

HEAR (*Health Evidence Awareness Report*)

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“How people die remains in the memory of those who live on”

Dame Cicily Saunders,
Founder of the Hospice Movement



Welcome:

This issue of HEAR 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”

World Health Organisation <http://www.who.int/cancer/palliative/definition/en/>

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.



01 679 3188



01 873 4735



AIHPC

All Ireland Institute of
Hospice and Palliative Care

[Learning Hub](#)

[Children and Young
People's Palliative Hub](#)

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/>

Advance Care Directives or "Living Will" – Citizens Information Board

http://www.citizensinformation.ie/en/health/legal_matters_and_health/advance_care_directives.html

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.alittlelifetime.ie/>

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

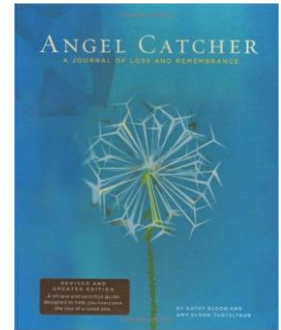
All Ireland Institute of Hospice and Palliative Care <http://aiihpc.org/>

Emotional & Mental Health

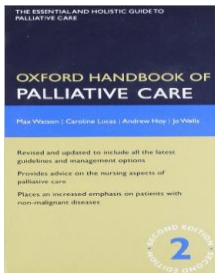
[Coping with bereavement](#) - NHS choices

Bereavement Care and Information Leaflets from the HSE and Irish Hospice Foundation

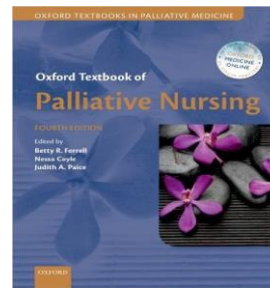
<http://www.hse.ie/eng/services/publications/Mentalhealth/Bereavement/>



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.

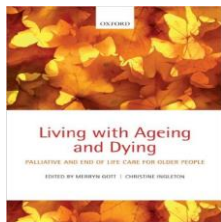
A textbook for all staff involved in palliative care nursing, or palliative therapy.

[Angel Catcher: A Journal of Loss and Remembrance.](#)

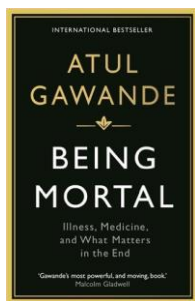


[When someone has a very serious illness.](#)

Children can learn to cope with loss and change. By Marge Eaton Heegard

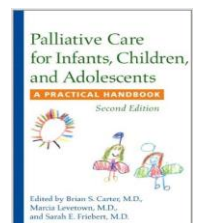


[Living with Ageing and Dying: Palliative and End of Life Care for Older People](#): 2011. This book identifies ways in improving end of life care and experiences of older people.

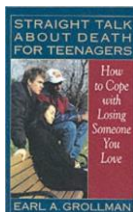


[Being Mortal: Illness, Medicine and what matters in the end](#) by Atul Gawande Written by a surgeon, this book looks at the modern experience of mortality, and the impact which medicine has had.

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



[Straight talk about death for Teenagers](#): how to cope with losing someone you love by Earl A Grollman



[Waterbugs and Dragonflies.](#)

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



Perceptions of Hospice Care- [Video](#)

What is Palliative Care? [Video –IAPC](#)

Reviews

Cox L., Darvill E. & Dorman S. (2015) Levomepromazine for nausea and vomiting in palliative care, Cochrane Database of Systematic Reviews

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009420.pub3/abstract>

Gardiner C. et al (2015) Exploring the transition from curative care to palliative care: a systematic review of the literature, BMJ Support Palliative Care, 5(4): 335-42.

<http://www.ncbi.nlm.nih.gov/pubmed/26586682>

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

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009231.pub2/abstract>

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,

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008006.pub4/abstract>

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>

Guidelines for supporting people with intellectual disabilities receiving bad news. <http://www.breakingbadnews.org>

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>

Pharmacological management of cancer pain in adults. NCEC 2015

<http://tinyurl.com/hver7xl>

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>

McKeown K. et al (2015) Determinants of care outcomes for patients who die in hospital in Ireland: a retrospective study, BMC Palliative Care 14:11 <http://tinyurl.com/j2awlei>

Palliative Care Competence Framework Steering Group (2014) Palliative Care Competence Framework, Dublin: Health Service Executive <http://tinyurl.com/j5umryd>

McLoughlin K. et al (2015) INSPIRE (INvestigating Social and Practical support at the End of life): Pilot randomised trial of a community social and practical support intervention for adults with life-limiting illness, BMC Palliative Care 14:65

<http://tinyurl.com/jg6yprd>

Ling J, (2016) Parental decision-making on utilisation of out-of-home respite in children's palliative care: findings of qualitative case study research - a proposed new model Child Care Health Dev. 2016 Jan;42(1):51-9 <http://tinyurl.com/hoeptt3>

Children's Palliative Care Working Group (2009) Palliative care for Children with Life Limiting Conditions in Ireland, Dublin: Department of Health & Children <http://tinyurl.com/qcrk7lt>

Home or Hospice – Patient & Family Preference

Metzger M, Norton S. A., (2013) “That Don’t Work for Me”: Patients’ and Family Members’ Perspectives on Palliative Care and Hospice in Late-Stage Heart Failure. *Journal of Hospice & Palliative Nursing* 15(3), 177-82

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



Cox, Karen, (2011) Is it recorded in the notes? Documentation of end-of-life care and preferred place to die discussions in the final weeks of life. *BMC Palliat Care*. 2011; 10: 18. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3227605/>

Gomes, Barbara (2015) Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study *BMC Med*. 2015; 13: 235.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4599664/>

Morris, Sara M (2015) Family carers providing support to a person dying in the home setting: A narrative literature review *Palliat Med*. 2015 Jun; 29(6): 487–495.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4436280/>

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”.
Farmleigh House, Phoenix Park, Dublin. 22nd – 23rd April 2016.

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.

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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.



DISCLAIMER

This newsletter contains information about Palliative or End of Life Care. This information is **not advice** and should not be treated as such.

The purpose of this newsletter is to provide specialised information to health professionals and patients about health related topics. HEAR is now in its second year and is a result of collaboration between librarians from a variety of health organisations in Ireland. www.hslq.ie or [contact us](#)

This month's issue was compiled by a collaborative group of health librarians. We are: **Joanne Callinan**, Milford Care Centre; **Marie Carrigan**, St Luke's Radiation Oncology network; **Bernadette Coley**, Temple St University Hospital; **Isabelle Delaunois**, University Hospital Limerick; **Catherine Dillon**, HSE, **Grace Hillis**, Daughters of Charity Disability Support Services; **Aoife Lawton**, Dr Steeven's Hospital Dublin, **Anne Madden**, St Vincent's University Hospital Dublin, **Margaret Morgan**, Regional Hospital Mullingar, **Caroline Rowan**, St Michael's Hospital Dublin, **Niamh O'Sullivan**, Irish Blood Transfusion Board.