The last days of life – in hospital and at home

Beaumont Multi-disciplinary Palliative Care Study Day 28/9/2017

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St Francis Hospice
Beaumont Hospital
Overview

- What are the priorities?
- Common symptoms at the end of life
- How to recognise the dying patient
- Rapid discharge pathway
- Community palliative care
- Questions
Figure 9 Deaths at Home in Ireland, 1885-2011

% Deaths at home in Ireland
% Deaths in hospitals & institutions in Ireland

1885: 85
1905: 80
1925: 75
1945: 70
1965: 65
1985: 60
2005: 55
2011: 50


***ENABLING PEOPLE TO DIE AT HOME***

74% of people in Donegal want to die at home but only 18% of people in Dublin die at home.

WHERE DO IRISH PEOPLE DIE?

- 43% of people die in hospital
- 26% in long-stay
- 26% at home
- 6% die in a hospice
- Ireland has a lower number of home deaths (26%) compared to Italy (33%), and the Netherlands (28%)

16% of people in Norway die at home.
From pyramid to kite
Japan’s population by age group, m

1950

2005

2055 forecast

Source: National Institute of Population and Social Security Research
Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

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Lauren McIntyre, PhD
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Context  A clear understanding of what patients, families, and health care practitioners view as important at the end of life is integral to the success of improving care of dying patients. Empirical evidence defining such factors, however, is lacking.

Objective  To determine the factors considered important at the end of life by patients, their families, physicians, and other care providers.

Design and Setting  Cross-sectional, stratified random national survey conducted in March-August 1999.

Participants  Seriously ill patients (n = 340), recently bereaved family (n = 332), phy-
What is important at the end of life?

Strong consensus amongst seriously ill patients, bereaved family members, physicians, and other HCPs

- Pain and symptom management
- Preparation for death
- Achieving a sense of completion
- Being involved in decisions about treatment preferences / sense of control
- Being treated as a ‘whole person’

Steinhauser et al JAMA 2000
<table>
<thead>
<tr>
<th>Attributes</th>
<th>Patients</th>
<th>Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be mentally aware</td>
<td>92</td>
<td>65</td>
</tr>
<tr>
<td>Be at peace with God</td>
<td>89</td>
<td>65</td>
</tr>
<tr>
<td>Not be a burden to family</td>
<td>89</td>
<td>58</td>
</tr>
<tr>
<td>Be able to help others</td>
<td>88</td>
<td>44</td>
</tr>
<tr>
<td>Pray</td>
<td>85</td>
<td>55</td>
</tr>
<tr>
<td>Have funeral arrangements planned</td>
<td>82</td>
<td>58</td>
</tr>
<tr>
<td>Not be a burden to society</td>
<td>81</td>
<td>44</td>
</tr>
<tr>
<td>Feel one’s life is complete</td>
<td>80</td>
<td>68</td>
</tr>
</tbody>
</table>

*P<.001 for all comparisons.

- Place of care rated least important of 9 attributes by patients
Physical care and place of care are important, but only components of overall care.

No one definition of a ‘good death’
- Quality of care at the end of life means different things to different people.

Collaborative MDT approach
- Important for good quality end of life care.
‘Dying is a psychological and social phenomenon with a physical dimension, not the other way round’
How can we achieve this for our patients?
Translates into better bereavement outcomes for caregivers too.

- Pain and symptom management – excellent symptom control
- Preparation for death – prognosticating as best can; communication
- Achieving a sense of completion – MSW memory work; life stories
- Being involved in decisions about treatment preferences / sense of control – advance care planning; having conversations to determine patient’s goals and wishes
- Being treated as a ‘whole person’ – person centred care
Physical examination
- Keep to a minimum to avoid unnecessary distress
  - Sites of potential pain
  - Mouth

