would maximise on the opportunity of getting involved in the campaign. Where an AllHPC partners identified a lead person for the campaign within their organisation and there was a notable increase in promotional activity and involvement for the campaign.

4. Campaign Planning

Audiences

Primary audiences included those who could benefit from palliative care, health and social care professionals, the general public and communities in the Republic of Ireland and Northern 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

Previous campaigns benefitted from the involvement of a reference group and again this group, with updated membership, was a key channel for communication and raising awareness of the campaign itself; and for testing thinking for the 2019 campaign. 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 the Health Service Executive (Republic of Ireland) and the Public Health Agency/Health and Social Care Board (Northern Ireland).

Two similar teleconference briefings were provided for colleagues from health and social care trusts in the north and from voluntary hospice partners, along with communications colleagues, on Thursday 22 and Wednesday 28 August. There was ongoing contact with these colleagues, who were members of the Reference Group, throughout campaign planning and delivery.

Key messages

In the promotional materials to accompany the campaign messaging was kept simple.

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.

Voices4Care

An update on the 2019 campaign was provided to Voices4Care members on 11 July 2019. A further email with information on campaign materials was sent on 12 August. An update for members on plans for Palliative Care Week 2019 was presented at a Voices4Care meeting in Dublin on 9 August and in Belfast on 27 August. Voices4Care members supported the campaign in various ways including the distribution of promotional materials in their communities and on social media.

5. Resources

As with previous years, the 2019 campaign included a suite of promotional materials, media engagement, the use of social media and supporting partner events. As well as printed copies of materials being available, people were directed to www.thepalliativehub.com where a range of resources could be viewed/downloaded.

Promotional Materials

The following materials were designed (see Appendix B):

- Campaign logo
- Leaflet (A5 size)
- Two posters
- Two screensavers & email signatures (Pat and Angela Smyth, Paul and Margaret FitzPatrick)
- Twitter header and Facebook cover
- Social media campaign picture frame sheet.

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.



More than a third of views of the seven videos incorporated in the Palliative Care Week campaign were of Paul FitzPatrick's story (left) which had 725 views and of Pat & Angela Smyth's story (right) which had 538 views from 6 to 16 September

The videos feature:

- Anthony and Rosemary O'Mullan, Ballymena, County Antrim - Anthony was supported by Marie Curie at home
- Aideen and Chris Herdman (father and daughter), Navan, County Meath. Aideen attended an HSE Special Care Unit and LauraLynn Ireland's Children's Hospice
- Paul FitzPatrick, Coolock, Dublin, attended the Exhale Programme at St Francis Hospice, Blanchardstown
- Collette Grealish Keane, Renmore, Galway, attended Day Hospice at Galway Hospice
- Kate Cameron, Loughrea, Galway, received palliative care at Galway Hospice
- Pat and Angela Smyth, Belfast – Angela attended a dementia service through Northern Ireland Hospice
- Catriona Hastings, Dublin, attended Blackrock Hospice Day Services

The support of Marie Curie Northern Ireland; LauraLynn Ireland’s Children’s Hospice; St Francis Hospice, Dublin; Galway Hospice Foundation; Northern Ireland Hospice; and Our Lady’s Hospice & Care Services, Dublin, are gratefully acknowledged for their support in involving participants in the videos. All of the videos can be viewed [here](#)

Social Media Plan

A social media plan was developed in preparation for the week and populated with prepared material for Twitter and Facebook around key video clips and other material each day. The social media plan was shared with key communication colleagues so that opportunities to share/repost material could be used. The hashtag **#pallcareweek** was used in 2019, as with previous campaigns.

Top media Tweet earned 6,229 impressions

Health Departments north and south are supporting Palliative Care Week 8-14 September 2019. @healthdpt @roinnsainte @hscpermsec @SimonHarrisTD #pallcareweek Find out what's happening buff.ly/2MW0tUL pic.twitter.com/7splr1jAeZ



20 46

[View Tweet activity](#)

[View all Tweet activity](#)



Top AIIHPC tweet earned 7,068 Impressions

Top mention earned 419 engagements

Milford Care Centre
@MilfordLmkCC · Sep 12

Milford's Flashmob demonstrating how we surround the community with support. Thanks to Lisa Hogan, choreographer & UL Photography & UL Filming Societies for making this possible #pallcareweek @AIIHPC #limerick youtu.be/6W6FzsEB2jg

3 17 43

[View Tweet](#)

Website

A direct link was provided to the Public Awareness section on the www.thepalliativehub.com home page where the Palliative Care Week section had a wide range of information including:

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

Media planning

AIIHPC commissioned Alice PR & Events for media communications services for the campaign in 2019. Communications planning began in early June. With the agreement of some of those involved in the palliative care experiences video project, it was planned that

personal stories would be a major feature of media activity, and that a press release would be issued at the beginning of the week.

A call to action press release was issued several weeks before the campaign on 29 July and tailored for regional/local media. This generated significant media coverage and resulted in several organisations which had not been involved in Palliative Care Week previously contacting AIIHPC to learn more and to request promotional materials.

Photocalls were facilitated with Minister Simon Harris at the Department of Health in Dublin and with Richard Pengelly, Permanent Secretary at the northern Department of Health. Press releases were issued on Sunday 8 September to launch the campaigns in the respective jurisdictions on the island. The messaging addressed misconceptions about palliative care and included comment from service users involved in the videos. AIIHPC is grateful to Professor Sonja McIlfratrick and colleagues at Ulster University for information from a research project on public perceptions of palliative care and advance care planning which AIIHPC was able to include in the northern press release.

See press releases in Appendix C.

AIIHPC shared a 'Palliative Care Week – Key messaging' document to 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.

6. Costs

The total campaign cost for 2019 was €24,000.

Costs included the design, printing and distribution of promotional materials, including postage etc, communications/PR services including media monitoring, production and printing of VIEW magazine, and associate costs for events.

The production of VIEW magazine added significantly to the investment in the 2019 campaign.

Overall costs for Palliative Care Week were kept to a minimum. These costs do not include the time and support provided by AIIHPC staff, which was absorbed within the Institute's running costs. AIIHPC invested in additional project support for the 2019 campaign.

Pictured are AIIHPC colleagues involved in delivering Palliative Care Week 2019 (from left) Brendan O'Hara, Programme Manager, Karen Charnley, Director, Bernadette Pirihi, Business Support, Anne Leahy, Project Manager.



7. Reach and Impact

Promotional materials

More than 18,200 leaflets and more than 800 posters were distributed to a range of locations and for events across the island of Ireland. These were requested for distribution by 78 contacts including service users, interested individuals, health and social care professionals and civic society organisations. There was a significant increase again (34%) in the 2019 campaign from the 13,500 leaflets distributed in 2018.

Promotional Materials	2017	2018	2019
Leaflet	10,300	13,500 (+31%)	18,200 (+34%)
Poster	550	538	814
Social Media Sheet	Figure not available	928	771

Coffee Morning 2019: For the third year running, 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 19 September 2019. The Coffee Morning team facilitated the distribution of 6,000 leaflets through Coffee Morning packs.

Hospice Friendly Hospitals: We were delighted to have the opportunity to send Palliative Care Week promotional packs to the 47 hospitals in the Hospice Friendly Hospitals Programme, an initiative of our partner The Irish Hospice Foundation. More than 1,400 leaflets, 94 posters and 141 social media sheets were distributed to hospitals taking part in this initiative. As part of #pallcareweek The Irish Hospice Foundation hosted a Twitter chat looking at palliative and end of life care in Hospice Friendly Hospitals and at what supports are important to staff and the public at the end of life.

