









Palliative Care Needs Assessment Guidance

National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Division

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

PALLIATIVE CARE

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Foreword

We all want to ensure that people with life-limiting conditions experience the best possible quality of life. The Palliative Care Needs Assessment Guidance is one way to help healthcare professionals achieve this goal. It serves as a framework that enables staff build up a holistic picture of patient and family needs and strengths. The framework considers all needs and not just those that individual services are interested in, thereby improving communication and integrated working between services. It is also acts a source of valuable information to specialist palliative care services when their involvement is sought. By helping patients and families identify their concerns, teams will be able to develop a care plan that is tailored to an individual patient's needs and that aims to improve outcomes by identifying and managing issues quickly. In this way, real differences can be made at critically important times in patients' lives. I hope that you find this guidance useful and encourage you to incorporate its use in your daily practice.

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Introduction

Palliative care is an approach that improves the quality of life of people and their families facing the problems associated with life-limiting 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. The palliative care approach aims to promote physical psychological, social and spiritual well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

A life-limiting condition means a condition, illness or disease which:

- Is progressive and fatal; and
- The progress of which cannot be reversed by treatment

All health and social care professionals working with people with life-limiting conditions are involved in providing palliative care. This care is given throughout the person's journey up to and including death, the care of the deceased and bereavement support. For many people with life-limiting conditions, palliative care delivered by their usual treating team is sufficient to meet their needs.

Some people have more complex physical, psychological, social or spiritual problems. The severity and/or intractable nature of these complex palliative care problems may exceed the resources of the primary treating team and may require referral to the specialist palliative care service. These services have palliative care as their core speciality and are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine, in partnership with the current treating team.

Eligibility criteria for referral to specialist palliative care services

Patients with both:

- a life-limiting condition and,
- current or anticipated complexities relating to symptom control, end of life care planning or other physical, psychosocial or spiritual care needs that cannot reasonably be met by the current care provider(s).

It is recognised that there are "grey areas" and individual referrals may be discussed with the local specialist palliative care service to discuss their appropriateness. Specialist palliative care teams are always available to advise or support other professionals in their delivery of palliative care.

This document aims to provide guidance to health and social care professionals providing or co-ordinating the current and future care of people with life-limiting conditions. It is intended to aid professionals in assessing the current and future palliative care needs of patients with life-limiting conditions and in deciding when it is appropriate to refer to a specialist palliative care service.

This guidance has been developed as part of the National Clinical Programme for Palliative Care within the Clinical Strategy and Programmes Division and has been informed by national consultation with multidisciplinary stakeholders.

Who, when, where and what?

Who should be assessed?

All people with life-limiting conditions irrespective of age or setting. This guidance focuses on identifying the needs of adult patients. Children and adolescents requiring palliative care have their own unique needs which are outside the remit of this document. Local specialist palliative care teams are always available to discuss individual cases. It is recognised that carers' needs may well have an impact on the level of care required and may prompt referral to specialist palliative care.

When should the assessment take place?

Good clinical practice dictates that assessment should be an ongoing process throughout the course of a patient's illness. We suggest that assessments be carried out at key transition points in the patient pathway, for example

- at diagnosis of a life-limiting condition,
- at episodes of significant progression/exacerbation of disease,
- a significant change in the patient's family/social support,
- a significant change in functional status,
- at patient or family request,
- at end of life.

Where should the assessment take place?

Assessing the palliative care needs for a patient can be carried out in any physical setting that ensures comfort and privacy and could include the patient's home or hospital setting.

Who should undertake the assessment?

The patient's current health and social care team is responsible for ensuring that the assessment takes place. For continuity of care, it is often helpful to have a single team member responsible for assessing an individual's needs. In line with good clinical governance, the patient's physician should be involved in the decision to carry out an assessment. The assessor should be a clinical professional with an appropriate level of knowledge of the disease, its symptoms, treatment and likely prognosis. The assessor should have reached an agreed level of competence in key aspects of the assessment process.

What action follows the assessment?

Where specific need is identified or anticipated, establish whether this can be met by the current health and social care team or whether referral to additional services is required.
Decide on the appropriate action – assessment may trigger the implementation of other care plans.

If the outcome is to refer to the specialist palliative care service this should be discussed with the patient and consent sought for referral and sharing of information

Figure 1 Palliative Care Needs Assessment Algorithm: when should palliative care needs assessment take place?

