



# AIIHPC

All Ireland Institute of  
Hospice and Palliative Care

## Palliative Care Week 2017 Report



DECEMBER 2017

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## Palliative Care Week 2017 at a glance

- 2** Government Ministers involved
- 3** Personal stories contributed to success
- 3** TV interviews
- 13** Radio interviews
- 30** Events across island
- 50** Media interactions in total
- 114** Thunderclap supporters
- 119** Social media competition entrants
- 856** Twitter posts
- 2,571** Palliative Hub sessions
- 4,000** Leaflets in Coffee Morning packs
- 10,300** Leaflets distributed
- 32,000** Viewers of one media story



Health Minister Simon Harris TD endorses Palliative Care Week 2017, pictured with Karen Charnley, Head of Institute

## 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 fourth 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 2017

Planning for Palliative Care Week 2017 began in late 2016. In the previous three years, Palliative Care Week had been held in October. Following approaches to AIHPC and discussion with partners, it was agreed that Palliative Care Week 2017 would be held from 3-9 September (Sunday to Saturday), a week ahead of Ireland's Biggest Coffee Morning for Hospice on 14 September 2017.

Notification of the dates was issued to key contacts in January 2017 and publicised in the February 2017 edition of AIHPC's Newsletter, so that organisations could begin planning local activities around this week. In the early stages of planning for Palliative Care Week, AIHPC indicated that it was anticipated that the experiences of service users and carers would feature prominently.

### **AIHPC's objectives for Palliative Care Week 2017 were to:**

- increase public understanding of palliative care
- get people to think about what they know/don't know and to discuss/find out more about palliative care by use of the tag line: Palliative Care: What have you heard?
- feature prominently the experiences of service users and carers (stories)
- focus on quality of life and celebration of life

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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)

### 3. Key Developments

Addressing an event in Belfast in June 2017, Professor Jane Seymour, Professor of Palliative and End-of-Life Care, School of Nursing and Midwifery, University of Sheffield, commended previous AllHPC Palliative Care Week campaigns for their simple key messages which enabled a dialogue with the community.

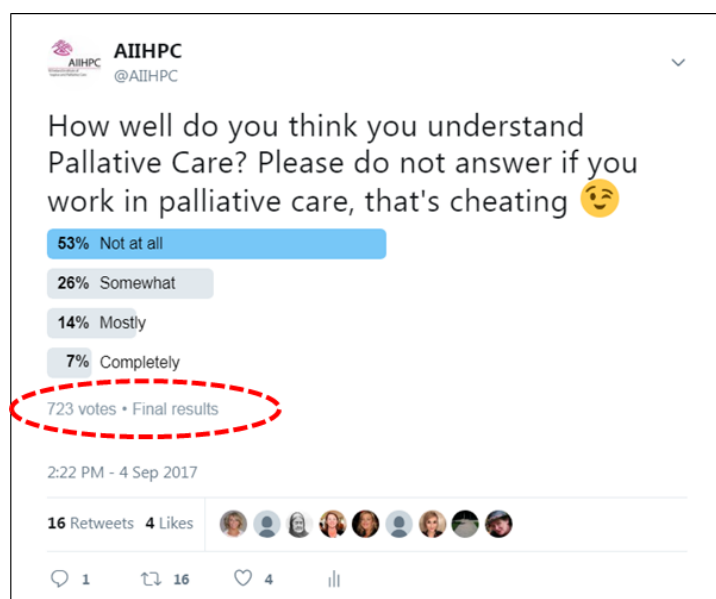
Among key contributing elements to success, which Professor Seymour highlighted were: short mass media campaigns – with trustworthy sources; using old and new media; mixed media campaigns and the use of stories.

- AllHPC and the Health Service Executive (HSE) Quality Improvement Division set out on a collaborative project in late 2016 with the aim of producing short videos to highlight a wide range of palliative care experiences. This video project of service user and carer stories was completed in mid-August 2017.
- As the result of an approach from AllHPC, three participants in the video project, including two people living the palliative care experience, agreed to be involved in the Palliative Care Week 2017 campaign. They were Evelyn Wakefield, from County Offaly; John Joyce, from County Mayo; and Claire Gray, from County Down (pictured below).



- Comments from Evelyn, John and Claire were included in promotional materials and their video clips were prominently featured on [www.thepalliativehub.com](http://www.thepalliativehub.com) during the campaign.

- AllHPC commissioned The Communications Clinic for the first time in 2017 to provide communications consultancy for the campaign.
- Evelyn, John and Claire were most generous in making themselves available for media interviews, being supported in this by the AllHPC team and by Aileen Gaskin of The Communications Clinic.
- As well as use of traditional media, there was extensive use of social media during the campaign.
- A competition was introduced this year to encourage the spread of key messages through the use of social media.
- Planning began much earlier for 2017 and key information and promotional materials were available well ahead of the week. Materials were available for distribution in late July.
- Planning and scheduling of briefings took account of the change of date to September.
- 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.
- The design of promotional materials was delivered in-house by the AllHPC team, particularly by Gareth Wescott, with photography by Anthony Edwards, Trinity Centre for Health Sciences, St James Hospital, Dublin. In-house design enabled more flexibility in revising drafts of materials and minimised costs considerably.



