South Island Palliative Care Workstream

Hospital Palliative Care Benchmarking Survey

Executive Summary

The South Island Palliative Care Workstream (the Workstream) undertook a survey of all South Island hospitals in mid-2015 to evaluate the provision of palliative care in the hospital setting and what progress has been made towards the implementation of the *Resource and Capability Framework for Adult and Palliative Care Services in New Zealand (2013)*[1]. The survey was sent to 14 hospitals in the South Island; seven Secondary/Tertiary hospitals level and seven community hospitals (these are referred to in the report as Category 1 and Category 2 hospitals respectively – see table on page 4).

The findings confirmed that specialist palliative care availability is variable in the hospital setting. The commitment of DHBs to proactively develop and support services is also highly variable.

While the survey showed that some useful relationships had been established between hospices and hospitals, there remain clear inequities and gaps in service and where services do exist they are vulnerable to staffing absences and professional isolation. The practicality of providing after-hours specialist support is also unrealistic and/or unsustainable.

The Workstream has made a number of recommendations that would see progress towards ensuring access to quality palliative and end of life care in the acute setting. This will be required in order to be true to the vision of a fully integrated healthcare system that can guarantee quality care wherever a person is located.

Recommendations

The Workstream is also undertaking surveys of hospice services and primary palliative care provision across the South Island. This report and recommendations should not be considered in isolation and will be augmented and supported by the subsequent reports. The Workstream views palliative care as requiring an integrated, whole of system approach and ultimately the three reports collectively will encapsulate the current situation and provide a direction for future work and priorities.

1. Every category 1 hospital should have at least one FTE on-site registered nurse or CNS with post-graduate training in palliative care, and every Category 2 hospital should employ one part-time nurse with palliative care as at least part of their designated role. If this is not possible due to skill availability, there should be a regular arranged visit from a hospice nurse (or a palliative care nurse from a regional hospital).

2. Access to a palliative medicine doctor must be available either as a DHB employee or by formal arrangement to attend to the needs of patients and staff in all hospitals and to support the on-site palliative care nurse(s). This is achievable even in the smaller hospitals, via an arrangement with a regional hospital where a doctor is employed for regular visits/sessions. This resource should not be at the discretion of a busy hospice. Where hospitals only have access via arrangement with a local hospice,

---

[1] http://www.health.govt.nz/system/files/documents/publications/resource-capability-framework-adult-palliative-care-services-v2.pdf

regular review of this support is required to ensure that sufficient and sustainable palliative care resources are available and that service quality is maintained.

3. In order to help embed the ‘hub and spoke’ model, it is recommended that DHBs should be required to facilitate closer links between hospitals and hospices, to maximize the available palliative care resources across all settings. This would help facilitate a regional approach, improving overall access to specialist care without putting undue stress on smaller hospitals to employ their own palliative care staff. There is also the possibility of larger DHBs supporting smaller ones, especially for positions such as allied health and palliative medicine where it may be more cost effective to share staff across DHB boundaries, facilitating collegiality and peer support.

4. All hospitals should critically look at their environment to ensure they meet the needs of palliative patients and their family/whanau. This includes access to single rooms for actively dying patients with space for family to stay as well as private spaces for conversation and contemplation. A focus on ensuring culturally appropriate care and treatment at the end of life is also required.

5. Telehealth facilities are increasingly necessary in all hospitals to allow patients to access essential support, not available on site. This could be achieved easily with minimal outlay, also benefiting many other services in the region. This resource could be used as leverage when formalizing relationships between larger and smaller facilities.

6. Bereavement support for complex grief is unavailable for most hospital deaths and is a well recognised gap – further illustrating inequities between hospitals and hospices. The issue requires further evaluation in conjunction with community providers.

7. All category 1 hospitals should ensure that palliative care staff are supported by an administration resource to improve service delivery and free up staff for clinical care. This would enable standardisation of data collection to give a clearer picture of the palliative care need in South Island hospitals, and help ensure services evolve to meet future demands. Regular audits should be conducted by palliative care to ensure safe and effective service delivery in the acute environment. Improved admin support would be required for hospital palliative care services to create discharge /transfer letters seamless.