Investigations
- Only with a clear purpose

Tablet burden - review of medications
- Discontinue ‘non essential’ oral medications
  - Including prophylactic LMWH, insulin
- Switch po meds to alternative route if patient is unable to swallow
- Avoid im route as painful; if buccal medications are used ensure the mouth is moist enough; consider the PR route
Advance care planning

To ensure patient’s wishes and goals are achieved

BEAUMONT & CONNOLLY HOSPITAL GUIDELINES FOR PATIENTS RETURNING TO / RESIDENT IN NURSING HOMES FOR SUPPORTIVE-COMFORT CARE

These are guidelines for the medical/nursing team based on the patient’s wishes. A COPY SHOULD BE KEPT IN THE PATIENT’S MEDICAL RECORD AND IN THE NURSING HOME and should accompany patient. This document should be discussed with patient/family, nursing home staff and transfer if patient is being discharged from hospital. THIS IS NOT A TICK

Name: ____________________________
Address: __________________________
Date of Birth: _______________________
M.R.N Number: _____________________
(if in hospital)
Diagnosis _______________________

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ Attempt Resuscitate (CPR)  ☐ Do Not Attempt Resuscitation (no CPR)

F.D.N.R, letter for ambulance crew
When not in cardiopulmonary arrest, follow B, C and D

MEDICAL INTERVENTIONS:

☐ Comfort measures: Treat with dignity and respect
Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Refer to Section C re antibiotic care plan. Refer to Section D for nutrition and fluid plan. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.

☐ Limited Additional Interventions: Includes care described above. Use medical treatment. Refer to Section C re antibiotic care plan. Refer to Section D for nutrition and fluid plan. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid intensive care

☐ Full Treatment: Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Include intensive care.
Other instructions: ______________________

Name of GP/Medical Officer with whom this plan discussed

Name of Director of Nursing / Clinical Nurse Manager with whom this plan discussed

Name/s of family members with whom this plan discussed

The basis for these orders is: ☐ Patient’s preferences  ☐ Patient’s best interest

ANTIBIOTICS
☐ No Antibiotics
☐ Oral Antibiotics
☐ IV Antibiotics (usually requires hospital admission, consider community intervention team if appropriate)
Other instructions: ______________________
When to refer to palliative care

Assess **need** rather than **prognosis**

- Difficult to control symptoms
- Psychological or social issues
- Dependent children or elderly vulnerable relatives
- Difficult ethical question e.g. feeding or hydration

“**There’s no easy way I can tell you this, so I’m sending you to someone who can.**”
## Domain 1: Physical Wellbeing
### Suggested Prompts
- **Pain**
  - Somatic, visceral, neuropathic.
  - Take a detailed pain history outlining:
    - location, quantity, intensity, duration, frequency
    - associated/aggravating/remitting factors
    - treatment interventions
- **Fatigue**
  - Fatigue disproportionate for level of activity or not relieved by rest.
- **Respiratory**
  - Dyspnoea, cough, oropharyngeal secretions.
- **Gastrointestinal**
  - Anaemia, nausea, vomiting, constipation.
- **CNS**
  - Insomnia, confusion, delirium, anxiety, depression.
- **Other**
  - Functional status, balance problems, oedema, wound problems.

## Domain 2: Social & Occupational Wellbeing
### Suggested Prompts
- **Family Support**
  - In-depth discussion about family & relationships:
    - who lives with you?
    - any children/adult dependents?
    - any concerns/worries regarding family or personal relationships?
- **Emotional & Social Support**
  - Do you have any other support e.g. PhD, home help, private carer, friends, neighbours?
  - Do you need more support? What would help?
- **Practical Concerns and Advance Care Planning**
  - Discussion about practical issues:
    - How are you managing?
    - Any difficulties in mobilising, managing the stairs, household chores e.g. washing, cooking, etc.
    - Any concerns about future care needs: income, finances, sorting out your affairs?
- **What are the person’s wishes regarding:**
  - goals of care?
  - acceptable levels of intervention?
  - preferred place of care (person and family)?

