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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 and end of life 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.

If you are willing to be filmed talking about your experiences, whether you are living with a life-limiting illness, or are caring for or have cared for someone with such an illness, AIHPC wants to hear from you.

We want to produce a widely available resource which can be used for raising awareness and understanding of palliative care; promotes wider conversation around palliative care; and supports learning and education among health and social care professionals.

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. We hope to have experience related to a range of these illnesses/conditions reflected in the video clips which will be two to three minutes long.

We want to include positive experiences and also welcome contributions from those who from their experience suggest how care could have been better or can be improved. We also want to hear of experiences across all age ranges - including children and young people - and places where care is provided - home, in a nursing home, hospital or hospice.

We plan to film participants in January 2017 and would invite people interested to contact us at the earliest opportunity.

Participation and filming arrangements

Participants will be resident on the island of Ireland.

They will be:

- a person living with a life-limiting illness who may be already receiving palliative care or expecting to receive palliative care;
- a family member/carer of a person who is living with a life-limiting illness and receiving palliative care;
- a family member/carer for someone who received palliative care who has died;

a young person living with a life-limiting illness;
a parent, family member/carer of a child or young person living with a life-limiting illness;
a parent, family member/carer of a child or young person with a life-limiting illness who has died.

We suggest that a person would wait at least 12 months following bereavement before considering taking part in a project such as this.

We also suggest that the experience which a person is willing to talk about should be within the past three-four years.

Filming will take place in January 2017 at a location in Dublin. 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.

To express your interest please contact Brendan O'Hara at bohara@aiahpc.org or 00353 1 4912948. People interested in taking part should contact AIIHPC at the earliest opportunity and by Thursday 5 January 2017 at the latest.