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





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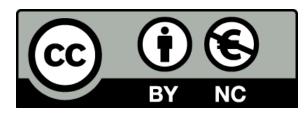
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## Introduction

Palliative care is an approach that improves the quality of life of patients 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 (WHO, 2004). In the last twenty years, the scope of palliative care has broadened to providing palliative care at an earlier stage in the disease trajectory. In 1990 a World Health Organisation expert committee proposed that palliative care should be a gradually increasing component of care from diagnosis to death (WHO, 1990).

It is important to recognise that the provision of palliative care is the responsibility of the whole healthcare system and not just specialist palliative care services. The term 'generalist palliative care providers' refers to all those services, health and social care providers who possess 'palliative care approach' or 'general' palliative skills. Their role is fundamental to the provision of high quality care for people with life limiting illnesses, and the needs of many patients with life-limiting conditions can be appropriately and effectively met with the support of generalist palliative care providers. However, should a patient experience unstable symptoms or problems of high intensity, complexity and/or frequency as a consequence of their illness, then input from specialist palliative care services should be provided.

In order to ensure that patients can transfer seamlessly between care settings or service levels when their condition or circumstances change, the place and relationships of individual service providers within the broader mosaic of palliative care provision must be clearly described. This document builds on the work of the National Advisory Committee Report on Palliative Care (2001) to identify the scope of practice and services provided within three recognised levels of palliative care service provision in the context of current organisation of the healthcare system in Ireland. It provides important planning, resource allocation and accountability functions and describes the links that should exist between palliative care services at all levels in order to ensure that all elements of the healthcare service are working in partnership to meet the needs of the patient and their family.

The aim of this framework is to provide a consistent language and set of descriptors that healthcare providers and planners can use when describing palliative care services and use as a tool when planning service development. It is one of a suite of documents and resources developed by the Programme to support palliative care service providers, e.g. the *Palliative Care Competence Framework*, the *Palliative Care Needs Assessment Guidance* document and education module, the *Specialist Palliative Care Referral Form* and *Eligibility Criteria* and the *Palliative Care Glossary of Terms* all available from the programme website <u>www.hse.ie/palliativecareprogramme</u>. The Programme collaborates closely with the HSE Primary Care Division, service providers and other stakeholders in the development of and in supporting implementation of tools and resources.

# 2. Adopting a needs-based approach to palliative care service provision:

Internationally, best practice models of care advocate a needs-based approach to palliative care service provision. To date, the main criterion identified as shaping palliative care needs and resource utilization is phase of illness (stable, unstable, deteriorating or dying). Other predictors of need include problem severity, level of available carer support, functional status and age (see *http://www.england.nhs.uk/2014/10/23/palliative-care/)*. In the Irish setting, distinct groups of patients with varying levels of palliative care need may be identified as existing within the population of people with life-limiting conditions.<sup>1</sup>

#### 1. Life-limiting illness with low/ intermediate complexity palliative care needs:

A number of individuals with life-limiting conditions will experience a relatively uncomplicated, though potentially distressing trajectory following the point of diagnosis. The characteristics of patients in this category include physical, psychosocial, emotional and spiritual needs that are readily addressed using palliative care approach or generalist palliative care competences.

#### 2. Life-limiting illness with intermittent complex palliative care needs:

An additional cohort of patients will have a more variable course and may experience episodes of increased distress associated with physical, emotional or social consequences of their illness. The characteristics of patients in this category include physical, psychosocial, emotional and spiritual needs that were previously addressed using palliative care approach or generalist palliative care competences but that now require a period of consultation with a specialist palliative care service for management.

#### 3. Life-limiting illness with ongoing complex palliative care needs:

A third subset of people will experience persistent problems of high intensity or complexity. The characteristics of patients in this category include physical, psychosocial, emotional and spiritual needs that require ongoing intervention by a specialist palliative care service.