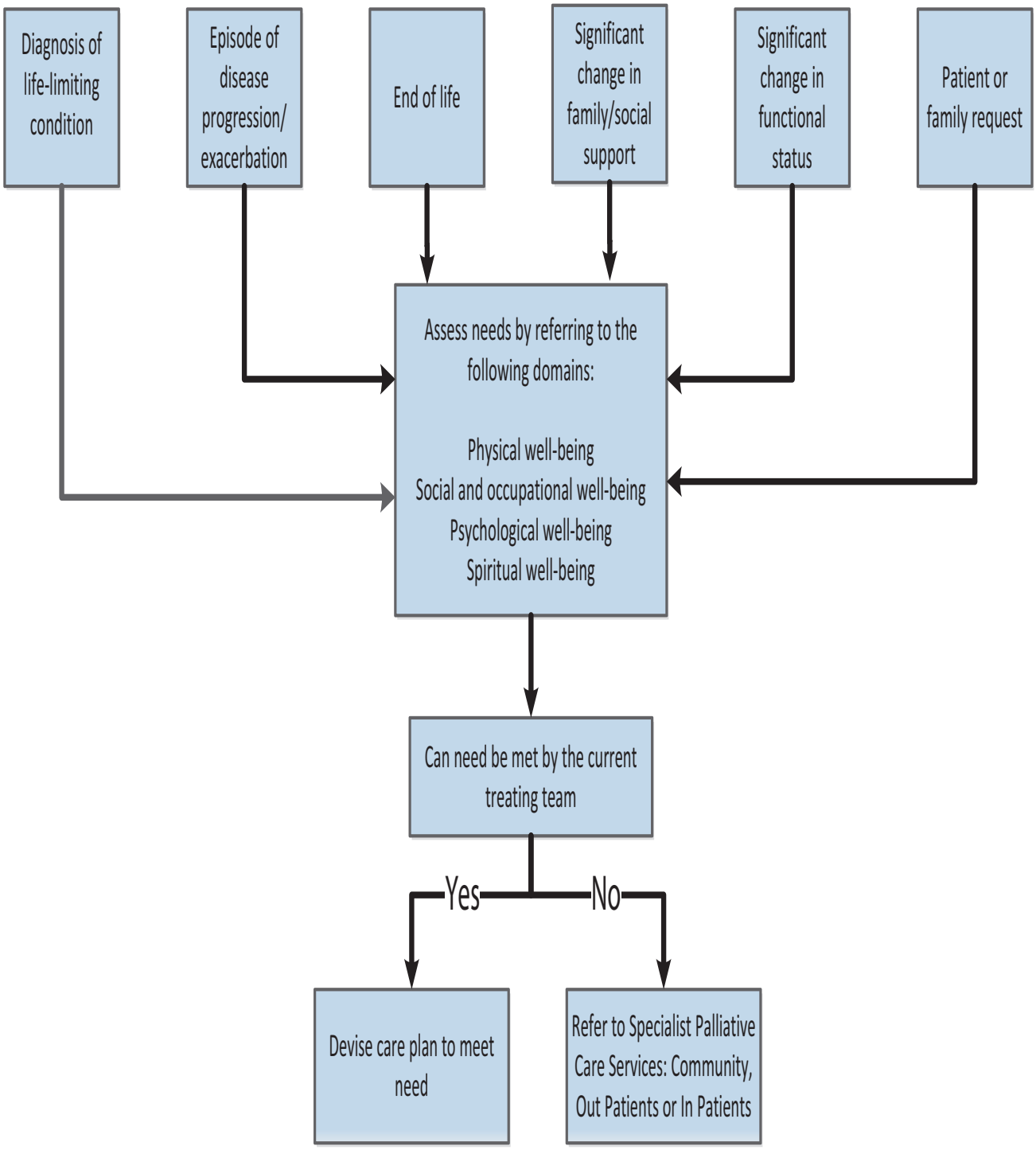

TABLE 1 PROMPTS FOR THE FOUR DOMAINS FOR PALLIATIVE CARE ASSESSMENT

DOMAIN 1 PHYSICAL WELLBEING: SUGGESTED PROMPTS

- **Pain**

Somatic, visceral, neuropathic.

Take a detailed pain history outlining:
- location, quantity, intensity, duration, frequency
- associated/aggravating/relieving factors
- treatment interventions

- **Fatigue**

Fatigue disproportionate for level of activity or not relieved by rest.

- **Respiratory**

Dyspnoea, cough, oropharyngeal secretions.

- **Gastrointestinal**

Anorexia, nausea, vomiting, constipation.

- **CNS**

Insomnia, confusion, delirium, anxiety, depression.

- **Other**

Functional status, balance problems, oedema, wound problems.

DOMAIN 2 SOCIAL & OCCUPATIONAL WELL-BEING: SUGGESTED PROMPTS

- **Family Support**

Invite 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. PHN, home help, private carers, 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 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?
Note the time since diagnosis and see if the person is still in shock, or has had a period of emotional adjustment (sadness and anger).
Sensitively explore the person's expectations/goals.

- **Resources and Strengths**

What is a source of support for you? Look for a range: people, hobbies, faith, beliefs.

- **Total Pain**

Uncontrolled multidimensional pain e.g. psychological, spiritual pain.
Consider whether distress is contributing to physical symptoms.
Are there psychological, emotional, social, spiritual issues that may be contributing to symptoms?

