Hospice community specialist palliative care core service components

A document for New Zealand hospice community specialist palliative care services

Te Kahu Pairuri o Aotearoa - Hospice New Zealand

8 November 2023

"*You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only die peacefully, but also to live until you die*" (Dame Cecily Saunders)

Hospice community specialist palliative care core services cover paper – Health system context and next steps

November 2023

Purpose

This cover note provides background as to how these Hospice community specialist palliative care core service components have got to this point and puts them into context with other related work. It then details the next steps and the anticipated outcome from this work.

The purpose of this work, and working with Te Whatu Ora – Health New Zealand, is to establish a consistent and fairly funded suite of hospice community specialist palliative care services provided by hospices that can be reasonably accessed by all New Zealanders. This work is underway in 2023 and will conclude in 2025. Following which this document should be reviewed.

These core service components are what Hospice New Zealand believes every person, and their whānau should expect to be available in their community when they need community specialist palliative care. Some hospices will already be providing the full range of core service components, but for others there are budget and resource constraints, which means some communities do not currently have ready access to all the core service components. We recognise that it will take time and additional resource to achieve national consistency, and that in some communities, delivery of the full suite of core service components may be achieved by collaborative working between hospice and a network of community providers.

Background

These core services are for hospice community specialist palliative care, i.e., what is predominately, but not entirely or only, delivered by hospice services. This document was developed by Hospice New Zealand following a national and international literature review on palliative care services funded or expected to be available in a community setting. The development process was guided by a multidisciplinary clinical working group from New Zealand palliative care services and finalised after hospice feedback.

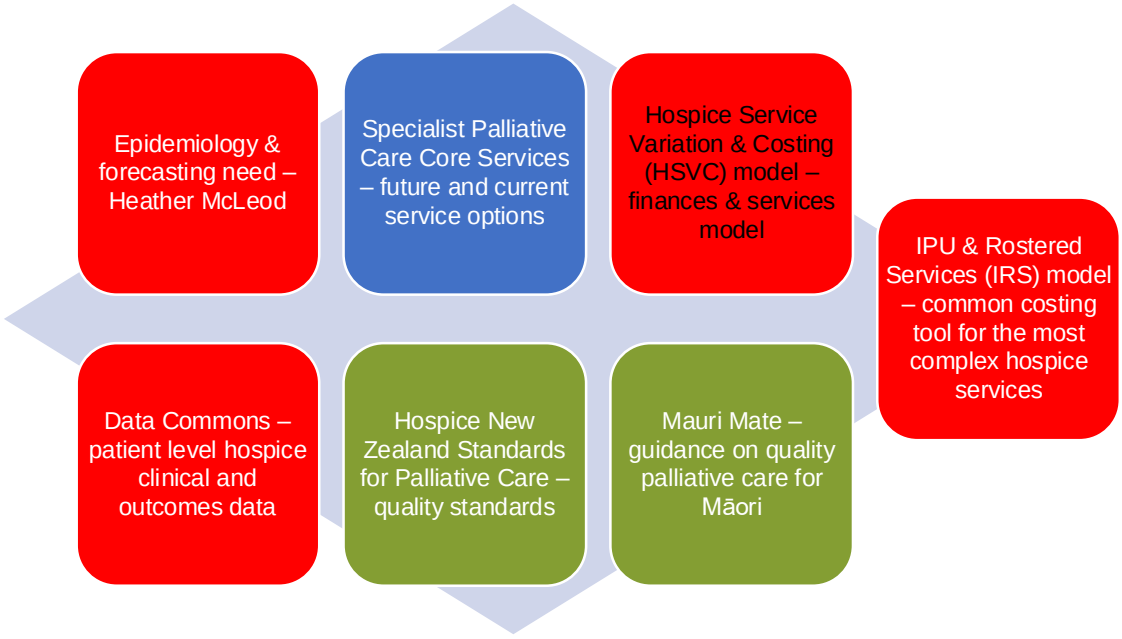
Leadership of the project now rests with the Hospice Equity and Sustainability Pathway Group (ESP). This is a group of Hospice regional representatives, Hospice New Zealand, and Te Rōpū Taki Māori representatives charged with leading the hospice component of the work required to establish a new sustainable service and funding model for hospices. In parallel to the work of the ESP group, Te Whatu Ora have a project to *develop a nationally consistent model for paediatric and adult palliative and end-of-life care that is integrated across primary and community health and strengthens the equitable provision of palliative care across Aotearoa*.[1] These two projects are collaborating.

Context

The Hospice community specialist palliative care core service components sit together with a suite of other work that forms an emerging foundation for a new way of commissioning and funding hospice palliative care services. Establishment of a new funding and commissioning model is a two-year project involving collaboration between hospices and Te Whatu Ora. This project is underway in 2023 and will conclude in 2025.

[1] Te Whatu Ora – Health New Zealand & Te Aka Whai Ora – Māori Health Authority. 2022. Te Pae Tata: Interim New Zealand Health Plan. Wellington, Te Whatu Ora. Available from: https://www.tewhatuora.govt.nz/publications/te-pae-tata-interim-new-zealand-health-plan-2022/.

Figure 1: Emerging foundations for co-commissioning and funding hospice services



Commissioning and funding - working standard or an aspirational statement?

Are these core services a working standard or an aspirational statement? The answer is that they perform both functions.

From the perspective of a patient and whānau, these core services should be considered a working standard. Every patient and whānau should, in some manner, have access to these services. How that happens is about enhanced networks of care. Particularly regional networks, but also localities and possibly some national networks. Commissioners, including hospices as co-commissioners, will need to answer the question, "What is the service network?" That is - what is the stitching together of all palliative care and all its providers and partners across a region and localities to determine what services are delivered by who, including hospices and other providers – that is what are the delivery partnerships that get us to full coverage?

From the perspective of a hospice, the real question is "what part do I play in the service network?" The answer will involve delivering some, probably many, but likely not all of these core services. Because the ***place of these core services as a working standard belongs to the service network, not to a single hospice***.

Having said that, an essential role of hospices as key providers of Hospice community specialist palliative care in the New Zealand health system is to be the informed and watchful co-commissioner of palliative care services and to be ever vigilant that all communities have access to these core services in some acceptable manner. Te Whatu Ora's role is to share that vigilance.

The reality of service provision

Funding availability and relative value always shape service delivery. So, the test of these core service components yet to come are the questions "what of these core services deliver the best value to the patient, community and the health system, as a system?". And "given what is the best value, and given what we can afford, what do hospices and Te Whatu Ora as co-commissioners want to fund?" The answers to these questions are unlikely to be "everything all at once"! The reason everything is not on the menu all at once include funding, but also include factors such as the resources currently available in a region – you can only plan for what you have and the workforce you might reasonably develop, and the geography of a region – that is some services need sufficient critical mass to operate or take time to develop. So, a prioritisation by hospices and Te Whatu Ora has to take place at a regional level. That said, planning at a regional level for how to develop a palliative care network of services that enables access to these core services should start promptly, even if the desired end-state takes time.

Service variation – how are these core services delivered now?