#### 4. End of life care:

End of life care is the term used to describe care that is provided during the period when death appears to be imminent, and life expectancy appears to be limited to a short number of hours or days. (HSE, 2014) The term has been used to describe the last 12 months of life, however, the clinical programme does not use the term in this way. In many situations where

<sup>&</sup>lt;sup>1</sup> Minimal, mid-range and maximal estimates of potential users of palliative care services (either the generalist and/or) can be estimated from mortality data and hospital admission data (Stevens and Raftery, 1997; Higginson I, 1997). However, there has been relatively little work carried out on quantifying the numbers of people who fall into each of the three categories of palliative care need. Higginson (1997) suggested that as a conservative estimate in the UK, between 15 and 25% of patients who die from cancer require in-patient SPC care and between 25 and 65% of patients require input from community palliative care services. She suggests that patients with non-malignant disease will have 0.5-1 times the needs of patients with cancer. The document 'Palliative Care Service Provision in Australia: A Planning Guide' (2003) provided the following guidance based on best available empirical evidence that specialist palliative care services should demonstrate the following levels of involvement:

<sup>•</sup> The assessment of 90% of patients within the area that die from cancer; an ongoing consultative capacity for approximately 70% of cancer patients; direct care for 20% of cancer patients.

Referral for assessment of 50% of patients expected to die from non- malignant diseases; an ongoing consultative capacity for 30% of these; ongoing direct care for 10% of these.

There is an urgent need for the collection of population-level descriptive data in Ireland on level of palliative care need experienced by patients and their families in order to provide a firm basis for future planning.

people are in the last days and hours of life, staff caring for them will find it helpful to seek support from specialist palliative care teams because although needs may be of low/ intermediate complexity, they are often of high intensity and can change rapidly.

#### 5. Bereavement:

The term bereavement, takes account of the unique individual grief experience of the bereaved person, through the anticipation of death and the subsequent adjustment to living following the death, of someone significant. A variety of bereavement services and support groups may be provided for bereaved adults and children. The type of service provided should be matched to the level of grief reaction experienced by the individual.

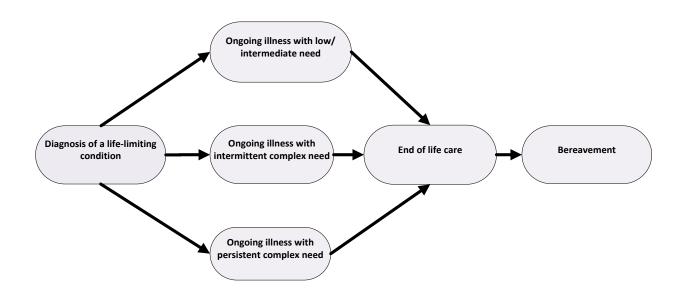
Figure 1 provides diagrammatic illustration of the different populations of people with palliative care needs. It is clear from this representation that palliative care should be available to patients and their families in such a way that ensures that they can easily access a level of palliative care service that meets their need. The Palliative Care Needs Assessment Guidance (2014) provides an overview of best practice in determination of palliative care needs. The Specialist Palliative Care Referral Guidance provides an overview of best practice in referral to specialist palliative care services (2014).

#### Key points:

In the Irish setting, distinct groups of patients with varying levels of palliative care need may be identified as existing within the population of people with life-limiting conditions

Regions must build service networks that are capable of responding to a diverse range of needs, from the relatively uncomplicated to those that require specialist support.

Figure 1. Populations of People with Palliative Care Need



## **3. Level of service provision- capability,**

### resource and responsibilities:

Palliative care services should be structured in three levels of ascending specialisation according to the expertise of the staff ordinarily providing the service (DOHC, 2001):

- Level one (Palliative Care Approach) Palliative care principles should be appropriately applied by all health care professionals.
- Level two (General Palliative Care) At an intermediate level, a proportion of patients 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.
- Level three (Specialist Palliative Care) Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

The Palliative Care Competence Framework (2014) provides additional detail on the competences that staff should possess in order to practice effectively at each of these levels. The document describes core competences are common to all health care professionals and represent the primary level of understanding required to provide the Palliative Care Approach in daily work. The document also describes additional domain indicators that detail discipline specific competences required for professional to provide General Palliative Care Specialist Palliative and Care services. The document may be found at http://www.hse.ie/palliativecareprogramme

The level of service is dependent on the capability of staff ordinarily working within that service, the presence of appropriate levels of resourcing of services and a process of effective collaboration between generalist and specialist palliative care services.