Voices4Care: A total of 16 AllHPC's Voices4Care members actively supported Palliative Care Week 2019 across the whole of Ireland. Between the members, who include people with palliative care needs, carers and interested citizens, almost 800 leaflets and 100 posters were distributed in the communities in which they live.

On 12 August (just under a month ahead of the campaign) AllHPC wrote to more than 500 contacts in its database alerting them to the campaign, inviting them to take part and offering to send promotional materials for any events that they may be holding. Links to available promotional materials were provided.

Events

Events and activities were held across the island to coincide with the campaign. These ranged from information stands, for example in canteens and hospital foyers, to programmes of events across geographical areas.

A sample of the larger events organised around Palliative Care Week included:

- Transforming Palliative Care: from policy to practice, La Mon Hotel, Belfast, Palliative Care in Partnership, regional palliative care programme, NI, Monday 9 September

- Launch of 'Management of Symptoms for Heart Failure Patients at end of life Guidance', Long Gallery, Stormont Buildings, Belfast, British Heart Foundation NI, in partnership with Public Health Agency (PHA), Health and Social Care Board (HSCB), and AIIHPC, Tuesday 10 September
- Seminar: Making Life Better - Where does public health meet palliative Care? Lagan Valley Island Centre, Lisburn, Public Health Agency, Ulster University and AIIHPC, Wednesday 11 September
- Supporting Palliative Care Approaches for Allied Health Professional and Social Work staff, The Silver Birches, Omagh, Western Health and Social Care Trust, Wednesday 11 September
- Launch of 53rd edition of View/digital magazine – focusing on Palliative Care: Facing the Future, The Conference Room, St Francis Hospice, Blanchardstown, Dublin, Thursday 12 September
- Showcasing Palliative Care Research in Northern Ireland, NI Hospice Palliative Care Learning Academy, Palliative Care Research Forum NI, Thursday 12 September
- Demystifying Death – an evening with Dr Kathryn Mannix, Institute for Lifecourse and Society, NUI Galway, The Irish Centre for Social Gerontology, NUI Galway and Cairde End-of-Life, Thursday 12 September.

Media – Broadcast, Print and Online

A total of 126 items of media coverage were identified referencing Palliative Care Week 2019 across national, regional, local and online media outlets, including RTE television, Newstalk radio, U105 Radio Belfast, and TheJournal.ie This was a major increase on the 57 items of media coverage identified for the 2018 campaign.

This increased media coverage was primarily due to the successful pick-up of a press release issued at the end of July inviting communities across the island to get involved in the campaign, well ahead of Palliative Care Week. Pick up on this 29 July press release accounted for 53 of the 126 total items of coverage from the campaign, including six radio interviews in the weeks before Palliative Care Week, and local print media and online.

A total of 20 radio interviews across national and regional radio took place in the context of the Palliative Care Week 2019 campaign. The majority of these involved AIIHPC Director Karen Charnley or were supported by the Institute, but some were arranged at local level. AIIHPC is grateful to its partners, other organisations and colleagues who supported raising the profile of palliative care through these media interview opportunities arranged locally.

There was extensive coverage on Newstalk's LunchTime Live radio programme with Dr Ciara Kelly on 12 September. The programme featured interviews with Kate Cameron, who spoke about her palliative care experience, Ger Tracey, from Our Lady's Hospice, Dublin, and Voices4Care member Annie McHale. The programme had a projected listenership of 105,000 people.

Radio interviews in the context of Palliative Care Week reached an estimated listenership of 300,000 listeners combined through the campaign.

Although there was a significantly increased number of radio opportunities in 2019, there were fewer TV opportunities.

AIHPC was pleased to work with our partner Galway Hospice Foundation to secure coverage on RTE Six One News on 12 September. This included an interview with Kate Cameron, featured in the palliative care experience videos, along with Mary Nash, CEO Galway Hospice Foundation, and Brendan O’Hara from AIHPC.

Participants from four of the seven palliative care experience videos took part in media activity around the campaign. We are grateful to Kate Cameron, supported by Galway Hospice; Pat and Angela Smyth, supported by Northern Ireland Hospice; Paul and Margaret Fitzpatrick, supported by St Francis Hospice, Dublin; and Tony and Rosemary O’Mullan, supported by Marie Curie Belfast, all of whom were involved in media coverage as part of Palliative Care Week 2019. They were supported by AIHPC and by media communications experts in this process.

One on-line media story placed on 10 September for Palliative Care Week had more than 67,000 viewers. Niall, from Athlone, wrote about how he used to think that palliative care was for “the old, the very sick and the dying”, but it’s helping him:

<https://www.thejournal.ie/readme/niall-keaney-cancer-palliative-care-week-ireland-4801230-Sep2019/>

Palliative Care Week was featured in a number of daily media publications circulating within and across the two jurisdictions on the island with articles appearing in print and online including: The Belfast Telegraph, The Echo (Cork), Daily Mirror, The Irish News (Belfast), The News Letter (Belfast).

A full list of media coverage is available at Appendix D.

Other promotion opportunities

Thanks to AIHPC’s link with colleagues in HSE Communications, a broadcast email was issued to all HSE staff which featured a brief explanation of Palliative Care Week with a link to the palliative care experience video of Chris Herdman and his daughter Aideen. Aideen attends an HSE facility as well as LauraLynn Ireland’s Children’s Hospice.

There was an opportunity to contribute an article on the European Association of Palliative Care blog [Link](#)

The Rural Community Network also provided an opportunity to publish an article which referenced the O’Mullan family’s palliative care experience [Link](#)

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 compared to 2018 but almost 86% of these were new visitors. Details of activity on the Palliative Hub are presented below:

	Sessions	Users	Page views	Pages per Session	Avg. Session Duration	% New Visitors
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 is presented below for the past four years

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

Twitter

There was a significant increase in campaign reach through the use of Twitter during 2019, although individual posts were lower than last year, and there was a small reduction in the number of contributors. This compares favourably with the 2018 campaign which saw a marked increase in individual posts on Twitter but this did not result in an increase in reach. Twitter activity figures for the past four years are presented in the table below:

Twitter	Individual Posts	Contributors	Reach	Impressions
2019 Sept 6 – Sept 16	2,677	773	2.2m	6.67m
2018 Sept 7 – Sept 17	3,128	799	1.6m	6.4m
2017 Sept 1 - Sept 10	856	1,090	1.7m	5.7m
2016 Oct 1 - Oct 10	720	255	535,000	4.2m

YouTube

There was an increase in the viewing of the palliative care experience videos incorporated in the 2019 campaign. There were a total of 3,700 views of the videos between 6 and 16 September with more than a third of these views (1263) of the videos of Paul FitzPatrick (725) and Pat and Angela Smyth (538). In 2019 there were seven videos of personal experiences incorporated in the campaign, compared to eight in 2018 and three in 2017.

