

Press Release

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

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Notes to Editors:

- Brendan O'Hara, AIHPC 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/>