Table 1 provides a description of capability, resourcing and responsibilities of organisations providing palliative care services. It is important that the levels of services are not viewed in a simplistic, one-dimensional manner as both generalist and specialist palliative care services play a part in the effective treatment and care of people with life-limiting conditions and need to be used in collaboration with each other. Quality palliative care provision is best realised when strong networks exist between generalist and specialist palliative care providers- working together to meet the needs of all people. This ensures that complexity of needs does not automatically dictate the setting of care. For example, even patients with complex needs can be cared for in the majority of services providing the organisations have access to in-reach support and expertise from specialist services.

#### Key point:

Quality palliative care provision is best realised when strong networks exist between generalist and specialist palliative care providers - working together to meet the needs of all people. This ensures that complexity of needs does not automatically dictate the setting of care.

Table 1. Levels of palliative care service provision- capability, resourcing and responsibilities of organisations

LEVELS OF PALLIATIVE CARE SERVICE PROVISION					
	Level 1- services using a palliative care approach:				
Capability:	Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with low/ intermediate complexity needs associated with a life-limiting illness and/or end of life care.				
Resource profile: <i>Structure:</i> <i>Staff:</i>	Organisations providing level 1 palliative care services have formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care when necessary. Health and social care workers possess competency in palliative care approach skills.				
<ul> <li>Responsibility: In addition to their non-palliative care responsibilities, level 1 services</li> <li>Undertake a holistic assessment of patients diagnosed with life- at the point of diagnosis and on an on-going basis,</li> <li>Develop a care plan for the individual with a life-limiting condition lead professional who will be responsible for ensuring that the acted on by the team looking after the patient,</li> <li>Communicate the care plan to appropriate members of th members of the primary care team, ambulance and out of hour</li> </ul>					
	<ul> <li>order to ensure co-ordination of care,</li> <li>Implement and undertake best practice referral policy and procedures to specialist palliative care.</li> <li>Following a referral to specialist palliative care services, organisations providing palliative care approach services ordinarily: <ul> <li>Negotiate and agree, as part of the consultation process, arrangements to meet the patient's needs with the specialist palliative care service, patient, carer and family,</li> <li>Review the plan of care with the specialist palliative care service, patient, carer</li> </ul> </li> </ul>				
	and family as required.				
	Level 2- general palliative care services:				
Capability:	Clinical management and care coordination including assessment, triage, and referral using general palliative care skills for patients with intermediate needs associated with a life-limiting illness and/or end of life care.				
Resource profile: <i>Structure:</i>	Organisations providing level 2 palliative care services have formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary. Palliative care support beds may be located in organisations providing level 2				
Staff:	palliative care services. The NACPC Report (2001) directed that palliative care support beds should provide an intermediate level of inpatient care for patients in a local environment. However, palliative care support beds have largely developed in an ad hoc manner in response to local need and circumstance. There is a need to more clearly describe the model of care for palliative care support bed services and this process is currently underway. Health and social care workers possess competency in palliative care approach skills; key staff who frequently care for patients with life-limiting conditions or who provide care for patients admitted to palliative care support beds possess competency in generalist palliative care skills.				
Responsibility:	<ul> <li>In addition to their non-palliative care responsibilities, level 2 services ordinarily:</li> <li>Undertake a holistic assessment of patients diagnosed with life-limiting illness at the point of diagnosis and on an on-going basis,</li> <li>Develop a care plan for the individual with a life-limiting condition and identify a lead professional who will be responsible for ensuring that the care plan is acted on by the team looking after the patient,</li> <li>Communicate the care plan to appropriate members of the team (e.g. members of the primary care team, ambulance and out of hours services) in</li> </ul>				

