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|  | All District Health Boards  |
| **Specialist palliative care SERVICES -****SPECIALIST MEDICAL AND SURGICAL SERVICES****Tier LEVEL two****Service Specification** |
| **STATUS:**The Recommended status to be reconsidered if suitable to be endorsed as Mandatory by DHB GMs Planning and Funding (proposed to be by 1 July 2016.) | **RECOMMENDED** |
| Review History | Date |
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| Specialist Palliative Care Services Service Specification  | **October 2014**  |
| Correction to Unit of Measure in M80015 | **January 2015** |
| Consideration for next Service Specification Review | within three years |

**Note:** Contact the Service Specification Programme Manager, National Health Board Business Unit, Ministry of Health to discuss proposed amendments to the service specifications and guidance in developing new or updating and revising existing service specifications.

Nationwide Service Framework Library website <http://www.nsfl.health.govt.nz>

**SPECIALIST PALLIATIVE CARE SERVICES-**

**SPECIALIST MEDICAL AND SURGICAL SERVICES**

**TIER LEVEL TWO**

**SERVICE SPECIFICATION**

**M80001, M80007, M80008, M80009, M80010, M80011, MS01001, M00010, M80015**

The Tier One Specialist Medical and Surgical Service Specification service specifications contain generic principles and content common to all the tiers of specifications below it so that the total requirements are explicit. This Tier Two service specification for Specialist Palliative Care Services (the Service) is also used (as appropriate) in conjunction with the following documents:

For service delivery:

* Tier One Services for Children and Young People (as age applicable)
* Tier One Community Health, Transitional and Support Service Specification and its tier two service specifications, such as Specialist Community Nursing Services, Allied Health Services (non-inpatient).

For service models:

* Resource and Capability Framework for Integrated Adult Palliative Care Services (the Resource and Capability Framework) (Ministry of Health 2013)
* Guidance for Integrated Paediatric Palliative Care Services in New Zealand (Ministry of Health 2012).

Refer to Appendix Two, Glossary of Terms for definitions of the terms used within this service specification, including definitions for *specialist palliative care* and *primary palliative care providers.*

# Background

This service specification incorporates development work previously undertaken by the Ministry of Health in conjunction with the sector and aligns with the Resource and Capability Framework that:

* describes the levels of palliative care required in New Zealand and what is needed to support service delivery
* provides guidance to funders, planners and policy makers to inform strategic planning and purchasing of accessible and equitable palliative care services for New Zealanders.

Palliative Care service models across the country recognise geographical barriers and demographics, particularly for small rural areas. These models recognise that shared care approaches will be required in some areas whilst a comprehensive palliative care service can best be delivered in other locations. Refer to Appendix One.

This service specification outlines a minimum service that District Health Boards (DHBs) are expected to purchase for their population. The key components of this Service are outlined in Section 6. Some providers (eg, hospices) contracted by DHBs to provide this Service may provide additional services (eg, non-clinical patient and family support services such as biography writing and day activities). These additional services are usually provided by volunteers and/or funded through community fundraising.

DHBs vary in their funding arrangements of specialist palliative care services due to long standing custom and practice between a DHB and their service provider.

# 1. Service Definition

The Service provides specialist palliative care to Service Users whose assessed needs exceed the capability of the primary palliative care provider. Specialist palliative care may be shared, episodic or continuous and delivered in any appropriate setting.

The Service will be delivered based on the service configuration model outlined in the Resource and Capability Framework for specialist palliative care, however, local arrangements may vary depending on the configuration of the organisations involved and the types of services provided.

The Service should:

* be provided in such a way as to meet the unique needs of individuals from particular communities or groups, including Māori, children and young people, immigrants, refugees, and those living in isolated communities
* be available wherever the individual may be, and
* support primary palliative care providers.

# 2. Service Users

Service Users are:

* Eligible[[1]](#footnote-1) people of any age who have been assessed as to their need for and ability to benefit from specialist palliative care services and meet the Entry Criteria 4.2 below
* families and whānau of Service Users receiving specialist palliative care services and meet the Entry Criteria 4.2 below
* primary palliative care providers and the public or community that receive education, training, support and advice from the Service to competently manage primary palliative care needs.