8. Improving information sharing between hospital and hospice palliative care services requires innovative and collaborative thinking. The South Island Information Services Service Level Alliance (IS SLA) is aware of this issue and is working with us to explore possible solutions.

9. To promote consistency, consideration should be given to explore palliative care staff requirements through a formal job-sizing process in every hospital. This would need South Island endorsement.

Introduction

Across New Zealand, specialist palliative care is provided by hospices (inpatient units and/or community services) and by hospital palliative care teams. The *Resource and Capability Framework for Adult and Palliative Care Services in New Zealand (Jan 2013)* – the Framework - emphasises that most of the care for people with palliative needs and their family/whanau will be delivered by *primary* palliative care providers, securing advice, support and education as needed from specialist services. This specialist back-up should be available in **all** settings - private homes, aged residential care facilities and in hospitals and also in rural areas.

The Framework also recommended that palliative care services implement a 'hub and spoke'[2] model where smaller areas/services providing specialist care (spokes) are assisted and supported by the larger areas (hubs). It is understood that there can be more than one hub within an individual DHB although this assumption has not been tested.

The requirement for implementation of hospital palliative care teams was one of the key priorities in the *New Zealand Palliative Care Strategy 2001*[3]: "Hospital palliative care teams have a particularly important role in ensuring that the palliative care option is available for dying people, as well as in providing advice and assistance to staff in hospitals on the care of dying people." This was reiterated in *The New Zealand Cancer Control Strategy 2005*[4], with a broad area for action being providing equality of access to hospital-based palliative care teams (Goal 4, Objective 6). According to the *National Heath Needs Assessment for Palliative Care (June 2011),* over a third (34%) of all New Zealanders die in hospital, with 31% dying in Aged Residential Care, 22% in a private residence and 6% in a Hospice inpatient unit[5].

Since 2013, variable progress appears to have been made towards implementation of the Framework and despite the Framework, there appears to be no commitment in many DHBs to proactively develop and support access to specialist palliative care in their hospital facilities. It is unclear as to what constitutes an *adequate* level of palliative care in hospitals and how such services should or could be configured, resulting in inequities throughout the country.

The quality of dying in New Zealand hospitals is also an unknown. This is in contrast to the UK where a recent 2016 audit reported on this issue. Of interest, almost all (97%) of trusts in the UK reported that they had their own specialist palliative care service. A situation that has taken some years to achieve[6].

In mid-2015, the Workstream conducted a South Island wide survey (via survey monkey) with regard to the provision of palliative care in hospital settings. The survey was sent to 14 hospitals across the South Island. Individuals from medicine, nursing and management were identified and asked to combine their knowledge to complete the survey for their hospital.

The hospitals were divided into two main categories: Category 1 hospitals are the Secondary and Tertiary level hospitals - those who provide some level of specialist care, for example surgery, intensive care, paediatrics etc. Category 2 hospitals are local hospitals, mainly staffed by rural hospital medicine specialists and/or GP's. It is important to note that the category 1 hospitals are not necessarily 'hubs' in regard to specialist palliative care. Palliative Care 'hubs' are generally hospice organisations.

---

[2] The palliative care sector has agreed that there should be one level of specialist palliative care provided to a population, using a hub-and-spoke approach. This approach involves one site, (the hub) acting as a base and providing services to support satellite sites (the spokes). Arrangements can vary depending on the configuration of the organisations involved and the types of service provided. In rural areas this model provides an identifiable local presence while facilitating access to services that are difficult to deliver locally. The principle of partnership underpins the hub-and-spoke model. This partnership includes primary palliative care providers, in particular general practice teams, who provide the majority of care to patients with palliative care needs. The hub-and-spoke approach is based on one level of palliative care, not a hierarchy. The hub-and-spoke model represents horizontal integration of services, ensuring that the local population has access to all the components of specialist palliative care (as defined by the SPC Service Specifications), even if the components of specialist palliative care are not delivered by one contracted provider. This enables the best use of existing resources within a region where the required expertise is not available from a single provider.