	LEVELS OF PALLIATIVE CARE SERVICE PROVISION				
	order to ensure co-ordination of care,				
	<ul> <li>Implement and undertake best practice referral policy and procedures to specialist palliative care.</li> </ul>				
	<ul> <li>Following referral to specialist palliative care services, organisations providing palliative care approach services ordinarily:</li> <li>Negotiate and agree arrangements to meet the patient's needs with the specialist palliative care service, patient, carer and family,</li> <li>Review the plan of care with the specialist palliative care service, patient, carer and family as required.</li> </ul>				
<b>A</b>	Level 3- specialist palliative care services:				
Capability:	Clinical management and care coordination including assessment, triage, and referral using specialist palliative care skills for patients with complex needs associated with a life-limiting illness and/or end of life care. Support of generalist palliative care providers through education and training. Leadership in the development of regional palliative care services and programmes of education and research.				
Resource					
profile:					
Structure: Staff:	Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. Each HSE region has undertaken a needs assessment that should guide the development of specialist palliative care services and ensure that services operate at a population level. Specialist palliative care units function as the "hub", around which all components of the specialist service revolve. A comprehensive specialist palliative care service provides in-patient care, Day Care, Community Palliative Care, Out-Patient and Bereavement services. All specialist palliative care services should have an essential minimum core of professionally trained staff with recognised post-qualification specialist training and clinical experience in palliative care services, because of the nature of the needs they are designed to meet, are analogous to tertiary health care services. They require a higher level of professional skills from trained staff and a high staff/patient ratio.				
Responsibility:	<ul> <li>Specialist palliative care services ordinarily:</li> <li>Assess the patient's specialist palliative care needs and take responsibility for co-coordinating the management of those needs,</li> <li>Negotiate and agree the arrangements to meet the patient's needs with the generalist palliative care provider, patient, carer and family,</li> <li>Review the plan of care with the generalist palliative care provider, patient, carer and family as required,</li> <li>Provide out of hours support and advice to the patient, carer, family and generalist palliative care provider,</li> <li>Offer bereavement support,</li> <li>Act as a resource for other health professionals in the area, by providing support and advice when needed,</li> </ul>				
	Provide facilities for research and education in palliative care.				

The success of generalist and specialist partnerships can be critically affected by lack of clarity and agreement regarding roles of the individuals who compose its membership. Table 2 outlines the respective roles of generalist and specialist providers.

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Table 2	Roles o	f generalist	and sr	pecialist	providers
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	Table 2. Roles of generalist and specialist providers			
Generalist provider	The generalist provider when working in partnership with specialist palliative care services ordinarily:			
	<ul> <li>Consults with the specialist palliative care service and provides care to the patient, carer and family as agreed;</li> <li>Negotiates, agrees and formalises the arrangements to meet the patient's needs with the specialist palliative care service, patient, carer and family;</li> <li>Reviews the plan of care with the specialist palliative care service, patient, carer and family as indicated.</li> </ul>			
Specialist provider	<ul> <li>The specialist palliative care provider when working in partnership with generalist palliative care services ordinarily:</li> <li>Reviews requests for referral and conduct assessment of palliative care need, as required</li> <li>Negotiates, agrees and formalise the arrangements to meet the patient's needs with the generalist palliative care service, patient, carer and family;</li> <li>Reviews the plan of care with the generalist palliative care service, patient, carer and family as indicated.</li> </ul>			

### 4. Organisation of palliative care services:

The settings in which palliative care services are provided are as varied as the living circumstances of the patients themselves. Services are delivered where the patient is, which may be in:

- Hospital settings;
- · Organisations where palliative care support beds are located;
- Specialist palliative care units (often referred to as 'hospices');
- The home of the patient or their carer (this includes residential care settings).

Patients with life-limiting conditions must be able to engage easily with the level of expertise most appropriate to their needs regardless of care setting or diagnosis. While the Capability, Resource and Responsibility Matrix (Table 1) provides an overview of the levels of palliative care service provision, the following sections provide guidance on the way that the three levels of palliative care service provision should be organised in hospital and community settings in order to ensure that an appropriate level of support is readily available to patients and their families.

#### Palliative Care within the Hospital Setting:

The Acute Medicine Programme has recommended that hospitals should be organised according to four generic hospital models. Initial commentary on palliative care service provision in hospitals was provided in the Report of the National Acute Medicine Programme (2010) and Table 3 adds further detail to that framework. As a general principle, the hospital consultant acts as the Most Responsible Physician when a person with a life-limiting condition is cared for in the hospital setting. Exceptions may arise when patients are cared for in model 1 hospitals (and the GP acts as the Most Responsible Physician) or where local services are configured to grant the Consultant in Palliative Medicine admission rights to a hospital.

The development of the Hospital Groups affords an opportunity to ensure that a balanced provision of palliative care services is achieved across the hospitals operating as members within a particular group. The creation of new organisations and institutional arrangements is a valuable opportunity to lever change in the development of palliative care services. Review of current generalist and specialist service provision should be undertaken and consideration given to addressing service gaps and integrating services both within the member hospitals and with community partners. Ensuring that a comprehensive model of palliative care service that hospitals meet the quality, prevention and productivity challenges facing them.