## Domain 3: Psychological Wellbeing
### Suggested Prompts
- **Mood & Interest**
  - How is your mood?
  - During the last month how have you:
    - been feeling down and/or hopeless? Lost enjoyment in interests?
    - been depressed? Do you feel tense or anxious?
    - have you ever had a panic attack?
    - Are there things you are looking forward to?
- **Adjustment to Illness**
  - Cultural and spiritual beliefs.

## Domain 4: Spiritual Wellbeing
### Suggested Prompts
- **Sources of Hope**
  - What gives you hope (strength, comfort, peace) in the time of illness?
- **Organised Religion**
  - Are you part of a religious or spiritual group? Does it help you? How?
- **Personal Spirituality & Practice**
  - What aspects of your spiritual beliefs do you find most helpful?
Common symptoms at the end of life

- Dying patients tolerate symptoms very poorly due to weakness

- Important factors:
  - Excellent nursing care
  - Prevention of new symptoms e.g. pressure mattress to prevent bed sores
  - Anticipating future symptoms or needs and putting plans in place
Common symptoms in the last 48 hours

- Noisy moist breathing - secretions
- Pain
- Breathlessness
- Nausea / vomiting
- Terminal delirium
Noisy, moist breathing - ‘secretions’

- Oro-pharyngeal secretions not being coughed or cleared normally + accumulate in the upper airway

- Exclude acute pulmonary oedema +/− Lasix s/c

- Hyoscine butylbromide ‘Buscopan’ 20mgs stat PRN s/c or up to 120mgs / 24 hours s/c infusion

- Glycopyrronium ‘Robinul’ 200 - 400mcg PRN s/c or up to 3200mcg / 24hrs s/c infusion

- Hyoscine hydrobromide – crosses blood brain barrier and can exacerbate agitation
Pain

- As per the WHO ladder
- Via s/c infusion if unable to manage the oral route
- Ensure breakthrough analgesia prescribed PRN s/c
Nausea / vomiting

- Dysmotility
  - Treatment: Maxalon

- Chemical causes
  - Treatment: Cyclizine / Haloperidol

- If also agitated
  - Treatment: Levomepromazine (Nozinan)

Breathlessness

- Opioids
- Benzodiazepines
- Measures such as fan, cool air
- Oxygen if ‘cooling sensation’ helpful
Agitation

‘Think list’ – reversible conditions to exclude:

- Pain
- Urinary retention
- Constipation
- Nausea
- Cerebral irritability / oedema
- Anxiety
- Side effects of medication
Delirium - ‘off the ploughed track’

- Common
- Underrecognised
- Undertreated

- Prevalence of 13 – 42% of patients in palliative care inpatient units

- Rising to 88% in days and hours before death

Hosie A et al Pall Med 2013
Medication review

- Opioid rotation
  - Shown to improve hallucinations and confusion in 29 / 42 patients rotated

- Parenteral hydration
  - Delirium is the only aspect of terminal symptom control which may benefit from hydration

- Antibiotics
  - If infective cause is suspected

Mercadante et al Cancer Treat Rev 2006
Dev R et al Curr Opin Support Palliat Care 2012
Management - combination of a sedating anti-psychotic with a benzodiazpine

- **First line**
  - Haloperidol 1-5mgs / 24 hours
  - Midazolam 10 – 60mgs / 24 hours

- **Second line**
  - Levomepromazine 12.5mgs / 24 hours+

- **Third line**
  - Phenobarbitol 100 – 200mgs s/c loading dose; followed by maintenance 600 – 1200mgs / 24 hrs s/c
Helping families understand delirium

- Distressing

- Higher levels of distress in spouses and carers who witness the delirium than in the affected patients

- Evidence demonstrates that distress is lowest in caregivers who were educated about the risk of delirium before it occurred

Breitbart et al Psychosomatics 2002
Cohen et al J Palliat Care 2009
How to recognise the dying patient
Nurses, care attendants and family members are better at predicting death than medical staff.

