



## ***SUPPORTING FAMILY CARERS AT END OF LIFE: REPORT FROM SEMINAR of 20 June 2011***

### **Introduction**

The aim of the seminar was to seek the views and suggestions from those involved in supporting carers (both paid and family) who are working with people facing death. Following a brief introduction from the Irish Hospice Foundation and Care Alliance Ireland, the majority of the 2 hour session was focussed on the enabling of participants to articulate their views via small discussion groups. In total 33 participants attended, representing a range of voluntary and statutory organisations - see list of participating organisations in Appendix 1.

This report is divided into two sections. The first section covers the feedback from the discussion groups where participants were asked to a) identify what issues their organisations meet in trying to support family carers as they care for someone within their last year/week/days of life, and b) what are responses to meet these needs and what gaps they are aware of. The second part of the report seeks to respond to the issues identified from the discussion groups via some short term actions that can be followed up by you or your organisation. Finally there are some more strategic recommendations listed that CAI and IHF have committed to in order to support on-going work and development in this area.

As a means of signposting existing resources and relevant links in this area appendix 2 lists some resources and websites available that may support those working in this area.

## **SECTION 1**

The feedback from the discussion groups has been grouped into issues and responses related to 1) Family carers; 2) Organisations supporting paid carers; 3) Health and social care systems and policy.

### **Family Carers**

#### **ISSUES**

##### **Poor communication**

- When diagnosis is communicated to carers often family receive information in a disjointed manner

##### **Adjustment.**

- As the needs of the person they are caring for deteriorate and change, carers need support to help adjust with regard to dealing with their loss, grief, guilt, fear, blame and isolation. This is particularly the case following transfer of the person to a different care setting or following bereavement. There is also a need to acknowledge the challenges faced by some carers when their caring has ended or changed in nature.

##### **Carers groups**

- Sometimes it is hard for carers to attend for support or training sessions

#### **RESPONSES**

*Voluntary and statutory organisations should*

- Introduce standardised information on illness progression
- Provide information on how to care, how and where to access more information at different points in time or during the final phases.
- Introduce support groups for specific diagnosis, peer support group helpful
- Champion local carers award to assist recognition

### **Organisation's Supporting Paid Carers**

#### **ISSUES**

##### **Poor communication**

- Health and social care professionals on diagnosis/change in health status to organisations providing care in the home

##### **Information**

- More information and awareness should be available to organisations providing care in the home as to what services are available to support death, dying and bereavement in the community
- More help to prioritise presenting need – often the loudest and not the most needy get the assistance, there is a need for standardised assessment tool for more equitable service
- More direction and clarity to organisations providing care in the home as to how to communicate and support re matters relating to end of life care; what information to give to family carers; when to give; who should give and when to refer for more supports

##### **Family dynamics**

- Paid carers often have to navigate and negotiate between family members and this

can be fraught at end of life – help with this role would be valuable

- More recognition on emotional impact of the course of illness on family carers and direction given to organisations as to how to support this area of need

#### **Children and young carers**

- Help and guidance as to how to support young carers and their grief
- Understanding and supporting the impact on parents re dying child, who can often be very sick over years

#### **Palliative care**

- Hard to stay positive when palliative care is introduced – more help with addressing loss of hope that paid carers witness as they deliver care in these circumstances
- Clarity as to whether palliative approach from day one appropriate for some diseases
- Need to guide / educate paid carers in their palliative care role, this is often not discussed or not formally acknowledged,
- Paid carers need more understanding as to what to expect and how to acknowledge this aspect of their care, and support in dealing with fears and anxieties of family members, person with the life limiting illness and their own fears
- Lack of knowledge at different transitions of care can generate isolation
- The uncertainty re end of life trajectory for some illness can generate difficulties in broad realms of care provision and anxiety for all
- Advance care planning, living wills – more clarity is needed re what these are and how to go about discussing them with family carers;
- The ethical and quality of life issues that present in care giving also need more guidance/support

#### **Training and professional support**

- There is no network for paid carers in this area, this lack of professional support can lead to sense of isolation
- Need to acknowledge and value the long term relationship that exists with carers if/when palliative care home care team come in