[3] http://www.health.govt.nz/publication/new-zealand-palliative-care-strategy

[4] https://www.health.govt.nz/system/files/documents/publications/cancercontrolstrategy.pdf

[5] https://www.health.govt.nz/system/files/documents/publications/national-health-needs-assessment-for-palliative-care-jun11.pdf

[6] https://www.rcplondon.ac.uk/file/3338/download?token=9u-kTz2H

Category 1	Category 2
Nelson	Buller
Wairau	Ashburton
Christchurch *(incorporating The Princess Margaret Hospital, Burwood and Christchurch Women's)*	Oamaru
Grey Base	Dunstan
Timaru	Clutha Health First
Dunedin	Gore
Southland	Lakes District

It was inevitable that many of the smaller hospitals would be unable to answer all the survey questions, as a direct consequence of not having designated palliative care staff due to their small size and limited resources. However, they were encouraged to provide *as much information as possible*, especially regarding the support they receive from other hospitals and from their local hospice. This survey is the first attempt to investigate and benchmark levels of hospital palliative care provision against the Resource and Capability Framework across a region in New Zealand.

This report outlines key information points discovered from this survey, such as, where the Framework is working well, specific areas that need attention, where inequities are occurring, and changes that could be made to improve palliative care delivery and support in South Island hospitals.

The survey analysis is in two parts. Part 1 refers to “all hospitals” – categories 1 and 2. Part two refers to just the larger, category 1 hospitals. The report is concluded by a summary of recommendations and overarching reflections.

Part One – All hospitals

Access to specialist palliative care staff (nursing and medical)

According to the Framework, to constitute a hospital palliative care ‘team’, there must be a minimum of at least one nurse and one doctor – either on site or available via a formal arrangement from another provider such as a hospice. Referrals to palliative care are made for complex issues that are *beyond the capacity* of the local provider to manage competently. Examples would include difficult symptom management such as pain, ethical dilemmas and decision-making, agitation at the end of life and family distress. This may result in patients near the end of their lives, being required to transfer to another facility if such expertise is unavailable in the hospital (away from their loved ones) or staying in place but potentially receiving sub-optimal care.

The survey asked about the employment of palliative care nurses and doctors in the hospital, and whether there are arrangements in place through a local hospice. Below are details about nurse and doctor availability on site and ways in which specialist support is secured if required.

Nursing

It is important to have palliative care nurses in the acute setting not only to respond promptly to clinical need but to ensure that palliative care is a visible and integral part of the continuum of care in the acute setting – where approximately a third of our population die. Having palliative care nurses on staff, serves to prioritize holistic end-of-life care, ensuring those patients are given treatment appropriate to their needs.

The survey showed that palliative care nurses are employed in less than half of South Island hospitals. The survey questioned the number and distribution of nursing positions and showed that at the time of the survey, one hospital had a full-time nurse practitioner, five had 1-2 palliative care clinical nurse specialists, and one hospital had a sole palliative care registered nurse. This shows there is much variability throughout hospitals, resulting in inequity. For hospitals not employing a palliative care nurse, five also have no arrangement with a local hospice to provide specialist palliative care nursing. This results in limited access to expertise when needed.

Medical

The survey showed that only four out of 14 hospitals employed a palliative care medical specialist (at a minimum of 0.2 FTE). Unlike hospices, hospitals do not employ Medical Officers who often have years of hospice, palliative care experience. The majority of hospitals are reliant on relationships within their local hospice to obtain medical expertise and support for palliative care – this is sometimes referred to as "in-reach". There are fewer doctors employed in hospitals than nurses, meaning that in some locations nurses are working in isolation and in reality there is no 'service' in operation, just a sole practitioner. Leaving a nurse in isolation is not regarded as adequate coverage in palliative care when only the most complex and challenging cases are referred for specialist input. The results show a severe lack of palliative care medical specialists available within even the larger hospitals.

