



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

All Ireland Institute of Hospice and Palliative Care
submission to The Citizens' Assembly

How we respond to the Challenges and Opportunities of an Ageing Population

May 2017

Executive Summary

All Ireland Institute of Hospice and Palliative Care (AIHPC)¹ welcomes this topic for discussion by the Citizens' Assembly, particularly considering that Ireland would appear to have the most rapidly rising need for palliative care in Europe⁶.

AIHPC has addressed this topic under the following headings, with accompanying recommendations under each area considered:

- A. Palliative care in the context of an ageing population
- B. Specific needs of older people in relation to palliative care
- C. Increasing number of people with dementia
- D. The context of caring at home
- E. A population-based health approach in the context of palliative care

Recommendations

A total of 10 recommendations are proposed as follows:

1. Every person with a life-limiting condition should be able to easily access a level of palliative care appropriate to their needs, regardless of their age, their condition or where they are being cared for.
2. The specific needs of older persons and their palliative care needs should be considered in national palliative care policy, strategy and commissioning of services.
3. Palliative care should be integrated into chronic disease management.
4. Generalist and specialist palliative care providers, whether in community and primary care, hospital or hospice, should be supported to work together to provide an integrated model of care provision.
5. Health care commissioning to develop palliative care services to meet the changing population needs in relation to the increasing number of people with dementia, including addressing pain.
6. Promote a wider societal normalisation of planning for the future, including planning for end of life.
7. Develop principles for involvement and formalise support for family, friends or others where appropriate, in order to encourage participation in supporting an individual with palliative care needs.
8. Support carers to manage their physical, mental and emotional health and well-being.
9. Recognition when commissioning services for older people of the importance and need for social care, taking account of the large percentage of older people living alone and the need to support carers.
10. Promote public awareness and access to a palliative approach to care for all individuals with a serious or progressive condition from which they are unlikely to be cured and which may limit or shorten life.

How we respond to the Challenges and Opportunities of an Ageing Population

All Ireland Institute of Hospice and Palliative Care (AIHPC)¹ welcomes this topic for discussion by the Citizens' Assembly and appreciates the opportunity to contribute to the debate by way of this submission.

A. Palliative care in the context of an ageing population

The starting point in palliative care is always the person. The goal of palliative care is to improve the quality of life for both the person living with an illness which cannot be cured and for those who matter most to them. While not denying the reality of death, palliative care offers a positive approach which holds space for living life to the full to the very last days of life.

Palliative care can be provided at home, in a nursing home, in hospital or in a hospice. Palliative care is focused on providing patients with relief from the symptoms, pain and stress of a serious illness - whatever the diagnosis. It is also appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment².

By 2050, estimates indicate that more than a quarter of the population of the European region will be aged 65 and older. The greatest percentage increase will be among people aged 85 years and older³.

- The population of Ireland is projected to increase by 13.4% from 4.575 million in 2011 to 5.188 million in 2031, with the number over 65 years of age projected to increase by 86.3% from 532,000 in 2011 to 991,000 in 2031⁴.
- Census 2016 shows that the over 65 population in Ireland increased by 19.1% since 2011. For those over 85, the male population increased by 24.8% to 23,062 while the female population increased by 11.4% to 44,493⁵.
- **Annually, 80% of deaths in Ireland are from conditions considered to have palliative care needs⁶.**

This higher proportion may be the result of the rapidly ageing population, particularly evident in the 13.9% increase of deaths among those aged 85 years or more. Given these findings, Ireland would appear to have the most rapidly rising need for palliative care in Europe⁶.

B. Specific needs of older people in relation to palliative care

When considering palliative care, problems faced by older people are different and often more complex than those of younger people.

As populations age, the pattern of diseases that people suffer and die from also changes.

Increasingly, more people die as a result of serious chronic diseases such as heart disease, cerebrovascular disease (including stroke), respiratory disease and cancer⁷. Many older people suffer from several conditions together, often over longer periods of time, which might all contribute to death.

Although palliative care has been traditionally offered to people with cancer, people aged 85 years and older are more likely to die from cardiovascular disease than cancer³.

AIHPC's Let's Talk About⁸ survey captured the experience of 528 people with palliative care needs and their carers across the island of Ireland - 419 in the Republic of Ireland and 109 in Northern Ireland.

Of those who took part, 71% were aged 60 years or more (41% were aged 60-79, and 30% were aged 80 or older). Survey participants were asked to identify the primary long-term condition(s) of the individuals who had the experience of palliative care:

- **Cancer equated to almost half (262 of 528) of all conditions identified**
- **Neurological disorders including Dementia (90 of 528) and Parkinson's disease (20 of 528) were the next biggest grouping.**

The survey provided a unique insight into the experience of living and dying with a life-limiting condition, identifying the following key themes:

- People need help to plan for the future
- People experience too little autonomy
- People feel helpless and frustrated
- People value clear and sensitive communication
- People value timely and appropriate information
- There are emotional and psychological needs that are not met
- People would like their family and friends more involved

Because it is more difficult to predict the course of many chronic diseases affecting older people, palliative care should be based on patient and family needs and not on prognosis⁷.