#### **Carer stress and burnout**

- Specific support is needed when carers are providing care where there are numerous or on-going deaths –
- Carers who have multiple carer role also need support

### **RESPONSES**

- Standardised information on illness. Fact sheets help to navigate the system: ie Fair Deal, HSE Home Care Packages, entitlements/benefits
- Appropriate and accurate disease related information
- Information packs at point of diagnosis
- Information on how to care, how to access more information
- Proper referral procedures – clarity re access
- Standardised assessment tool
- Case work support for staff
- Advocacy
- Family mediation

## **Health and Social Care System / Policy**

### **ISSUES**

#### **Access to services - challenges**

- After-hours care for supporting family carers
- Red tape in accessing services
- Need for counselling – formal and informal
- Is there specialist palliative care support for family carers
- What /when do people get access to specialist palliative care
- Cost of providing care

#### **Equity of access**

- Lack of equity in palliative care access for some diseases, some get great palliative care service – others don't... why and how can this be changed – who makes these decisions.
- Patients get lost in the system, particularly those who are aged under 65; those with early onset dementia and those who present with dual diagnosis

#### **Poor co-ordination of services**

- There are times when patients receive either under or over specialised services at different times; this can create difficulty and frustration for family carers and those who require care, as well as being an inefficient use of resources

### **RESPONSES**

- 24 hour helpline

## **SECTION 2      Short Term Actions**

These actions are based on the feedback from the discussion groups at the seminar. Hopefully they will sign post to you and/or your organisation, suggestions and opportunities to develop and enhance supports and services for carer of people nearing end of life.

1. Encourage use of existing and emerging resources in this area, to assist in understanding the needs of people with life limiting disease, family carers and paid carers in this area and identify guidance materials available to help – see Appendix 2
2. Encourage disease specific organisations to provide helpful practical information, in the form of fact sheets / FAQs on how to support when diseases progresses, to include reference to planning ahead and the need for discussions about care at end of life. These could be developed from the carers.ie website. These fact sheets could also include a directory of services available.
3. Offer and develop telephone, email or other forms of remote supports for carers who cannot or do not want to participate in carers support groups
4. Organisations to ensure that their needs assessment systems identifies the issues that paid and family carers face when they are supporting people who are approaching end of life, and that guidance and supports are available to respond to these identified need.
5. Organisations and individuals to foster relationships with local specialist palliative care services. This will help to clarify the nature and extent and access to specialist palliative care services for people with life limiting disease as well as the advice, expertise, education and training they offer to health care providers supporting people with palliative care needs.
6. In addressing the perception of inequity of access, it would be helpful if organisations could identify and report to HSE where undue/unnecessary burden is faced in accessing services for people with life limiting disease, as well as tracking and reporting to HSE identified unmet need/inequity of service provision.

### **Longer Term Recommendations**

7. IHF to include a workshop for carers working in this area, based on issues identified at this seminar, in its annual training programme
8. IHF and CAI to develop a mechanism for health care professionals to interact and share experiences of their work in this area
9. IHF to review how [www.carers.ie](http://www.carers.ie) website is responding to range of information needs for family carers and whether there is a need for developing a link or dedicated site for professionals supporting carers,
10. Circulate via CAI and IHF mailing list the grants that are available to support good practice in this area, ie Lottery, IHF grant stream.

**APPENDIX 1:** List of Organisations in attendance

Care Alliance Ireland	The Alzheimer Society of Ireland
Irish Hospice Foundation	MS Ireland
Wicklow Dementia Support group	Trinity College
Blackrock Hospice	Open University
Irish Heart Foundation	HSE
The Carers Association	Children Sunshine Home
KARE	Irish Cancer Society
St Vincent's University Hospital, Department of Psychiatry	Home Instead
Disability Federation of Ireland	Acquired Brain Injury Ireland
Headway	

*This is not by any means exhaustive – but meant to be a start in pooling information and resources on this topic – covering Irish and International resources, research and developments. Initially it is intended that this will be stored on the Links page as a resource on the carer’s website [www.carers.ie](http://www.carers.ie).*

*Please contact [marie.lynch@hospice-foundation](mailto:marie.lynch@hospice-foundation) if you wish to add to this list.*

### **1. Irish Projects / Resources**

#### **Carers Website**

This website has been developed to provide practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness

<http://www.carers.ie/>

#### **Carers Association Midlands**

In 2011, the Carers Association, Midlands, were successful in their application grant application for a pilot programme offering further training for in-home respite workers providing palliative care. Contact Emma Murphy, Carers Association for more information.