ORGANISATION OF PALLIATIVE CARE SERVICES IN THE HOSPITAL SETTING					
Hospital descriptor			desc	riptor	Palliative care services
Model	1	Hospitals	are	community/district	All Model 1 hospital clinical staff have capability to

Table 3. Organisation of Palliative Care Services in the Hospital Setting

Hospital descriptor	Palliative care services
hospitals with sub-acute in-patient beds. Patients who remain under the care of their GP can be admitted to this hospital. Palliative care support beds may be located in Model 1 hospitals.	<ul> <li>provide care for patients with life-limiting conditions and low/ intermediate palliative care needs. Types of care ordinarily provided:</li> <li>Clinical management by GP or consultant-led team including issues that are readily addressed using palliative care approach or generalist palliative care competences</li> <li>Rehabilitation,</li> <li>Respite,</li> <li>End of life care for those who cannot (or do not wish to be) managed in non-hospital settings</li> <li>Bereavement care for individuals with low level of risk for complicated bereavement</li> <li>The hospitals have formal links with an in-reach specialist palliative care as necessary for patients with more complex need.</li> <li>If patients have complex palliative care needs it may be possible to continue to provide care team, however it may prove necessary to transfer the patient to a specialist palliative care team.</li> </ul>
Model 2: hospitals provide in-patient and out- patient care for differentiated, low-risk medical patients and there is an MAU medical assessment unit in existence. An MAU sees GP-referred, differentiated medical patients who have a low risk of requiring full resuscitation. It has assessment beds in a defined area and serves a clinical decision support function. Palliative care support beds may be located in Model 2 hospitals.	<ul> <li>All Model 2 hospital clinical staff have capability to provide care for patients with life-limiting conditions and low/ intermediate palliative care needs. Types of care ordinarily provided:</li> <li>Clinical management by GP or consultant-led team including issues that are readily addressed using palliative care approach or generalist palliative care competencies</li> <li>Rehabilitation,</li> <li>End of life care for those who cannot (or do not wish to be) managed in non-hospital settings</li> <li>Bereavement care for individuals with low level of risk for complicated bereavement</li> <li>Model 2 hospitals may have an on-site specialist palliative care service depending on local configuration of services. If the hospital does not have an on-site team then it should have formal links with an in-reach specialist palliative care service for purposes of referral, consultation and access to specialist care as necessary for patients with more complex need.</li> </ul>
Model 3 Hospital: This hospital admits undifferentiated acute medical patients; has an AMAU (acute medical assessment unit) which will open on a 12 to 24 hour basis every day of	Model 3 and 4 hospitals have an on-site specialist palliative care service. Services should at least comprise a consultant in palliative medicine, a clinical nurse specialist, a social worker and

#### ORGANISATION OF PALLIATIVE CARE SERVICES IN THE HOSPITAL SETTING

Hospital descriptor	Palliative care services
the year (where the AMAU is closed at night medical patients will be managed by the on-call senior medical doctor in the 24 hour ED); ED on site; level 2 ICU Model 4 Hospital: This hospital admits undifferentiated acute medical patients; Level 3 or 3S ICU on site; AMU present which is open on a continuous basis (24 hours, every day of the year); ED, including a CDU on site. Specialist palliative care units may be co- located with Model 3 or 4 hospitals.	<ul> <li>administrator. Depending on local service configuration, the Consultant Physician in Palliative Medicine may:</li> <li>Provide care in consultation with the Most Responsible Physician</li> <li>Act as Most Responsible Physician</li> </ul>

#### Palliative Care in the Community Setting:

Palliative care service provision in the community setting is provided by General Practitioners, Primary Care teams, specialist palliative care teams and staff of residential care services (e.g. designated centres for older people, organisations providing services to people with intellectual disabilities and mental health units). Informal carers, such as family and friends, play a vital role as care partners and the National Carers' Strategy (2012) signals the Government's commitment to recognising and respecting their role. The voluntary sector has traditionally played an important role in both specialist and generalist palliative care service provision, for example, the Irish Cancer Society and the Irish Hospice Foundation provide a night nursing service which is free of charge to the service user.<sup>2</sup> Indeed, the interface between organisations and staff providing palliative care services in the community setting is arguably more complex than that in the hospital setting due to the multiplicity of service providers and local context. The following paragraphs detail community services who have a particularly prominent role to play as palliative care providers. It should be noted that service availability may vary according to local context.

