Welcome, this issue of the Health Evidence Awareness Report focuses on Palliative / End of Life Care.

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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”


This newsletter contains information for patients, families and carers with links to support groups & organisations, nutrition, legal information, books, multimedia and patient education. Other sections include links to clinical articles, guidelines and systematic reviews.

Remember
Christina Georgina Rossetti

Remember me when I am gone away, gone far away into the silent land;
When you can no more hold me by the hand, nor I half turn to go, yet turning stay.
Remember me when no more day by day you tell me of the future that you planned;
Only remember me; you understand it will be late to counsel then or pray.
Yet, if you should forget me for a while and afterwards, remember, do not grieve:
For if the darkness and corruption leave a vestige of the thoughts that once I had, better by far you should forget and smile than that you should remember and be sad.
HEAR: HEALTH EVIDENCE AWARENESS REPORT

HSE Information

The HSE has a National Clinical Programme for Palliative Care, established in 2010 with the aim to ensure that persons with life limiting conditions can access the palliative care appropriate to their needs. [http://www.hse.ie/palliativecareprogramme]

Nutrition

Diet and Nutrition in Cancer Survivorship and Palliative Care [http://www.hindawi.com/journals/ecam/2013/917647/]

Carer Information: Why Won't They Eat? Dealing With Appetite Changes in Palliative Care - Irish Nutrition and Dietetic Institute. [http://tinyurl.com/hsrlc75]

Patient Information: Dealing With Appetite Changes in Palliative Care - Irish Nutrition and Dietetic Institute [http://tinyurl.com/z5uljpv]

Legal Information

Making a will - guidance from the Law Society of Ireland [https://www.lawsociety.ie/Documents/pdfs/will.pdf]

Ethical Framework for End of Life Care Irish Hospice Foundation [http://hospicefoundation.ie/publications/ethics/]


Support Groups & Associations

The Irish Hospice Foundation, national charity dedicated to all matters relating to dying, death and bereavement in Ireland. [http://hospicefoundation.ie/]

Paediatric Palliative Care (PPC) has seen a growth in interest and commitment in the last 15 years. See information on children’s palliative care at The Irish Hospice Foundation [http://tinyurl.com/huzdehw]

LauraLynn Ireland’s Childrens Hospice, caring for children with life limiting conditions [https://lauralynn.ie/]

A Little Lifetime Foundation – providing stillbirth and neonatal death support and information to bereaved families since 1983 [http://www.allittlelifetime.ie/]

Féileacáin- still birth and neonatal death association of Ireland offering support and information [http://www.feileacain.ie/]

All Ireland Institute of Hospice and Palliative Care [http://aiihpc.org/]
Emotional & Mental Health

Coping with bereavement - NHS choices

Bereavement Care and Information Leaflets from the HSE and Irish Hospice Foundation
http://www.hse.ie/eng/services/publications/Mentalhealth/Bereavement/

Books & Multimedia

Oxford Handbook of Palliative Care 2nd ed. This book provides a theoretical background and evidence base on palliative care.


Oxford Textbook of Palliative Nursing. 2015. A textbook for all staff involved in palliative care nursing, or palliative therapy.

Being Mortal: Illness, Medicine and what matters in the end by Atul Gawande Written by a surgeon, this book looks at the modern experience of mortality, and the impact which medicine has had.

Palliative care for infants children and adolescents, a practical handbook a guide for professionals involved in paediatric end of life care.

Waterbugs and Dragonflies. By Doris Stickney Explaining death to young children using the example of the short life of a waterbug

VIDEO

Perceptions of Hospice Care- Video

What is Palliative Care? Video –IAPC
Reviews


Shepperd S. et al (2016) Hospital at home: home-based end-of-life care, Cochrane Database of Systematic Reviews,

Chan R.J., Webster J. & Bowers A. (2016) End-of-life care pathways for improving outcomes in caring for the dying, Cochrane Database of Systematic Reviews,

Guidelines

Care of dying adults in the last days of life. NICE guidelines, 2015
http://www.nice.org.uk/guidance/ng31

End of life care for infants, children and young people currently in development, due December 2016
http://tinyurl.com/hn4sd2m


Practical guidance for the management of palliative care on neonatal units. Royal College of Pediatrics & Child Health & NHS 2014
http://tinyurl.com/hakjly

Palliative care for adults: strong opioids for pain relief. NICE guideline 2012
http://www.nice.org.uk/guidance/cg140

Irish Authored Reports and Research

Fox S. et al (2016) Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson’s disease: a definite role but uncertainty around terminology and timing BMC Palliative Care 15:15
http://tinyurl.com/hu32fhy


http://tinyurl.com/jq6yprd


Patient Care & Quality of Life

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3640611/


TEDTalk: BJ Miller: What really matters at the end of life
http://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life

UPCOMING EVENTS

2nd International Children’s Palliative Care Conference.
“Building Bridges: Home, Hospital and Hospice”.

Compassionate Care at the End of Life in Hospitals.
Strand Hotel, Limerick, 27th April 2016. The conference is organized by the Irish Hospice Foundation’s Hospice Friendly Hospitals Programme, HSE and the University of Limerick Hospital Group.

9th World Research Congress of the European Association of Palliative Care, University College Dublin, 9th-11th June 2016.
Patient Education & Information

Hospice Services in Ireland

There are nine inpatient hospices in the Republic of Ireland; three in Dublin and one each in Cork, Limerick, Galway, Sligo, Donegal and Kildare and in Northern Ireland; Northern Ireland Hospice, Marie Curie Hospice, Macmillan Unit, Southern Area Hospice and Foyle Hospice. These cater for patients living within their catchment area only. Most hospice/palliative care in Ireland is delivered in the form of home care.

Think Ahead

The purpose of Think Ahead is to guide members of the public in discussing and recording their preferences in the event of emergency, serious illness or death.

Compassionate Communities

It can be really difficult to talk about illness and death, that’s why Compassionate Communities, Limerick have developed a series of leaflets and videos which you, your family and the general public can use. Click HERE

Bereaved

BEREAVED.ie provides advice and information for bereaved people, those supporting them and professionals working with them. It is an initiative of the Irish Hospice Foundation

Irish Childhood Bereavement Network

The Irish Childhood Bereavement Network (ICBN) was founded in 2012 to act as a hub for those working with bereaved children, young people and their families.