Evidence from the Hospice Service Variation and Costing model (HSVC) shows considerable variation in the range of services delivered between different hospices. Understanding what constitutes unwarranted variation, and reducing unwarranted variation, is a key objective of both the hospice ESP programme and the Te Whatu Ora National Palliative Care Work Programme.

Service intensity

Not only do the range of services vary between hospices, but the resources and front-line staff currently available or applied to deliver each service varies considerably. This is variation in the intensity of each service provided, and it varies a lot. The question of "what is the best mix and amount of resources" to apply to each service is at the heart of the question of "what is an efficient and fair price for a service?" And, "what is a quality service?" Again, answering these questions is an important part of both the hospice ESP programme (particularly the HSVC component) and the Te Whatu Ora national Palliative Care Work Programme.

Hospice Service Variation and Costing (HSVC) model

To give effect to these core services requires that they can be priced and commissioned. To enable pricing and commissioning these core services are linked to the service components of the Hospice Service Variation and Costing (HSVC) model. HSVC reveals where, how and to whom these services are provided by hospices, and at what cost, by analysing staffing and other resources used to deliver each service component. HSVC does this in a manner that enables services to be commissioned and performance monitored. HSVC and related service commissioning is also an important tool for service change and enabling the adaptation of hospice services to meet changing need and community preferences.

Service change

An important part of these Hospice specialist community palliative care core service components is therefore to inform and enable the collaborative Hospice and Te Whatu Ora work to establish a consistent and fairly funded suite of Hospice community specialist palliative care services that can be reasonably accessed by all New Zealanders. This work is underway in 2023 and will conclude early in 2025.

Service improvement and innovation

By defining core Hospice community specialist palliative care service components and developing service descriptions that enable services to be counted, costed, and commissioned, we give visibility to service gaps, create opportunities for change, and enable service improvement. This core service components document is therefore an important component in a suite of tools (see figure one above) to enable our palliative care system to adapt to future needs and for hospices (and other Hospice community specialist palliative care service providers) to thereby secure their continuing relevance.

Service improvements can be advanced by adding new services to these core service components, costing and counting them via HSVC, and funding and monitoring them via responsive co-commissioning. Examples of new services that are not, but in future could be, in either the current core services, commissioning agreements, or the HSVC service components include:

- access agreements for in-reach specialist palliative care between Hospices and Age-related Residential Care (ARC) or community hospitals to extend access to in-patient care (particularly outside main centres)
- rapid response teams to provide out of hours care and reduce admissions to hospital
- funded ambulance transfers / budget holding for dying patients from hospital to (particularly more remote) home / hospice, and
- Iwi developed services for people with a terminal illness where the specialist palliative care in-reach is provided by hospice

- specialist medication review and coordination by palliative care pharmacist at care transition

Next steps

Sharing with Te Whatu Ora

These Hospice community specialist palliative care core service components will now be shared with Te Whatu Ora. The key vehicle for engagement on these core services with Te Whatu Ora is the Te Whatu Ora National Palliative Care Work Programme. The Steering Group for this programme has been established and both Hospice New Zealand and Hospices are represented. The principal vehicle for taking the core services further is the Te Whatu Ora Adult Palliative Care Model of Care Working Group running from January 2024 to June 2024

Hospice New Zealand

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Introduction

These core services are for hospice community specialist palliative care, i.e., what is predominately, but not entirely or only, delivered by hospice services. By hospice community specialist palliative care services, we mean services delivered in the community, this includes hospice in-patient facilities (but excludes hospital services). It could include where hospice community specialist palliative care might be delivered by other providers. We describe how hospice community specialist palliative care should interact and support Primary or Generalist Palliative Care (for example as provided by General Practice or ARC). It is not within the scope of this document to define the core services for Primary or Generalist Palliative Care. However, by defining the connections between Hospice community specialist and Primary or Generalist Palliative Care and the expectations / aspirations of Primary or Generalist Palliative Care we believe this document is an important input into any work to define Primary or Generalist Palliative Care and develop service specifications for that sector. It may likewise be a useful input into any work to define core services and service specifications for Hospital Palliative Care.

These core services describe what people and whānau should expect to receive from Hospice community specialist palliative care services across the country, no matter where they live or how old they are. Death is a universal experience, and good, appropriate palliative care should be too. Each locality and region should have a comprehensive palliative care service network so that all people who are dying and their whānau have timely access to quality palliative care services – both specialist and primary or generalist - that are culturally appropriate and are provided in a co-ordinated way.

These service components support creating nationally consistent, integrated, equitable palliative care services in line with Te Pae Tata Interim New Zealand Health Plan 2022. This document was created by Hospice New Zealand following a national and international literature review about palliative care service delivery. Its development was overseen by a multi-disciplinary clinical working group from New Zealand hospices and finalised after hospice feedback. Further review and feedback was provided by a multidisciplinary and multi-service specialist palliative care group, as well as senior hospice clinical and leadership staff.

These service components are focused on what people should be able to expect to receive from their Hospice community specialist palliative care service network and not what might be currently available. Current Government and Hospice funding does not cover all services in this document, and Crown contracts currently do not require all these services to be delivered. Many regions face workforce shortages and have geographies that create further challenges for delivering all service components. This does not mean that these components should not be delivered, just that they currently are not. This document describes what should be provided in every region to ensure equitable access to palliative care for everyone in New Zealand, across all ages. Further work is required to understand the gaps in service provision and what is needed to fill them.

Palliative care context

The guiding strategy for palliative care services in New Zealand[2] aims to ensure that:

> *All people who are dying and their family/whānau who could benefit from palliative care have timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way.*

This will be achieved when there is a systematic and informed approach to the provision and funding of palliative care services. Furthermore, any approach must identify and understand, and then address inequalities in palliative care.

[2] Manatū Hauora - Ministry of Health, 2001, *The New Zealand Palliative Care Strategy*, https://www.tewhatuora.govt.nz/publications/the-new-zealand-palliative-care-strategy/

Palliative Care is care for people of all ages with a life-limiting illness, which aims to:

- Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
- Support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person may be.

Palliative care should be provided in such a way as to understand and meet the unique needs of individuals and whānau from all parts of our community.

This holistic approach is encapsulated in the philosophy 'Te Whare Tapa Wha' (four-sided house). This model of wellbeing includes the components Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health), Te Taha Tinana (physical health) and Te Taha Whānau (family health).

Palliative care should be provided by all heath care professionals, supported where necessary, by specialist palliative care services.

Generalist (now more commonly known as primary) palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It 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 instance oncology, respiratory, renal and cardiac teams.

Some of the generalist providers, e.g., general practice teams, will have ongoing contact with a family throughout and following illness. Others, such as district nurses or ward nurses will have episodic contact, depending on the needs of the patient and family.

Specialist palliative care is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, 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 licensed 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 generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

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

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

Structure of this document

The service components are split into three sections: general principles, Hospice community specialist palliative care services, and enabling services as shown in Figure 1.

Figure 1 Overview of the core service components



General principles apply across all service components to ensure that patients and whānau have positive experiences of Hospice community specialist palliative care services.