# 3. Exclusions

The Service does not apply to:

* people eligible for palliative care services funded under the Injury Prevention, Rehabilitation, and Compensation Act 2001 except for diagnosis of Mesothelioma that is included in this Service
* services normally provided by Disability Support Services (DSS)[[2]](#footnote-2)
* Services already funded by DHB under other service specifications (including home help and personal care[[3]](#footnote-3).)
* routine nursing care or supplies provided to residents of a residential care facility, or those residential homes where nursing services are an integral part of the facility
* services usually provided by volunteers[[4]](#footnote-4)
* services for older people that continue to be funded through aged care agreements with input, as required, from specialist palliative care providers for support and advice.

# 3. Service Objectives

## 3.1 General

The Service will:

* optimise a Service User’s quality of life until death by addressing their physical, psychological, social, spiritual and cultural needs
* support a Service User’s family, whānau, and other caregivers where needed, through the illness and after death
* improve quality of care outcomes for Service User’s (and their family and whānau) who are living with a life limiting condition
* improve service integration by working in partnership with primary palliative care providers, who are likely to provide the main ongoing care to Service Users
* ensure equitable access to all the components of the Service for their DHB resident population
* make the best use of existing resources within a region where the required expertise is not available from a single provider.

## 3.2 Māori Health Objectives

The ‘Te Whare Tapa Wha’ (four sided house) model of wellbeing provides a holistic framework for considering palliative care (and other health care) provision. This approach to wellbeing includes Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health), Te Taha Tinana (physical health) and Te Taha Whānau (family health).

The Service will:

* address the specialist palliative care needs of Māori
* be clinically sound, of good quality and culturally appropriate
* be accessible, timely and effective
* ensure equitable quality of care outcomes for Māori
* collect ethnicity data for Māori in accordance with the Ethnicity Data Protocols for the Health and Disability Sector (Ministry of Health 2004)[[5]](#footnote-5)
* have strategies in place to understand and address beliefs and values regarding physical, psychological, spiritual and cultural needs of Māori and their whānau.

# 4 Access

## 4.1 Referral to the Service

Referral to the Service may be made as follows:

* self-referral, as appropriate (family and whānau / carers may self-refer for bereavement, grief and loss, social and/or spiritual support services)
* community organisations / providers
* other hospital services including community hospital services, or
* primary palliative care providers (for example general practice teams, Māori health providers, aged care providers).

## 4.2 Entry Criteria

Eligible people of any age who:

* have an active, progressive and advanced disease, and
* are reasonably expected to die within 12 months (this timeframe may be longer especially for children and young adults, and those with non-malignant disease)
* have assessed needs that exceed the capability of the primary palliative care provider.

A Service User’s family and whānau / carers are assessed by the Service as needing specialist palliative care input for bereavement, grief and loss, social and spiritual support services, as appropriate.

## 4.3 Exit Criteria

Service Users will be discharged from the Service when they are assessed by the specialist palliative care team as:

* no longer meeting the entry criteria, although episodic care will be offered if required, after a re-referral or
* not currently having a specialist palliative care need, or
* no longer needing specialist palliative care input for additional home support or respite care, bereavement, grief and loss, social and spiritual support services for the Service User’s family, and whānau / carers, or
* they self-discharge, or
* they move to another DHB domicile, or
* they die, or
* following a Service User’s death family and whānau / carers may access appropriate Specialist Palliative Care services for a period of up to 6 months, or as agreed with the Service Provider and DHB Funder.

## 4.4 Time

24/7 hour telephone services must be available.

As agreed with the DHB funder, some specialist palliative care services may be provided outside of normal working hours, such as home visits.

# 5. Service Components

The Service includes the following service components.[[6]](#footnote-6)

| **SERVICE COMPONENT** | **DESCRIPTION** |
| --- | --- |
| **Comprehensive assessment** | An assessment / reassessment of the Service User, family and whānau undertaken by the most appropriate members of a specialist interdisciplinary palliative care team. The assessment will include:* identification and assessment of the specialist palliative care needs including physical, psychological, social, cultural, and spiritual aspects of care as appropriate to the Service Users’ circumstances
* development of a plan of care in conjunction with the Service User, primary palliative care provider and appropriate clinical and support service providers.
* other relevant heath assessments and care plans should be considered and integrated as appropriate to reduce duplication.