YouTube	Watch Time (minutes)	Views	Average View Duration
2019 Sept 6 – Sept 16	8,600	3,700	02:18
2018 Sept 7 - Sept 17	7,600	3,200	02:25
2017 Sept 1 - Sept 10	2,200	1,100	02:02

8. Commentary

A very successful public awareness campaign was delivered again through Palliative Care Week 2019. Key points to note from this year's campaign:

- The personal experiences of palliative care captured through the video project and other personal stories enabled the public to connect with the campaign and attracted media interest.
- By enabling the public to connect with the campaign, the personal stories help people to learn more about the quality of life benefits of palliative care.
- Palliative Care Week continues to be an opportunity not only to raise awareness and understanding of palliative care with the public but also to keep palliative care on the government and policy agenda. AIHPC was pleased to be able to facilitate conversations with people with palliative care experience with Minister Simon Harris and Permanent Secretary Richard Pengelly in conjunction with launch photocalls.
- There was a significant increase in media coverage in 2019. This was primarily due to the early press release issued on 29 July encouraging communities to get involved. There were fewer TV opportunities than in 2018 but more radio opportunities. The TV opportunity – RTE Six One News – was for a prime time broadcast which meant a wider reach than any of the TV opportunities achieved in 2018.
- Some media coverage, particularly during the week, was generated by partners and by other organisations making reference to and incorporating messaging from Palliative Care Week. The engagement of the Palliative Care Unit at Kerry University Hospital in the campaign this year is of particular note, reflected in print, broadcast and social media activity. These local efforts using the hook of the all-island campaign is very much welcomed, and essential for increasing the reach of Palliative Care Week.
- Where a lead person is identified for the campaign within a partner or other organisation there is a notable increase in promotional activity, particularly where the person and the campaign is supported within their organisation.
- There was increased Voices4Care involvement - 16 members - in bringing the campaign to their communities. This was perhaps boosted by the refresh of the group during 2019 and also by the opportunity to engage with members in August, close to the campaign.
- Website and social media activity results were mixed. Views and watch time for videos increased on 2018. While individual tweets were down slightly there was an extended reach across Twitter on the previous year. There was a slight decrease in Palliative Hub sessions on the previous year. Where organisations are posting material without using the #pallcareweek hashtag this activity won't be captured through AIHPC monitoring and reducing our opportunity to reflect a fuller picture.

- AllHPC is a facilitator of Palliative Care Week and, while every effort is made for the campaign to reach across every part of Ireland, the Institute needs its partners to bring the campaign to each of the local communities where they are working. Developments such as our partner The Irish Hospice Foundation helping to bring the campaign to the Hospice Friendly Hospitals Network are to be welcomed, and are opportunities to build upon.
- Publication of VIEW Magazine was invested in by AllHPC to coincide with this year's Palliative Care Week. It was envisaged that the magazine would be published once and would not be a recurring publication for Palliative Care Week. This edition was an opportunity for 13 partners to contribute. It is a valuable resource which we at AllHPC will continue to be making use of over the coming year.

9. Planning for 2020

As AllHPC begins planning for 2020, key considerations for the Institute and its partners include:

- Continuing to plan and engage early for the campaign
- Buy in for the campaign from AllHPC partners, government, health agencies, community and voluntary sector and wider interest is essential for increased reach and success of the campaign.
- Increased awareness that the campaign will succeed in as much as AllHPC partners get involved
- Consideration of theme in light of ongoing policy development across the island
- Regional and local efforts using the hook of the all-island campaign is essential for increasing the reach of Palliative Care Week
- As well as being external funding dependent, a palliative care experiences video project requires significant AllHPC team resources. As this project has been undertaken for three years it may be opportune to consider a different focus for such a project for 2020, subject to any funding being received
- Personal experiences will be a central feature of the campaign and Institute partners will be essential to sourcing these narratives
- The benefits of having a named person within the organisation who will be facilitated with time and with support/buy-in from their organisation for success
- Maximising partnership and mutual support
- There will be a need to focus on involving new audiences/agents for activity to increase social media profile.

APPENDIX A – Palliative Care Week Reference Group

Member	Organisation
Aisling Kearney	Galway Hospice Foundation
Alex McGreevey	Northern Ireland Hospice
Alice Coffey	University of Limerick
Anne-Marie Hayes	Milford Care Centre
Anthony Staines	Dublin City University
Audrey Houlihan	Our Lady's Hospice and Care Services
Bob Brown	Western Health and Social Care Trust
Carina O'Neill	Our Lady's Hospice and Care Services
Caroline Dalton	University College Cork
Caroline McIlwain	Marie Curie Belfast
Charlene Hurley	Galway Hospice Foundation
Charles Normand	Trinity College Dublin
Claire McFall	Northern Health and Social Care Trust
Corrina Grimes	Public Health Agency
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
Eamon O'Kane	Marie Curie Belfast
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
Gemma Burns	British Heart Foundation
Georgina Gethin	National University of Ireland Galway
Geraldine Tracey	Our Lady's Hospice & Care Services
Graham Lynch	Marymount University Hospital & Hospice
Greg Price	Health Service Executive
Hazel O'Shea	Ireland's Biggest Coffee Morning for Hospice
Heather Monteverde	Macmillan NI
Heather Weir	Northern Ireland Hospice
Joanne Reid	Queen's University Belfast
John Joyce	Voices4Care
Karen Dawson	Department of Health Northern Ireland
Kiran Kaur	South Eastern Health and Social Care Trust
Lisa McGirr	St Francis Hospice, Dublin
Louise Hagan	Belfast Health and Social Care Trust
Marie Heaney	Belfast Health and Social Care Trust
Mary Marsden	Health Service Executive
Mary Nash	Galway Hospice Foundation

Megan	Mason	Public Health Agency
Melanie	McClements	Southern Health and Social Care Trust
Michael	Connolly	University College Dublin
Mila	Whelan	Health Service Executive
Nicki	Patterson	South Eastern Health and Social Care Trust
Orla	O'Brien	LauraLynn Ireland's Children's Hospice
Pamela	Yeh	Health and Social Care Board
Pat	Quinlan	Milford Care Centre, Limerick
Paul	Turley	Health and Social Care Board
Paul	O'Mahoney	The Irish Hospice Foundation
Paula	McGovern	Marymount University Hospital & Hospice
Pauline	Meskell	University of Limerick
Phil	Hughes	Northern Health and Social Care Trust
Ray	Elder	South Eastern Health and Social Care Trust
Rebecca	Lloyd	The Irish Hospice Foundation
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
Sinead	Morrissey	Nursing Homes Ireland
Siobhan	McCarthy	Royal College of Surgeons in Ireland
Tony	O'Brien	Marymount University Hospital & Hospice

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 2019: notification of the date (November 2018); inviting ideas and suggestions for theme (February 2019); asking for assistance in promoting the opportunity to take part in the palliative care experience video project (March) notification of theme (June); draft promotional materials (July); sharing finalised materials (July); final call to action (August); sharing embargoed press releases (September). Engagement was two-way, with reference group members invited to make suggestions/propose ideas throughout the process, and comment on draft materials, for example, the content of the Palliative Care Week leaflet. Reference group members' input informed the theme and contributed to some helpful additions to the leaflet, as well as contributing to the overall success of the campaign.

APPENDIX B – Promotional Materials

Information Leaflet

PALLIATIVE CARE WEEK

Sunday 8 September to Saturday 14 September 2019

Palliative Care Week aims to raise awareness of the difference palliative care can make to people with a life-limiting illness or condition, to carers and to families throughout the island of Ireland.

Palliative care:

- Ensures that a person with a serious and/or 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.