Each service component is framed as what the person or whānau with specialist palliative care needs should expect to receive. This is to keep them at the centre of Hospice community specialist palliative care services. The person should receive the services that they need, and so may not require every component of service available. This document does not indicate the level of service provision required for different conditions or different patient cohorts. Rather, both equity and good service quality require that Hospice community specialist palliative care services understand the needs of individuals and whānau, and tailor services to meet individual needs as fully as resources allow. The outcome should be that patients and whānau experience hospice as “about me and for me”.

Components cover entry and referral to service, any service delivery, and components specific to community or inpatient services. These service components also include the work that Hospice community specialist palliative care services provide to primary / generalist palliative care providers.

The final section is enabling services – and sets out the components related to workforce (including building broader sector capability and capacity), service improvement and quality, and leadership and governance.

Throughout the document, components are linked to the Hospice New Zealand Palliative Care Standards 2019 where applicable.

Service improvement and innovation

By defining core palliative care services and developing service descriptions that enable services to be counted, costed, and commissioned, we give visibility to service gaps, create opportunities for change and enable service improvement. Together with other tools, such as the Hospice Service Variation and Costing model (HSVC) and regional co-commissioning of services this core services document is therefore an important component in the suite of tools that will enable our palliative care system to adapt to future needs and for hospices to thereby secure their continuing relevance. Appendix 2 shows the connection between these core services and the HSVC service components.

Companion documents

These core services should be considered alongside the following documents:

- NZ Palliative Care Strategy
- Hospice New Zealand Palliative Care Standards 2019
- Mauri Mate: A Māori Palliative Care Framework
- Ngā Paerewa Health and Disability Service Standards 2021
- Te Ara Whakapiri: Principles and guidance for the last days of life
- Hospice Service Variation and Costing (HSVC) model - for costing hospice services and revealing service and staffing variation between hospices and communities. See appendix 2 for the HSVC service components that map to this document.

1 General principles

There are principles which inform the service components and how they should be delivered. At the foundation of palliative care, we need to recognise that dying and death are natural life experiences that take place in the context of community, which includes health services.

The following principles should inform all palliative care services:

Patient and whānau centred	The person and their whānau are central to the palliative care system and enabled to work in partnership with service providers.
Needs based	Palliative care is based on the needs and preferences of the person and their whānau. Care is responsive to changing needs over time, from the point of diagnosis to bereavement. These needs may be physical, psychological, cultural, social and/or spiritual.
Upholding Te Tiriti o Waitangi	Hospices of New Zealand acknowledge the unique partnership with Māori as tangata whenua of Aotearoa/New Zealand. Hospice New Zealand acknowledges that hospices have a responsibility to ensure that quality compassionate palliative care is available and delivered to Māori patients/tūroro and whānau, alongside the care delivered to all members of the community. Mauri Mate: A Māori Palliative Care Framework further details these expectations for palliative care services. Palliative care services should provide health services in a way that aligns with their responsibilities under Te Tiriti o Waitangi (Treaty of Waitangi), and staff should understand what Te Tiriti o Waitangi means to their practice. Meeting these responsibilities includes: *Relationships with Māori Communities* • Have enduring and trusting relationships with Māori communities in your regions - this includes mana whenua (local iwi and/or hapū); Māori community groups, Māori health providers and/or Māori social service providers. • To work in partnership with Māori to develop co-design opportunities, to deliver culturally appropriate services and ensure equitable access to those services. *Services* • Deliver whānau-centred services. • Deliver services that embraces, supports, and encourages Te Ao Māori (Māori world views) perspectives and wellbeing. • Support Māori (staff and whānau) develop their aspirations and knowledge of Māori world views – that is, supporting Mana Motuhake – alongside all staff. Understanding of, and ability to bring, the five Te Tiriti principles[3] into conscious practice: tino rangatiratanga, equity, active protection, options, partnership.
Integrated	Palliative care services must be integrated, responsive and locally appropriate. Collaboration between a number of service providers may be necessary to meet the needs of the person and their whānau.

[3] Waitangi Tribunal. 2019. *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*. Wellington. Waitangi Tribunal. pp. 163–164

Accessible	Palliative care services must be accessible wherever the individual may be. The person's preferred setting of care is considered and met wherever possible.
Inclusive	Palliative care services and environment are inclusive of people of all parts of our community.
Responsive	Palliative care must take the time to first understand and then be responsive to the cultural, spiritual, psychological, and social needs, of the person, their whānau and caregivers in their community. This includes specifically enquiring and engaging with Māori patients and whānau about their intentions, preferences or needs in respect to tikanga Māori.
Partnership	Everyone has a role to play in palliative care – this includes the person, their whānau, their community, social services, and other health and disability services. Specialist palliative care service providers will work in partnership with, and support, all of these people and services.
Skilled workforce	Specialist palliative care is provided by appropriately qualified, skilled, and experienced multidisciplinary teams. Where additional skills and experience are required, the specialist palliative care provider will find and engage them.

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2 Hospice community specialist palliative care services

This section describes the components for the different parts of the services provided by Hospice community specialist palliative care providers. They include:

1. Referral criteria
2. Service delivery
3. Community-based specialist palliative care services
4. Inpatient specialist palliative care services.
5. Integration with other services.

Apart from referral criteria, the components are presented as what a person or whānau with palliative care needs can expect to receive from Hospice community specialist palliative care providers and associated service network. Each section concludes with the relevant standards from the Hospice New Zealand Palliative Care Standards 2019.

The service delivery components describe the processes and care people with palliative care needs, and their whānau, should expect to receive across all services, including both community and inpatient settings. Specific components for community and inpatient settings follow the service delivery section. These sections focus on what people under direct care of the specialist palliative care provider should expect from the specialist palliative care service. Expectations for integration with other partner providers, and how Hospice community specialist palliative care Services should support workforce capacity and capability building, service improvement, and leadership, are covered in the later sections.

2.1 Referral criteria to Hospice community specialist palliative care

There should be nationally agreed, evidence-based referral criteria to Hospice community specialist palliative care services that includes timeframes for engagement. The criteria should be accessible to all referrers and the referral process must be auditable. The key referral criteria are listed below and there is further detail in the *Referral Criteria for Adult Specialist Palliative Care Services in Aotearoa New Zealand 2023* (Appendix 3.

Referral criteria to Hospice community specialist palliative care	
2.1.1	The person has a progressive life-limiting/life-threatening illness[4], where the focus of care is on quality of life. • People of Māori and Pacific ethnicity, as well as those who have less equitable health outcomes, should be pro-actively assessed early in the disease trajectory to identify the need for referral to specialist palliative care.
2.1.2	The person has unresolved complex needs that cannot be met by their current health provider team.
2.1.3	The person agrees to the referral if competent to do so (or an advocate agrees on their behalf).
2.1.4	The person has New Zealand residency or has reciprocal rights and is resident within the area covered by the hospice service. Noting that hospices may offer services to non-residents on

[4] WHO. 2020. Palliative Care. Available from URL: https://www.who.int/news-room/fact-sheets/detail/palliative-care

	humanitarian grounds within their own fundraising, however, referral must be discussed with the local Hospice community specialist palliative care service.
2.1.5	The person should be registered with a local primary healthcare provider. If the person is not registered with a local primary healthcare provider, this this element of the referral must be discussed with the local Hospice community specialist palliative care service.