Physicians more accurate as death draws near

- Clinician experience may improve accuracy
Palliative Prognostic Scale
Modified functional score

### PPS in Prognostication

<table>
<thead>
<tr>
<th>PPS</th>
<th>Mean</th>
<th>Median</th>
<th>Range</th>
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<tbody>
<tr>
<td>60</td>
<td>64</td>
<td>40</td>
<td>6-348</td>
</tr>
<tr>
<td>50</td>
<td>51</td>
<td>27</td>
<td>1-287</td>
</tr>
<tr>
<td>40</td>
<td>36</td>
<td>17</td>
<td>1-347</td>
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<td>18</td>
<td>9</td>
<td>1-295</td>
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<td>20</td>
<td>6</td>
<td>2</td>
<td>1-81</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>1</td>
<td>1-12</td>
</tr>
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</table>

Lau 2006
# THE PALLIATIVE PROGNOSTIC SCORE (PaP)

<table>
<thead>
<tr>
<th>CRITERION</th>
<th>ASSESSMENT</th>
<th>PARTIAL SCORE</th>
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<tbody>
<tr>
<td>Dyspnea</td>
<td>No</td>
<td>0</td>
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<tr>
<td></td>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>Anorexia</td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1.5</td>
</tr>
<tr>
<td>Karnofsky Performance Status</td>
<td>≥ 30</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>10 – 20</td>
<td>2.5</td>
</tr>
<tr>
<td>Clinical Prediction of Survival</td>
<td>&gt; 12</td>
<td>0</td>
</tr>
<tr>
<td>(weeks)</td>
<td>11 – 12</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>7 – 10</td>
<td>2.5</td>
</tr>
<tr>
<td></td>
<td>5 – 6</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>3 – 4</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>1 – 2</td>
<td>8.5</td>
</tr>
<tr>
<td>Total WBC (x10⁹/ L)</td>
<td>≤ 8.5</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>8.6 – 11</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>&gt;11</td>
<td>1.5</td>
</tr>
<tr>
<td>Lymphocyte Percentage</td>
<td>20 – 40 %</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>12 – 19.9 %</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>&lt; 12 %</td>
<td>2.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RISK GROUP</th>
<th>30 DAY SURVIVAL</th>
<th>TOTAL SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>&gt; 70 %</td>
<td>5.6 – 11</td>
</tr>
<tr>
<td>B</td>
<td>30 – 70 %</td>
<td>11.1 – 17.5</td>
</tr>
<tr>
<td>C</td>
<td>&lt; 30 %</td>
<td>0 – 5.5</td>
</tr>
</tbody>
</table>
End of life

- Day to day deterioration of strength, appetite, and awareness

- Signs and symptoms of death approaching:
  - Profound weakness / bed bound
  - Gaunt appearance
  - Reduced po intake / difficulty swallowing medication
  - Drowsiness / reduced cognition / difficulty concentrating
If end of life care at home is being planned
Rapid Discharge Planning Pathway

Palliative Care Clinical Care Programme
What is the aim of RDP?

To facilitate a safe, smooth and seamless transition of care from hospital to community for persons who have expressed a wish to die at home.
Who does the RDP involve and concern?

- All health and social care professionals working in the HSE and in any organisation providing services on behalf of the HSE.

- People affected by the guidance i.e. service users and their families/carers, and the general public.
What are the steps in RDP process?

**Step 1**
The **Person** chooses to die at home

- No anticipated post mortem or organ donation

**Step 2**
**Doctor** confir*ms it is appropriate and the **Family/Carer** support

- Doctor documents in person’s notes

**Step 3**
**CNM** identifies **Lead Nurse** to coordinate

- Lead nurse identified from person’s ward/unit

**Step 4**
**Lead Nurse** implements process

- Lead nurse leads on implementation of RDP action plan
What does the Lead Nurse do?

Contact GP, PHN/DoN and other members of the primary care and/or specialist palliative care team as soon as possible.