To find out more about Palliative Care visit:

www.thepalliativehub.com [#pallcareweek](https://twitter.com/pallcareweek)

GET IN TOUCH

www.thepalliativehub.com

+353 (0)1 491 2948

info@aiihpc.org

All Ireland Institute of Hospice and Palliative Care
2nd Floor, Education and Research Centre
Our Lady's Hospice & Care Services
Harold's Cross, Dublin 6w.

To find out more about palliative care talk to your GP or any health and social care professional

PALLIATIVE CARE



SURROUNDING YOU WITH SUPPORT

www.thepalliativehub.com [#pallcareweek](https://twitter.com/pallcareweek) [Palliative Care Week 8-14 Sept 2019](https://www.facebook.com/aiihpc)

PALLIATIVE CARE

SURROUNDING YOU WITH SUPPORT

Q. What is palliative care?
A. Palliative care focuses on helping a person, of any age, with a life-limiting illness to live well, seeking to help them achieve the best quality of life as their illness progresses. Palliative care involves the management of pain and other symptoms and provides social, emotional and spiritual support.

Q. Is palliative care only for people with advanced cancer?
A. Palliative care is not only for people with advanced cancer but also for people living with advanced heart or lung disease, kidney failure and other conditions such as motor neurone disease or dementia. For babies, children and young people, palliative care can begin at diagnosis or recognition of a life-limiting condition.

Q. Is palliative care only for people who are in the last days or weeks of life?
A. Palliative care can benefit people who are living with a life-limiting illness for years as well as people who are in the last days or weeks of life. Some people live with their condition for a long time and have extended periods of being well. People can move in and out of palliative care services as their needs change.

Q. Who provides palliative care?
A. Palliative care is provided by a range of professionals, alongside family carers and communities, supporting the person and family whether they are at home, in a nursing home, hospital or hospice.

MY PALLIATIVE CARE EXPERIENCE

"We feel safe and confident with the care Aileen gets while she's there." - **Chris Herdman, father of Aileen, Navan, Meath**

"I found out 'palliative' comes from the Latin word for a cloak and this cloak is wrapped around you to embrace you, as you are." - **Calliona Hastings, Killiney, Dublin**

"If I wasn't getting this care I'm getting I'm not so sure where I would be." - **Anthony O'Mullan, Ballymena, Antrim**

"The treatment, the love and care and kindness has helped me progress through this, and from this time last year I'm out and about which I thought I'd never be able to do again." - **Paul FitzPatrick, Cooleck, Dublin**

"Only for the palliative care, I wouldn't be as good as I am today." - **Collette Grealish Keane, Galway**

"It's the emotional and the physiological support that the hospice provides that's priceless." - **Pat Smyth, husband of Angela Smyth, Belfast**

"They supported me and still are supporting me. So my day-to-day life was made much more easy." - **Kate Carson, Athey, Galway**

To watch these people tell their stories visit www.thepalliativehub.com

PALLIATIVE CARE

IT'S EVERYONE'S BUSINESS

The starting point in palliative care is always the person. Palliative care aims to improve the quality of life of a person living with a life-limiting illness and of those who matter to them.

By focusing on the person's physical, social, emotional and spiritual needs, and involving friends and family, palliative care can help to maintain a person's quality of life.

Palliative care is often associated with hospices and hospitals, but it can also be provided in people's own homes, or in nursing homes. It involves support from GPs, nurses, other health and social care professionals, and the wider community beyond formal services.


Palliative care creates connections, through day services and respite for carers; it helps to reduce isolation and supports people to plan for care - Surrounding You With Support.

Posters

PALLIATIVE CARE

SURROUNDING YOU WITH SUPPORT


"It's the emotional and the physiological support that the hospice provides that's priceless."
- **Pat Smyth, Belfast, with wife Angela who is living with dementia**



PALLIATIVE CARE

SURROUNDING YOU WITH SUPPORT

"The treatment, the love and care and kindness has helped me progress through this, and from this time last year I'm out and about, which I thought I'd never be able to do again."
- **Paul FitzPatrick, Dublin, with wife Margaret**




www.thepalliativehub.com

[#pallcareweek](https://twitter.com/pallcareweek)



www.thepalliativehub.com

[#pallcareweek](https://twitter.com/pallcareweek)



Email signatures



Twitter Cover



Facebook Cover



Social Media Picture Frame



APPENDIX C – Press Releases

29 July press release tailored to locality/county

Photo Caption: Brendan O’Hara, Programme Manager at AIIHPC, and Karen Charnley, AIIHPC Director, review Palliative Care Week 2018 and look forward to wide community involvement in this year’s campaign.

PRESS RELEASE

Date of issue TBC – week beginning 29th July 2019

Calling on [Mayo] communities to get involved in Palliative Care Week this September

Raising awareness of the difference palliative care can make to people with palliative care needs, carers and families

[Mayo] communities are being encouraged to get involved in the sixth annual Palliative Care Week taking place this September (8th to 14th September). The week aims to raise awareness of the difference palliative care can make to people with a life-limiting illness or condition, to carers and to families throughout the island of Ireland.

Palliative Care Week is coordinated by All Ireland Institute of Hospice and Palliative Care (AIIHPC). This year’s theme is ‘Palliative Care: Surrounding You With Support’, focusing on how people with palliative care needs are being supported in the community.

This can involve support from primary care (such as GPs, public health nurses, district nurses), from hospices, hospitals, nursing homes, and wider community supports beyond formal health and social care services. Support can be provided for weeks, months and years.

AIIHPC is encouraging individuals and communities to get involved in Palliative Care Week 2019.

“Palliative care ensures that a person with a serious and progressive illness, regardless of age or condition, can have the best possible quality of life,” said Karen Charnley, AIIHPC Director. “Palliative care puts the person at the centre of care with a range of supports around them, whether that is their family or friends, including carers, or health professionals such as GPs, nurses or wider community supports.

“This year, we’re calling on the people of [Mayo] to help us to raise awareness of the importance of palliative care. If you are interested in learning more about palliative care and the campaign, or are involved in a community organisation interested in health and well-being, we would love to hear from you.

“Individuals and groups can get involved through holding a small event, or by distributing promotional leaflets which AIIHPC would be happy to supply, or by posting their own palliative care experience story on social media during Palliative Care Week using the #pallcareweek hashtag.

“AIIHPC works with our partners in hospices, other health care organisations, universities and charities, along with voluntary and community organisations to promote Palliative Care Week. We want as many people as possible to have a greater understanding of palliative care and we would

love to have more groups and individuals from [Mayo] getting involved in supporting this year's campaign."

For more information on Palliative Care Week visit www.aiihpc.org

Any groups or individuals wishing to get involved e.g. by planning an event, and to obtain leaflets and/or posters can contact AIHPC by calling them on +353 1 4912948 or by emailing Bernadette at bpirihi@aiihpc.org

ENDS

ROI Contact: Katie Morris, Alice PR & Events, Tel: 086-4044678, email: media@alicepr.com

NI Contact: Julie Sherlock, Alice PR & Events, 0044-7834776519, email: julie@alicepr.com

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. <http://aiihpc.org/about>

The 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 25 partners are:

- 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
- Marie Curie
- Marymount University Hospital & Hospice, Cork
- Milford Care Centre, Limerick
- National University of Ireland Galway
- Northern Health and Social Care Trust
- Northern Ireland Hospice
- Our Lady's Hospice & Care Services
- Public Health Agency (Northern Ireland)
- 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, Dublin
- Ulster University
- University College Cork
- University College Dublin
- University of Limerick
- Western Health and Social Care Trust

Press Release (Northern Ireland)

Better public understanding of palliative care required to improve care for end of life patients

8 September 2019 (Embargoed to 12noon, Sunday 8 September 2019)

A research report from Ulster University has found that better public understanding of palliative care is required to improve care for end of life patients and their families in Northern Ireland.