The Service Provider will:* ensure that the Service User understands the assessment process and the nature of services to be provided and how the information collected about them will be used, and consents to the provision of the Service
* take account of the Service User’s cultural and linguistic diversity and access appropriate support and interpreter services to best meet their needs.
* ensure that the initial assessment follows a planned and documented process.

In addition, refer to section 5 Assessment, Diagnosis and Treatment, Tier One Specialist Medical and Surgical Service Specification. |
| **Clinical care**  | Clinical care includes:* ongoing follow-up care and symptom management for complex and/or unstable medical and/or psychological conditions
* specialist palliative care delivered in the community by specialist community nursing or allied health professionals according to the Service User’s care plan
* social and spiritual support that recognises the culturally sensitive issues relating to these services
* engaging in advance care planning processes initiated by the primary palliative care provider.

In addition, refer to section 5 Assessment, Diagnosis and Treatment, Tier One Specialist Medical and Surgical Service Specification. |
| **Care co-ordination**Care co-ordination, as part of clinical care, is provided to facilitate continuity of care and services to Service Users. Care co-ordination services may include: * a designated care co-ordinator to be the point of contact for the Service User and their family and whānau
* liaison with all services and disciplines relevant to the Service User to enhance service delivery and reduce duplication
* enabling the Service User to receive the necessary range of services, care and support within the timeframes required by their health needs within available resources
* assisting the Service User with their transition between services to enhance their pathway across all settings.
 |
|  | **Bereavement, grief and loss**The following bereavement, grief and loss counselling service components may be funded as agreed with the DHB funder[[7]](#footnote-7):* Counselling services provided by appropriately qualified staff and made available for the Service Users’ family, whānau or carer to meet their assessed Specialist Palliative Care needs.
* Social and spiritual support may also be provided for the Service Users’ family, whānau or carer as agreed with the DHB funder, that recognises their cultural needs and focuses on the holistic:
	+ taha Māori perspective of health
* community approach to health for Pacific Peoples’ cultures.
 |
| **End of life care guidance**Specialist palliative care provides a dedicated end of life care approach, including:* collaborating in developing a systematic approach to end of life care
* implementing specific end of life care guidance
	+ providing leadership, education and support to primary palliative care providers to implement end of life care.
 |
| **Education and training**Specialist palliative care education and training is provided for primary palliative care providers: * to build their capacity and capability to provide palliative care as an integral part of their clinical practice
* enable and empower the development and maintenance of an appropriately skilled primary palliative care workforce
1. to promote and support the provision of collaborative and integrated models of care with primary palliative care providers.

Training programmes:* are provided across a range of settings
* are evidence based
* use national programmes to avoid duplication (where available and appropriate)
* locally consistent
* link with academic institutions as appropriate.

Training should include the following competencies as a minimum:* introduction to palliative care (including integrated models of care as outlined in the Resource and Capability Framework)
* age-appropriate care, for example children and young people, and older people
* pain and symptom management
* ethical decision making in palliative care
* communication
* grief and loss
* spirituality
* end of life care education and support to implement end of life care
* syringe driver use
* specialist palliative care education and training may also be provided to the general public to increase understanding and awareness of palliative care.
 |

## 6.2 Settings

The Service will be provided across the following settings as (see Appendix One for further detail):

1. **community services** generally provided by hospices to people in their own environment (these services may also include day programmes as well as overnight care in an accredited facility)
2. **consultancy services** provided by:
* hospital-based specialist palliative care teams
* hospices to support primary palliative care providers or for services outside the DHB district.

## 6.3 Equipment and supplies

There is variation between DHBs in the funding arrangements of specialist palliative care services due to long standing custom and practice between a DHB and their Service provider.

For community services, the Service will supply or facilitate timely access to the following consumables and equipment for Service Users as determined by the Service User’s management / care plan delivered under this specification:

* intravenous, enteral and parenteral supplies
* subcutaneous pumps and supplies
* lymphoedema bandages and support hosiery
* short-term aids and equipment to support independence in activities of daily living.