2.2 Service delivery

The following components apply across all Hospice community specialist palliative care services, whether provided in the community or in an inpatient unit.

The person with palliative care needs, and their whānau, should expect…	
2.2.1	That the service they receive will be focused on their needs, expressed wishes, and that whānau will be supported to be involved with their palliative care in line with the person's preferences.
2.2.2	That when their referral is accepted by the local hospice community specialist palliative care service, the service will carry out a comprehensive interdisciplinary/multidisciplinary assessment of the person and their whānau, including children and siblings. This may be done by the specialist service or be a collaboration between the primary team and Hospice community specialist palliative care service. Ongoing assessment will be conducted by team members directly involved in the person's care.
2.2.3	That their local hospice community specialist palliative care service will develop, document, and keep up to date a plan of care that details the support needs, goals and care preferences of the person and their whānau, and the care and services necessary to meet the needs, and goals identified in the comprehensive assessment or throughout follow up care. The plan should align with tikanga Māori for Māori patients and whānau if they desire.
2.2.4	That they and their whānau will have an identified care co-ordinator [or key worker] from their local specialist palliative care service. May be a team rather than an individual.
2.2.5	That their local Hospice community hospice community specialist palliative care service will provide the following clinical care services: • On-going assessment based on need and symptom/problem management based on the person's identified needs and goals, those of their whānau, and the capability of their primary palliative care providers. • Grief and bereavement support for whānau, including children and siblings, provided in a culturally appropriate way and in collaboration with primary bereavement services. • Social, psychological and spiritual care that is culturally appropriate and is aligned with the person and whānau's identified needs. • Support for development and implementation of end-of-life care pathways, plans and guidelines. • Support to carry out Advance Care Planning, either directly or to other providers, such as Primary Care and /or whānau.
2.2.6	That their local hospice community specialist palliative care service will facilitate access to medical supplies, appliances, and medical equipment [within the scope of services provided, e.g., may not include specialist pain delivery devices or specialist mobility equipment]
2.2.7	That they will receive appropriate grief and bereavement support, in the context of the person's or whānau's cultural practices and wishes, during illness and into bereavement by appropriately qualified staff, including: • counsellors/psychologists. • social workers and spiritual carers. • cultural liaison staff

2.2.8	That they will have access to other services either through direct provision or advice and input for services such as: • Dietetics • Speech and Language Therapy • Clinical Pharmacist services • Specialists in interventional pain management • Lymphoedema services
2.2.9	That their local hospice community specialist palliative care service will partner with other services to support access to health and wellbeing services funded through other mechanisms, which may include but are not limited to: • Rongoā Māori and other Kaupapa Māori services • Traditional medicine and therapies embedded in non-Western cultures • Complementary therapies • Creative and expressive therapies
2.2.10	That their local hospice community specialist palliative care service will maintain a relevant clinical record containing past and current health information and findings for them, and their whānau or caregivers receiving support.
2.2.11	That their clinical record will be securely maintained electronically in a way that can be shared with other health and disability service providers when appropriate and with consent of the person.
2.2.12	That their local hospice community specialist palliative care service will develop and provide specific information that describes local palliative care services, and which are designed and tested with Māori patients and whānau.

Relevant Palliative Care Standards

- Paerewa 1: Te arotake hiahia - Standard 1: Assessment of need
- Paerewa 2: Te whakarite mahere manaaki tāngata - Standard 2: Developing the care plan
- Paerewa 3: Te manaaki tāngata - Standard 3: Providing the care
- Paerewa 4: Te tautāwhi whānau me ngā kaitautoko Standard 4: Supporting and caring for the family, whānau and carers
- Paerewa 5: Te whakawhitinga o ngā ratonga - Standard 5: Transitions within and between services
- Paerewa 6: Te tautoko me te manaaki pāpouri - Standard 6: Grief support and bereavement care

2.3 Community-based specialist palliative care services

This section describes the expectations of community-based specialist palliative care services. By community-based, we mean any support that is not delivered in a hospice inpatient unit. These components build on those in 2.2. service delivery.

The person with palliative care needs, and their whānau, should expect …	
2.3.1	That their local hospice community specialist palliative care community service will provide, or coordinate access to, physical, psychological, social, and spiritual care to the person and their whānau in their setting of choice in the community.
2.3.2	That their local specialist palliative care community service will have access to allied health professionals (such as physiotherapy, occupational therapy, and pharmacy/ social work / counselling).

2.3.3	That their local hospice specialist palliative care community service will provide day facilities for patients and carers via different modalities such as in-person, or virtual, that may include: • Outpatient (ambulatory) services • Day case admission for clinical care/procedures • Nurse led outpatient clinics • Day services delivered by psychosocial and spiritual care staff • Day-stay programmes (for individuals or groups)
2.3.4	That their local hospice specialist palliative care community service provides care and / or support wherever the person calls 'home' (private residence, retirement village, age related residential care, supported living, homeless, prison, etc).
2.3.5	That their local hospice specialist palliative care community service will provide access to advice and support 24 hours a day, seven days a week in the community, including responding to acute situations, and should be staffed accordingly, this could be locally or remotely for advice. • 24/7 response may require a collaborative arrangement between a number of service providers and responding to acute situations may be by hospice staff or ambulance; district nurse etc. • Access to assessment, advice and active management may include different forms of contact including face-to-face visits in an appropriate setting for the person, telephone, telehealth (including live video call) and digital media.
2.3.6	That their local hospice community specialist palliative care community service will facilitate access to appropriate equipment and medical consumables to enable a person to stay safely at home. Access to appropriate equipment may require a collaborative arrangement between different service providers.
2.3.7	That in areas where there is no local hospice specialist palliative care service, that a regional/district specialist palliative care service may establish a satellite base from where specialist palliative care staff provide services in the locality. The satellite bases will function as an extension of the regional/district specialist palliative care service and operate as part of the local provider network.

Relevant Palliative Care Standards

- Paerewa 3: Te manaaki tāngata - Standard 3: Providing the care
- Paerewa 4: Te tautāwhi whānau me ngā kaitautoko - Standard 4: Supporting and caring for the family, whānau and carers
- Paerewa 5: Te whakawhitinga o ngā ratonga - Standard 5: Transitions within and between services

2.4 Inpatient specialist palliative care services

These components cover what patients and whānau can expect to receive if they require inpatient care from the Hospice community specialist palliative care service. These components build on 2.2 service delivery components.

The person with palliative care needs, and their whānau, should expect …	
2.4.1	That their local hospice specialist palliative care service will provide, or have access to, dedicated inpatient palliative care beds.
2.4.2	Where there is no dedicated palliative care inpatient facility or beds in their locality, that there will be options for inpatient care in other settings, such as residential aged care or (community) hospital. Where a patient requires an admission to another setting, the local hospice community specialist

	palliative care service will provide either direct care for the person and their whānau or provide support and consultancy to the primary palliative care providers operating the inpatient setting.
2.4.3	That their local hospice community specialist palliative care inpatient service will have an appropriate nurse to patient ratio (based on bed numbers, occupancy, care complexity and staffing resource).
2.4.4	That their local hospice community specialist palliative care inpatient service will have clear criteria for inpatient admission, and that this may include criteria for symptom management (spanning physical, psycho-social, and spiritual needs), acute carer crisis/relief and respite, and care in the last days of life.
2.4.5	That their local inpatient palliative care inpatient service allows people to conduct important cultural and spiritual practices, including offering appropriate spaces, food, and cultural and spiritual support.
2.4.6	That their local hospice community specialist palliative care inpatient service meets all required national/local standards for inpatient health facilities.