Lead researcher Professor Sonja McIlfratrick hopes that the findings and recommendations released during Palliative Care Week (8-14 September) will contribute towards the ongoing development of a public health framework for palliative care.

While 86% of people reported being familiar with the term palliative care, research found misconceptions still existed with many respondents assuming palliative care was only for older people, those in the final six months of life and only available in a hospital setting. The government has identified palliative care as a key public health priority with numerous tools and guidelines available. The study found that the most common source of knowledge is close friends and relatives receiving palliative care.

The study provided evidence that there was broad support for promoting advance care planning, with the majority of respondents detailing they would be comforted to know they had left guidance with their family about their wishes. However, fear, taboo and shame, along with perceived lack of information plus an absence of public debate, were cited as reasons why such discussions do not take place.

Those living in rural settings possessed more accurate perceptions of palliative care than those living in urban settings.

Lead researcher, Head of School of Nursing at Ulster University Professor Sonja McIlfratrick commented: "With people living longer and often with progressive illness we all have an important role to play in both educating and empowering people to take control of their future health care. We're starting to see growing awareness of the benefits that palliative care and advance care planning can provide, however they are not well understood by the public. Greater efforts are needed to promote palliative care and reduce the misconceptions among the public."

Karen Charnley is Director of All Ireland Institute of Hospice and Palliative Care which is coordinating Palliative Care Week. Karen said: "This Ulster University research shows the need for continued efforts to raise awareness and increase understanding of palliative care and to continue these conversations so people are empowered to think about how palliative care could help them.

"Palliative Care Week aims to raise awareness of the difference palliative care can make to people with a life-limiting illness or condition, to carers and to families throughout the island of Ireland. This year's theme 'Palliative Care: Surrounding You With Support', is focusing on how people with palliative care needs are being supported in the community."

Palliative Care Week is supported by the Department of Health. Richard Pengelly, Permanent Secretary at the Department said: "I am pleased once again to support Palliative Care Week. This year's theme 'Surrounding You With Support' recognises the importance of community in ensuring

that people living with a life-limiting condition have access to the holistic care and support they need to help them not only to live with their illness but to live well.

“Our health and social care professionals play a valuable role in supporting people with palliative care needs. At a community and individual level, we also have a role to play. Being part of the wider conversation to raise awareness and understanding of palliative care is something we can all contribute to. At an individual level, having conversations with our loved ones about their, and our own, preferences for care and planning ahead for this can help provide peace of mind that, if the time does come when it is needed, our preferences and wishes for future care are known and can be acted upon.”

Experiences of people with palliative care needs feature in the campaign and videos reflecting these experiences are being promoted to coincide with the week. Pat Smyth, from Belfast, is among those featured in Palliative Care Week promotional materials who have spoken about the benefits of palliative care. Pat is caring for his wife Angela who is living with dementia. They have received support at Northern Ireland Hospice.

Pat said: “Dementia is a terminal illness, and it’s a long process. It’s about 10 years now for Angela and just to see the deterioration week by week, and Angela’s fairly advanced now. It’s the emotional and the physiological support that the hospice provides is priceless.”

Corrina Grimes, at the Public Health Agency, said: “It is encouraging that there is public awareness of palliative care, however there is further work to do to ensure people living with serious and progressive conditions are supported, to help them achieve the best quality of life, whether through addressing pain, fatigue, and loss of function or distress, when facing life-limiting illness. It is also encouraging to know that people want to discuss palliative care with their health and social care professionals to look at how best to achieve this. As well as the ongoing delivery of palliative care, the regional palliative care programme – Palliative Care in Partnership – is supporting health and social care professionals to be skilled in listening to and supporting people with serious and progressive conditions, so people can discuss what really matters to them.”

ENDS

Contact: Julie Sherlock, Alice PR & Events, 0044-7834776519, email: julie@alicepr.com

Or Ulster University at pressoffice@ulster.ac.uk 028 90 366178

Notes to Editors:

- Brendan O’Hara, AllHPC Programme Manager is available for comment and interview.
- A number people with palliative care needs and their families are willing to share their experience of palliative care with the media including Pat Smyth. A video of Pat and his wife Angela is available [here](#)
- Photographer Brian Morrison has been commissioned to cover the launch of Palliative Care Week and will issue images to photo desks today for reproduction free-of-charge.
- For more information on Palliative Care Week visit <http://www.thepalliativehub.com/public-awareness> **#PallCareWeek**

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. <http://aiihpc.org/about>

This is the sixth annual Palliative Care Week coordinated by AIHPC. 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 25 partners are across the island of Ireland. More information about AIHPC is available here: <https://aiihpc.org/>

Press Release (Republic of Ireland)

Minister for Health launches Palliative Care Week and urges people to have conversations about their care

8 September 2019 (Embargoed to 12noon, Sunday 8 September 2019)

Minister for Health Simon Harris TD has today (Sunday 8 September) launched Palliative Care Week aimed at encouraging more people to learn about palliative care.

The number of people aged over 65 is set to increase by almost 80 per cent over the next 20 years and Ireland has the most rapidly rising need for palliative care in Europe.

Palliative Care Week is coordinated by the All Ireland Institute of Hospice and Palliative Care (AIHPC), across the island of Ireland.

AIHPC Director Karen Charnley said she hoped Palliative Care Week will encourage people to learn more about palliative care.

Palliative care focuses on helping a person, of any age, with any life-limiting illness, to achieve the best quality of life. It involves the management of pain and other symptoms and provides support for social, emotional and spiritual needs, and can be provided at home, in a nursing home, hospital or hospice.

Ms Charnley said: "In the Republic of Ireland, the number of people over 65 is projected to increase by almost 80% from 673,400 in 2018 to almost 1.2 million by 2038. Advances in public health, medicine and technology mean that people are living for many more years today than previous generations and this is something to be celebrated.

"As populations age, the pattern of diseases that people live with and die from changes. As well as being for people with advanced cancer, palliative care is also for people living with advanced heart or lung disease, kidney failure and other conditions such as motor neurone disease or dementia.

"Although the number of people over 65 is a key factor in determining the needs of palliative care services in populations, many people well below the age of 65, including from birth, will require palliative care due to their life-limiting illness or condition.

"Palliative Care Week aims to raise awareness of the difference palliative care can make to people with a life-limiting illness or condition, to carers and to families throughout the island of Ireland. This year's theme 'Palliative Care: Surrounding You With Support', is focusing on how people with palliative care needs are being supported in the community. As we create conversations around palliative care, particularly involving people with direct experience, we hope more people will feel empowered to think about how palliative care could help them."

Paul FitzPatrick from Coolock is supported by St Francis Hospice in Raheny. In January 2018, he was diagnosed with a life-changing condition: a lung disease called Idiopathic Pulmonary

Fibrosis (IPF). Before he became ill, he was working full-time as a truck driver and living an active life which included plenty of trips to the park with his six grandchildren.