Twitter poll

## 4. Campaign Planning

### Audiences

- The campaign was targeted at the public, particularly those who could benefit from palliative care.
- AllHPC's partners and the wider sector with an interest were a key vehicle to reach this audience, although the people involved in these organisations are also part of the wider public and therefore were also an audience for the campaign.

### 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 2017 campaign.

- AllHPC engaged with the reference group at key points in the planning and delivery of Palliative Care Week 2017: notification of the date (January); notification of theme (June); draft promotional materials (4 July 2017); sharing finalised materials (19 July); final call to action (28 August); sharing embargoed press releases (1 September). Reference Group membership and their terms of reference are in Appendix A.
- The Reference Group included Strategic/Service Improvement Leads in Northern Ireland and briefing opportunities for these leads, with communications colleagues, was provided in July and August 2017.
- 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) also contributed greatly to the success of the campaign.
- In addition to the Reference Group involvement, a focussed piece of engagement with Voices4Care on 5 May 2017 informed project planning. An update on the 2017 campaign was provided to Voices4Care members on 30 June 2017, with an invitation to get involved. A further email with campaign materials and a reminder of the opportunity to be involved was sent on 1 August.

### Key messages

In the leaflet to accompany the campaign, messaging was kept simple and reiterated key messages from previous campaigns to include: 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 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.

## 5. Resources

As with previous years, the 2017 campaign included a suite of promotional materials, media engagement, the use of new media and supporting 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 in-house (see Appendix B):

- Campaign logo
- Leaflet (A5 size)
- Poster
- Three screensavers (Evelyn, John, Claire)
- Email signature (featuring Evelyn, John, Claire)
- A social media campaign picture frame sheet.

### Videos

Three short videos of Evelyn, John and Claire were available on the Palliative Hub.

### Events

In all communications with partners and interested organisations they were encouraged to let AIIHPC know if they were organising any events, no matter how big or small, and it would be promoted on the Palliative Care Week 'What's happening' page.

### 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 themes for each day:

Sunday	Introducing the week
Monday	Basic introduction to palliative care
Tuesday	Dispelling myths
Wednesday	Focus on family carers
Thursday	Different professional roles
Friday	Children's palliative care
Saturday	The role of volunteers

The hashtag *#pallcareweek* was used in 2017, as with previous campaigns.

### Social Media Competition

A competition was introduced as part of the 2017 campaign to encourage the spread of key messages through the use of social media. Entrants could take part in the competition through Twitter by replying and retweeting a specified post related to what the entrant had heard about palliative care, or through Facebook by commenting on and liking AIIHPC's Facebook page on the same theme. The prize was a €200 Ticketmaster voucher.

### Thunderclap

A thunderclap was set up again this year, to which participants were invited to sign up through their social media accounts, enabling this message to be automatically sent on 3

September at 12 noon: "I'm supporting #PallCareWeek 2017! Get involved this week to help spread the word and learn about #Palliative Care." A link was included in the message by which others could also sign up to the thunderclap.



Tweet with highest activity

### Website

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

- Details of events
- Competition information
- Video stories (Evelyn, John, Claire)
- All of the promotional materials
- Explanations about palliative care
- Myth-busting video scribes

### Media planning

Discussions began in early June with The Communications Clinic in relation to media planning for Palliative Care Week. With their agreement, it was planned that the personal experiences of Evelyn, John and Claire would be a major feature of media activity, and that a press release would be issued at the beginning of the week.

Evelyn, John, and Claire took part in media interviews in their local areas and with print and broadcast media organisations with a much wider reach across the Republic of Ireland and Northern Ireland.

A media/press release was issued at the beginning of the week on Monday 4 September. The press release referenced research by Dr Bridget Johnston, Trinity College Dublin. Its messaging was to address misperceptions about palliative care.

Comment was included in the press release from Dr Johnston, and from the Head of the Institute. The release was tailored for the two jurisdictions on the island. For the Republic, the press release included comments from Evelyn Wakefield, Jim Daly T.D., Minister of State for Mental Health and Older People and Sheila Reaper Reynolds, HSE Lead for Palliative Care. For the northern version, comment was included from Claire Gray, Richard Pengelly, Department of Health Permanent Secretary, and Mary Hinds, Director of Nursing and Allied Health Professions at the Public Health Agency. The releases are included in Appendix D.

## **6. Costs**

The total campaign cost for 2017 was €12,000.

This breaks down into:

- Production and printing of promotional materials (including photography) - €4,000
- Communications Consultancy - €4,600
- Distribution (postage etc.) - €1,600
- Media monitoring and social media - €1,800

Costs were kept to a minimum for the 2017 campaign, including through the provision of additional resources in-house. This did mean additional time and support was provided by AIIHPC staff and this was absorbed within the Institute's running costs.

## 7. Impact

### Promotional materials

A more targeted approach for the distribution of promotional materials was taken in 2017. In 2016 packs were posted to approximately 400 organisations on the AIIHPC contact database (with 1,200 leaflets – 3 per pack, and 1,200 posters – 3 per pack). In addition to the packs, more than 1500 leaflets were provided to 25 contacts.

For the 2017 campaign, on 2 August (a month ahead of the campaign) AIIHPC wrote to almost 900 people 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.