#### **Disease Specific Resources**

Irish Hospice Foundation action research projects in Dementia, Heart Failure and Advanced Respiratory Disease [http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=110&Itemid=42](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=110&Itemid=42)

See this link for the range of Irish Cancer Society information leaflets

<http://www.cancer.ie/cancerInfo/cancerinformation.php>

#### **Irish Heart Foundation**

The Irish Heart Foundation has an online stroke forum so people can chat and share experiences [www.stroke.ie/strokeforum](http://www.stroke.ie/strokeforum).

#### **Bereavement Support**

Information on bereavement services, resources and leaflets

[http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=105&Itemid=37](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=105&Itemid=37)

#### **Specialist Palliative Care Directory**

This provides contact details of the specialist palliative care services in Ireland.

[http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=338&Itemid=201](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=338&Itemid=201)

#### **Education and training courses**

- The Irish Hospice Foundation runs a number of education and training programmes, primarily concerned with bereavement and loss. [http://www.hospice-foundation.ie/index.php?option=com\\_content&task=view&id=132&Itemid=58](http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=132&Itemid=58)
- This database which provides information about palliative care, end-of-life care and bereavement courses from both the Republic of Ireland and Northern Ireland. [http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=397&Itemid=264](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=397&Itemid=264)

## **Irish Hospice Foundation Library**

This library has a number of publications relating to needs of carers who are supporting people nearing the end of their life.

[http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=102&Itemid=34](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=102&Itemid=34)

## **2. UK Resources**

- Help the Hospice UK, have a web resource for professional carers  
<http://www.helpthehospices.org.uk/our-services/developing-practice/carers/>
- NHS/ UK neurological Alliance and National Council For Palliative care publication on 'End of life Care in long term neurological conditions – a framework for implementation'. <http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework> 2010

## **3. Irish Research**

Below lists some research work emerging in Ireland which refers to needs of carers supporting people at end of life.

- *Between Worlds: The Experiences and Needs of Former Family Carers. For publication in September 2011. (McCarron M. Breen, M., Cronin, P. Hynes, G., McCallion, P. O'Sullivan, L) School of Nursing & Midwifery, Trinity College Dublin, 2011.*
- *Informal Care-giving in Advanced COPD: Lay knowledge and experience, Hynes, G., Stokes, A., McCarron, M, Ireland, Trinity College Dublin, 2008*

## **4. International Research**

The links below direct you to some recent international research and developments in this area.

- A Carer Support Needs Assessment (CSNAT) tool is currently under development. This assessment tool is a two-page questionnaire that formally assesses the physical, social and emotional needs of end-of-life carers. It is currently being piloted in one hospice at home service as well as a feasibility trial to test the impact of the CSNAT as an intervention on carer health and well-being in bereavement. See the following links for more information:  
<http://www.australianageingagenda.com.au/2011/06/28/article/Do-end-of-life-carers-have-unmet-needs/YSHJVPBHTT.html>;  
<http://www.ppsis.cam.ac.uk/CFR/about/people/ewing.php>
- The European Association of Palliative care has produced a White Paper on improving support for family carers in palliative care, based on the work of the Task Force on Family Carer (2010). For more information see the EAPC website. [www.eapcnet.eu/LinkClick.aspx?fileticket=z4a-8JkAnFo%3D&tabid=732](http://www.eapcnet.eu/LinkClick.aspx?fileticket=z4a-8JkAnFo%3D&tabid=732)
- A systematic review of psychosocial interventions for family carers of palliative care patients. Peter L Hudson, Cheryl Remedios and Kristina Thomas. **Centre for Palliative Care c/o St Vincent's Hospital and The University of Melbourne, Australia and Queen's University, Belfast, UK**  
*BMC Palliative Care* 2010, **9**:17; [www.biomedcentral.com/content/pdf/1472-684X-9-17.pdf](http://www.biomedcentral.com/content/pdf/1472-684X-9-17.pdf)