Speaking at the launch of Palliative Care Week 2019, Paul said: “After the first couple of sessions I could feel my breathing getting better and I could start to do the simple things in life, like going up the stairs or going to the shops which I found very hard to manage before. From being down in the hospice and the treatment I’ve got down there, and the love and care and kindness has helped me progress through this and from this time last year I’m out and about which I thought I’d never be able to do again.”

Speaking ahead of Palliative Care Week, Minister Harris said: “Palliative Care Week provides an opportunity to highlight the positive impact that palliative care can have in improving quality of life for people diagnosed with a life-limiting or life-threatening illness. I would like to thank those who are sharing their stories with us during this Week.”

On palliative care provision in Ireland, Minister Harris said “We in Ireland can be proud of our position as a leading nation in the provision of palliative care. The Department of Health and the HSE remain committed to ensuring that Ireland’s palliative care system is fit for purpose, and offers targeted care to patients who avail of these services.”

Sheilagh Reaper-Reynolds, HSE Planning Lead for Palliative Care, said: “Palliative care services are vitally important for people living with a progressive illness that may limit or shorten their lives, and also for the people who care for them. The purpose of Palliative Care Week is to help us explain how much palliative services can improve a person’s quality of life throughout the course of their illness. The focus for 2019 is on how people with palliative care needs are being supported right across our health services including primary care, hospices, hospitals and nursing homes. This support also stretches beyond formal health and social care services to include the many volunteers and support organisations working in the wider community.”

ENDS

Contact: Emily Brennan, Alice PR & Events, Tel: 086-1658629, email: media@alicepr.com or Julie Sherlock, Alice PR & Events, 0044-7834776519, email: julie@alicepr.com.

Notes to Editors:

- Karen Charnley, AIHPC Director is available for comment and interview.
- A number people with palliative care needs and their families are willing to share their experience of palliative care with the media including Paul FitzPatrick. A video of Paul is available [here](#)
- Photographer Marc O’Sullivan has been commissioned to cover the launch of Palliative Care Week and will issue images to photo desks today for reproduction free-of-charge.

- For more information on Palliative Care Week visit <http://www.thepalliativehub.com/public-awareness> #PallCareWeek

Additional Information on Ireland's Ageing Population & Palliative Care Requirements

1. Well over 600,000 people in the Republic of Ireland are aged 65+ (673,400 people, 2018) and this is projected to increase by almost 80% (77.2%) (+ 522,600 people) to 1,196,000 by 2038.
2. Increases are particularly marked amongst those aged 85+: the number of people over the age of 85 is projected to increase to over 2.5 times the current figure (2018) by 2038.

(1 & 2. Department of Health, 2018. *Health in Ireland Key Trends, 2018.*)

3. The rate of population ageing in ROI is a good deal faster than the average for EU countries (while the population is still young in comparison to other European countries) - Department of Health, 2016. *Health in Ireland Key Trends, 2016*
4. The number of deaths in the Republic of Ireland (which is a good indicator of likely palliative care needs) is projected to rise to approximately 55,400 by 2050 representing a rise of some 78% from 2018 (Eurostat online database of baseline projections - Eurostat online database: Demographic balances and indicators by type of projection [proj_18ndbi]. Baseline projections. Last update: 03.07.19)
5. All of this means that Ireland appears to have the most rapidly rising need for palliative care in Europe (Kane et al. 2015) - Kane, P. M., Daveson, B. A., Ryan, K., McQuillan, R., Higginson, I. J., & Murtagh, F. E. (2015). "The need for palliative care in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of non-malignant conditions". *Journal of pain and symptom management*, 49(4), 726-733.

About All Ireland Institute of Hospice and Palliative Care

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This is the sixth annual Palliative Care Week coordinated by AIHPC. 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 25 partners are across the island of Ireland. More information about AIHPC is available here: <https://aiihpc.org/>

APPENDIX D – Media Coverage

1. 30 July 2019, www.carlowlive.ie, Calling on Carlow Communities to get involved in Palliative Care Week this September (online) July PR with pic
2. 30 July 2019, dundalkdemocrat.ie, Calling for Louth communities to get involved in Palliative Care Week (online) July PR
3. 30 July 2019, con-telegraph.ie, Mayo Communities urged to get involved in Palliative Care Week this September (online) July PR
4. 30 July 2019, clarepeople.com, Clare communities urged to get involved in Palliative Care Week (online) July PR
5. 30 July 2019, leitrimobserver.ie, Leitrim communities urged to get involved in Palliative Care Week (online) July PR
6. 30 July 2019, dundalkdemocrat.ie, Calling for Louth communities to get involved in Palliative Care Week (online) July PR
7. 30 July 2019, kildarenow.com, Kildare communities urged to get involved in Palliative Care Week this September Raising awareness of difference palliative care can make (online) July PR
8. 30 July 2019, leinsterleader.ie, Kildare communities called to get involved in Palliative Care week this September, Make a difference (online) July PR
9. 31 July 2019, Weekly Observer, Calling on Limerick and Cork communities to get involved in Palliative Care week this September, (ROI) July PR
10. 1 August 2019, www.cry104fm.com, Community Radio Youghal, Youghal Today: Interview with Karen Charnley (Radio) July PR
11. 1 August 2019, www.derryjournal.com, Derry People urged to support Palliative Care Week (online) July PR with pic
12. 1 August 2019, traleetoday.ie, Call for Kerry communities to get involved in Palliative Care week (online) July PR
13. 1 August 2019, Radio Kerry, Palliative Care Week, (ROI) July PR
14. 1 August 2019, Kerry's Eye, Palliative Care Week in September (ROI) July PR
15. 1 August 2019, East Cork Journal, Calling on Cork communities to get involved in palliative Care Week this September (ROI) July PR with pic
16. 1 August 2019, radiokerry.ie, Kerry communities urged to support Palliative Care Week (online) July PR
17. 1 August 2019, Mallow Star, Calling on Limerick and Cork communities to get involved in Palliative care Week this September (ROI) July PR

18. 1 August 2019, Vale Star, Calling on Limerick and Cork communities to get involved in Palliative Care Week this September (ROI) July PR
19. 3 August 2019, Southern Star, Palliative care Week theme (ROI) July PR
20. 3 August 2019, Offaly Independent, Palliative Care Week (ROI) July PR with pic
21. 4 August 2019, donegaldaily.com, Donegal communities urged to get involved in Palliative Care Week (online) July PR
22. 7 August 2019, Inish Times, Communities to get involved in Palliative Care Week 2019, (ROI) July PR with pic
23. 7 August 2019, Ulster Star, Call for support of Care Week, (NI) July PR
24. 8 August 2019, Galway Bay FM, Palliative Care Week, Interview with Karen Charnley, AIIHPC Director, (Radio) July PR
25. 8 August 2019, Cork Independent, Taking care of those who need it most (ROI) July PR with pic
26. 8 August 2019, Northern Standard, Calling on Monaghan communities to get involved in Palliative Care Week this September (ROI) July PR with pic
27. 9 August 2019, Dungarvan Observer, Calling on Waterford communities to get involved in Palliative Care Week this September (ROI) July PR with pic
28. 10 August 2019, Meath Chronicle, Meath communities urged to support Palliative Care Week (ROI) July PR with pic
29. 12 August 2019, Dublin City FM, Palliative Care Week, Valerie Vetter interview with Karen Charnley, AIIHPC Director, (Radio) July PR
30. 12 August 2019, Connemara Community Radio, Karen Charnley, AIIHPC Director, interview (Radio) July PR
31. 12 August 2019, Dundalk FM, Town Talk, Brendan O'Hara, AIIHPC Programme Manager, interview (Radio) July PR
32. 13 August 2019, Connaught Telegraph, Mayo communities urged to get involved in Palliative Care Week this September, (ROI) July PR
33. 13 August 2019, Drogheda Independent, Spotlight on palliative care raises awareness (ROI) July PR with pic
34. 13 August 2019, Mid-Louth Independent, Spotlight on palliative care raises awareness (ROI) July PR with pic
35. 14 August 2019, newrytimes.com, Newry community urged to get involved in Palliative Care Week (online) July PR with pic