Since 2001, palliative care services in Ireland have been guided by the National Advisory Committee on Palliative Care (NACPC) Report⁹. Since the publication of the NACPC Report, significant initiatives to enhance services have taken place across and between organisations within the palliative care sector in Ireland.

These include the creation of the HSE's National Clinical Programme for Palliative Care¹⁰ to improve quality, facilitate equitable access and promote efficient use of resources, and the establishment of the All Ireland Institute for Hospice and Palliative Care and The Palliative Hub¹¹, with the potential to transform and promote palliative care education, research and practice across the island of Ireland.

By 2014, all services were operating to universal eligibility criteria, and admitting patients based on need rather than disease. Nonetheless, the current model of palliative care in Ireland is one that primarily provides care to those with cancer, which is the case in palliative care internationally⁶.

The number of deaths from cancer in Ireland is increasing in line with international findings. The increase in cancer as a cause of death is likely to continue, given that the incidence of cancer diagnoses in Ireland is predicted to double by 2040⁶. However, it has also been shown that deaths from neurodegenerative conditions in Ireland increased over a five year period studied from 2007 to 2011. There has also been an increase in deaths from dementia⁶.

Palliative care will continue to support people living with advanced cancer but services also need to be equipped for increased numbers of patients with neurodegenerative diseases in a country with one of the fastest ageing demographics in Europe⁶.

These findings provide an invaluable reference point from which to identify the different models of generalist¹² or specialist palliative care that may benefit these patients.

As well as being affected by multiple medical problems of varying severity; older people may have also issues with medication, and could be facing physical or mental impairment, economic hardship and social isolation⁷.

The wide range of health and care needs of older people often requires joint working between many sectors, such as specialists in care for older people, palliative care, primary care and social care.

Although most people wish to die at home, the majority of people in the European Region die in a hospital. Ensuring that older people receive good palliative care in an acute hospital setting is therefore important³.

In many countries, care homes play an increasing role in caring for frail older people at end of life. Specialist palliative care services may be required for a small number of residents, whereas generalist palliative care is appropriate for all residents regardless of their diagnosis.

Much of the suffering of older people could be alleviated if currently available treatments were used more widely. One problem seems to be lack of training in pain and symptom control. Tackling this will involve expanding education and training for staff providing care in all settings, including residential and nursing homes as well as hospitals and the person's own home⁷.

Currently AIHPC is being funded by the HSE, with the support of the National Clinical Programme for Palliative Care, to undertake a demonstration project on the use of ECHO to support nursing home staff in South Dublin to improve their knowledge and skills in the care of patients with a wide range of palliative healthcare needs. The ECHO model™ (Extension for Community Healthcare Outcomes) is an innovative alternative to face to face training with a high quality 'tele-mentoring' training, coaching and development programme.

Recommendations:

1. Every person with a life-limiting condition should be able to easily access a level of palliative care appropriate to their needs, regardless of their age, their condition or where they are being cared for.
2. The specific needs of older persons and their palliative care needs should be considered in national palliative care policy, strategy and commissioning of services.
3. Palliative care should be integrated into chronic disease management.
4. Generalist and specialist palliative care providers, whether in community and primary care, hospital or hospice, should be supported to work together to provide an integrated model of care provision.

C. Increasing number of people with dementia

As a result of ageing populations, the number of people with dementia is predicted to double every 20 years, to 81 million by 2040. One quarter of people aged 85 years and older in Europe are estimated to have dementia with 4.6million new cases of dementia every year worldwide. Dementia is an example of one condition that is regularly underdiagnosed^{3,7}.

In Ireland there was a 51.3% increase in dementia deaths from 2007 to 2011 and it is predicted that there will be a 63% increase in people living with dementia, from 41,477 in 2006 to 67,493 in 2021⁶.

Work has been undertaken to produce a consensus on how to provide care and support to Irish people living with dementia, including palliative care. AllHPC supports the 'Understand Together'¹³ National Dementia Campaign launched in October 2016.

Older people with dementia are at particular risk of poor pain control, because their communication problems make them less able to report pain and it is more difficult for those caring for them to assess it properly^{3,7}. A survey commissioned by AllHPC in autumn 2016 found that the overwhelming majority of people (70%) identified 'pain management' as the most important part of a good experience of palliative care¹⁴.

Identifying the best ways to make sure that people with palliative care needs receive adequate pain and symptom relief was identified as the third of the top 10 research priorities in palliative care in Ireland, in a systematic process supported by AllHPC involving care providers, patients and carers¹⁵.