Overall, just over a third of hospitals have regular input from a palliative medicine specialist (either in house or in-reach). It is preferable to have regular sessions as being 'ad hoc' makes it a resource that can be deployed elsewhere at the discretion of the hospice. Routine visits provide certainty for both patients and staff and mean that referrals do not have to wait until they are urgent which is what can happen when such input is being provided from an outside service. Although it is good that palliative care advice can be obtained on request, it would be preferable to have formal DHB appointments.

A routine palliative medicine presence fosters palliative care expertise in junior doctors and makes it accessible to medical students. This is necessary to ensure that doctors recognise the importance of providing good palliative and end of life care in the acute environment.

The hub and spoke model

One of the aims of this survey was to highlight how well the 'hub and spoke' model for palliative care (outlined in the Framework) was operating in the South Island. The survey found strong connections between DHB hospitals where this model was being utilised. For example, in the CDHB, palliative care resources are distributed as needed between Christchurch Hospital, in collaboration with the Nurse Maude Hospice, and Grey Base, Buller and Ashburton Hospitals. In the SDHB, links are also evident between Dunstan, Oamaru, Clutha Health First and Gore Hospitals with both the Otago Community Hospice and Dunedin Hospital. Southland Hospice also provides good support to Lakes District Hospital.

As noted above, less than half of South Island hospitals employ a dedicated palliative care nurse, and less than a third employ a dedicated palliative care doctor. In lieu of dedicated staff, formal arrangements with a local hospice are encouraged but this appears to be dependent on the individual hospices rather than driven by the DHBs.

On a positive note, the survey found that in the majority of hospitals, general ward staff were able to contact their local hospice when needed for advice and support, including after hours. The survey did not, however, show how often this was occurring, if or how communication was promoted and encouraged, or if it was meeting the needs of the hospital staff and the palliative patients themselves. This is an indication of the 'hub and spoke' model at work, however more formal collaboration is needed to ensure palliative care needs are fully met.

Palliative care resources

The survey asked about participation in outpatient clinics for new patients and/or follow ups. Out of the 10 hospitals who answered the question, only one did weekly clinics, two did monthly, and seven did not conduct clinics. This is not necessarily an issue in areas where there is a hospice to support GPs for community based patients but many hospitals do not have a hospice in their locality. Clinics are one way of providing specialist support to outpatients on an as needed basis.

The survey asked about dedicated palliative care beds within the hospital setting. This is the case in three hospitals, presumably in lieu of a local hospice. It is debatable as to whether this is a necessary arrangement given that palliative care patients are routinely admitted into acute care beds in all hospitals. Having palliative care beds has traditionally enabled patients to stay long term but this is now considered to be part of the role of aged residential care. In smaller hospitals "palliative care beds" are often synonymous with single rooms which are larger, enabling family to sleep over and generally more conducive to care of the dying. In reality, rooms such as these should be available in **all** acute settings.

All hospitals were surveyed to ask if palliative care patients within their hospitals had access to a variety of often requested specialist consultation services, considered necessary in order to meet the complex needs of palliative patients. These included; acute pain consultation, chronic pain consultation, mental health liaison, clinical psychologist, discharge coordinator, specialist paediatric palliative care, cultural liaison, spiritual support, interpreter services and advance care planning.

Not surprisingly, results show that there is very limited access to some services, such as clinical psychologists (40%), specialist paediatric palliative care (22%), and advance care planning facilitation (29%) meaning that many patients go without based on which hospital they are admitted to. Those without on-site access should ideally be able to contact these services via Telehealth - a resource that could and should be better utilised.

The survey also asked hospitals some additional questions. The following results are concerning;

- 20% do not always have single rooms for actively dying patients
- 40% do not always have private spaces for distressed families
- 30% do not always have funding for palliative care patients in aged residential care,
- and only 10% have funded bereavement support (50% never do, 40% rarely/sometimes).

Part 2 - Category 1 hospitals

Seven South Island hospitals are considered either secondary or tertiary facilities; these are Nelson, Wairau, Christchurch, Grey Base, Timaru, Dunedin and Southland. They offer a range of specialist services in house and ideally should be able to act as a ‘hub’ for delivery of specialist palliative care within the DHB (apart from Grey which is closely aligned with Christchurch). For the remainder of this document, data has been obtained by comparing only these category 1 hospitals. Data has been more critically analysed than from smaller category 2 hospitals.