Relevant Palliative Care Standards

- Paerewa 3: Te manaaki tāngata - Standard 3: Providing the care
- Paerewa 4: Te tautāwhi whānau me ngā kaitautoko - Standard 4: Supporting and caring for the family, whānau and carers
- Paerewa 5: Te whakawhitinga o ngā ratonga - Standard 5: Transitions within and between services

2.5 Integration with other services

Specialist palliative care providers play an important role in supporting health providers who care for palliative patients who do not require specialist palliative services. This includes advice, support, and relationship development.

This section describes the components of that role and how Hospice community specialist palliative care services can be expected to work with other providers on service delivery.

The person with palliative care needs, and their whānau, should expect …	
2.5.1	That their local hospice specialist palliative care service will work collaboratively with general practice teams and other health and disability, and social support services in the community to meet the person and whānau's needs. This includes: • When the person is under direct care of the specialist palliative care service and continuity of care and timely access to services need to be guaranteed. • When the person is not under direct care of the specialist palliative care service, but other health professionals can access specialist assessment, support, and advice from the specialist palliative care service either through formal and informal networks, partnerships or 'ways of working'. This may include support for Advance Care Planning (ACP) within the district/locality.
2.5.2	That their general practice team is regarded as the main provider of medical care for community-based generalist palliative care and is an integral part of the primary palliative care network along with other health and disability, and social service providers.
2.5.3	That there are formal links established between primary and local hospice community specialist palliative care providers to support collaboration and continuity of care. These links enable information sharing, timely access to advice, support, and training, and ensure appropriate referral pathways are in place.

2.5.4	That their local hospice community specialist palliative care service has links with mana whenua and/or local Kaupapa Māori, Pasifika, and other culturally embedded health and disability and social service providers.
2.5.5	That all primary palliative care providers can access 24-hour, 7 day a week specialist palliative care advice and support through appropriate communications systems, e.g., telephone, telehealth, online resources, and/or an electronic care coordination system (when such systems are available and with appropriate consent).
2.5.6	That their local hospice community specialist palliative care service has formal links with the local or regional hospital and specialist services (for example, oncology, pain and dementia services, mental health services), as well as with regional clinical and/or service networks, including other palliative care providers. And that where there is a hospital and a hospice specialist palliative care service in the same locality/region, there is formal collaboration to ensure referral criteria, clinical guidelines and clinical governance are aligned across both services and the community and secondary care sectors.
2.5.7	Where there is agreement between agencies, a local specialist palliative care service may provide hospital in-reach consultation / liaison services for people with specialist palliative care needs who are hospital inpatients where the hospital does not have a specialist palliative care team.
2.5.8	That, where necessary and appropriate, local specialist palliative care services will develop formal links/agreements with services in other districts/localities to provide access to the full range of Hospice community specialist palliative care services. This may include such services as inpatient hospice care, complex pain intervention, specialist medical assessment and advice, etc.
2.5.9	That their local hospice community specialist palliative care service supports the implementation and use of a single, evidence-based end-of-life care pathway across all health and disability services that provide palliative care within the district/locality (e.g., Te Ara Whakapiri[5]).
2.5.10	That where the person with palliative care needs requests assisted dying, their local hospice community specialist palliative care service has, as a minimum, a process in place to support patient choice and allow staff to meet their legal obligations under the End-of-Life Choice Act 2019.
2.5.11	That their information will be shared between necessary providers with informed consent, and that information systems are able to support this sharing and communication effectively and securely.

Relevant Palliative Care Standards

- Paerewa 5: Te whakawhitinga o ngā ratonga - Standard 5: Transitions within and between services
- Paerewa 8: Te whakapakari kounga me te rangahau - Standard 8: Quality improvement and research

[5] Ministry of Health. 2017. *Te Ara Whakapiri Toolkit*. Wellington: Ministry of Health.

3 Enabling services

These are the services which support direct patient care.

3.1 Workforce

This section describes the core service components around the requirements for a specialist palliative care workforce, and how a specialist palliative care service can support the broader health workforce.

Within the specialist palliative care service

The person with palliative care needs, and their whānau, should expect …	
3.1.1	That their local hospice specialist palliative care service will employ a multi-disciplinary team of health professionals who are appropriately trained in palliative care
3.1.2	That their local hospice specialist palliative care community service will provide, or facilitate access to, trained caregivers [health care assistant, care assistant] to provide support in the home.
3.1.3	That their local hospice specialist palliative care service will promote the employment of qualified health professionals who identify as Māori and Pacific People, and there are strategies in place to support the recruitment, training, retention, and succession planning for this workforce.
3.1.4	That they will receive culturally appropriate care with local hospice community specialist palliative care staff having undergone training for cultural safety and Te Tiriti o Waitangi. This includes paid and unpaid staff, contractors, and volunteers.
3.1.5	Their local hospice community specialist palliative care service continues to provide training opportunities for medical, nursing, and allied health students to create a workforce pipeline.

Relevant Palliative Care Standards

- Paerewa 7: Te ahurea o te tari - Standard 7: Culture of the organisation
- Paerewa 8: Te whakapakari kounga me te rangahau - Standard 8: Quality improvement and research
- Paerewa 9: Ngā tohu me ngā mahi whakangungu a ngā kaimahi - Standard 9: Staff qualifications and training

Specialist palliative care provides training and capability development (health sector capability in palliative care)

The person with palliative care needs, and their whānau, should expect …	
3.1.6	That the wider health and social service workforce can access education, training and continuing professional development in palliative care provided by their local or regional specialist palliative care service. This education and training should support culturally safe care.
3.1.7	That their local hospice specialist palliative care service has appropriate resource (capacity and capability) to work in partnership with primary palliative care providers, hospital and

	specialist services, and community groups, to determine their priorities and provide education, training and continuing professional development accordingly.
3.1.8	That their local hospice community specialist palliative care service has formal links with local tertiary education providers or relevant academic departments and participates in undergraduate and postgraduate teaching across the disciplines of medicine, nursing, paramedicine, pharmacy, and allied health.
3.1.9	That their local hospice specialist palliative care service is resourced to provide specialist training programmes for registrars or general practitioners with special interest in palliative care [not all services will have this]. The service may also be resourced to provide training programmes for other health practitioners, such as Nurse Practitioners, nursing, social work and counselling students, psychology trainees.
3.1.10	That education and training provided by their local hospice community specialist palliative care service, is accredited where appropriate and meets appropriate standards and has measurable outcomes that can evidence the impact of programmes.
3.1.11	That their local hospice community specialist palliative care service contributes to, and encourages, public awareness and understanding of palliative care through a range of equitable approaches that are accessible to people of different cultures and may include: • Education programmes • Resources (in a range of media types and languages) • Training in practical support (informal carers in particular) • Compassionate community initiatives

Relevant Palliative Care Standards

- Paerewa 8: Te whakapakari kounga me te rangahau - Standard 8: Quality improvement and research
- Paerewa 9: Ngā tohu me ngā mahi whakangungu a ngā kaimahi - Standard 9: Staff qualifications and training

3.2 Service improvement and quality

This section describes the expectations of the quality of services and improvement programmes for hospice community specialist palliative care services. Each hospice community specialist palliative care service is expected to have a continual focus on quality improvement.

