



Submission from Care Alliance
Ireland to The Oireachtas Joint
Committee on Health and Children
for End of Life Care in Ireland

'Carers have an expert knowledge of the person and of the condition of the person for whom they are caring. However, many can feel that this expertise is undervalued and often ignored when decisions relating to the care recipient are being made'

Introduction:

Care Alliance Ireland is an Alliance of over 95 not-for-profit organisations who support Family Carers. This includes a number of organisations who provide palliative care at home and who provide counselling and bereavement services.

What We Do: We work with organisations to provide better information and supports to Family Carers. We provide them with opportunities to collaborate on initiatives including National Carers Week, a multi-agency and multi-disciplinary Family Carer Research Group, and joint policy submissions. We act as a distribution channel for information on Family Carer issues. We actively encourage collaboration in all our projects. We provide cohesion to those organisations working to support Family Carers. We commission relevant research that supports focussed and quality interventions in the lives of Family Carers.

Care Alliance Ireland welcomes the opportunity from the Oireachtas Joint Committee on Health and Children to make this submission in respect to its consideration of End-of-Life Care in Ireland.

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Executive Summary:

Family Carers play a significant role and provide palliative and end of life care on a daily basis in Ireland. Therefore there is a need for consideration, awareness and expertise among service providers of the legal, emotional, financial and future planning issues, bereavement and aftercare needs of Family Carers.

Family Carers have significant support needs when providing care and when their caring role ceases. Family Carers are faced with challenges on a daily basis. Many people provide full time care to a relative or loved one and often request no support when taking on this role. Most people would prefer to die at home. Care Alliance Ireland believes that this can become a reality for many more people if Family Carers are provided with adequate amounts of information and support in their caring roles.

This submission focuses on the role of Family Carers in providing palliative and end-of-life care. It is highlighted that Family Carers often provide this care but also require support from formal professional palliative care services. The benefit of having a carers' assessment is outlined along with issues around planning for end-of-life care and the role of the Family Carer in this.

Finally the bereavement needs of Former Carers is raised. Bereavement care for this group of people has previously gone undetected, but Care Alliance Ireland point out that it is a significant issue for many former carers and one that warrants urgent addressing.

Recommendations:

1. At all stages of the End of Care journey, Family Carers should be seen as Partners in Care, in keeping with latest research on good practice and in keeping with the 2012 National Carers Strategy.
2. Family Carers' needs should be considered in a holistic sense, that may appropriately include a full Family Carer Needs Assessment.
3. All healthcare education and induction programmes should include information on the core principles of palliative care that emphasise the importance of the role the Family Carer plays in the care of someone who is at the end of their life.
4. Patients, their families and their Family Carers should have access to appropriate and relevant information.
5. The National Clinical Programme for Palliative Care within the HSE should review the 2010 Centre for Palliative Care Clinical Practice Guidelines with a view to amending and subsequently endorsing them for use in Ireland's health and social care services.
6. Open discussion is needed within the health and social care sector and the wider community about palliative and end of life care. Family Carers need to be involved in this process and to have the opportunity to engage in the debate about end of life care.
7. Palliative and end of life care services should be planned and developed with meaningful patient, family and Family Carer involvement and should be provided in a flexible manner that will meet individual and changing needs.
8. Access to specialist palliative care advice and support should be available across all care settings, 24 hours a day, 7 days a week.
9. An end of life care and bereavement strategy is required that will address the care needs of people dying at home with care from family members.

Background:

There are approximately 274,000 Family Carers in Irelandⁱⁱ. A carer is defined as a person who provides unpaid personal help for a friend or family member with a long term illness, health problem or disabilityⁱⁱⁱ. 4.1% of the population identified themselves as a carer in the 2011 Census. However, it must be acknowledged that many people may not classify themselves as a carer but will say that the care they provide is a normal part of being a family member and is a duty attached to being a relative or friend of the person requiring care therefore the actual number of carers in Ireland remains unknown.

Palliative care is defined by the World Health Organization as an approach that improves the quality of life of individuals **and their families** facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care is defined as care that:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system **to help the family** cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients **and their families**, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

There are three types of palliative care.