The GP and PHN/DoN: may confirm that rapid discharge is appropriate

Contingent on certain supports/services

Rectify and proceed or

Poses a clinical risk to safety or well-being

Rectify and proceed or

Unable to rectify, abandon and discuss with patient, family and team

Proceed with plan

Published 2013 Version 1
What are the next arrangements to implement?

Within 24 hours before discharge:

**Ambulance**
Liaise with Ambulance Service re:
- Transport arrangements
- Ambulance letter

**Primary Care Team**
- Liaise with GP/PHN/DoN
- Develop care plan
- Liaise with MDT
- Fax copy of prescription to GP & community pharmacy

**Equipment**
- Organise equipment
- Medical supplies
- Write nursing discharge letter

**Family**
- Support family
- Clarify expectations
- Provide carer education

Published 2013 Version 1
Liaison with Hospital/Community MDT

Physiotherapy Dept:
  As appropriate

Medical Social Work
Dept re:
  • Assessment and addressing of psychological needs
  • Essential practical needs

OT Dept re:
  Essential equipment

Community Pharmacy re:
  • Unlicensed meds
  • Meds difficult to source
  • Meds not on GMS

Published 2013 Version 1
What are the considerations when planning with CNS in Palliative Care?

- Is Night Nursing Service required?
- Is Community Specialist Palliative Care Team (SPCT) required?
- Advise re complex needs for potential symptoms
What is the role of the NCHD in RDP planning?

The NCHD will:

- Write discharge letter.
- Write prescriptions - regular medications/p.r.n. medications (24 hours prior to discharge).
- Contact GP re verifying and issuing the certificate of cause of death.
- Complete section in ambulance service letter.

Published 2013 Version 1
What are the Final Actions?

On discharge:

**Letters to:**
- GP,
- PHN/ DoN
- SPCT
- Other member of the primary care or specialist teams as appropriate.
- Letter to Ambulance Service including DNAR order as appropriate.

**Syringe pump:**
- Change immediately prior to discharge if in use.

**Prescriptions:**
- Hand to family unless transferring to residential care facility.

Published 2013 Version 1
### Rapid Discharge Action Plan - Summary of Key Steps

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>STEP 1:</strong></td>
<td>The imminently dying patient chooses to die at home and no issues are identified regarding the potential need for a coroners post mortem or organ donation</td>
<td>7.1, 10, 11</td>
</tr>
</tbody>
</table>
| **STEP 2:** | Doctor:  
- Confirms that it is appropriate to focus on palliation at home.  
- Family / carer support patient decision (where a family / carer exist and patient has indicated that information may be shared).  
- Medical Consultant/designate records in the patient’s health care record that they are satisfied that discharge can occur. | 7.1 |
| **STEP 3:** | CNM:  
- Identifies the lead nurse to manage the rapid discharge process  
- Supports the process | 7.2 |
| **Step 4:** | Lead Nurse:  
**Initiation**  
- Contacts GP, PHN/DoN and other members of the primary care or specialist team as soon as possible in order to inform them of the patient’s prognosis and wishes and to discuss the potential for rapid discharge.  
- The GP and PHN/DoN may confirm that rapid discharge is appropriate.  
- The GP and PHN/DoN may state that rapid discharge is appropriate but that its feasibility is contingent on certain supports/ services being provided.  
- Taking advice into consideration, the GP and PHN/DoN may state that in their considered opinion that rapid discharge poses a clinical risk to the safety or well-being of the patient or their carers. Every effort is made to reduce or eliminate the risk where possible. If not possible, liaise with patient and family.  
- Communicate the outcome to the patient and family | 7.2 - 7.8 |
|   | **Planning**  
- Liaise with PHN/DoN and develop care plan  
- Involve members of the MDT as required - Medical Social Worker, Occupational Therapist, Physiotherapist, Pharmacist, Palliative Care CNS, Community based Palliative Care, Community Intervention Team  
- Support family. Ascertain their level of understanding of what is expected of them.  
- Provide carer education as per Appendix 3  
- Organise equipment and medical supplies  
- Organise transport  
- Write nursing discharge letter |
AMBULANCE TRANSFER LETTER