More than 10,300 leaflets were distributed in 2017 compared to 2,700 leaflets in 2016. These were sent directly to 55 contacts supporting Palliative Care Week information events. Almost 550 posters were distributed in 2017. There was just one poster printed for the 2017 campaign, compared to three different versions in 2016.



*Minister Jim Daly TD with Karen Charnley, Head of Institute, Sarah McCloskey, Marymount University Hospital and Hospice CEO, and colleagues*

### Events

There was significant activity for events in 2017 with 30 events held between Friday 1 September and Thursday 14 September. These were predominantly led by AIIHPC partners and other organisations with an interest in palliative care. AIIHPC colleagues attended a number of events including:

- Marie Curie's Walk Ten Northern Ireland event in the Stormont Estate Belfast, 1 September

- Visit of Minister Jim Daly TD to Marymount University Hospital and Hospice, Cork, 4 September
- Northern Health and Social Care Trust 'Palliative Care in Practice' Conference at Mossley Mill, Newtownabbey, County Antrim, 4 September
- AllHPC Knowledge Transfer and Exchange Workshop for Palliative Care Research, Dublin, 5 September
- Southern Health and Social Care Trust, Motor Neurone Disease: A Palliative Approach Conference, Lough Neagh Discovery Centre, Oxford Island, Craigavon, 7 September
- Marie Curie, 'Hiding who I am' - a lunch time policy seminar on end of life care for LGBT people, 7 September
- NI Regional Palliative Care Programme, 'Palliative Care in Partnership' Advance Care Planning Event, Seamus Heaney Home Place, 13 September
- Events/information stands were also hosted during the week by: Milford Care Centre, Limerick; Northern Ireland Hospice; The Public Health Agency, Northern Ireland; St James Hospital, Dublin; University of Limerick Hospitals; Belfast City Hospital; ARC Cancer Support, Dublin; Galway University Hospital; Hospice Friendly Hospitals Programme (Irish Hospice Foundation/HSE); North West Hospice, Sligo; Our Lady's Children's Hospital Crumlin, Dublin.

## Media

Although there was some pick-up of the press release issued for Palliative Care Week, the majority of media activity for the 2017 campaign featured Evelyn, Claire or John.

Evelyn, John and Claire were readily available to facilitate requests for media interview. This not only required a major commitment of time and effort but they willingly developed their skills for media interviews, accepting advice and support, and undertaking training when provided.

More than 50 media interactions during Palliative Care Week included three TV interviews, four national and nine regional radio interviews, coverage in four national newspapers, 10 online pieces of coverage and items in 19 regional newspapers. Please see Appendix C for list of media coverage.

In a contribution to one media news website, more than 32,000 people viewed Evelyn's story, and very positive comments were received:

<http://www.thejournal.ie/readme/palliative-care-i-felt-that-if-i-brought-the-nurse-into-my-life-i-was-really-facing-death-3572751-Sep2017/>

Following a media interview, the following message was received from a group of cancer patients: "I was talking about you yesterday and how you spoke about palliative care, not one person in the room knew anything other than that word meant curtains!!! So thank you on behalf of everyone, you are a remarkable woman."



Evelyn Wakefield on The Elaine Show, TV3, 4 September 2017

### Website and Social Media

Overall there was a significant increase in web traffic and Twitter activity.

Visits to [www.thepalliativehub.com](http://www.thepalliativehub.com) were up significantly compared to 2016:

	Sessions	Users	Page views	Pages per Session	Avg. Session Duration	% New Visitors
<b>2017 Sept 1 - Sept 10</b>	2,571	2,269	4,349	1.69	01:30	84.52%
<b>2016 Oct 1 - Oct 10</b>	1,141	925	2,108	1.85	02:02	76.77%
<b>Difference</b>	<b>125.33%</b>	<b>145.30%</b>	<b>106.31%</b>	<b>-8.44%</b>	<b>-26.52%</b>	<b>10.09%</b>

Details on the source of the traffic to the [www.thepalliativehub.com](http://www.thepalliativehub.com) is presented below (with a comparison to 2016)

	Direct	Social (redirected from social media)	Referral (link from another website/ newsletter)	Organic Search
<b>2017 Sept 1 - Sept 10</b>	1033	798	512	228
<b>2016 Oct 1 - Oct 10</b>	372	344	301	124
<b>Difference</b>	<b>177.69%</b>	<b>131.98%</b>	<b>70.10%</b>	<b>83.87%</b>

Twitter activity was also markedly increased from last year:

Twitter	Individual Posts	Contributors	Reach	Impressions
2017 Sept 1 - Sept 10	856	1,090	1.7m	5.7m
2016 Oct 1 - Oct 10	720	255	535,000	4.2m
Change	18.8%	327.4%	217.7%	35.7%

AIHPC organised a social media competition this year which had 119 entrants.



Whilst there was a 72.7% increase in contributors for the Thunderclap campaign - up from 66 to 114 supporters - the actual reach was less than last year. The reason for this was that accounts with large followings such as @Ireland and @krowdster joined during 2016:

Thunderclap	Supporters	Social Reach
2017	114	164, 280
2016	66	195, 485
Change	72.7%	-15.9%

In terms of trending we were on the cusp for most days and did indeed trend at times, however it was not as pronounced as last year. Despite an overall increase in Twitter activity we were missing an influential account (like an @Ireland) to get trending consistently. However, the overall footprint for Palliative Care Week 2017 was much larger, which is key.