-Level one palliative care indicates that palliative care principles should be practiced by all health care professionals.

-Level two palliative care indicates that a proportion of patients and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care have had some additional training.

-Level three specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Family Carers provide aspects of this type of care on a regular basis but it is clear that they also require particular supports to deliver some aspects of this type of care in their role as a Family Carer at home. The National Carers Strategy acknowledges the difference that carers make to the health, wellbeing and quality of life of those that they care for and the subsequent significant contribution to the economy in doing so. The National Carers Strategy also identifies that carers require recognition, support, information and empowerment in their role as carer which is reflective of some aspects of palliative care presented above.

The Irish Hospice Foundation indicates that most people would prefer to die at home. Currently only 26% of deaths occur at home^{iv}. Government policy for those with an illness or disability is to support them to live with dignity and independence in their own homes and communities for as long as possible. Family carers are a means of making this a reality. Life expectancies in Ireland are increasing^v. This, coupled with treatment and technology advances in healthcare has and will continue to result in a greater number of people living at home longer with chronic and often times multiple illnesses with care provided by family members. The role of Family Carers in providing palliative and end of life care is paramount and reflects the continued key role of Family Carers as the backbone of care provision in Ireland.

Recent Policy Developments:

Thursday, July 19th 2012, marked the publication of the first ever National Carers Strategy by the government. Care Alliance Ireland considers this a significant milestone in advocacy for and in recognition of Family Carers in Ireland.

The vision statement says;

'Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life.'

The strategy says that;

'carers should be considered as key partners in the caring process and should be consulted with when decisions are being made about the care recipient's needs.'^{vi}

The Strategy identifies three principles, namely; recognition, support and empowerment and also sets out high level goals and objectives.

The 4 national goals are to;

1. Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for
2. Support carers to manage their physical, mental and emotional health and well-being
3. Support carers to care with confidence through the provision of adequate information, training, services and supports
4. Empower carers to participate as fully as possible in economic and social life

Family Carers and End of Life Care:

Ireland's 2012 National Carer Strategy is worryingly quiet on the issue of Palliative Care and Family Carers, though it does acknowledge the challenges experienced by Family Carers when their caring ends.

'It is also acknowledged that the transition to life after caring, once the need for care has ended, can be difficult for some carers. It is expected that the implementation of this Strategy will assist in this transition process.'^{vii}

Speaking on family caregiver support, Professor Peter Hudson, a leading international practitioner in Palliative Care and Director of the Australian based Centre for Palliative Care said;

'support for family caregivers is a core function of palliative care. ... It is clear that many family caregivers have unmet needs and would like more information, education, preparation and personal support to assist them in the caregiving role.'

His team have developed a set of Clinical Practice Guidelines^{viii}. The guidelines, published in 2010, were developed for multidisciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in a variety of care sites throughout Australia. Central to their report are 14 Principles for Family Carer Support.

Key aspects of these are;

- Family Carers as partners in care, a principle upheld in the 2012 National Carers Strategy.
- Needs assessment for Family Carers, an approach that is currently being rolled out on a pilot basis in a number of HSE areas and which we believe will become a default assessment tool by health and social care professionals where there is a significant Family Carer involvement in a client's life. This can be as simple as asking a few key questions to the Family Carer; for example;
 - *"How are things for you at the moment?"*
 - *"What are your main concerns?"*
 - *"What would be helpful to you?"*
- Other principles include clear and open communication, training for health and social care professionals, evidence based intervention and targeted bereavement counselling.

We in Care Alliance Ireland believe that a specific recommendation from this Oireachtas Committee could be for the National Clinical Programme for Palliative Care within the HSE to review these 2010 guidelines with a view to amending and subsequently endorsing them for use in Ireland's health and social care services.

Professor Hudson in his June 2013 editorial of a special Family Carer edition of Palliative Care Medicine reported;^{ix}

‘Current indications are that palliative care providers should assist carers by targeting social support and resources and provide education that focuses on coping strategies and preparation for the carer role. Carers typically want to know what the role entails, how to manage symptoms, signs of imminent death and resources and strategies to sustain their own well-being.

