

Palliative Care for All Communique

July 2014



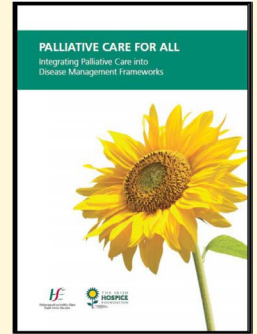
For better end of life care, everywhere

INTRODUCTION

The Irish Hospice Foundation (IHF) Palliative Care for All programme commenced in 2007. As part of this work the joint Health Service Executive (HSE) and IHF [Palliative Care for All report](#) was published in 2008.

Since its publication, IHF has worked with many organisations in an effort to implement its recommendations and support the delivery of palliative care for people with a non-malignant illness. The IHF particularly welcomes the commitment from the HSE to review the Palliative Care for All report in their service plan for 2013 and 2014 with an aim to integrate its findings into the HSE's forthcoming Chronic Disease Strategy.

This communique will highlight some of the progress and signpost the IHF resources with regard to developments addressing palliative care for people with advanced respiratory disease, heart failure, end stage kidney disease, advancing neurological illness & dementia.

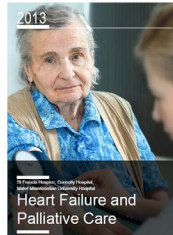


ACTION RESEARCH PROJECTS

Two action research projects took place between 2011-2012. Both projects aimed to devise, implement and evaluate appropriate palliative care responses for people with heart failure and advanced respiratory disease.

HEART FAILURE

This project was based in the Mater Misericordiae University Hospital, (Connolly Hospital, St. Francis Hospice and Fairview General Practice were participating sites). The outcomes of the project include patient and staff information leaflets, education seminars, e-learning modules, protocols supporting both palliative and heart failure medication & [poster presentations](#). Access to Specialist Palliative Care day services for people with heart failure has also increased. A report on this project is due for publication in 2014.

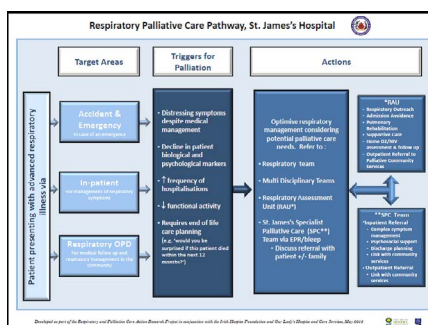
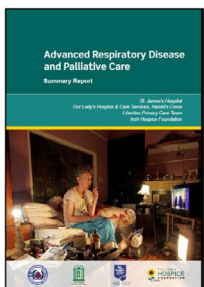


In addition, the Irish Heart Foundation, in conjunction with IHF is preparing a patient information leaflet outlining the benefit of planning for the future for people with advanced heart failure, which will also be available by the end of 2014.

ADVANCED RESPIRATORY DISEASE

This project was based in St James's Hospital (Our Lady's Hospice and Liberties Primary Care were the participating sites). The project outcomes include a [summary report](#), the development of a [care pathway](#); support and education for staff; and enhanced access to specialist palliative care in the community and in the hospice.

Although this project concluded in June 2013 the activities have had a sustainable impact in the participating sites and informing new COPD outreach programmes. For more information please contact Bettina Korn: Bkorn@stjames.ie



END-STAGE KIDNEY DISEASE

Susan McKenna, Renal CNS in Cavan General Hospital is developing a booklet on 'Choosing not to have dialysis' to support people with end stage renal disease understand their options for conservative treatment. This is being funded by the IHF. For more information you can email Susan at Susan.McKenna@hse.ie

In the meantime, the IHF will support the implementation of a feasibility proposal (being prepared by leading palliative care and renal specialists) to determine mechanisms to introduce palliative care for people with ESKD based on international best practice.

ADVANCING NEUROLOGICAL ILLNESS

In the past few years a number of projects have commenced in Ireland supporting the development of palliative care for people with advancing neurological disease. Details of these projects are available [here](#).



Later this year, IHF with Neurological Alliance of Ireland (NAI) will plan an event to support the dissemination of this work, highlight the unmet palliative care needs of people with advancing neurological disease and support further development in this area.

Following feedback from NAI member organisations, IHF has also developed web-based information pages on this topic for people with advancing neurological disease and staff - they are available [here](#).

NURSES FOR NIGHT CARE



This IHF service enables people with a non-malignant illness to die at home with the provision of a night nurse. The service is provided through the Irish Cancer Society's night nursing service. This service has grown by up to 30% each year since 2006, and in 2013 reached 317 people. The service is accessed through the SPC team—click [here](#) for more information. As a result of its growth, IHF is seeking ways to support its long-term sustainability.

Resources & presentations

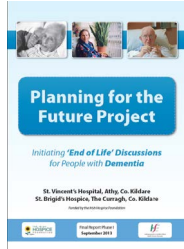
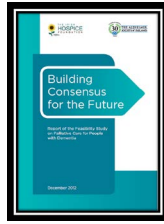
The Palliative Care for All [website](#) hosts links to all these resources as well as the presentations from the [Palliative Care for All conference](#) which was held in Sept 2012.