## 8. Commentary

A very successful public awareness campaign was delivered through Palliative Care Week 2017, and a number of factors contributed to this:

- The campaign benefitted greatly from the investment and involvement of the HSE Quality Improvement Division, through Greg Price, Assistant National Director, working with AIIHPC to deliver the palliative care experiences videos project.
- Not only was a valuable video resource produced but it was through participation in this project that Evelyn, John and Claire became the faces of Palliative Care Week 2017.
- The personal stories of Evelyn, John and Claire enabled the public to connect with the campaign and to learn more about the quality of life benefits of palliative care. AIIHPC has received very positive feedback in relation to the impact of these personal stories in promotional materials and in the overall campaign.
- Evelyn, John and Claire were Palliative Care Week ambassadors in their own communities, for example, through the distribution of promotional materials including leaflets and posters to health facilities, pharmacies and other community centres where they lived. Not only did they participate in traditional media activity but they promoted the Palliative Care Week messages through their own social media channels, including Facebook and Twitter.
- Beginning to plan early assisted greatly in helping partners and the palliative care sector to be campaign ready. AIIHPC has received positive comments about receiving briefings and promotional materials early.
- Partners and leaders across the sector were more engaged and involved in 2017 with many holding events/hosting information stands which AIIHPC was aware of.
- Linking with other major events/initiatives, for example coffee morning, helped with the reach to a very wide audience, raising awareness across the sector, and also assisted the most effective use of resources by availing of others' distribution networks.
- Being able to manage the design in-house saved on both costs and time for promotional materials. That colleagues involved in the video project were able to support the design process made the process run smoothly and this is thanks to the input of Anthony Edwards and Paul Quinlan, Trinity Centre for Health Sciences, St James Hospital, Dublin.

## 9. Planning for 2018

As AIIHPC begins planning for 2018, key guiding principles/considerations include:

- Personal experiences informing the campaign
- AIIHPC will continue to be a co-ordinator and facilitator – supporting partners and the sector to maximise on the campaign
- Engagement of partners and the sector in the campaign will be crucial for impact and success
- Building on the success of previous Palliative Care Week campaigns, AIIHPC and partners/sector maximise:
  - on the benefit of linking into other initiatives, (coffee morning etc.)
  - on links across palliative care and wider community sector and the palliative care programmes in both jurisdictions
- Continuing to use both traditional and newer media and explore opportunities provided through the arts
- Taking account of suggestions in relation to a ribbon or a pin for Palliative Care Week
- Continuing to plan and engage early for the campaign.



## APPENDIX A – Reference Group

Member	Organisation
Aileen Mulligan	Southern Health and Social Care Trust
Angela McVeigh	Southern Health and Social Care Trust
Anne Molloy	Voice4Care Member
Anne-Marie Hayes	Milford Care Centre
Anthony Staines	Dublin City University
Audrey Houlihan	Our Lady's Hospice & Care Services
Audrey Lambourn	Health Service Executive
Brenda Creaney	Belfast Health and Social Care Trust
Carina O'Neill	Our Lady's Hospice & Care Services
Catherine Sweeney	University College Cork
Charles Normand	Trinity College Dublin
Claire Bradshaw	Northern Ireland Hospice
Corrina Grimes	Public Health Agency
Craig Harrison	Marie Curie
Dee Kinane	St Francis Hospice
Diane Walker	Marie Curie
Donall Henderson	Foyle Hospice
Eamon O'Kane	Marie Curie
Eileen Wright	Voice4Care Member
Eleanor Flew	Our Lady's Hospice & Care Services
Emma King	Western Health and Social Care Trust
Fiona Gilmour	Northern Health and Social Care Trust
Greg Price	Health Service Executive
Heather Weir	Northern Ireland Hospice
Helen Mallen	Patient and Client Council
Irene Hegarty	Marymount University Hospital and Hospice
Jane Flynn	Irish Hospice Foundation
Joanne Reid	Queen's University Belfast
John McGarvey	Western Health and Social Care Trust
Karen Ryan	National Clinical Programme for Palliative Care
Kellie Myers	National Clinical Programme for Palliative Care
Kiran Kaur	Belfast Health and Social Care Trust
Laura Dempsey	National University of Ireland Galway
Louise Hagan	Belfast Health and Social Care Trust
Maeve Hully	Patient and Client Council
Margaret Mulholland	Northern Health and Social Care Trust
Mary Nash	Galway Hospice
Megan Mason	Public Health Agency
Michael Craig	Galway Hospice
Niamh Clowry	Irish Association of Palliative Care