Overall, suggestions for policy development and improvement need to be cognisant of the latest research in this area of palliative care and in particular the work and publications of the International Palliative Care Family Carer Research Collaboration.

<http://centreforpallcare.org/index.php/research/ipcfrcr/publications/>

This research collaboration has identified 100 peer reviewed research articles on Family Carers/Palliative Care.

<http://centreforpallcare.org/assets/uploads/Publication%20Alerts%20Aug%202012.pdf>

For example a 2012 report^x found that ‘

‘directive nursing styles tended to be denser and nurse oriented and offered less opportunity for caregiver self-expression, while facilitative styles were more caregiver oriented and more vivid and responsive and made more space for caregiver expression’.

This points to opportunities to promote better practice through Palliative Care nursing training and on-going professional development.

Thought leaders in this area in Ireland may benefit from being familiar with this research database and by reflecting the findings in policy and practice documents into the future.

Planning for end of life care:

All involved in caring for people need to be able to facilitate and support decisions about future care management. Therefore it is a necessary requisite that Family Carers be included in care decisions. Everyone should have the right to make choices about their care at the end of life. Those involved in the care of people need to be able to support decisions. One way of achieving this is through the use of advanced directives.

An advanced directive (or living will) is where a person sets out their views in writing regarding future medical care to cover a situation should they become mentally incapable or unable to make decisions themselves. A living will can only relate to lawful treatments (such as withdrawal of medical treatment). There is no legislation in Ireland governing living wills and it remains uncertain whether a Living Will has any definitive legal standing in Ireland. The advantages of a living will to a Family Carer cannot be underestimated. At times of crisis the Family Carer is often under a huge amount of stress. When presented with end of life care decisions an advanced directive has the potential to reduce the stress of making decisions on behalf of the person they are caring for. While there is no legislation at present to underpin advanced directives, they are a means of ensuring wishes are respected following the onset of incapacity and not just at the end of life.

The 2012 Carers Strategy speaks about the knowledge and expertise of the Family Carer.

'Carers have an expert knowledge of the person and of the condition of the person for whom they are caring. However, many can feel that this expertise is undervalued and often ignored when decisions relating to the care recipient are being made'^{xi}

The Assisted Decision Making (Capacity) Bill is to replace the wards of court system in Ireland, with a modern framework governing decision-making on behalf of persons who lack capacity and acknowledges the role of Family Carers. Under the proposals it is indicated that account must be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made known and any act which is done or any decision made under this Bill for or on behalf of a person who lacks capacity must be done or made in his best interests. This legislation is of substantial relevance to Family Carers. The Bill has the potential to ensure that people are facilitated as far as possible in making decisions and where this is not possible, those in charge on their behalf are facilitated and supported to act on their behalf. For this Bill to be implemented successfully, a wider debate within health and social care and the wider community about palliative and end of life care is required. Family Carers can add depth to that debate.

Care Alliance Ireland maintains that Family Carers should be seen as partners in health and social care. Carers assessments can contribute to achieving this. Professor Hudson articulates nicely the specifics of what is needed by Family Carers;

'Most family carers do not want to discuss their needs and concerns in front of their relative; they therefore need one-to-one time with healthcare and social-care professionals.'^{xii}

Carers assessments are a means of identifying service needs and unresolved problems. The outcomes of carers assessment is fundamental to developing a plan that supports and strengthens the family as a whole, where most care is given and received. Carer assessment models are currently being trialled in a number of HSE regions. The outcomes of using Carers Assessments internationally have indicated that the assessment process enhances the carers' relationship with the community healthcare team and leads to more integration of support services for both the dependent person and the carer. Carers assessments have the potential to enhance planning and delivery of services in a meaningful and flexible way that meets individual and changing needs – something that Care Alliance Ireland believe to be crucial in the delivery of palliative and end-of-life care.