36. 16 August 2019, Wicklowvoice.ie, Wicklow communities asked to get involved in Palliative Care Week (online) July PR
37. 17 August 2019, Nenagh Guardian, Tipperary urged to support Palliative Care Week (ROI) July PR with pic
38. 19 August 2019, NICVA (NI Council for Voluntary Action) eNews Calling on Northern Ireland communities to get involved in Palliative Care Week this September (online) July PR
39. 20 August 2019, Connaught Telegraph, Castlebar & District, Palliative Care Week (ROI) July PR
40. 21 August 2019, Weekly Observer, Dromcollogher, Palliative Care Week (ROI) July PR
41. 22 August 2019, Mallow Star, Dromcollogher, Palliative Care Week (ROI) July PR
42. 22 August 2019, Vale Star, Dromcollogher, Palliative Care Week (ROI) July PR
43. 27 August 2019, Belfast Telegraph, 'Angela has a rare form of dementia and can't speak but music triggers something in her brain and it's amazing to hear her singing again', Pat and Angela Smyth (online)
44. 28 August 2019, Weekly Observer, Palliative Care Week (ROI) July PR
45. 29 August 2019, Mallow Star, Dromcollogher, Palliative Care Week (ROI) July PR
46. 29 August 2019, Vale Star, Dromcollogher, Palliative Care Week (ROI) July PR
47. 3 September 2019, 4ni.co.uk, NI Hospice Calls For Palliative Care Support (online) July PR
48. 3 September 2019, nuigalway.ie, NUI Galway host special talk on palliative care, Dr Kathryn Mannix event (online)
49. 4 September 2019, viewdigital.org, Guest editor Brendan O'Hara, AllHPC Programme Manager for VIEW edition (online)
50. 4 September 2019, Weekly Observer, Palliative Care Week (ROI) July PR
51. 4 September 2019, newswireni.com, Western Trust celebrates 'Palliative Care Week', Western Health and Social Care Trust team with comments (online)
52. 5 September 2019, advertiser.ie/Galway, the truth about dying to be explored at event with palliative care author Dr Kathryn Mannix interview (online)
53. 5 September 2019, Galway Advertiser, The truth about dying to be explored at event with palliative care author, Dr Kathryn Mannix interview (ROI)
54. 5 September 2019, Mallow Star, Dromcollogher, Palliative Care Week (ROI) July PR
55. 5 September 2019, Vale Star, Dromcollogher, Palliative Care Week (ROI) July PR
56. 6 September 2019, LIFE FM, Cork, Karen Charnley, AllHPC Director (Radio) July PR
57. 6 September 2019, Connacht Tribune, Learn about death to ease path of dying, Interview with Dr Kathryn Mannix (ROI)

58. 6 September 2019, Galway City Tribune, Learn about death to ease path of dying, Interview with Dr Kathryn Mannix (ROI)
59. 6 September 2019, Derry Journal (City Edition), Palliative Care Week in Western Trust area, Western Health and Social Care Trust team with comments and photo (NI)
60. 6 September 2019, rte.ie, Is access to palliative care a human right? References Milford Care Centre, Limerick and Our Lady's Hospice, Dublin (online)
61. 8 September 2019, derryjournal.com, Palliative Care Week in Western Trust Area, Western Health and Social Care Trust team with comments (online)
62. 9 September 2019, Highland Radio, Palliative Care Week, Reference Minister Simon Harris (Radio) PR
63. 9 September 2019, Midlands 103, Palliative Care Week (Radio)
64. 9 September 2019, Ocean FM, Palliative Care Week, Reference Minister Simon Harris, and Karen Charnley, AIHPC Director (Radio) PR
65. 9 September 2019, LM FM, Palliative Care Week, Brendan O'Hara, AIHPC Programme Manager (Radio) PR
66. 9 September 2019, East Coast Radio, Palliative Care Week, Reference Minister Simon Harris 9:01, 10:04, 11:02, 11:33, 12:06 (Radio) PR
67. 9 September 2019, Limerick's 95 FM, Palliative Care Week, Dr Marion Conroy, Milford Care Centre (Radio)
68. 9 September 2019, The Echo (Cork), Share your story during Palliative Care Week, Dr Sarah McCloskey, CEO Marymount University Hospital and Hospice, talks about the services they offer to individuals and families (ROI)
69. 9 September 2019, ulster.ac.uk Better public understanding of palliative care required to improve care required to improve care for end of life patients Prof Sonja McIlpatrick, Ulster University (online)
70. 9 September 2019, irishhealth.com, Demand for palliative care expected to jump, references Karen Charnley, AIHPC Director, Paul FitzPatrick, Sheilagh Reaper Reynolds, HSE (online) PR
71. 9 September 2019, Daily Mirror, Get talking about care, Minister Simon Harris, Karen Charnley AIHPC Director (online)
72. 9 September 2019, Newstalk, Palliative Care Week, Karen Charnley, AIHPC Director (Radio) PR
73. 9 September 2019, BBC Radio Foyle Mark Patterson Show, interview with Dr Damien McMullan, Western Trust and James talking about palliative care support for his wife Mary (Radio) PR

74. 10 September 2019, irishnews.com, New guidance to support heart failure patients at the end of their life, Gail McComb speaks about the care for her husband David, context of launch of British Heart Foundation guidance to support people with heart failure at end of life (online)
75. 10 September 2019, LM FM, Palliative Care Week, Brendan O'Hara, AllHPC Programme Manager (Radio) PR
76. 10 September 2019, East Coast Radio, Palliative Care Week, Evanne Cahill, Wicklow Hospice Foundation, Karen Charnley, AllHPC Director (Radio) PR
77. 10 September 2019, U 105.8, Palliative Care Week, Helen Smyth (daughter of Pat & Angela) speaks of family experience, Brendan O'Hara, AllHPC Programme Manager (Radio) PR
78. 10 September 2019, Dundalk FM, Talk of the Town, Karen Charnley interview, AllHPC Director (Radio) PR
79. 10 September 2019, Kildare FM, Palliative Care Week, Karen Charnley interview, AllHPC Director (Radio) PR
80. 10 September 2019, 'The Afternoon Show', Belfast 89 FM with Louis Edmunson and Libby Hunter, interview with Karen Charnley, AllHPC Director, and Brendan O'Hara, AllHPC Programme Manager (Radio) PR
81. 10 September 2019, Echolive.ie, Share your story during palliative care week, contributed by Marymount University Hospital & Hospice (online)
82. 10 September 2019, Newry Democrat, Palliative Care, Southern Trust, Brian Beattie, Interim Director of Older People's Service and contact details for David Calvin, Service Improvement Lead (NI)
83. 10 September 2019, thejournal.ie Opinion: 'My name is Niall, I'm 32, and I have cancer. I never imagined saying those words' Niall speaks of his experience and support at St James Hospital Dublin, Rory (Wilkinson) of St James Hospital referenced (online)
84. 10 September 2019, Irish News, Palliative care gave my husband the peaceful, dignified death he wanted, Gail McComb speaks about the care for her husband David, context of launch of British Heart Foundation guidance to support people with heart failure at end of life (NI daily)
85. 10 September 2019, Daily Mirror, 'Time to talk about dying', Dr Kathryn Mannix
86. 11 September 2019, Dublin City FM, St Francis Hospice including CEO Fintan Fagan and patients (Radio)
87. 11 September 2019, CRY FM, Community Radio Youghal, Karen Charnley, AllHPC Director, interview (Radio) PR