Nicki Patterson	South Eastern Health and Social Care Trust
Pat Quinlan	Milford Care Centre
Paul McIvor	Foyle Hospice
Paul Turley	Health and Social Care Board
Paula McGovern	Marymount University Hospital and Hospice
Phil Hughes	Northern Health and Social Care Trust
Philip Larkin	University College Dublin
Ray Elder	South Eastern Health and Social Care Trust
Regina McQuillan	St Francis Hospice
Sarah McCloskey	Marymount University Hospital and Hospice
Sarah Meagher	Laura Lynn Children's Hospice
Sharon Foley	Irish Hospice Foundation
Sharon Morrow	Laura Lynn Children's Hospice
Sheilagh Reaper-Reynolds	Health Service Executive
Sinead Morrissey	Nursing Homes Ireland
Siobhan McCarthy	Royal College of Surgeons Ireland
Sonja McIlpatrick	Ulster University
Terri Sythes	Foyle Hospice
Tony O'Brien	Marymount University Hospital and Hospice

The role of the Reference Group was to advise on a campaign which:

- Identifies messages and content which are representative of thinking across the sector
- Is reflective of patient perspectives
- Integrates harmoniously with messages and activities of other stakeholders in the sector
- They would be a link and champions of Palliative Care Week within their organisations, where appropriate, and across the health system.

The reference group included:

- members of Voices4Care which is AllHPC's panel of service users, carers and citizens interested in palliative care
- the representative from each organisation on AllHPC's Council of Partners
- the communications contacts for voluntary hospices which are members of AllHPC's Council of Partners
- Palliative Care Strategic/Service Improvement Leads in the five NI Health and Social Care Trusts (which are also AllHPC Partners)
- Key strategic leads in palliative care in both jurisdictions on the island of Ireland (Health Service Executive (HSE), Public Health Agency (PHA) /Health and Social Care Board (HSCB)) and
- Key communications leads in these organisations (HSE, PHA/HSCB).

## APPENDIX B Promotional Materials Information Leaflet

### Palliative Care Week

Sunday 3 September to Saturday 9 September 2017

Palliative Care Week aims to raise awareness of the difference palliative care can make to patients, carers and families throughout the island of Ireland.

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



### Get in touch

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

or

Email: [info@aihpc.org](mailto:info@aihpc.org)  
 Tel: +353 (0)1491 2948

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



### Palliative Care What have you heard?



“When the palliative care nurse contacted me my first reaction was, I don't want to see you

I was surprised...she had so many suggestions of how to give me back my quality of life”

**Evelyn Wakefield,  
Offaly**

PALLIATIVE CARE WEEK  
 3-9 SEPTEMBER

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



### Palliative Care – What have you heard?

**Q. What is palliative care?**  
**A.** Palliative care focuses on helping people of all ages to live well with an illness that is life-limiting 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 social, emotional and spiritual support.

**Q. Is palliative care only for people with advanced cancer?**  
**A.** Palliative care is just as important if you are living with advanced heart or lung disease, kidney failure and other conditions such as motor neurone disease or dementia.

**Q. Is palliative care only for people who are in the last days or weeks of life?**  
**A.** Some people who receive palliative care are in the last days and weeks of life but some 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. Where is palliative care provided?**  
**A.** Palliative care is provided by a range of professionals supporting the person, whether they are at home, in a nursing home, hospital or hospice.

“She had lots and lots of adventures. They made her life more lovely”  
 Claire Gray, Matilda's mummy, Down



### Personal Stories

**They have taken the fear out of the words palliative care**  
 I was an inpatient in hospital roughly a year and a half ago when I was introduced to the palliative care team. My first reaction was, OK, I'm gone. My perception of palliative care has changed so much. The palliative care team complements your treatment - manages your pain relief, your welfare needs, your everyday life really. I would have been afraid of palliative care at the start. Now I would have no fear, they have taken the fear out of the words palliative care.”  
 John Joyce, Mayo

**My first reaction was, I don't want to see you**  
 The day the oncologist mentioned palliative care, myself and my husband started to cry because, in our opinion, palliative care was end of life. When the palliative care nurse contacted me my first reaction was, I don't want to see you. We talked and I was surprised because she had so many suggestions of how to give me back my quality of life... I had the most normal day I'd had maybe in a year and a half, where I could look after my kids and take them to their activities. It absolutely blew my mind how successful we were.”  
 Evelyn Wakefield, Offaly

**They made her life more lovely**  
 “Matilda had palliative care from when she was five days old. The consultant told us our little girl had a very serious condition called Edwards' Syndrome, Trisomy 18. My husband and I immediately began to cry. We took Matilda home on her two week birthday and for us to have that moment felt like we had just climbed Everest and that she had climbed Everest. She had lots and lots of adventures and hospice at home made a lot of them possible. They made her life more lovely.”  
 Claire Gray, Matilda's mummy, Down

### Don't be afraid to ask!


Don't be afraid to ask your GP or any other healthcare professional if palliative care could help you or someone you love.