Destination address:

Destination address in event of patient dying en route (please detail whether the ambulance should continue to the home destination/ divert to the nearest hospital/ return to the original hospital):

Date:

Dear Advanced Paramedic / Paramedic / EMT,

Mr/ Ms is being transported to the above address for the purpose of facilitating his/ her wish to die at home. Therefore, the focus of care is solely on palliation and cardiopulmonary resuscitation should not be attempted in the event of a cardiopulmonary arrest.

In the event of Mr/ Ms dying while being transported home by ambulance, you should:

- Follow Clinical Practice Guideline 5/6.4.31 End of Life Care/DNR
- Contact NAS Control to Confirm Geographic Location at time of death.
- Inform NAS Control of intent to complete journey to destination, as per Rapid Discharge Planning Pathway.
- Transport the patient to the destination address detailed above
- Inform the family/carer at the destination that death has occurred (if family/ carer have not accompanied the patient).
- Place the patient’s remains in the bed prepared for receiving the patient.
- Contact the GP to verify death (unless diverting to hospital destination in which case hospital doctor will verify death).
- Contact the PHN to notify of death (unless travelling to a residential care facility, in which case the DON will contact GP/ PHN)

Yours sincerely,
<table>
<thead>
<tr>
<th>Action</th>
<th>By whom</th>
<th>Prompts for action</th>
<th>Provide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor confirms the patient is fit to travel</td>
<td></td>
<td>Discuss concerns</td>
<td>Discharge letter</td>
</tr>
<tr>
<td>Carer preparation:</td>
<td></td>
<td>Explain medications use</td>
<td>Prescription</td>
</tr>
<tr>
<td>PHN/DoN Handover:</td>
<td></td>
<td>Confirm patient has been discharged/is not fit for discharge</td>
<td>Fax discharge letter</td>
</tr>
<tr>
<td>GP Handover:</td>
<td>Family</td>
<td>Confirm patient has been discharged/is not fit for discharge</td>
<td>Fax discharge letter</td>
</tr>
<tr>
<td>Transport</td>
<td>Ambulance</td>
<td></td>
<td>Letter for ambulance crew</td>
</tr>
</tbody>
</table>
Supports for end of life care at home
Community palliative care (CPC)

‘Deluxe dying for the privileged few’

Increasing recognition of benefit of palliative care input – aging population, diagnoses other than cancer, underserved populations

90% of care in the last year of life happens in the home

Increasing importance of supporting generalist palliative care provision

Douglas, 1991
St Francis Hospice

- Inpatient units
  - 17 beds Raheny
  - 24 beds Blanchardstown
Community palliative care
- 260 – 300 patients between east and west teams
- > 1100 deaths / year

Hospice Day Care

Outpatients
- CT, physiotherapy, nursing

Medical social work/ chaplaincy
- Bereavement services
- Carer support group
- Drop in carer support

Complementary therapy
- Lymphoedema / MLD

Breathlessness / Heart Failure programmes
- EXHALE

Volunteer services
- Life stories
- Volunteer bereavement support service
- Public health nurse
- Home care package
- Community Intervention Teams
- GP
- Community OT, PT, MSW
- Irish Cancer Society night nursing service
Education and Research
- Short courses and e-learning
- Library
- Kaleidoscope conference
- TCD / SFH MSc in Palliative Care
- Community and schools outreach

Introduction to Palliative Care of the Older Person

Centre for Continuing Studies, St Francis Hospice Dublin

Dates:
Mon 16th October 2017
(Pain and Symptom Management)
Tues 24th October 2017
(Psychosocial Interventions)

"The course was very good and took great pleasure attending it. I feel more competent and confident taking care of people and their needs."
Questions?