88. 11 September 2019, The Kerryman (North Kerry Edition), Palliative Care Week in Kerry, 'The care here is second to none', Daly family and Kerry Specialist Palliative Care Services Director of Nursing Mari O'Carroll with pics of patient and team (ROI)
89. 11 September 2019, The Kerryman (South Kerry Edition), Palliative Care Week in Kerry, 'The care here is second to none', Daly family and Kerry Specialist Palliative Care Services Director of Nursing Mari O'Carroll with pics of patient and team (ROI)
90. 11 September 2019, The Kerryman (Tralee Edition), Palliative Care Week in Kerry, 'The care here is second to none', Daly family and Kerry Specialist Palliative Care Services Director of Nursing Mari O'Carroll with pics of patient and team (ROI)
91. 1 September 2019, 4ni.co.uk, Research Highlights Need for Palliative Care Awareness (online) PR
92. 11 September 2019, Weekly Observer, Limerick, Milford Care Centre takes part in Palliative Care Week, Pat Quinlan CEO (ROI)
93. 12 September 2019, Radio Kerry, John Kieran speaks about care for his wife Kathleen, and Margaret O'Driscoll, Clinical Nurse Specialist, Kerry (Radio)
94. 12 September 2019, RTE Six-One News, Pat McGrath interview with Kate Cameron, Mary Nash, CEO Galway Hospice Foundation, Brendan O'Hara, AIHPC (TV) PR
95. 12 September 2019, Tipperary Star, Milford participate in Palliative Care Week, Pat Quinlan, CEO (ROI)
96. 12 September 2019, Kerry's Eye, PALLIATIVE CARE WEEK runs until this weekend to highlight the vital supports available throughout the community. Reporter Audrey Reidy visits the unit at UHK (University Hospital Kerry) to learn more about their message – 'Surrounding You With Support', A place of calm and tranquillity (ROI)
97. 12 September 2019, Kerry's Eye, 'I owe my life to the Care Unit', John Ward attends the Palliative Care Unit at University Hospital Kerry (ROI)
98. 12 September 2019, Kerry's Eye, 'They treated my mom like a person not as a patient', Downey family; Mari O'Connell, Director of Nursing, and Dr Patricia Sheahan, Kerry Specialist Palliative Care Services (ROI)
99. 12 September 2019, The Clare Echo, Milford open their doors for Palliative Care Week 2019, Pat Quinlan CEO (ROI)
100. 12 September 2019, Vale Star, Milford takes part in Palliative Care Week, Pat Quinlan CEO (ROI)
101. 12 September 2019, Mallow Star, Milford Care Centre takes part in Palliative Care Week, Pat Quinlan CEO (ROI)

102. 12 September 2019, Limavady Northern Constitution, Palliative Care – Surrounding you with Support, Western Health and Social Care Trust team with comments and photo (NI)
103. 12 September 2019, traleetoday.ie, Over €2,000 donated to Palliative Care Unit in Michael's Memory, presentation during Palliative Care Week (online)
104. 12 September 2019, irishnews.com, Derry consultant highlights the need for improved palliative care services in north, Dr Damien McMullan (online)
105. 12 September 2019, Farm Week, Praise for 'amazing' Marie Curie Community Nursing team, Tony and Rosemary O'Mullan (NI)
106. 12 September 2019, Ulster Herald, Communities at the heart of palliative care, Dr Conn Haughey, Western Trust (NI)
107. 12 September 2019, Irish News, The focus of palliative care is to live well for as long as possible, Dr Damian McMullan, Foyle Hospice and Altnagelvin Area Hospital (NI daily)
108. 12 September 2019, Newstalk, Palliative Care Week, Kate Cameron, Galway (ROI), G Tracey, Our Lady's Hospice, Dr Ciara Kelly, Annie McHale Voices4Care (Radio)
109. 13 September 2019, Radio Kerry, Palliative Care Week, Margo living with breast cancer and visits to the Palliative Care Centre at University Hospital Kerry (ROI) Radio
110. 13 September 2019, independent.ie, 'The care here is second to none' Daly family and Kerry Specialist Palliative Care Services (online)
111. 14 September 2019, Westmeath Independent, 'Hospice issue raises question about palliative care', Comment Sharon Foley, CEO Irish Hospice Foundation (ROI)
112. 14 September 2019, News Letter, 'Amazing' role of Marie Curie nurses praised (Rosemary and Tony O'Mullan) (NI)
113. 15 September 2019, Newstalk, Palliative Care Week (Radio)
114. 17 September 2019, Newry Democrat, Palliative Care Week, Southern Trust, Brian Beattie, Interim Director of Older People's Service and contact details for David Calvin, Service Improvement Lead (NI)
115. 18 September 2019, The Kerryman (North Kerry Edition), Countywide, Kerry Hospice Foundation, Palliative Care Week (ROI)
116. 18 September 2019, The Kerryman (Tralee Edition), Club News, Kerry Hospice Foundation, Palliative Care Week (ROI)
117. 18 September 2019, The Kerryman (South Kerry Edition), Countywide, Kerry Hospice Foundation, Palliative Care Week (ROI)
118. 18 September 2019, Mourne Observer (Down Edition) Life & Times organises coffee morning to mark Palliative Care Week (NI)

119. 19 September 2019, Ballymena Guardian, Local farmer and his family heap praise on amazing Marie Curie Nursing team (NI) PR
120. 23 September 2019, The Examiner (Crossmaglen), Priorities for Care at End of Life, Southern Trust (NI)
121. 23 September 2019, Medical Independent, Launch of Palliative Care Week, pic of launch (ROI) PR
122. 24 September 2019, Newry Democrat, Priorities for Care at End of Life, Southern Trust (NI)
123. 24 September 2019, Ballymena Times, Amazing role of Marie Curie Nurses praised, Tony and Rosemary O'Mullan (NI) PR
124. 26 September 2019, Ulster Gazette, Trust conference on priorities for care at end of Life, Southern Trust (NI)
125. 2 October 2019, Newry Reporter, Kilbroney Vintage Car Show, Coffee morning to mark Palliative Care Week raising £2,500 for Life and Time (NI)
126. 10 October 2019, Highland Radio, interview re bereavement support group in Donegal with Harry Cheevers who mentioned that he had been on the programme during a previous Palliative Care Week

APPENDIX E – Themes

Palliative Care Week 2019 was the sixth annual campaign facilitated by All Ireland Institute of Hospice and Palliative Care.

The tag lines for the six 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)

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