Specialist palliative care

To constitute a palliative care service there must be a doctor **and** nurse providing palliative care to referred patients and families. Overall, six out of seven of the category 1 hospitals have some form of designated palliative care nursing +/- medical service, either through direct employment or through a local hospice arrangement. Most category 1 hospitals do not employ a medical specialist and three of the seven do not employ a palliative care nurse. Two hospitals have all of their nursing provided by in reach from their local hospice. There remains one hospital which has no arrangement and the fact that many hospitals are relying on hospices to provide specialist palliative care, instead of it being a core service is concerning.

Hospital palliative care nurses are often working in isolation and only rarely are hospice nurses able to cover them for annual, education or unplanned leave. This potentially leaves those staff very vulnerable and at risk of burnout.

Workforce development

The survey addressed palliative care workforce development asking if the DHB provided *nursing* development/ training in specialist palliative care through formal placements within the hospital team. Only one hospital does so on an occasional basis (depending on funding).

The survey also showed that only 1 DHB in the South Island provided medical training/ experience in palliative care through formal placements with the hospital team. The lack of training opportunities is a reflection of the number of palliative medicine specialists in the South Island as there must be a minimum of two per site for accreditation purposes. This is likely to have a trickle-down effect in later years, when future specialists are unable to be trained locally and a foundation of palliative care knowledge is not developed in New Zealand trained RMOs.

Staff training and education is a responsibility of all larger hospitals but palliative care education is not available across the board for any of the following; registered nurses, post-graduate nurses, medical students, resident medical officers, and allied health professionals.

Service support

In accordance with the Framework, it is expected that larger hospitals have an established palliative care service. It is also essential that this service is supported so that it can function optimally, and support the health professionals who work in palliative care. The survey analysed what support services are available for the palliative care services, and if this is sufficient.

The survey found that only one of the category 1 hospitals routinely collects data, including referral numbers and referral characteristics. Data should be collected from every hospital to give a full picture of what is occurring and it is imperative that the data collected is consistent between services.

The survey asks if hospitals had administration support to assist with tasks such as collection of palliative care referral data, secretarial duties etc. The report showed that no hospital had a dedicated resource, with two hospitals sharing the resource with another service. This potentially impacts how efficiently the service runs, how much time staff have for looking after patients instead of performing administration tasks and how unmet need is quantified.

The survey also asked if services conduct audits, consumer surveys, or other quality improvement (QI) activities. The results were not encouraging with most not engaging in QI activities or doing so less than yearly. Hospital-based palliative care research is rarely conducted, despite this being a priority overseas. Designated staff and formal relationships with academic departments and research institutes would be required to realise this in the South Island.

Model of care

The survey asks about the type of service provided by palliative care. The standard model of providing specialist palliative care in a hospital setting is referred to as “consult liaison” which is ideally available **on-site** (as opposed to by phone) at the request of the referring team. All category 1 hospitals indicated that they were able to provide consultations on request, although some of the input was referred to as “ad-hoc” and the majority is nursing lead with more limited access to a doctor.

Only one hospital was able to routinely provide after-hours palliative care *advice*, while a further three were able to provide limited after-hours advice. This situation perpetuates an inequity of access and potentially leaves hospital staff and patients vulnerable. It is also contrary to expectations outlined in the Framework. Further, regarding after-hours services, the survey showed that none of the category 1 hospitals provided a routine *on-site* weekend service which is unsurprising.

The survey found that all hospitals report being involved in activities such as discharge planning, family meetings, advance care planning, allied health referrals, and community referrals. This shows that where present, palliative care staff are well accepted in the acute environment and able to positively influence the provision of care and the transition of patients back into the community.

The survey asked if palliative care services had been running with any unfilled vacancies over the past two years. Only one hospital reported that they had; this shows that services are fully staffed albeit at low staffing numbers. This also suggests that such jobs are sought after and could almost certainly be filled in more hospitals if posts were created.