PALLIATIVE CARE AND DEMENTIA

Since 2008, IHF has supported several projects to enhance the development of palliative care for people with dementia. This provides a summary of reports and resources for people with dementia, their carers and staff on this topic.

Reports

In 2012, in collaboration with the Alzheimer Society of Ireland (ASI) the [Building Consensus on Dementia Palliative care](#) report was published. This report signposted the developments in service, education, and policy to support the provision of palliative care for people with dementia.



St Vincent's Hospital Athy in 2009, in conjunction with St Brigid's Hospice Kildare sought to develop a framework to support staff to initiate discussions on end of life care for people with dementia. Their report '[Planning for the Future](#)' describes how service improvement responds to palliative care needs of people with dementia and has also produced some prompts to support and [document end of life care](#) conversations with people with dementia.

Seminars

Between 2014 and 2016 IHF will have hosted 6 seminars across Ireland aimed at building capacity amongst staff as they recognise and respond to the palliative care needs of people with dementia that they care for. The first seminar was held in Limerick in March 2014, Slides from this seminar are available [here](#). The second seminar will take place in the Fairways Hotel, Dundalk on Sept 25th. Click [here](#) for booking form and programme. Next year's seminars will be in the south east and north west.

WHAT MATTERS TO ME

Workshops on communication and end of life care for staff working in residential care settings, provided on-site for groups of up to 16 staff (cost: €450)

LIMITED AVAILABILITY LEFT FOR 2014

Please contact Claire Banks for bookings
Claire.banks@hospicefoundation.ie

Patient and Carer Information Leaflets

In 2013, IHF & ASI developed and published a booklet "[I have dementia...How do I plan for the future?](#)" The booklet provides information and practical advice to support people with dementia in making decisions about what is important to them now and into the future.



IHF with ASI are now preparing the following three Fact Sheets aimed at carers of people with dementia:

- **Understanding late Stage Dementia'**
- **Loss and grief when you care about someone living with Dementia**
- **Understanding loss following the death of someone with Dementia**

These are due to be published by the end of 2014. A factsheet on transfer documents in use between care settings currently in use in Ireland will shortly be available to view online.

Changing Minds Service Innovation

As part of this IHF programme to assist in the development of evidenced based excellence in end-of-life care for people with dementia, the following initiatives are underway:

Building Growing & Strengthening End of life care in residential care centres:

IHF have developed an exciting new initiative to support residential care centres (RCCs) wishing to develop end of life care.

All RCCs engaging with the initiative will become members of a new on-line learning and support network where they will receive regular bulletins on best practice and can share successes, learning and information. All members will also receive an end of life care resource pack which will include the newly developed end of life care toolkit for residential care centres. Centres can choose to deepen their level of engagement through training in end of life care review and models for development.

Full details will be circulated in September 2014. For more information contact: anna.desiun@hospicefoundation.ie

Grants:

- North West Hospice is undertaking an audit of its work with people with dementia to highlight how Specialist Palliative Care Services support people with dementia.
- As part of the Outreach programme in Connolly Hospital, Dublin, interventions that support quality medical care and end-of-life planning in nursing home settings for people with dementia will be highlighted.
- St. James' Hospital, Dublin is developing a feasibility plan to develop an integrated care pathway addressing the end-of-life care of people with dementia
- Milford Compassionate Communities project will seek to introduce a social model of care for people living at home with advanced dementia - The Good Neighbour Scheme.
- Building on the Planning for the Future Project, St Vincent's Hospital, Athy is evaluating the tools developed as part of phase one, and rolling them out to the other wards in the hospital.

Guidance for Staff

Over the next two years up to 9 guidance documents are being developed to support healthcare professionals in the provision of good end-of-life care to people with dementia. These will be developed based on evidenced based information and will include easy to use prompts for practice.

List of Guidance Documents

1. Facilitating difficult conversations
2. Future planning
3. Assisted decision making act
4. Anticipated loss and bereavement
5. Intellectual disability
6. Ethical decision making
7. Hydration & nutrition
8. Pain assessment & management
9. Medication

Work is underway on the first guidance document - Facilitating difficult conversations, and UCC have been awarded the tender to develop documents 6,7,8 & 9 - as per above list.

Resources for Staff

In addition, an information guide on the range of transfer documents that are currently in use to support continuity of end of life care between care settings will be made available.

The guide to symptom control at end of life in advanced dementia developed in St Vincent's hospital Athy is available [here](#).

Prompts for practice "[End of life care for people with dementia](#)" is one of eight free guidance documents from IHF relating to good practice in end of life care - these printable documents are available [here](#).

IHF, Hospice Friendly Hospitals have a range of resources available for use, more information on these are available [here](#).

[Think Ahead 2](#) was launched on July 17th 2014. It assists people to document their end of life care preferences and is currently being used in nursing homes in Kildare.

A [pilot project](#) is underway in South Doc that is introducing a formal system for GPs to communicate on the palliative care needs of their patients, that might arise outside of traditional working hours.

More details on the dementia programmes activities are available. If you would like to receive regular updates on this programme please email your contact details to:
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Marie.lynch@hospicefoundation.ie