The person with palliative care needs, and their whānau, should expect …	
3.2.1	That their local hospice community specialist palliative care service meets relevant palliative care and general health and disability standards.
3.2.2	That their local hospice community specialist palliative care service participates in benchmarking, audit and has a continuous quality improvement programme.
3.2.3	That their local hospice community specialist palliative care service understands the needs in their community through available data and engagement.
3.2.4	That their local hospice community specialist palliative care service has a process of evaluating service user experiences of information, and access to and provision of services. The process should ensure feedback is sought from specific population groups, including Māori and Pacific people, and alternative methods of consumer engagement should be available to meet the needs of these groups.
3.2.5	That their local hospice community specialist palliative care service identifies and implements a cultural audit tool to assess the service to identify gaps, opportunities for service change, and training needed to improve the service.
3.2.6	That their local hospice community specialist palliative care service has a process for implementing, monitoring, and reporting on Patient Related Outcome Measures and an ability to benchmark performance to ensure best quality of care for patients, carers, and whānau.
3.2.7	That their local hospice community specialist palliative care service has a process of patient and service level data collection and sharing to ensure service improvement at local and national level.
3.2.8	That their local hospice community specialist palliative care service participates in research in line with the service's objectives and capability.
3.2.9	That their local hospice community specialist palliative care service has a process for complaints and resolution of disputes that complies with the Code of Health and Disability Services Consumers' Rights.
3.2.10	That their local hospice community specialist palliative care service has established and maintains an emergency preparedness program.
3.2.11	That their local hospice community specialist palliative care service maintains and documents an effective infection prevention and control program.

Relevant Palliative Care Standards

- Paerewa 8: Te whakapakari kounga me te rangahau - Standard 8: Quality improvement and research

3.3 Leadership and governance

This section describes the components of leadership and governance that people and whānau can expect of their Hospice community specialist palliative care service. These include how decisions are made and appropriate representation.

The person with palliative care needs, and their whānau, should expect …	
3.3.1	That their local hospice community specialist palliative care service has a governing body (or designated persons so functioning) that assumes full legal authority and responsibility for the oversight of the specialist palliative care service, the provision of all services, its fiscal operations, and continuous quality assessment and performance improvement.
3.3.2	That their local hospice community specialist palliative care service has Māori representation on the governing body.
3.3.3	That their local hospice community specialist palliative care service has a formal structure for clinical governance.
3.3.4	That their local hospice community specialist palliative care service has Māori and specialist palliative care clinical leadership at strategic level (e.g., Senior Management Team level within organisations).
3.3.5	That their local hospice community specialist palliative care service will organise, manage, and administer its resources to provide specialist palliative care services to patients, caregivers and whānau.
3.3.6	That their local hospice community specialist palliative care service has systems and processes in place that encourage and allow primary palliative care providers, hospital and specialist services, patients, whānau and community contribution to the development and evolution of palliative care services within their locality/region.
3.3.7	That their local hospice community specialist palliative care service has appropriate health and safety policies and risk management processes in place.
3.3.8	That their local hospice community specialist palliative care service has appropriate data and digital systems in place that support service delivery and meet interoperability and security recommendations.

Relevant Palliative Care Standards

- Paerewa 7: Te ahurea o te tari - Standard 7: Culture of the organisation

Appendix 1: Links with the Palliative Care Standards and Health and Disability Service Standards

CSC		PC Standard 2019	HDSS 2021
1 General principles	1 General principles	Te whakamahi paerewa ki ngā iwi katoa – Applying the standards to all populations	1
2 Service Delivery	2.1 Referral criteria		
	2.2 Service delivery	1,2,3,4,5,6	2.3. 3.1, 3.2, 3.6
	2.3 Community palliative care services	3,4,5	3.1, 3.2, 3.6
	2.4 Inpatient community palliative care services	3,4,5	3.1, 3.2, 3.6
	2.5 Integration with other providers		1.1, 2.5,3.2
3 Supporting service	3.1 Workforce	7,8,9	1.4, 2.1, 2.2, 2.3, 2.4, 4.1
	3.2 Service improvements	8	2.1, 2.2, 2.3
	3.3 Leadership and governance	7	2.3, 2.4

Appendix 2: Hospice community specialist palliative care service components - Hospice Service Variation and Costing (HSVC) model

These Hospice community specialist palliative care service components translate these core services into individual components that are used by the Hospice Service Variation and Costing (HSVC) model.

The purpose of these service component descriptions is to succinctly describe the full range of possible services elements a hospice can offer in a manner that that enables FTE to be allocated to the service and for the service to then be costed using the HSVC model.

Community Services – service descriptions

No.	HSVC Service component	Core Services Reference
1.	Specialist palliative care co-ordination (including initial triage) – this is when for example District Nurses provide the bulk of the hands-on care	2.2.2
2.	Community based specialist palliative care nursing service – hands on care provided by Hospice Nurses (this is when for example District Nurses or others are partners or secondary providers)	2.2.5 2.3.1
3.	Community based specialist psycho-social service	2.2.5 2.2.7 2.3.1
4.	Bereavement service in the community	2.2.5 2.2.7 2.3.1
5.	Spiritual care in the community	2.2.5 2.2.7 2.3.1
6.	Community based specialist allied health e.g., physio, OT	2.2.8 2.2.9 2.3.1 2.3.2
7.	Nurse or Allied Health out-patient clinics for patients with specialist palliative care needs	2.3.1 2.3.3
8.	Day unit activity/services to meet social connection and creativity for patients with specialist palliative care needs	2.2.5 2.2.7 2.3.1
9.	After hours (extended hours /overnight/weekends) nursing advice service for patients in service (provided by community staff, e.g., community nurses)	2.3.5
10.	Specialist children's teams community service – non-medical clinical staff with training in working with children and a service designed to meet the specific needs of children	Not core
11.	In-home care (hospice at home) – extended hours (evenings and/or weekends) call-out service for patients admitted to service	2.3.5
12.	Full time care in the last 72 hours of life	2.3.5
13.	Culturally specific psycho-social and spiritual care for Māori, Pacific and other communities. Including cultural liaison in the community	2.2.5 2.2.7

No.	HSVC Service component	Core Services Reference
		2.2.9 2.2.12
14.	Advanced nurse training - training of Nurse Practitioners, Nurse Prescribers, Physician Assistants, in a community setting - NOTE this is the training component - not the service delivery component	3.1.7
15.	Care giver support service / education programmes	2.3.3
16.	Medication management by a clinical pharmacist in a community setting	2.2.8 3.1.5