The Service will facilitate access to, but not provide:

* **continence products** will continue to be provided by Continence Education and Consumables Services where the Service User is already under the care of this Continence Service before entering the Specialist Palliative Care Service
* **community oxygen therapy and stomal consumables** are the responsibility of the community oxygen therapy or stomal therapy service, even if the need arises during the palliative episode of care
* **long-term aids and equipment to support independence in activities of daily living.** Where the Service User is likely to need aids or equipment for long term use (for example, over 6 months) to maintain their mobility or independence in activities of daily life, they will be referred to Equipment and Modification Services (EMS) service providers.

## 6.4 Support Services

In addition to the Support Services outlined in Tier One Specialist Medical and Surgical Service Specification, the Service will also facilitate access to:

* chemotherapy and/or radiotherapy as needed
* other support services as required (for example transport).

## 6.5 Key Inputs

The Service must:

* be provided by health professionals who have undergone specific training and / or accreditation in palliative care / medicine including an appropriate level of training and / or accreditation to care for children and young people, working in the context of an interdisciplinary team of specialist palliative care health professionals
* be provided through accredited services or organisations, that work exclusively in palliative care and meet specific palliative care standards as they are developed and agreed on nationally
* be provided by people working with an accredited specialist palliative care facility under the supervision of a specialist palliative care provider
* provide pharmaceutical supplies used or consumed during assessment or treatment[[8]](#footnote-8).

Refer to The Resource and Capability Framework for the indicative staffing profile for Specialist Palliative Care.

# 7. Service Linkages

The Service will collaborate with primary palliative care providers to facilitate open communication, continuity of care, timely referral, assessment and treatment, follow-up and discharge processes.[[9]](#footnote-9)

The Service will have links with regional clinical and/or service networks, other hospital specialties (for example, oncology services, pain management interdisciplinary team) and other specialist palliative care providers and regional/national palliative care bodies/organisations.

Where appropriate, the Service Provider will ensure the Service User has access to whānau and Pacific advocacy and support services, and home based support and respite care services as required.

# 8. Quality Requirements

## 8.1 General

The Service Provider must comply with the Provider Quality Standards described in the Operational Policy Framework.[[10]](#footnote-10)

In addition, the Provider will:

1. participate in an evidence based quality improvement programme that is able to measure and report the service performance and progress against quality initiatives
2. have a process for complaints and resolution of disputes that complies with the *Code of Health and Disability Services Consumers’ Rights*
3. report as required on the development and implementation of the quality improvement plan and compliance with standards (including palliative care standards as they are developed and agreed on nationally)
4. undertake regular evidence based outcome monitoring, process review, clinical and process audits and peer review relevant to the Service
5. meet professional standards of practice required by regulatory authorities as per the Health Practitioner Competence Assurance Act (2003) and the Health Social Workers Registration Act (2003), and relevant professional authorities for self-regulated professions.

## 8.2 Acceptability

The Service will be acceptable to Service Users and their families and whānau. This will be supported by Service User participation in on-going evaluation of the Service and by feedback contained in annual Service User surveys that will assess their experience with:

1. the quality and outcome of services they received:
2. the level of information they are given on their treatment programme or support service
3. their level of involvement in the planning and delivery of their care, including their transition into and discharge from the Service
4. how well their cultural and linguistic needs were recognised and met.

The Service Provider should link with nationally coordinated patient experience surveys where possible.

## 8.3 Safety and Efficiency

The Service will ensure that all employees who supply, provide or assist in the provision of this Service are competent, appropriately qualified and, where relevant, currently registered with or licensed by the appropriate statutory and / or professional body.

Services based in a facility should be easily accessible to the Service User and should meet New Zealand Standards 4121: 2001, Design for Access and Mobility – Buildings and Associated Facilities.

The Service Provider will have an incident management and monitoring process.

The Service will have in place strategies, plans and reporting mechanisms to ensure that at all times:

* Service Users are aware of their Health Practitioners current scope of practice as set by the relevant Responsible Authority; and of any changes to their scope of practice
* the relevant Responsible Authority is informed whenever a Health Practitioner employee resigns or is dismissed from their employment or under their contract for reasons relating to competence
* risks are mitigated to ensure a safe care environment for the Service User and the Service Provider’s employees.