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

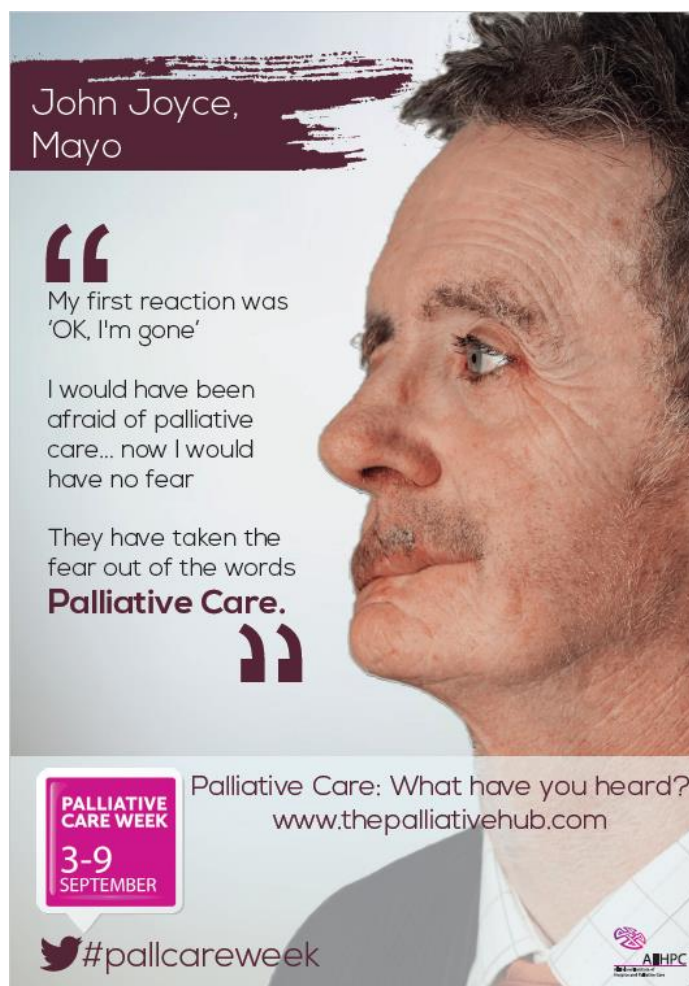
Whatever the age, people are enabled to make the most of the life that's there and the time that's left. Knowing a loved one is comfortable and respected, with their pain managed, can make it easier to talk and to laugh.

Palliative care maximises the quality of life for the person at the centre of care and those important to them and it continues that care into bereavement.

“They have taken the fear out of the words palliative care”  
 John Joyce, Mayo



## Poster



## John Joyce, Mayo

“My first reaction was 'OK, I'm gone'


I would have been afraid of palliative care... now I would have no fear

They have taken the fear out of the words  
**Palliative Care.**”

PALLIATIVE CARE WEEK  
 3-9 SEPTEMBER

Palliative Care: What have you heard?  
[www.thepalliativehub.com](http://www.thepalliativehub.com)

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




## Web Banners

**Palliative Care**  
What have you heard?

Find out how palliative care is helping people and families everyday  
[www.thepalliativehub.com](http://www.thepalliativehub.com)

**PALLIATIVE CARE WEEK**  
3-9 SEPTEMBER

 #pallcareweek

"When the palliative care nurse contacted me my first reaction was, I don't want to see you

I was surprised...she had so many suggestions of how to give me back my quality of life"


**Evelyn Wakefield, Offaly**



**Palliative Care**  
What have you heard?

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**PALLIATIVE CARE WEEK**  
3-9 SEPTEMBER


 #pallcareweek

"My first reaction was ok, I'm gone

I would have been afraid of Palliative Care...now I would have no fear

They have taken the fear out of the words **Palliative Care**"

**John Joyce, Mayo**



**Palliative Care**  
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 #pallcareweek

"We took Matilda home on her two week birthday and for us to have that moment felt like we had just climbed Everest and that she had climbed Everest.

She had lots and lots of adventures and hospice at home made a lot of them possible.

They made her life more lovely."


**Claire Gray, Matilda's mummy**



## Social Media Picture Frame


**PALLIATIVE CARE WEEK**  
3-9 SEPTEMBER

**SOCIAL MEDIA PICTURE CAMPAIGN**  
Palliative Care Week 2017

 **AIHPC**  
All Ireland Institute of Hospice and Palliative Care

Please write a word or a short phrase that describes what you've heard about palliative care. Photograph yourself with the poster and post to Twitter, Facebook or Instagram using #pallcareweek.

Palliative Care: What have you heard?