Local, regional and national representation

The survey found that most hospitals are participating in or contributing to strategic planning or priority setting for their wider DHB /organisation. This is very positive but the degree to which this is effecting change and development is unknown.

Only one hospital is able to provide specialist palliative care input to Cancer MDMs (Tumour Boards). This is a missed opportunity for collaboration around care planning and decision-making and is a reflection of a specialist resource spread too thinly.

The survey asked about whether DHBs encourage palliative care team members to attend or participate in local, regional, or national networks/groups/committees. This is occurring to some extent in all but two hospitals leaving significant room for improvement.

Community involvement

It is important that an understanding of palliative care is embedded within communities. This maximises the population’s knowledge-base and helps them be more supportive of each other and more empowered to access help and support when required.

The survey asked if services provide public education, support, or facilitation directed at family / carers or community groups. The survey found that no hospital regularly provided this and most hospitals never do. This is a role traditionally provided by Hospices but participation by hospital teams would positively impact on community awareness.

The final survey question explored if services provide access to complementary and alternative medicines (CAM) while patients are in hospital (either directly or via facilitation). It found this is not the case in nearly all South Island hospitals. This is a contentious issue but something the community at large feels strongly about. CAM is more commonly available in hospices but acceptability is highly variable. This is an issue worthy or more study and discussion.

Referral guidelines

Palliative care referral guidelines that are nationally consistent are used to inform practice in most South Island hospitals. However, the survey found that two hospitals do not use formal referral guidelines which may be the cause of uncertainty and/or inequity.

Information Service issues

It is important that palliative care staff working in hospitals have full access to the electronic patient record (e.g. Health Connect South) to view investigations, correspondence etc. and the survey found that this is indeed the case. However, no hospitals routinely wrote palliative care discharge letters or discharge notifications that would be visible in the electronic record. This may be a reflection of a stretched workforce or to lack of awareness and risks patients falling through the cracks at the critical time of transfer out of the acute care setting.

Few hospitals had members of staff with full access to the patient management systems of their local hospice, unsurprising when they are separate organisations but with many patients being shared, there is a clear risk of critical information not being shared. Accessing records in a timely way helps hospitals treat hospice patients when they enter acute care, and will often change how they are treated and affect patient outcomes.

The survey also found that access to Telehealth (e.g. videoconferencing) was very variable with one hospital having no access at all. Access is increasingly important as it allows hospitals to make available its support and expertise to the wider region, especially rural hospitals and remote areas.

Recommendations

The Workstream is also undertaking surveys of hospice services and primary palliative care provision across the South Island. This report and recommendations should not be considered in isolation and will be augmented and supported by the subsequent reports. The Workstream views palliative care as requiring an integrated, whole of system approach and ultimately the three reports collectively will encapsulate the current situation and provide a direction for future work and priorities.

10. Every category 1 hospital should have at least one FTE on-site registered nurse or CNS with post-graduate training in palliative care, and every Category 2 hospital should employ one part-time nurse with palliative care as at least part of their designated role. If this is not possible due to skill availability, there should be a regular arranged visit from a hospice nurse (or a palliative care nurse from a regional hospital).

11. Access to a palliative medicine doctor must be available either as a DHB employee or by formal arrangement to attend to the needs of patients and staff in all hospitals and to support the on-site palliative care nurse(s). This is achievable even in the smaller hospitals, via an arrangement with a regional hospital where a doctor is employed for regular visits/sessions. This resource should not be at

the discretion of a busy hospice. Where hospitals only have access via arrangement with a local hospice, regular review of this support is required to ensure that sufficient and sustainable palliative care resources are available and that service quality is maintained.

12. In order to help embed the ‘hub and spoke’ model, it is recommended that DHBs should be required to facilitate closer links between hospitals and hospices, to maximize the available palliative care resources across all settings. This would help facilitate a regional approach, improving overall access to specialist care without putting undue stress on smaller hospitals to employ their own palliative care staff. There is also the possibility of larger DHBs supporting smaller ones, especially for positions such as allied health and palliative medicine where it may be more cost effective to share staff across DHB boundaries, facilitating collegiality and peer support.