# 9. Purchase Units and Reporting Requirements

## 9.1 Purchase Units are defined in the joint DHB and Ministry’s Nationwide Service Framework Purchase Unit Data Dictionary. The following Purchase Units apply to this Service. The DHB hospital based Service Providers must comply with the requirements of national data collections.

| **Purchase Unit Code** | **Purchase Unit Description** | **Purchase Unit Definition** | **Unit of Measure** | **National Collection** |
| --- | --- | --- | --- | --- |
| M80001 | Specialist Palliative Medical Services - Inpatient Services (DRGs) | DRG WIESNZ Discharge. Additional Information is found in the NZ Casemix Framework for Publicly Funded Hospitals which gets updated every year. [[11]](#footnote-11) | Cost Weighted Discharge | National Minimum Data System (NMDS) |
| M80007 | Specialist Palliative Care community inpatient (occupied bed) | Specialist Palliative clinical care delivered by the specialist palliative care team for Service Users who stay overnight in a community facility (eg, hospice, aged residential care). Includes facility costs. | Occupied bed day | Not applicable |
| M80008 | Specialist Palliative Care community inpatient (available bed) | Specialist Palliative clinical care delivered by the specialist palliative care team for Service Users who stay overnight in a community facility (eg, hospice, aged residential care). Includes facility costs. | Available bed day | Not applicable |
| M80015 | Specialist Palliative Care – Day case admission | Clinical care delivered in the hospice by the specialist palliative care team to palliative care clients admitted as a day case, including family/whanau as appropriate. | Day Attendance  | Not applicable |
| M80009 | Specialist Palliative care education & liaison service | Education, training, consultation and liaison services provided by a specialist palliative care team to assist primary palliative care health professionals to identify and respond appropriately to the needs of Service Users. | Service | Not applicable |
| M80010 | Specialist Palliative Care – First attendance | First attendance for Specialist Palliative Care assessment by a medical specialist or medical officer at registrar level or above or Nurse Practitioner. | Attendance | National Non Admitted Patient Collection (NNPAC) |
| M80011 | Specialist Palliative Care – Subsequent attendance  | Subsequent attendance for Specialist Palliative Care assessment by a medical specialist or medical officer at registrar level or above or Nurse Practitioner. | Attendance | NNPAC |
| MS01001 | Nurse Led Outpatient Clinics | Assessment, treatment, or education and/or management outpatient clinics led by a nurse specialist not covered under other education management PUCs. This excludes clinics led by a Nurse Practitioner. Activity should be reported to NNPAC with the health specialty code. | Attendance | NNPAC |
| M00010 | Medical non contact First Specialist Assessment – Any health specialty | A review is undertaken by a Registered Medical Practitioner of Registrar level or above, or a Registered Nurse Practitioner, of patient records and any diagnostic test results from Primary to Secondary or Secondary to Tertiary. GP referral can come from tertiary and secondary referrals. The original referral should only be generated after a face to face contact by the referrer. A written plan of care is developed for the patient and provision of that plan and other necessary advice is sent to the referring clinician and the patient. The non-contact FSA does not include the triaging of referral letters. The patient should not be present during the assessment. | Written plan of care | NNPAC |

| **Unit of Measure Name**  | **Unit of Measure Definition**  |
| --- | --- |
| Attendance | Number of attendances to a clinic/department/acute assessment unit or domiciliary. |
| Available bed day | Total number of inpatient beds that are available to be occupied during the period multiplied by the number of days they are available during that period. To be counted as available the bed must be resourced, and either empty or occupied by a user of this service. |
| Cost Weighted Discharge | A numerical measure representing the relative cost of treating a patient through to discharge. |
| Day Attendance | Number of attendances to a day session lasting 3 hours or more. |
| Occupied bed day | Total number of beds that are occupied each day over a designated period. For reporting purposes, count beds occupied as at 12 midnight of each day. Leave days, when the bed is not occupied at midnight are not counted. Counting formula is discharge date less admission date less leave days |
| Service | Service purchased in a block arrangement uniquely agreed between the parties to the agreement |
| Written Plan of Care | Written plan of care provided by the specialist to the referring GP. |

**Other related Purchase Unit Codes:**

M80012 Specialist Palliative Care - community nursing services are described in the Tier Two Specialist Community Nursing Service Specification.

MS01001 Nurse Led Outpatient Clinics are generally used to count outpatient activity delivered by DHB Hospital specialist nurses.