#### 1. General Practitioners:

GPs may provide either level 1 (a palliative care approach) or level 2 (general palliative care) service to patients who are registered with their practice. Types of care provided include:

- Clinical management of issues that are readily addressed using palliative care approach or generalist palliative care competences
- End of life care

#### 2. Primary Care:

Primary Care Community Services/Primary Care teams may provide either level 1 (palliative care approach) or level 2 (general palliative care) services. Types of care provided that are particularly relevant to patients with palliative care needs (dependent on team members) include:

<sup>&</sup>lt;sup>2</sup> In 2014, the Irish Cancer Society provided 9521 nights of service to 2338 patients at a cost of €3 million and the Irish Hospice Foundation provided 1473 nights of service at a cost of € 500,000

- Occupational therapists work with clients who have a physical or sensory disability to achieve their optimum level of independence and quality of life in the context of a life-limiting condition. A variety of areas may be addressed including activities of daily living; recommendations of adaptations to the home environment; prescription of enabling equipment/ appliances; wheelchair/ seating/ pressure care assessments; falls prevention.
- **Physiotherapists** work with clients who have a physical or sensory disability to achieve their optimum level of independence and quality of life in the context of a life-limiting condition. A variety of areas may be addressed including exercise programmes to maximise flexibility, strength and function; falls prevention; manual lymphatic drainage; respiratory care; and pain management.
- **Speech and language therapists** assess, diagnose and treat people with lifelimiting conditions for speech, language, fluency, voice or swallowing difficulties.
- **Dietitians** provide specialised nutritional assessment, education and support to patients and their families on the dietary management of their condition to maximise comfort and quality of life.
- **Social Workers** assess individual and family needs in relation to a variety of social and emotional issues including mental and physical illness, relationship concerns, and can also identify risk associated with loss and preparation for change. They provide advocacy, support in relation to practical, emotional and social need, bereavement support and liaise with professional colleagues in order to support the families of individuals with life-limiting conditions when necessary.

#### 3. Public Health Nursing Service:

**Public Health Nurses and Community RGNs** may provide either level 1 (palliative care approach) or level 2 (general palliative care) services to patients with palliative care needs. Types of care provided that are particularly relevant to patients with palliative care needs include:

- Holistic nursing care which includes physical, emotional, psychological and spiritual care
- Assessment following discharge from hospital and coordination of referrals where necessary to other services i.e. GP, home support, aids and appliances etc.
- Coordination in the delivery of a range of services in the community
- Health education e.g. medication management, nutrition, skin care, hygiene, safety, bowel management, continence.
- Advocacy for patient and family
- Support for carers

#### 3. Health Care Assistants

Healthcare assistants provide level 1 (palliative care approach) services to patients with palliative care needs as part of the Public Health Nursing Service. The care provided by the HCA is identified from the nursing care plan and given under the direction and supervision of

the PHN Service or the Hospice Home Care Service case holder who carries the overall responsibility and accountability for the patient's quality and safety of care. Types of care provided that are particularly relevant to patients with palliative care needs include:

- Assistance in the provision of personal care
- Assistance in activities of daily living

#### 5. Community Intervention Teams:

The service of the community intervention teams (CIT) is provided through the PHN service as a support for patients and carers for a defined period of time until regular, scheduled services can be provided. CIT services may provide either level 1 palliative care (palliative care approach) or level 2 services (general palliative care). Types of care provided that are particularly relevant to patients with palliative care needs include:

- General nursing care
- Family support at initial discharge
- Specific clinical skills that may facilitate an individual remaining at home in their preferred place of care include:
  - Supra-pubic catheterisation
  - Male catheterisation
  - Intravenous antibiotic therapy

#### 6. Home Care Package Services:

Home Care packages provide level 1 palliative care services (palliative care approach). The Home Care Package may consist of a range of services provided directly by the HSE, services provided by voluntary groups/organisations, or a combination of these. The package is tailored to meet the individual's assessed needs and may be put in place for a person with a life-limiting condition and palliative care needs, to support them to remain at home. Types of care provided that are particularly relevant to patients with palliative care needs include:

