



Guidance for Applicants

What is palliative care?

Palliative care focuses on improving the quality of a life of a person, of any age, with a life-limiting illness as their illness progresses and at end-of-life. It puts the individual at the centre of care and supports their physical, social, psychological and spiritual needs.

Palliative care:

- Ensures that a person with a life-limiting illness, regardless of age or condition, can have the best possible quality of life
- Involves the person and those close to them
- Supports planning for their 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.

What is AllHPC and what is Voices4Care?

All Ireland Institute of Hospice and Palliative Care (AllHPC) an all-island organisation working to improve palliative and end-of-life care for people with life limiting conditions and their families in Northern Ireland and the Republic of Ireland.

AllHPC established Voices4Care in 2013 to learn from people's personal experiences of palliative care, to help inform our work and influence future palliative care. We focus on education, research, policy, and practice that can improve people's experiences of palliative care. Voices4Care considers palliative care for adults.

Who are Voices4Care members?

Voices4Care members are individuals aged 18 and over living in Northern Ireland or the Republic of Ireland from all backgrounds who are either:

- people with a life limiting illness and palliative care needs
- carers or former carers of people with palliative care needs

- citizens with an interest in palliative care

Some group members will have personal experience of palliative care and some may not.

Members join on a voluntary basis and participate as individuals, not representing any particular profession, organisation or interest group.

We advise that if you are recently bereaved that you should wait for at least 12 months following a bereavement before considering applying for membership of Voices4Care.

How will Voices4Care members influence palliative care?

We work with a wide range of people and organisations who plan, research, educate or provide palliative care. We do not provide palliative care services but support those that do.

People with palliative care needs, their families, carers and interested citizens bring unique insights about care which are invaluable for those providing or making decisions about palliative care.

As a Voices4Care member you will be supported and offered opportunities to share your views and experiences. Here are some examples:

- giving your views on education programmes, for example providing feedback on training materials
- helping to identify areas for research and advising researchers with their projects
- helping to develop palliative care policy
- support development of the online gateway to information and resources about palliative care, AllHPC's The Palliative Hub
- Informing public understanding and awareness around palliative care, death, dying, loss and caring, including through AllHPC's annual Palliative Care Week. This may include commenting on draft materials, participating in interviews or recording promotional videos
- Voices4Care members in Northern Ireland will also be offered the opportunity to attend meetings of 'Palliative Care in Partnership - Voices4Care' which is a sub group of the Regional Palliative Care Programme. At the meetings, members will be consulted regarding the key priorities of the Regional Palliative Care Programme (for more information please visit their website: [Palliative Care in Partnership \(hscni.net\)](https://www.hscni.net/palliative-care-in-partnership)).

Voices4Care members may be invited to help with AllHPC's governance committees that ensure that we are following good governance guidelines and are fully transparent in our work.

How will Voices 4 Care members be supported to participate?

If you decide to join Voices4Care we will provide training and support so that you feel comfortable and confident to be involved in different opportunities. For example, you will get an opportunity to participate in a workshop which will explain how you can get involved in research and give you a chance to talk with the AllHPC team, researchers and people with palliative care experience.

We will provide you with information and updates on a regular basis and support you with any additional training needs you may have. We will organise at least two Voices4Care meetings every year where you will get the opportunity to meet with other members of Voices4Care and get an update on all AllHPC activities from the AllHPC team.

This is a voluntary role and any out of pocket expenses in relation to your involvement, such as travel to an event will be paid, in line with our established policies.

What is expected of a Voices4Care member?

As a Voices4Care member you will be expected to:

- be willing to be involved for a period of up to 24 months (we appreciate that it may not always be possible to be involved for the entire period). Members will be asked whether they would like to renew their membership for a further 24 months
- be willing to attend three meetings at venues across the island of Ireland as well as online events
- share your personal experience of palliative care and skills to influence our work in education, research, policy and practice
- be involved through attendance and participation in Voices4Care meetings, discussions, and through other committee meetings, where required
- be willing to provide your feedback on materials that can support palliative care, for example, reports
- prepare for meetings in advance by reading any information provided about the meeting
- be prepared to think how your personal and local experience of palliative care may support the needs of the wider population
- interact sensitively and respectfully with all Voices4Care members
- respect the confidentiality of personal matters discussed at Voices4Care meetings
- be willing to take part in training to support your involvement in Voices4Care
- be willing to take part in any evaluation of the activities of Voices4Care

- are able to access emails as this is the main form of communication (AIIHPC will provide support if required on how to setup an email address)
- be able to access video-conferencing solutions such as Zoom for online events (AIIHPC will provide support to help you use these applications).

If you would like to hear the experience of a Voices4Care member, please read Janet's story [here](#). She's been a Voices4Care member since 2016.

Our commitment to Voices4Care members

We will

- always interact sensitively and respectfully with all Voices4Care members
- respect your time, experiences, and input as a Voices4Care member
- support Voices4Care members with technical and practical support while they are volunteering on a project
- provide training to support your involvement in Voices4Care
- arrange meetings at times and in venues that suit the majority of people, as best we can
- ensure meetings are not overly long in duration, to respect people's varying abilities
- ensure sufficient breaks are included in any meetings and that refreshments are provided at in person meetings
- pay any out of pocket expenses in relation to your involvement, such as travel to an event, in line with our established policies
- ensure diversity and inclusion is part of everything we do. We want to make sure there is a balance of people with life-limiting conditions, carers and wider community members from diverse backgrounds across the whole island of Ireland.
- ask anyone including researchers who want to work with Voices4Care members that they also respect the above commitments to you

How do I apply to become a member of Voices4Care?

If you would like to be considered for membership of Voices4Care please complete an expression of interest form.

You can get this form by:

1. Downloading it from our website: www.aiihpc.org
2. Emailing: info@aiihpc.org or
3. Calling: 00353 1 491 2948

What do I do when I have my expression of interest form completed?

Please email or post your form through either of the contacts below by Monday 9 May 2022.

By email to: Paula Pinto ppinto@aiahpc.org

Or by post to:

Paula Pinto
All Ireland Institute of Hospice and Palliative Care
Second Floor, Education & Research Centre
Our Lady's Hospice & Care Services
Harold's Cross
Dublin 6W

What happens after I submit an expression of interest form?

You will receive acknowledgement of your expression of interest and information on what happens next by the end of May 2022.

All expressions of interest will be reviewed and we will select volunteers that reflect a diverse membership including geographical spread, age and palliative care experience.

We may need to follow up on some expressions of interest to get a better understanding of your expectations and ours. This may involve contacting you by telephone.

If you are currently working or researching within palliative care, we will contact you to understand your interest in joining the group and to discuss any possible conflict of interest that may arise.

The first meeting of Voices4Care is being tentatively planned for Tuesday 28 June 2022.

If you have any further questions, please contact Paula Pinto at All Ireland Institute of Hospice and Palliative Care on (00353) 1 491 2948 / (00353) 87 1961430 or email: ppinto@aiahpc.org