13. All hospitals should critically look at their environment to ensure they meet the needs of palliative patients and their family/whanau. This includes access to single rooms for actively dying patients with space for family to stay as well as private spaces for conversation and contemplation. A focus on ensuring culturally appropriate care and treatment at the end of life is also required.

14. Telehealth facilities are increasingly necessary in all hospitals to allow patients to access essential support, not available on site. This could be achieved easily with minimal outlay, also benefiting many other services in the region. This resource could be used as leverage when formalizing relationships between larger and smaller facilities.

15. Bereavement support for complex grief is unavailable for most hospital deaths and is a well recognised gap – further illustrating inequities between hospitals and hospices. The issue requires further evaluation in conjunction with community providers.

16. All category 1 hospitals should ensure that palliative care staff are supported by an administration resource to improve service delivery and free up staff for clinical care. This would enable standardisation of data collection to give a clearer picture of the palliative care need in South Island hospitals, and help ensure services evolve to meet future demands. Regular audits should be conducted by palliative care to ensure safe and effective service delivery in the acute environment. Improved admin support would be required for hospital palliative care services to create discharge /transfer letters seamless.

17. Improving information sharing between hospital and hospice palliative care services requires innovative and collaborative thinking. The South Island Information Services Service Level Alliance (IS SLA) is aware of this issue and is working with us to explore possible solutions.

18. To promote consistency, consideration should be given to explore palliative care staff requirements through a formal job-sizing process in every hospital. This would need South Island endorsement.

Conclusion

Until all hospitals have a specialist palliative care resource with both nursing and medical personnel, all the elements required to ensure equitable access to quality care at the end of life cannot be realised. Staff should be employed by the DHB in the larger hospitals, with smaller hospitals having staff available through formal relationships with other hospitals or hospice organisations. This support must be available in a transparent, sustainable and joined up way. A South Island vision for this may be worth considering.

Only once adequate day time services are in place, can issues such as after-hours advice and training positions be realised. A palliative care presence on tumour boards (MDMs) is unattainable until there is sufficient resource in place to do the day to day clinical work and this is only the case (in part) in one south island hospital at present.

Staff education and training as well as advocacy and participation at a strategic and policy level in our larger hospitals is impossible without designated staff on site. Enablers such as IT access, telehealth facilities, admin support, clinic space etc. require deliberate attention at a DHB level. Palliative care is not just about cancer so it is necessary to decide where services sit and how governance and oversight is provided. Without this, services cannot develop and thrive and we will continue to fall short of our vision to ensure all dying patients, wherever they are, are given the best possible care.

Reflection

This was a complex survey to undertake, and in retrospect, survey monkey was probably not the best choice. Structured interviews would have been easier to analyse given the highly variable narratives that were gleaned.

Despite this, a 100% completion rate was achieved and we are confident of our findings. Many useful and informative conversations were held in order to facilitate completion, and this was hugely beneficial in itself. As a Workstream, we demonstrated our willingness to liaise with services and individuals to promote their understanding of local and regional initiatives and of the South Island Alliance and it was identified that some services have been quite isolated to date. We believe that the personal contact was well received and that some improvements have already eventuated as a consequence of being empowered to initiate change. This may have been directly related to our suggestion that dialogue be held between nursing, medical and management at the individual hospitals prior to the survey being completed which resulted in an improved understanding of the issues each facility was facing.

A repeat of the survey will be required in 18-24 months as there is a great deal of progress still to be made. Guidance from the South Island Alliance would be much appreciated both about the survey itself and about how best to approach individual DHBs to look at more effective ways of ensuring equitable access to specialist palliative care in the hospital environment.

Addendum – April 2016

There have been some notable developments since the survey was conducted that have come to our attention.