M80013 Allied Health Specialist Palliative care – community allied health services are described in the tier two Allied Health Services service specification.

M80014 Bereavement counselling for family and whānau (below) is a local code available for DHBs who have agreed to purchase this service in addition to the Specialist Palliative Care services described in this service specification.

Note: COPL005 and COPL006 are available in the PUDD and can be used for purchasing short term primary palliative care beds in a residential facility. If patient requires specialist palliative care the specialist component should be purchased separately.

# 9.2 Annual Reporting Quality Measures

For Non-Governmental Organisations the reporting requirements as detailed below should be forwarded to:

The Performance Reporting Team, Sector Operations

Ministry of Health

Private Bag1942

Dunedin 9054

Email: performance\_reporting@moh.govt.nz.

Details of any additional information collected and frequency of reporting to Sector Operations are as specified by the Funder and documented in the Provider Specific Schedule of the contract.

As a minimum, the Service Provider must report annually to the Funder:

* a summary of the assessed Service User experience
* areas identified for improvement and strategies to address these areas
* demonstration of examples of the Service’s responsiveness to Māori, Pacific, Asian and other ethnic peoples Service Users.

## 9.3 Information Requirements

A core set of minimum information will be collected by the Service Provider according to the *National Specialist Palliative Care Data Definition Standard[[12]](#footnote-12)* as follows. The Funder may request this information to support monitoring of the Service provision, purposes to support national consistency for service development and benchmarking including:

* Service User NHI
* referred by: health professional (name) or self-referral
* date of referral to Service
* date of assessment
* date of the treatment commencement
* number of contacts between the Service Provider and the Service User within the reporting period as requested
* date of discharge / transfer of care from the Service
* place of death (e.g. home, hospital, hospice).

# Appendix One: Models of specialist palliative care delivery

|  |  |
| --- | --- |
| **What** | **How** |
| **1. Community services** | Community specialist palliative care services are provided:* for people in their current environment with specialist palliative needs that cannot be adequately managed by their primary palliative care providers.
* by hospice based specialist palliative care services and/or paediatric specialist palliative care teams.[[13]](#footnote-13)

Community specialist palliative care providers facilitate access to appropriate equipment for Service Users who have been assessed as requiring palliative care support services.Community specialist palliative care may provide activities-based day programmes and overnight care in an accredited facility. |
| **2.** **Consultancy services** | i) **Hospital-based specialist palliative care teams to support primary palliative care providers in hospitals**Hospital based specialist palliative care teams provide liaison services that:* provide support to primary palliative care providers to ensure they can deliver high quality palliative care within the limits of their knowledge and ability
* provide specialist palliative care when the needs of a patient/family exceed the capability of the patient’s principle care team.

Hospital based liaison services also provide advice on symptom management, patient, carer and staff support, technical expertise, and bereavement support. The services also provide advice and information to a patient’s principle care team, conducting patient consultation and assessment, offering short-term interventions, or providing complex ongoing care.ii) **Hospices to support primary palliative care providers or for services outside the DHB district**Hospice based specialist palliative care services provide:* non-contact specialist palliative care advice to support primary palliative care providers. This advice may include supporting the development and implementation of a written care plan.
* assessment for people with specialist palliative care needs who are hospital inpatients (and the hospital does not have an existing hospital-based specialist palliative care team)
* end of life care input to support primary palliative care providers
* support to other DHBs to have access to a full specialist palliative care service (for example, hospices without medical input, or where there is no hospice or hospital-based specialist palliative care team in the DHB of Domicile).

Consultancy services are also provided to individuals who have not been referred to the Service but where a specialist opinion is sought. |

**Appendix Two: Glossary of terms**

**DHB of Domicile**

The DHB of Domicile is the DHB that is responsible for funding services for its resident population.

**End-of-life care**

End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end-of-life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and their family and whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms, and provision of psychological, social, spiritual and practical support and support for the family.

**Family**

Those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets). See also whānau.

**Interdisciplinary team**

A group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve problems that are too complex to be solved by one discipline or many disciplines in sequence.

Membership of the team varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. A specialist palliative care interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, pharmacists, allied health workers and personal care workers. Other disciplines will be part of the team as resources permit.