 #pallcareweek

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

## APPENDIX C – Media Coverage

- Offaly Independent, 26 August 2017, Palliative Care is not just for end-of-life
- Derry Journal, 1 September 2017, Don't be afraid to ask if palliative [care] could help
- Today with Sean O'Rourke, RTE Radio, 1 September 2017, Evelyn & Dr Regina – 15 minute interview
- Clare Champion, 1 September 2017, What have you heard about Palliative Care?
- Belfast Telegraph, 2 September 2017, A lifetime crammed into 90 days.... how an NI couple made every moment count when their new born baby was given just months to live (full story pages 12&13)
- Journal.ie, 2 September 2017, Palliative care: I felt that if I brought the nurse into my life, I was really dying
- Limerick Leader, 3 September 2017, Milford Care Centre seeks to alter public attitude to vital palliative care service
- Belfast Live, 3 September 2017, Matilda's life was short, but Hospice she lived it to the full
- Love Belfast, 3 September 2017, Northern Ireland Hospice invites public to café conversations during palliative care week
- The Tommy Marren Show, Midwest Radio, 4 September 2017
- CRC FM, 4 September 2017
- The Pat Kenny Show & the Best of Newstalk, 4 September 2017, Remember little Matilda during Palliative Care Week
- Elaine Show, TV3, 4 September 2017
- HSE Website, 4 September 2017, Palliative Care Week 2017, Research Reveals, Four out of Five People Think Palliative Care Can Only be provided by Specialist Palliative Care Teams, Almost One Third of People Think Palliative Care is only Available in a Hospice or Hospital
- Midlands Today, Midlands 103, 5 September 2017
- Morning Focus, Clare FM, 5 September 2017
- Joe Finnegan Show, Northern Sound, 5 September 2017
- Woman's Way, 5 September 2017, Caring about Palliative Care
- The Last Word, Today FM, 5 September 2017
- The Sligo Champion, 5 September 2017, Support charity coffee morning
- RTE One o'clock News, 6 September 2017, Our Lady's Hospice
- RTE Six One News, 6 September 2017, Our Lady's Hospice
- RTE.ie, 6 September 2017, Four times more people access palliative care in the community
- Leitrim Observer, 6 September 2017, Kevin's final 25 days were 'remarkable'
- Larne Times, 7 September 2017, NI hospice inviting people to join Café Conversations
- Carrick Times, 7 September 2017, NI Hospice inviting people to join Café Conversations
- Limerick Today, Limerick Live 95, 7 September, 2017
- Newtownards Chronicle, 7 September 2017, Extensive work of palliative care highlighted
- Derry Daily, 7 September 2017, Durkan: Health inequalities in LGBT community must be addressed

- Cork Independent, 7 September 2017, Meeting at Marymount – CEO, Minister Jim Daly, Head of Institute
- Midland Tribune, 7 September 2017, Palliative Care – What have you heard?
- The Ten to One Show, Highland Radio, 8 September 2017
- Independent.ie, 9 September 2017, I was 33 when I was told I had two and a half years to live – Mum on preparing her young children for her death
- Best of Pat Kenny, Newstalk, 9 September 2017
- The Early Morning Show, Kildare FM, 9 September 2017
- Hindsight, Clare FM, 10 September 2017
- Irish Independent Facebook, 10 September 2017, An Offaly mum has spoken out about being told she was terminally ill at just 33
- Health & Living, Irish Independent, 11 September 2017, Understanding Palliative Care
- Patient & Client Council, 12 September 2017, Caring for someone at the end of their life
- Newry Democrat, 12 September 2017, Taking ‘A Palliative approach to Motor Neurone Disease’
- Mayo News, 12 September 2017, I’ve had palliative care for the last two years, and I’m still here
- Independent.ie, 13 September 2017, We’ll always be so grateful for that time – Grieving woman on heart-breaking reality of losing a parent
- Irish Examiner 14 September 2017, Palliative care gave me a better quality of life
- Coffee and Charity Photographs, 15 September 2017:
  - Ireland ‘s Biggest Coffee Morning at St Francis Hospice, Raheny, Dublin
  - 15 September, AIB’s Killarney coffee morning
  - 15 September, Maymount coffee morning in Cork
  - 15 September, Our Lady’s Hospice & Care Services
- Nenagh Guardian, 16 September 2017, Picture of the Week, Nenagh Hospital Palliative Care Week
- Banbridge Chronicle, 4 October 2017, Palliative approach to motor neurone disease
- Health Matters (HSE Magazine), Autumn Edition, 2017, Palliative Care holds no fear
- Sunday Independent, Our Lady’s Hospice & Care Services article re patient

#### Summary of coverage:

- 3 TV Interviews
- 4 National Newspapers
- 4 National Radio Interviews
- 1 Magazine
- 10 Online pieces of coverage
- 19 Regional Newspapers
- 9 Regional Radio Interviews

## APPENDIX D – Press Releases (RoI and NI)

**EMBARGOED UNTIL MON 4<sup>th</sup> SEPT @11AM**

### Press Release

**4<sup>th</sup> September 2017**

#### **Research Reveals Four out of Five People Think Palliative Care Can Only be Provided by Specialist Palliative Care Teams**

##### **Almost One Third of People Think Palliative Care is only Available in a Hospice or Hospital**

Research published to coincide with Palliative Care Week 2017 (3<sup>rd</sup> to 9<sup>th</sup> September) reveals four out of five people think palliative care can only be provided by specialist palliative care teams. It also found that almost one third of people think palliative care is only available in a hospice or hospital. Palliative Care Week is facilitated by All Ireland Institute of Hospice and Palliative Care (AIHPC) across the Republic of Ireland and Northern Ireland.

Karen Charnley, AIHPC Head of Institute, said: “Hospices and hospitals are key for the provision of palliative care, especially for people with complex needs, but many people will receive palliative care within their own community. Palliative Care is provided by a range of professionals supporting the person, whether they are at home, in a nursing home, hospital or hospice.”

Dr Bridget Johnston of Trinity College Dublin carried out the research as part of a project supported by AIHPC. Interviews were carried out with 75 patients accessing specialist palliative care services and 69 caregivers.

“This research found that misperceptions about palliative care are common among people receiving this care and caregivers. Four out of five people assumed that palliative care can only be offered by specialist teams and this was consistent for both patients receiving care and for caregivers. It was also interesting to find that almost one third of people believe palliative care is only available in a hospice or hospital. This shows there’s still important work to be done to increase people’s understanding of palliative care, so that they are able to make informed choices about care,” said Dr Johnston.