- Personal care
- Supervision
- Practical assistance

#### 7. Home Help Services:

Home Help services provide level 1 (palliative care approach) services. Types of care are specific to the immediate needs of the client and include:

- Assistance with personal care
- Light household duties
- Assistance with preparing meals and shopping
- Companionship

#### 8. Community Pharmacists:

Community Pharmacies may provide either level 1 (palliative care approach) or level 2 (general palliative care) services. Types of care provided that are particularly relevant to

patients with palliative care needs include:

- Timely access to palliative medicines and information relating to the use of same
- Safe and appropriate procurement and dispensing of medications
- Provision of prescribing advice
- Liaison with other healthcare professionals on issues related to patients pharmaceutical care
- Provision of information / education for patients / carers in relation to medication regimens, especially managing symptoms with PRN medicines, common medication side-effects, adverse effects etc.
- Act as a medicines information resource in the community for other healthcare professionals

#### 9. Respite Services:

Respite services are available in some residential units and voluntary settings. Such organisations may provide either level 1 (palliative care approach) or level 2 (general palliative care) services. Some Palliative Care Units / Hospices also provide respite services and these organisations provide level 3 (specialist palliative care) services.

#### **10. Night Nursing Services:**

The Irish Cancer Society (ICS) Night Nursing Service is a level 2 (general palliative care) service where night nurses provide end of life care to patients and families in their own homes. Types of care provided include:

- Provision of advice, reassurance and pain and symptom management.
- Administration of oral or subcutaneous medication that has been prescribed to ensure patient symptom management and comfort.

#### **11. Citizens Information Centres:**

Citizens Information Centres provide free, impartial and confidential information. Types of care provided that are particularly relevant to patients with palliative care needs includes:

• Provision of integrated information across the full range of state services and entitlements, as well as local services and supports.

#### 12. Bereavement Services:

There are a variety of bereavement services and support groups available for bereaved adults and children. The type of service provided should be matched to the level of grief reaction experienced by the individual.

- Level 1 bereavement services provide general support and information for those individuals who are experiencing uncomplicated grief reactions.
- Level 2 bereavement services provide counselling services for individuals who are experiencing uncomplicated grief reactions and for selected individuals with complicated grief reactions.
- Level 3 bereavement services provide medical or psychotherapeutic interventions for individuals who are experiencing complicated grief reactions.

#### 13. Specialist Palliative Care services:

The specialist palliative care team may provide direct or indirect support to generalist (level 1

and 2) service providers. Types of direct care provided include:

- Community Palliative Care team support (in-reach services to the patient's/ carers home)
- Day Hospice
- Out-Patient Services
- Admission to the Specialist Palliative Care Unit for symptom control, rehabilitation, respite or end- of-life care
- Bereavement support

Types of indirect care include staff support, education, involvement in guideline, policy and protocol development and engagement in community-based palliative care quality improvement projects.

## **5.0 Conclusion**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. A needs-based approach to palliative care service provision is accepted as best practice. Palliative care may be provided in: the home of the person/or their carer, specialist palliative care units, organisations with palliative care support beds and in hospitals. Building strong networks between generalist and specialist palliative care providers is essential to ensure that complexity of care needs does not necessarily prevail over the patient's preferred setting of care.

The Role Delineation Framework for Adult Palliative Care Services is a key document in a suite of resources developed by the National Clinical Programme for Palliative Care (NCPPC) in collaboration with key strategic partners, to address the recommendations contained in the National Advisory Committee Report on Palliative Care (2001). The Framework clearly describes capability, resourcing and responsibilities of organisations providing palliative care and the close partnership and links required between palliative care providers, at all three levels, to meet the palliative care needs of the patient and their family.

The programme will collaborate with strategic partners, (the Department of Health, Primary Care Division and all Divisions in HSE, the All Ireland Institute of Palliative Care, the Irish Association of Palliative Care, the Irish Cancer Society, the Irish Hospice Foundation, other National Clinical Programmes and national bodies), to raise awareness and support implementation of this Framework. The vision for implementation is to:

- support improved planning for palliative care services to *ensure optimal resource utilisation,*
- strengthen specialist palliative care services to improve access and quality of care,
- strengthen generalist palliative care services in order to strengthen access and quality of care
- improve partnerships in care to improve continuity and quality of care.

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