Inpatient Unit Services – service descriptions

No.	HSVC Service component	Core Services Reference
17.	Resourced adult in-patient beds	2.4.1
18.	Resourced paediatric in-patient beds	2.4.1
19.	Aged care, other Hospice or rural hospital contracted beds	2.4.1
20.	IPU based specialist palliative care nursing service	2.4.1 2.4.2
21.	IPU based specialist psycho-social service	2.2.5 2.2.8 2.3.1
22.	IPU based specialist allied health e.g., physio, OT	2.2.5 2.2.8
23.	Spiritual care in an inpatient setting	2.2.5 2.2.7 2.3.1
24.	Culturally specific psycho-social and spiritual care for Māori, Pacific and other communities. Including cultural liaison in an inpatient setting	2.2.5 2.2.7 2.3.1 2.4.4
25.	Advanced nurse training - training of Nurse Practitioners, Nurse Prescribers, Physician Assistants, in an in-patient setting. NOTE this is the training component - not the service delivery component	3.1.7
26.	Afterhours telephone advice and support – for patients / families and providers (e.g., ARC) who phone into the IPU	2.3.5
27.	Medication management by a clinical pharmacist in an in-patient setting	2.2.8
28.	Specialist children's teams in-patient service - non-medical clinical staff with training in working with children and a service designed to meet the specific needs of children	Not core

Partnership Services – service descriptions

No.	HSVC Service component	Core Services Reference
29.	Nurse led General practice partnership support in-person (e.g., MDT meetings) and telephone support to Primary Care staff (not direct patient care)	2.5.1 2.5.3
30.	Hospice Clinical FTE Support to Palliative care planning PPA /POI/ PCP payments to GP and/or ARC	2.5.2 2.5.3 3.1.10 3.1.14
31.	ARC partnership care - in-person and telephone support to ARC staff (not direct patient care)	2.5.5
32.	External education for General Practice and / or ARC, District Nursing and general Health sector	3.1.8
33.	Compassionate Communities and External partnerships with non-clinical organisations e.g., communities, events, groups, members of the public	3.1.12
34.	Link nurse training and support for ARC and / or GP practice nurses and District Nursing	3.1.8 3.1.9 3.1.14

Doctors – service components provided by Doctors and Nurse Practitioners

No.	HSVC Service component	Core Services Reference
35.	Community based specialist palliative medical care - Doctors and NPs	3.1.1 3.1.7
36.	IPU specialist palliative medical care - Doctors and NPs (employed, DHB provided, visiting PalCare specialists, GP in-reach)	3.1.1 3.1.5
37.	After hours (overnight / weekends) on-call Doctors service for patients admitted to service	3.1.1
38.	Doctor or NP led out-patient clinics for patients with specialist palliative care needs	2.3.1 2.3.3
39.	Hospice provision of palliative care Doctors to Te Whatu Ora services and/or other providers	3.1.1
40.	Community Medical training - training of Registrars, GPs, Medical Students in a community setting - NOTE this is the training component - not the service delivery component	3.1.7
41.	Inpatient Medical training - training of Registrars, GPs, Medical Students in an in-patient setting - NOTE this is the training component - not the service delivery component	3.1.7
42.	Medical support - clinical advice / medical education to General Practitioners, hospital Doctors, medical trainees or other health professionals - by Doctors or NP	2.5.1 2.5.2 2.5.3 2.5.5 3.1.7
43.	Specialist paediatric palliative care qualified Doctors in a community setting	Not core
44.	Specialist paediatric palliative care qualified Doctors in an in-patient setting	Note core

Appendix 3: Referral Criteria for Adult Palliative Care Services in Aotearoa New Zealand

This is an update to the 2014 Referral Criteria for Adult Palliative Care Services in New Zealand released by the Palliative Care Council of New Zealand. Review was provided by a hospice clinical advisory group, and representatives from Australia and New Zealand Society of Palliative Medicine and Hospital Palliative Care NZ.

Both nationally and internationally, it is recommended that there are agreed specialist palliative care referral criteria that are understood by all potential referrers (Ministry of Health, 2012; ACSQHC, 2015; NHS England, 2016). There should also be a clear referral process that has timeframes and is auditable.

This document outlines the criteria and additional resources that should be used to support decision making about a referral to specialist palliative care services.

If there is any doubt about appropriateness of a referral, the Referrer should contact the specialist palliative care service to discuss further. It will be at the discretion of the Service as to whether patients who do not meet all the criteria will be accepted.

Referral criteria

1. *The person has a progressive life-limiting/life-threatening condition.*

Patients likely to benefit from Specialist Palliative Care are those with active, progressive, advanced disease, or who have experienced a sudden or traumatic event in the absence of a pre-existing palliative condition (such as an intracranial haemorrhage or out of hospital cardiac arrest), and for whom prognosis is limited and the focus of care is quality of life.

Prognostic uncertainty (such as exists when embarking on a trial of chemotherapy for an aggressive malignancy where the likelihood of response is low) should not necessarily be a barrier to referral. If the person is experiencing general indicators of poor or deteriorating health (as described in the Supportive & Palliative Care Indicators Tool (SPICT) in Appendix 4) they should be assessed for unmet supportive and palliative care need and referred as appropriate to a local specialist palliative care service (hospice or Hospital Palliative Care). The SPICT also provides specific guidance for different life-limiting conditions that may assist with a decision to refer for specialist palliative hospice care.

2. *The person has unresolved needs that cannot be met by the capability of their current care team.*

Palliative care services should “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.” (Ministry of Health, 2012). Referrals to specialist palliative care are appropriate when the palliative care needs exceed the capability of the wider primary caring team. Examples of complex palliative care needs may include:

- uncontrolled or complicated symptoms
- specialised nursing requirements relating to mobility, functioning or self-care
- emotional or behavioural difficulties related to their condition, such as uncontrolled anxiety or depression
- cultural and/or spiritual distress related to, or exacerbated by, palliative care need
- concern or distress involving children, family or carers, physical and human environment (including home or hospital), finance, communication or learning disability
- unresolved issues around self-worth, loss of meaning and hope, suicidal behaviours, requests for assisted dying and complex decisions over the type of care, including its withholding or withdrawal.

In some areas, specialist palliative care services are limited and so it is important to consider referral to other appropriate health and social service agencies to meet social, psychological,

cultural, and spiritual needs, in particular when the person with the life-limiting condition is stable and their needs are not the main reason for the referral.

3. *The person agrees to the referral if competent to do so (or an advocate agrees on their behalf).*

4. *The person has New Zealand residency or has reciprocal rights and is resident within the area covered by the hospice service.*
   If the patient is not a New Zealand resident the referral must be discussed with the specialist palliative care service and approval gained from the appropriate person prior to the referral being made to ensure funding is authorised.

5. *The person is registered with a local primary healthcare provider.*
   If the person is not registered with a local primary healthcare provider, the referral must be discussed with the Hospice community specialist palliative care Service Hospital inpatients without a GP must have this addressed prior to discharge if a Hospice or community primary palliative care referral is made.