The research also found that eight out of ten people agreed palliative care was about quality of life and that it offers support to family and friends.

36-year-old Evelyn Wakefield from Birr in Co. Offaly was diagnosed with stage four metastatic breast cancer in 2014. When she was contacted by a palliative care nurse, she initially didn’t want to see her.

“I felt if I brought the palliative care nurse in, I was facing death and I wasn’t ready for that. We talked and I was surprised by the suggestions she gave me to give me a better quality of life. I very quickly realised what palliative care was and that the nurse was there to give me the best quality of life I could possibly have and I’ve

succeeded. My perception has obviously changed because I'm on the receiving end of palliative care and I now understand what it is but there are people out there that are still afraid when it's mentioned. What I'd say to them is take all the support you can get. It helps greatly and I now have a better quality of life with my family."

Karen Charnley continued: "Our aim for Palliative Care Week is to encourage people to think about their understanding of palliative care and to encourage them not to be afraid to ask their GP or any other healthcare professional if palliative care could help them or someone they love. People tend to associate palliative care being for people with advanced cancer but it's equally important if you're living with advanced heart or lung disease, kidney failure and other conditions such as motor neurone disease or dementia."

Jim Daly T.D., Minister of State for Mental Health and Older People, is supporting Palliative Care Week. Minister Daly said: "I was delighted to hear about Palliative Care Week and the work of AIHPC during a visit to Marymount University Hospital & Hospice, Cork. It is important for people to be aware of the support that is available to make the most of life when they have a life-limiting illness. Through our National Clinical Programme for Palliative Care, and by supporting Palliative Care Week, our aim is to increase awareness and understanding of palliative care, and support those who need this care."

Sheilagh Reaper Reynolds, HSE Lead for Palliative Care, said: "Palliative care services aim to meet the physical, social, emotional and spiritual needs of patients and carers facing progressive illness that may limit or shorten their lives. People can sometimes have a fear of palliative care and the Palliative Care Week helps us to explain how palliative services can improve a person's quality of life throughout the course of their illness."

## **ENDS**

For further information contact Aileen Gaskin 087 7724 717

## **Editor's Notes**

Palliative Care Week is being facilitated by All Ireland Institute of Hospice and Palliative Care and takes place from the 3<sup>rd</sup> to the 9th of September. For more details see [www.thepalliativehub.com](http://www.thepalliativehub.com)

**EMBARGOED UNTIL MON 4<sup>th</sup> SEPT @11AM**

**Press Release**

**4<sup>th</sup> September 2017**

**Research Reveals Four out of Five People Think Palliative Care Can Only be Provided by Specialist Palliative Care Teams**

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The research also found that eight out of ten people agreed palliative care was about quality of life and that it offers support to family and friends.

Claire Gray from Newtownards, Co Down, lost her three-month-old daughter Matilda in 2013 to Edward’s Syndrome.

“Throughout Matilda’s short time with us, we had support from Hospice at Home. They nursed Matilda overnight so myself and my husband, Kris, were able to get the same rest. It meant we were both refreshed at the same time so we could take Matilda out on little adventures to let her experience the duckpond and the seaside. We were able to make memories together even if it was just for a short period of time. The nurses were so caring with Matilda. Not only did they nurse her; but they

sang to her and read her stories. They offered Kris and I a listening ear too as it was all emotionally overwhelming. They were there for all three of us and will always be so special to our little family,” said Claire.

Karen Charnley continued; “Our aim for Palliative Care Week is to encourage people to think about their understanding of palliative care and to encourage them not to be afraid to ask their GP or any other healthcare professional if palliative care could help them or someone they love. People tend to associate palliative care being for people with advanced cancer but it’s equally important if you’re living with advanced heart or lung disease, kidney failure and other conditions such as motor neurone disease or dementia.”

Endorsing Palliative Care Week, Department of Health Permanent Secretary, Richard Pengelly, said: “Being diagnosed with a progressive, life-limiting condition can be devastating. Palliative care cannot change that diagnosis, but it can help people live well until the end of life, whether that is for years, months or weeks. Palliative Care Week challenges all of us to recognise the importance of good palliative care in helping people live with and manage their illness, making a real difference both for them and those who are important to them.”

Mary Hinds, Director of Nursing and Allied Health Professions at the Public Health Agency (PHA) said: “The Public Health Agency and the Health and Social Care Board, on behalf of the Northern Ireland Palliative Care Programme Board ‘Palliative Care in Partnership’ are delighted to support the messages of Palliative Care Week, which aims to address some of the fears and concerns that may surround the topic of palliative care. Is it important to help people understand that a palliative care approach can be provided across all care settings including people’s own homes, often by the professionals who have been involved in the individual’s care so that their quality of life is improved and also the experience for those important to them.”

## **ENDS**

For further information contact Aileen Gaskin 00 353 87 7724 717

### **Editor’s Notes:**

Palliative Care Week is being facilitated by All Ireland Institute of Hospice and Palliative Care and takes place from the 3<sup>rd</sup> to the 9<sup>th</sup> of September. For more details see [www.thepalliativehub.com](http://www.thepalliativehub.com)

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All Ireland Institute of  
Hospice and Palliative Care