- **Pre-existing Mental Illness**

Persons with a history of current or past mental health problems may be particularly at risk of psychological distress

DOMAIN 4 SPIRITUAL WELL BEING: SUGGESTED PROMPTS

- **Sources of Hope**

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

- **Organised Religion**

Are you part or member of religious or spiritual group? Does it help you? How?

- **Personal Spirituality & Practice**

What aspects of your spiritual beliefs do you find most helpful and meaningful personally?

- **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 1: Physical Well-being

Patients with life limiting conditions frequently have multiple symptoms. Patient self report of symptoms varies from person to person. Some physical symptoms are readily reported by patients while others often require prompting. Some of the frequently encountered physical problems in the last year of life are outlined in table 1.

Table 2 Frequently Encountered Physical Problems in the Last Year of Life

Frequently encountered physical problems in the last year of life	
Pain	**Somatic, visceral, neuropathic** **Take a detailed pain history outlining** • **Location, quality, intensity, duration, frequency** • **Associated/aggravating/relieving factors** • **Treatment interventions to date**
Fatigue	**Fatigue disproportionate to level of activity or not relieved by rest**
Respiratory	**Dyspnoea, cough, oropharyngeal secretions**
Gastrointestinal	**Anorexia, nausea, vomiting, constipation**
Neurological	**Insomnia, confusion, delirium, anxiety, depression**
Other	**Functional status, balance problems, oedema, wound problems**

This is neither a prescriptive nor an exhaustive list- it serves to illustrate the variety of physical problems encountered and need for systematic assessment to identify physical problems

Approach:

- An introductory question to prompt the person to identify the physical needs of most concern to them.
- Thereafter a thorough and careful systems review will determine the presence and severity of physical symptoms.

After identification of symptoms:

- Elicit a history of symptoms including previous treatments received.
- Ascertain the effect of the problem on the patient's normal activities/function.
- Consider treatment options.

Action:

- Agree and implement a care plan with the patient and multidisciplinary team.
- Establish whether these symptoms can be managed by the current treating team.
- If severe or intractable physical problems are identified or anticipated, consider referral to the specialist palliative care service.

Domain 2: Social and Occupational Well-being

The family is the unit of care. When assessing patients with life-limiting illness it is important to explore their concerns in relation to their home, family and community, and to identify risk in relation to their autonomy and social functioning.

Approach:
A social assessment seeks to gain some understanding of an individual's life experience with regard to their:

- Background,
- Family support,
- Emotional and social support,
- Practical concerns.

Table 3 Suggested Prompts; Social and Occupational Well-being Assessment

Suggested Prompts	
Family Support	**Invite discussion about 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 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:** o **Goals of care?** o **Acceptable levels of intervention?** o **Preferred place of care (person and family)?**

After identification of concerns:
Elicit history of concerns including previous supports/interventions received.
Ascertain the effect of the problem on the patient's normal activities/functioning.
Consider treatment options/interventions.

Action:
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 3: Psychological Well-being

Patients with life limiting conditions frequently have psychological concerns. In order to identify these concerns, it is important that the assessor is proactive in asking about emotional and psychological issues.

Approach:
Begin with an open exploratory question that invites the person to identify any concerns. “Is there anything worrying you?”
Followed by consideration of the following:

- Mood and interest
- Adjustment to illness
- Resources and strengths
- Uncontrolled multidimensional pain (total pain)
- Pre-existing mental illness

Table 4 Suggested Prompts; Psychological Well-Being

Suggested Prompts	
Mood and interest	• **How is your mood?** • **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 contributing to physical symptoms** • **Are there psychological, social, emotional, spiritual issues that may be contributing to symptoms?**
Pre-existing mental illness	**Persons with a history of current or past mental health problems may be particularly at risk of psychological distress**

After identification of concerns

- Ascertain the effect of the problem on the patient's normal activities/function.
- Consider treatment options/interventions.

Action:

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 Well-being

People have many different understandings to the word spiritual and how it impacts on their lives. When completing spiritual assessment, assessors need to be aware of alternative terms i.e. faith, belief, philosophy, religion, inner strength.

Approach:

An introductory question/s to alert individuals to a change in focus from clinical is required e.g. How has this illness impacted on your life? The following is a suggested approach to assessment.

Table 5 Suggested Prompts: Spiritual Well-Being Assessment

Suggested Prompts		
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 aspect 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?**

After identification of concerns:

- Elicit history of concerns including previous supports/interventions received.
- Ascertain the effect of the problem on the patient's normal activities/function.
- Consider treatment strategies/interventions.

Action

- 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.

- 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

- Where specific needs or concerns are identified, establish whether these can be met by the current health and social care team or whether referral to additional services is required.
- Decide on the appropriate actions.
- If the outcome is to refer to the specialist palliative care service, this should be discussed with the patient and consent sought for referral and sharing of information.
- Contact details for your local specialist palliative care service can be found at:

http://www.iapc.ie/iapc-directory.php
http://www.icgp.ie/palliative

An educational resource to support assessing palliative care needs will be available on the National Programme for Palliative Care webpage www.hse.ie/palliativecareprogramme

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