Dying at Home:

Irish policy documents since 2001 identify that people with an illness other than cancer should have their palliative care needs met. There is growing evidence that indicates that people with life limiting illness have similar palliative care needs as those with cancer, albeit at times with multiple other illnesses and uncertain illness trajectories. Emerging evidence also suggests that where people die impacts on how they die and that those who die at home and in a place that they prefer have a better quality of dying^{xiii}. The National Audit of end of life care in hospitals found that up to a quarter of the deaths examined could have been facilitated to occur at home^{xiv}. The Irish Hospice Foundation point out that most people would prefer to die at home. With an in-depth knowledge of the persons condition, likes and dislikes the Family Carer is extremely well positioned to provide care to their loved one and facilitate them at the end of life to die at home.

Providing care can be both an enriching and rewarding experience where expectations placed on family carers are reasonable and adequate supports are provided. Evidence from research undertaken by Care Alliance Ireland identified the satisfaction that family carers may feel in being able to support people that they care about. It is however crucial that family carers are given adequate assistance and information to sustain them in their role. Informational support is a necessary requisite for the delivery of any service. Professor Hudson speaks to this topic in his recent editorial of Palliative Care medicine saying:

'Given the majority of patients want to be cared for in their home environment, initiatives that assist carers to achieve this are needed. The period of time most people receive palliative care services is typically quite short; hence, the challenge is to design interventions that are as brief as possible, readily accessible and easily delivered. The significant number of carers who support patients in the hospital/hospice setting should also not be neglected; their needs are often hidden'.^{xv}

Caring can sometimes be a source of burden and stress. While providing care to a loved one may be willingly given, there may be costs to many aspects of the Family Carers' life – emotionally, physically, socially and financially. Family Carers across Ireland provide vital unpaid support to elderly, sick or disabled relatives in the home every day, thus saving the exchequer considerable amounts of money. It is estimated that Family Carers contribute over €5 billion to the economy every year. It is also estimated that every week 8 million hours of care is provided by Family Carers across Ireland. While the income supports available to Family Carers through the Department of Social Protection go some way towards assisting them in their role, major gaps for Family Carers in Ireland persist.

In addition, access to community supports may vary according to geographic location and diagnosis. Inequity in the availability of palliative and specialist palliative care services exists due to the variation in how services have been developed. Parents of Children with life limiting illnesses face particular challenges, as they experience on a regular basis the ups and downs of knowing their child may come close to dying any day only for the child to

recover to fight another day, thanks to medical advances and the child's own determination to live. This also impacts significantly on the siblings of the ill child and often on the employment situation of parent/s; with most services Dublin based, particular strain is experienced by families living outside of the Dublin region. More home and community based supports would go some way to addressing these difficulties.

The Irish Hospice Foundation, ICGP and HSE have commenced a Primary Palliative Care initiative attempting to identify improvements and initiatives that would support the primary care teams palliative care provision to those living with a life limiting illness in the community. During a consultative process carried out by this initiative 72% of healthcare professionals expressed wanting access to a specialist palliative care 24 hour helpline and 60% sought education in symptom control. Studies indicate that the difficulties of relatives were more often a cause for hospital admission than those of patients. These identified potential improvements in Primary Care provision have the potential to impact hugely on Family Carers and could be a means to provide support to Family Carers in their role as a result Care Alliance Ireland would welcome such changes to primary care provision.

Bereavement Care:

In Ireland, we have been unsuccessful in recognising the needs of those whose caring has ceased. The 2006-2016 National Partnership agreement specifically identifies the need to give support to former carers. In 2010 Care Alliance Ireland in collaboration with the School of Nursing and Midwifery in TCD undertook primary qualitative research that looked at the needs of those whose caring had ended. Some recommendations coming out of this report include:

1. Support for former carers in the form of bereavement and/or accessing a carers group.
2. A toolkit to prepare carers for when their caring role ends to include information on how to integrate into working life.
3. Encouragement to help share information acquired about Irish health and social care services.

It must be recognised that the bereavement needs of former carers has gone unrecognised for a considerable amount of time. This study did not however address the loss associated with a loved one moving to a hospice or nursing home which can often cause a lot of anguish and ambiguous grief.