**Primary palliative care (generalist)**

Care provided by all individuals and organisations that deliver palliative care as a component of their service, but whose substantive work is not the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team.

In the context of end-of-life care, a primary palliative care provider is the main medical, nursing or allied health professional who undertakes ongoing care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. This care is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses and residential care staff, etc. It is provided in hospitals by general ward staff, as well as disease-specific teams (for example, oncology, respiratory, renal and cardiac teams).

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient’s needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

Note: this terminology is in a transitional phase, moving from the term ‘generalist palliative care’ to ‘primary palliative care’. Only the term ‘primary palliative care’ is used in the Framework.

**Specialist palliative care**

Palliative care provided by health professionals who have undergone specific training and/or accreditation in palliative care/medicine including an appropriate level of training and/or accreditation to care for children and young people, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice- or hospital-based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by primary palliative care providers and reflects a higher level of expertise in complex symptom management, psychological, social, cultural and spiritual support, grief and bereavement. Specialist palliative care provision works in two ways.

1. Directly – to provide direct management and support of patients, their families and whānau, where more complex palliative care need exceeds the resources of the primary palliative care provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on changing need. Complex need in this context is defined as a level of need that exceeds the resources of the primary palliative care team. This may be in any of the domains of care – physical, psychological, spiritual, cultural etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the provision of primary palliative care.

**Whānau**

The extended family or family group. In the modern context the term whānau is sometimes used as a familiar term of address to a number of people, including friends who may not have any kinship ties to other members.

1. Not all Service Users who are referred or present to the Service are eligible for publicly funded services. The eligibility criteria for publicly funded health and disability services are prescribed by Ministerial Direction. Refer to http://www.health.govt.nz/new-zealand-health-system/eligibility-publicly-funded-health-and-disability-services for information on the latest eligibility criteria. [↑](#footnote-ref-1)
2. Disability Support Services (DSS) are a range of support services funded by the Ministry of Health, for people with long-term physical, sensory or intellectual disabilities or a combination of these who are generally under the age of 65. Note: specialist palliative care services for those who receive DSS are not excluded- the exclusion refers to *usual* DSS services. [↑](#footnote-ref-2)
3. Where specialist palliative care services are provided by a hospice and the hospice uses home and community services, a formal agreement should be in place to ensure there is no duplication of service and funding. [↑](#footnote-ref-3)
4. For example non-clinical patient and family support service such as biography writing and day activities [↑](#footnote-ref-4)
5. http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector [↑](#footnote-ref-5)
6. The Service User’s general practice team continue to have primary responsibility for the care of the Service User while they are in their usual place of residence and as long as the primary palliative carer can meet the needs of the Service User, their family and whānau/carers. While in a public hospital or a specialist inpatient unit, primary responsibility for the care of the Service User is provided by the specialist physician. [↑](#footnote-ref-6)
7. Note there is regional variation in the DHB funding of bereavement, grief and loss services based on long standing practice. [↑](#footnote-ref-7)
8. Note there is regional variation in the DHB funding of pharmaceuticals in hospices based on long standing practice. [↑](#footnote-ref-8)
9. Refer to the Resource and Capability Framework for guidance http://www.health.govt.nz/publication/resource-and-capability-framework-integrated-adult-palliative-care-services-new-zealand [↑](#footnote-ref-9)
10. The Operational Policy Framework is updated annually and is published on the Nationwide Service Framework Library website: http://www.nsfl.health.govt.nz/apps/nsfl.nsf/menumh/Accountability+Documents [↑](#footnote-ref-10)
11. The NZ Casemix Framework for Publicly Funded Hospitals provides definitions for inclusion of hospital events in casemix funding together with information related to the calculation of cost weights for these events and the assignment of events to purchase units. [↑](#footnote-ref-11)
12. The Service must collect all data relevant to the business of the Service in line with the *National Specialist Palliative Care Data Definition Standard.* This data must be readily available, at Service User/patient activity level, upon request by the DHB or the Ministry of Health [↑](#footnote-ref-12)
13. When these services are not able to be provided by either a local hospice or a DHB hospital-based specialist palliative care team, these services will be delivered as in the agreed care plan by specialist community nursing and/or allied health (non in patient) services under their service specifications. [↑](#footnote-ref-13)