Notes

- ***Criteria 4 and 5 above are not a requirement for referral to a Hospital Palliative Care Service***.

- Patients who meet the above criteria should be referred for specialist palliative care assessment; performed by a specialist palliative care Interdisciplinary Team. The subsequent level of involvement/intervention, treatment plan and care package will be negotiated with the patient, carer and referring team. This may include:
  - specialist assessment and advice with care continuing under the referrer or other primary palliative care provider service (GP, ARC, Māori Health provider, etc).
  - a short period of specialist care followed by referral back to the referrer or other primary palliative care provider.
  - episodic care from specialist palliative care service, provided in partnership with the referring service.
  - ongoing care from specialist palliative care service in collaboration with the referring service.

- If the patient is in an acute hospital with no Hospital Palliative Care Service, contact the local Hospice community specialist palliative care service/hospice to assess their capacity/capability to give advice and support should that be required.

Referral Guidance

The clinical indicators described in the SPICT (Appendix 4 may be assessed when deciding if a referral is appropriate or not. A good starting point is to assess the person for general indicators of poor or deteriorating health, as listed in the first section of the SPICT (note that the SPICT tool does not differentiate between those with primary palliative care needs and those with complex needs who may require specialist palliative care).

For further guidance on referral criteria for specific diseases and conditions, the SPICT contains clinical indicators that may be used to help determine if a referral is appropriate for people with different life-limiting conditions.

Most referrals to specialist palliative care services will have an expected prognosis of less than 12 months. However, not uncommonly it will either be impossible to determine prognosis with any certainty or the clinical need will be sufficient to warrant referral in the context of a life-limiting condition with a more chronic course. When in doubt, contact the specialist palliative care service directly.

People of Māori and Pacific ethnicity, as well as those who have less equitable health outcomes, should be pro-actively assessed early in the disease trajectory to identify the need for referral to specialist palliative care. This is because these population groups are often referred late in the course of their illness and may therefore present with a high symptom burden and significant patient and caregiver distress.

Less appropriate referrals

Specialist Palliative Care is largely inappropriate for:

- Patients with chronic stable disease or disability with a life expectancy of several years.
- Patients with chronic pain problems not associated with progressive terminal disease.
- Competent patients who decline referral
- Patients who are unaware of their underlying disease (unless this is a cultural preference in which case this needs to be sensitively addressed).
- Those patients whose problems are principally psychiatric and need specialist psychiatric referral, whether or not they have declined such help.

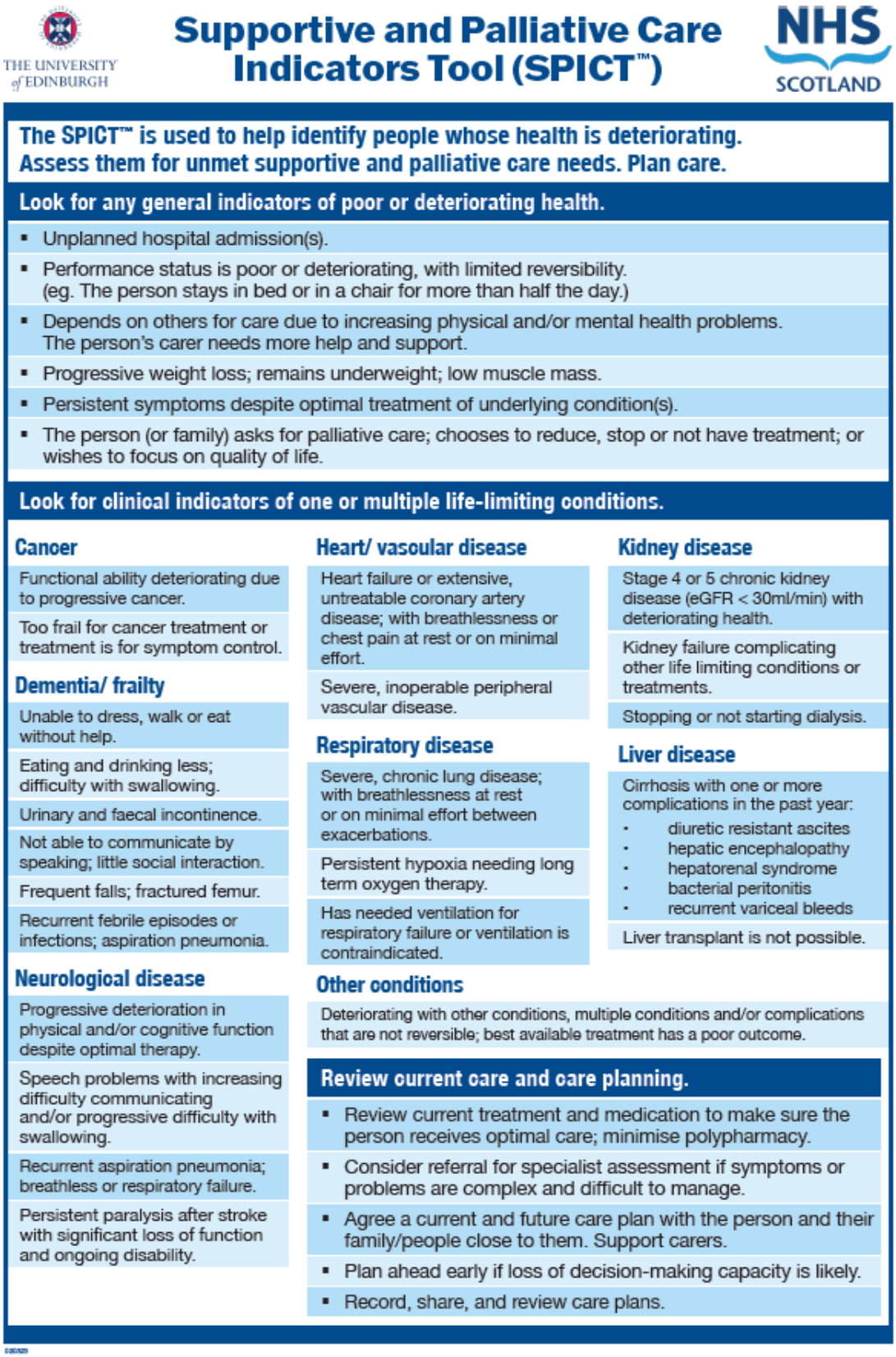
Discharge

Support may be episodic or continuous, depending on the need as assessed by the specialist team in partnership with the primary care team. The specialist and primary care service will take a partnership approach and the level of support will be dependent on the complexity of palliative care need.

Patients can stabilise following specialist palliative care interventions and may no longer require input from the specialist service, with their ongoing care being managed by their primary palliative care provider. Discharge from the specialist palliative care service should be planned in collaboration with the primary team. Re-referral back to specialist palliative care can be made at any time should the need arise.

Appendix 4: Supportive & Palliative Care Indicators Tool (SPICT™)[6]

Further information and instructions for use can be found at https://www.spict.org.uk.



THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Other conditions

Deteriorating with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

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[6] Supportive & Palliative Care Indicators Tool (SPICT™). 2022. The University of Edinburgh & NHS Scotland https://www.spict.org.uk.