Palliative Care Needs Assessment Guidance

National Clinical Programme for Palliative Care
What is palliative care?

Palliative care is an approach that improves the quality of life of people and their families facing the problems 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, 2002)
Palliative Care Principles

- Affirms life and regards death as a normal process
-Neither hastens or postpones death
-Provides care that is person-centred and focused on the whole person
-Provides relief from pain and other distressing symptoms
-Offers a support system to help individuals live as actively as possible until death
-Promotes quality of life and choice for the individual and family
-Offers a support system to help families cope during the person’s illness and during their own bereavement
-Values and promotes interdisciplinary team-working
Who should receive palliative care?

All persons with a life-limiting condition irrespective of age or setting
What is a life limiting condition?

A life-limiting condition is a condition, illness or disease which is progressive and fatal and cannot be reversed by treatment.

(Glossary of Terms 2014, National Clinical Programme for Palliative Care)
Who provides palliative care?

Everyone working in a service that provides health and social care to persons with life limiting conditions is obliged to understand and provide a level of palliative care using a palliative care approach.
What is a palliative care approach?

Open sensitive communication with the person, family and colleagues

- Provides effective symptom control and management
- Concerned with promoting quality of life
- Holistic approach including life experiences and current situation
- Care for dying person and those who matter to them and bereavement support to family
What are the levels of palliative care provision?

**Level 1 – Palliative Care Approach:**
The palliative care approach should be a core skill of every clinician at hospital and community level. Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.

**Level 2 – General Palliative Care:**
At an intermediate level, a proportion of individuals and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level.

**Level 3 – Specialist Palliative Care:**
Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources.
What is the role of the specialist palliative care team?

Act as a resource for other health and social care professionals in the area, by providing support and advice when needed.

Provides bereavement support to families.

Clinical management and care coordination including assessment, triage, and referral using specialist palliative care skills for persons with complex needs associated with a life-limiting illness and/or end of life care.

Provide facilities for research and education in palliative care.
What is the eligibility criteria for referral to specialist palliative care service?

Persons with a life-limiting condition and with current or anticipated complexities that can no longer be provided by current care provider relating to:

- Symptom control
- End of life care planning
- Physical needs
- Psychosocial needs
- Spiritual care needs
When should a palliative care needs assessment take place?

- At diagnosis of a life-limiting condition
- At episodes of significant progression or exacerbation of disease
- At significant change in the person’s family/social support
- At significant change in functional status
- When the person or family make a request
- At end of life
Who should undertake a palliative care needs assessment?

- Initial assessment undertaken following decision by the health/social team responsible for the person’s care.

- Assessment should be undertaken by a suitably qualified professional with knowledge of:
  - Disease
  - Symptoms
  - Treatment
  - Likely prognosis
What is a palliative care needs assessment?

A palliative care needs assessment is an individualised assessment of palliative care needs based on the principles/domains of palliative care.........
4 domains of a palliative care needs assessment

Domain 1: Physical wellbeing

Domain 2: Social and occupational wellbeing

Domain 3: Psychological wellbeing

Domain 4: Spiritual wellbeing
**Domain 1: Physical wellbeing: what are the presentations?**

*(Unique to the person and may require prompting to share)*

<table>
<thead>
<tr>
<th>Pain</th>
<th>Fatigue</th>
<th>Respiratory</th>
<th>Gastrointestinal</th>
<th>Neurological</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic, visceral, neuro-pathic</td>
<td>Fatigue not relieved by rest and not appropriate to level of activity</td>
<td>Dyspnoea, cough, oropharyngeal secretions</td>
<td>Anorexia, nausea, vomiting, constipation</td>
<td>Insomnia, confusion, delirium, anxiety, depression</td>
<td>Functional status, balance problems, oedema, wound problems</td>
</tr>
</tbody>
</table>
Suggested actions to address physical symptoms

Approach
- Gentle prompting to identify physical needs of most concern

  Identification of symptoms
  - History of symptoms and previous treatment
  - How are symptoms effecting normal activities?

  Actions
  - Take a detailed pain history outlining:
    - Location, quality, intensity, duration, frequency
    - Associated / aggravating / relieving factors
    - Treatment interventions to date
  - Agree care plan with person and MDT
  - Can symptoms be managed by current team?
  - For intractable or anticipated symptoms consider referral to specialist palliative care team
Domain 2: Social and occupational wellbeing

- Family support
- Emotional and social support
- Practical concerns
Suggested prompts to enable discussion on social and occupational wellbeing

Family support: Family and relationships
- *Who lives with you?*
- *Any children/adult dependents?*
- *Any concerns/worries regarding family or personal relationships*

Emotional and social support
- *Do you have any other support, for example, PHN, Home Help, private carers / friends / neighbours?*
- *How often do you see them?*
- *Do you need more support?*
- *What would help?*

Practical concerns (Discussion about practical issues)
- *How are you managing?*
- *Any difficulties in mobilising? Managing stairs? Household chores e.g. washing, cooking, etc.*
- *Any concerns about future care needs, income, finances, sorting out your affairs?*
Suggested actions to address social and occupational wellbeing

- Establish history of concerns including previous supports/concerns.
- Effect of problem on normal activities/functioning.
- Consider treatment/intervention options.
- Agree implementation plan with the person and MDT.
- Can needs be met by current treating team?
- If sufficiently complex then consider referral to SPC service.
Domain 3: Psychological wellbeing

- Mood and interest
- Adjustment to illness
- Resources and strengths
- Uncontrolled multidimensional pain (total pain)
- Pre-existing mental illness
Domain 3: Suggested prompts

Mood and interest
During the last month have you:
  Been feeling down and/or hopeless?
  Lost enjoyment in interests?
  Are you 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
What is your understanding of your illness?

Resources and strengths
What is a source of support for you?
Look for a range of possible supports: people, hobbies, faith, beliefs.

Total pain
- Uncontrolled multidimensional pain e.g. psychosocial, spiritual pain
- Consider if distress is contributing to physical symptoms.
- Are there psychological, social, spiritual issues that may be contributing to symptoms?
Domain 3: suggested actions

✓ Agree and implement a care plan with the patient and multidisciplinary team.

✓ Establish whether these needs can be managed by the current treating team.

✓ If significant complex family and social concerns are identified or anticipated, consider referral to the Specialist Palliative Care Service.
Domain 4: Spiritual wellbeing

Suggested approach

H  Sources of hope:
   What gives you hope (strength, comfort, peace) in the time of illness?

O  Organised religion:
   Are you part or member of religious or spiritual community? Does it help you?

P  Personal spirituality & practices:
   What aspects of your spiritual beliefs do you find most helpful and meaningful personally?

E  Effect on medical care and end of life issues:
   How do your beliefs affect the kind of care you would like me to provide over the next few days/weeks/months?
Domain 4: Suggested actions

✓ Agree and implement a care plan with the patient and multidisciplinary team. This may include referral to pastoral care service.

✓ Establish whether these needs can be managed by the current treating team.

✓ If significant complex spiritual concerns are identified or anticipated, consider referral to specialist palliative care service.
On completion of assessment

- Can specific needs be met by current treating team?

  Yes
  
  Decide on appropriate actions

  No
  
  Discuss option to refer to SPC service with person and gain consent
  
  Refer to SPC service
For further information on the national clinical programme for palliative care please visit the website on:
www.hse.ie/palliativecareprogramme