Communication with people with advanced dementia is difficult, which presents particular challenges in assessing and treating symptoms such as pain and ascertaining their wishes for end-of-life care. Advance care planning needs to be initiated at an early stage to consider personal wishes.

More than two thirds (68%) of participants in the Let's Talk About survey⁸ said that 'planning for the future' was their biggest worry.

Planning for the future covers many issues, including planning for the end of life. Let's Talk About challenges us as a society to provide a supportive space to think about, discuss and plan for care.

Another recent study found that between 2004 and 2014 people in Ireland were increasingly seriously considering or actively planning for end-of-life. However most people did not have arrangements in place and those who did were least likely to have included advance care directives or sharing information with regard to their preferred place of death¹⁶.

These findings appear to signify the need to 'normalise' the task of planning ahead linked to the more general need to promote public awareness and understanding of palliative care¹⁷.

Ongoing initiatives which promote advance care planning such as the Irish Hospice Foundation's Think Ahead¹⁸ project need further dissemination and ongoing support in this regard.

Recommendations:

5. Health care commissioning to develop palliative care services to meet the changing population needs in relation to the increasing number of people with dementia, including addressing pain.
6. Promote a wider societal normalisation of planning for the future, including planning for end of life.

D. The context of caring at home

Caring for a person throughout an illness and at the end of life is something that is both deeply rewarding and can be extremely challenging. Carers need to be supported to sustain their role.

The availability of (often family) carers is a key factor in determining whether older people are cared for and die at home, if they want to. Living with relatives and having extended family support has been identified as one of the main factors related to supporting people to die at home³.

A related aspect of population ageing is a decrease in the proportion of younger people as fertility rates decline. The age of informal caregivers, particularly women who have traditionally been relied on to care for and support people towards end of life, is therefore also increasing. As the proportion of working age to older people declines, fewer women (and men) will be able to find the time to provide support and care⁷.

Census 2016⁵ shows an increasing likelihood of people living on their own as they get older:

- **27% of people over 65 live alone**
- **45% of people over 85 live alone.**

Caregiving can be rewarding when caregivers feel that they have improved the quality of life for a loved one. Sometimes, however, the burden can result in physical and emotional exhaustion, conflicting emotions, restrictions on the caregiver's own life and a strain on financial resources. Further, caregivers are often older people with health problems of their own³.

Providing palliative care outside of 'working hours' to help people to stay in their place of choice, how best to provide care in a person's home for as long as possible, and the needs of carers and families have been identified by AIIHPC as priorities for further research^{15,19}.

Recommendations:

7. Develop principles for involvement and formalise support for family, friends or others where appropriate, in order to encourage participation in supporting an individual with palliative care needs.
8. Support carers to manage their physical, mental and emotional health and well-being.
9. Recognition when commissioning services for older people of the importance and need for social care, taking account of the large percentage of older people living alone and the need to support carers.

E. A population-based health approach in the context of palliative care

The scale of need for palliative care for the growing population of older adults suggests that it requires a multifaceted approach and the application of public health methods to make an impact.

This means identifying needs within populations, monitoring trends and the effectiveness of interventions, increasing professional education and public awareness, and setting up systems that can support the changes needed in behaviour and practice⁷.

Palliative care has a role to play in promoting health and wellbeing. Serious illness, death, dying, loss and grief are universal experiences.

Health promoting palliative care approaches these experiences by taking a population-based health approach so as to change the ways in which: people consider their own death; communities care for people and their families as they encounter death; healthcare service providers meet the needs of people facing the end of life; palliative care services reach out to share their expertise in death, dying, loss and care; and national policy and plans are developed and understood²⁰.

Such an approach emphasises the need to work in partnership with communities to stimulate community change and develop community led supports.

Engaging all of society in a health promoting palliative care approach, including those who are older and have life experience, has the potential to raise public awareness and change the culture around death and dying in Ireland with a view to reducing inequity, fear and stigma.

A survey commissioned by AIIHPC found that more than half of adults surveyed in Ireland (55%) had a basic or minimal understanding of what palliative care involves. Eighty-five percent of respondents did not believe that there is sufficient public understanding of palliative care¹⁴.

AIIHPC has facilitated an annual Palliative Care Week¹⁴ since 2014. This is a dedicated campaign to raise public awareness and understanding of palliative care.

These approaches and initiatives can contribute to supporting communities to provide care to anyone with palliative care needs, creating a space for difficult end of life conversations to take place and reducing fear around planning for the future.

Recommendation:

10. Promote public awareness and access to a palliative approach to care for all individuals with a serious or progressive condition from which they are unlikely to be cured and which may limit or shorten life.

The discussion at the Citizens' Assembly provides a welcome opportunity to consider the key issues addressed in this submission, in the context of Ireland's rapidly aging population. We look forward to the Assembly debate and to it considering the positive contribution palliative care can make to citizens to support their quality of life to the very last days of life.

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Notes

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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.
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