It is known that post caring many carers health and well-being often deteriorates. Bereavement is a risk to health. There are documented mortality links to bereavement, highest in the early period but maintaining over time; and highest for subgroups including widowers and bereaved parents. Physical and psychological illnesses are more common in bereaved than non-bereaved people, and these are accompanied by increased use of health service – including hospitalisations. Former Family Carers represent a significant proportion of the population having bereavement needs. Care Alliance Ireland maintains that a national strategy which focuses on end of life and bereavement care is required to adequately address on a national level the bereavement needs of Former Family Carers.

Conclusion

Family Carers play a significant role and provide palliative and end of life care on a daily basis in Ireland. Therefore there is a need for consideration, awareness and expertise among service providers of the legal, emotional, financial and future planning issues, bereavement and aftercare needs of Family Carers. Many patient organisations have stepped in to play a vital role in supporting people in addressing these aspects care. There is a crucial need to recognise and support this aspect of service provision as a vital aspect of care.

Put simply;

'An increased investment in support for Family Carers is likely to result in improved patient well-being, longer period of care at home, enhanced bereavement outcomes and less burden on the healthcare system.'^{xvi}

When we reflect on the quality of the service that we offer;

'A key measure of quality palliative care should be the well-being of family carers in the years after relinquishing the role'^{xvii}.

A handwritten signature in black ink, appearing to read 'Liam O'Sullivan', with a long horizontal line extending to the right from the end of the signature.

Liam O'Sullivan

Executive Director

Care Alliance Ireland

Nov 19th 2013

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- ⁱ Government of Ireland (2012) National Carers Strategy, Recognised, Supported and Empowered. p9
- ⁱⁱ McCarron, M., Breen, M., Cronin, P., Hynes, P. & O'Sullivan, L. (2011) *Between Worlds The Experiences And needs of Former Family Carers*. Dublin.
- ⁱⁱⁱ Central Statistics Office (2010) Census 200 Make your Mark. Available at www.census.ie/The-Census-Form/Each-question-in-detail.109.1.aspx
- ^{iv} Irish Hospice Foundation (2013) *Access to Specialist Palliative Care Services And Place of Death in Ireland What The Data Tells Us*. Dublin.
- ^v Department of Health & Children (2009) *Health in Ireland Key trends 2009*. Department of Health and Children. Dublin.
- ^{vi} Government of Ireland (2012) National Carers Strategy, Recognised, Supported and Empowered.
- ^{vii} Government of Ireland (2012) National Carers Strategy, Recognised, Supported and Empowered.
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- ^{ix} Hudson, P (2012) Improving support for family carers: Key implications for research, policy and practice in Palliative Medicine 2013 27: 581 <http://pmj.sagepub.com/content/27/7/581.full.pdf+html>
- ^x Cloyes, K et al (2012) Exploring Communication Patterns Among Hospice Nurses and Family Caregivers: A Content Analysis of In-home Speech Interactions. *Journal of Hospice & Palliative Nursing* (J HOSP PALLIAT NURS), 2012 Aug; 14 (6): 426-37 (43 ref)
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- ^{xii} Hudson, P (2012) Improving support for family carers: Key implications for research, policy and practice in Palliative Medicine 2013 27: 581 <http://pmj.sagepub.com/content/27/7/581.full.pdf+html>
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- ^{xiv} Irish Hospice Foundation (2010) *National Audit of End of Life Care in Hospitals in Ireland 2008/9 Dying in Hospital in Ireland. An Assessment of the quality of care in the last week of life*. Dublin.

^{xv} Hudson, P (2012) Improving support for family carers: Key implications for research, policy and practice in *Palliative Medicine* 2013 27: 581
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^{xvi} Hudson, P (2012) Improving support for family carers: Key implications for research, policy and practice in *Palliative Medicine* 2013 27: 581
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^{xvii} Abernethy AP, Currow DC, Fazekas BS, et al. Palliative care services make a difference to short- and long-term caregiver outcomes. *J Support Care Cancer* 2008; 16(6): 585–597. Referenced in Editorial by Hudson, P (2012) Improving support for family carers: Key implications for research, policy and practice in *Palliative Medicine* 2013 27: 581
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