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AIHPC

All Ireland Institute of
Hospice and Palliative Care

Could your palliative care story help others?

Would you like to use your experience of palliative care to help others who could benefit from this care?

All Ireland Institute of Hospice and Palliative Care (AIHPC) and the Health Service Executive (HSE) Quality Improvement Division are collaborating to produce short video clips which will highlight a wide range of palliative care experiences.

The focus of this project is specifically on the experiences of people living with a life-limiting illness, along with someone supporting them. If you are living with a life-limiting illness, and are willing to be filmed talking about your experiences, AIHPC would like to hear from you.

Palliative care focuses on helping people of all ages to live well with an illness which is life-limiting, seeking to help them achieve the best quality of life as their illness progresses.

Often people think that palliative care is just for those who have advanced cancer, but it 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.

Aim

The aim is to have short videos (approximately three minutes long) which will be available for raising awareness and understanding of palliative care and as a learning resource to promote the provision of good quality care. Therefore, the project will aim to reflect what it is that contributes to good quality palliative care. It is planned that these videos will be made widely available and some may be used for the annual Palliative Care Week campaign taking place across the island of Ireland from Sunday 9 to Saturday 15 September 2018.

Participants

We want to involve the person with the illness him/herself and someone providing care – whether a family carer, a healthcare or other professional, or a volunteer. Our aim is to have short videos of an experience where the person with the illness and the person providing care are both involved.

What is important to you?

The story will be around what has been important in your experience – this could be around any of the elements of palliative care – addressing physical symptoms, dealing with

emotional and psychological issues, addressing social issues, and dealing with spiritual concerns (which includes, but is not limited to, religious considerations).

This could also include experiences around how people were communicated with or wishes/plans that have been discussed and how they might be carried out.

Videos of any experiences that could have been better will be with a view to letting others know what would contribute to a better experience.

Range of experiences

We want to achieve a range of experiences across different life-limiting illnesses, across all age groups from children's palliative care through to older people, and to reflect a range of care settings – home, nursing home, hospice, hospital. We also aim to have a representation of people from different parts of the island.

Participation requirements and filming arrangements

Participants will be resident on the island of Ireland.

They will be:

- a) a person living with a life-limiting illness who is receiving palliative care or expecting to receive palliative care;
a family carer/professional/volunteer supporting the person who is living with a life-limiting illness and receiving palliative care; or
- b) a young person living with a life-limiting illness;
a parent, family carer/professional/volunteer supporting the child or young person living with the life-limiting illness;

Filming will take place in early 2018 at a convenient location to be confirmed with participants. This could be in the person's home, (and with the agreement of the person responsible for the facility) nursing home, hospice, or hospital setting.

We are mindful that this is a very sensitive topic, which can be difficult to talk about, and a supportive environment for participants will be provided during the filming process.

Reasonable out of pocket expenses will be reimbursed in line with guidance for supporting service user involvement in health and social care services. As it is planned that filming will take place as close as possible to the location where the person is being cared for, it is not anticipated that there will be significant expenses incurred.

To express your interest:

If you are interested in taking part, please contact AIIHPC at the earliest opportunity and by **Wednesday 28 March 2018** at the latest. Please contact **Brendan O'Hara** at **bohara@aiihpc.org** or **00353 1 4912948**.