- A 6 month pilot has just started with a palliative care nurse from Nelson Hospice deployed to Nelson Hospital to provide a consultation/liaison service. If successful, an ongoing arrangement will need to be made, that will require input from the NMDHB to ensure sustainability and medical back-up.
- The palliative care nurse in Southland Hospital is being more closely supported by the new palliative medicine specialist at Hospice Southland. This again is a very positive step but in order to be secure and sustainable it needs greater support from the SDHB. The service is particularly vulnerable given that there is only one medical specialist providing specialist palliative care in the Invercargill catchment.
- Palliative medicine input and oversight/support for the clinical nurse specialists covering Grey Hospital has been identified as an ongoing issue of concern by senior management at the WCDHB. It will be discussed at a West Coast Palliative Care Planning Day organised at the end of April.
- Of concern, is the ongoing difficulty recruiting a permanent palliative medicine specialist in SCDHB. There has been some discussion about having the service covered medically by a rehabilitation specialist with an interest in palliative care (currently in post). This would be a backward step and would leave the DHB without the required specialist resource necessary to ensure safe and equitable palliative care.

Appendix one: Glossary of palliative care terms[7]

Advance Care Plan: the desired outcome of the Advance Care Planning process. It is an articulation of wishes, preferences, values and goals relevant to all current and future care.

An advance care plan may itself be regarded as an advance directive and should be consistent with, and considered in conjunction with, any advance directive that exists.

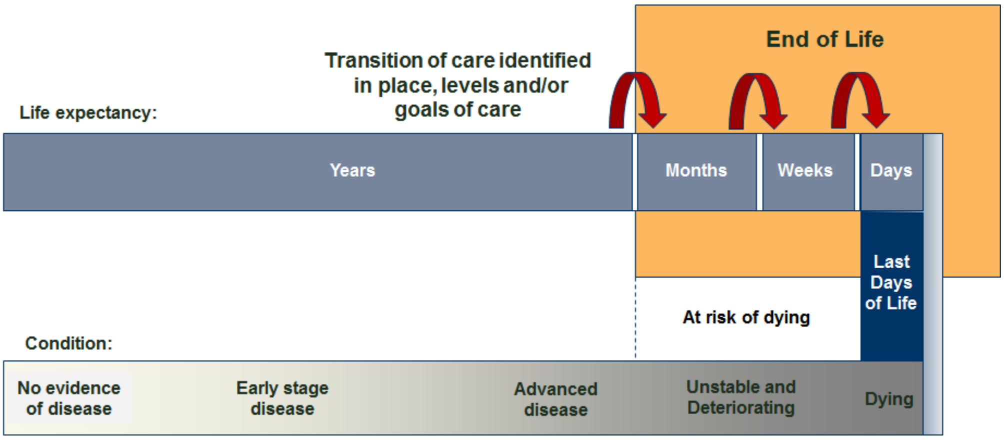
End of Life: is that period of time prior to death but the duration can never be precisely defined in advance (National Gold Standards Framework Centre 2011).[8]

Recognising and identifying those people who are at risk of dying at some point in the year ahead enables the health and social systems to respond to the deteriorating person and their families/whānau/carers in a holistic and comprehensive way.

Although prognostication is inherently difficult, being better able to predict when people are reaching the end of life phase, whatever their diagnosis, makes it more likely that they receive well-coordinated, high quality care. This is more about the health care system meeting needs than giving defined timescales. The focus is on anticipating the needs of the person and families/whānau/carers so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. The major transition to the end of life period is in changing the focus on the person from curative and restorative care, which aims to extend the quantity of life, to palliative care which aims to improve the quality of life.

Figure 1: End of life and last days of life[9]



End of Life Care: is the care guided by the person's needs and goals, and is the responsibility of all who work within the health sector.

Planning for coordinated end of life care across all levels of the health system is essential for District Health Boards. Tools such as the Gold Standards Framework, (National Gold Standards Framework Centre 2011) the Supportive and Palliative Care Indicators Tool (SPICT™) (Boyd and Murray 2014) or the interRAI Palliative Care assessment (interRAI 2014) can assist to identify those people who need a transition of care. This may include a transition in the place of care, levels of care and/or goals of care.

End of Life Care covers the full range of clinical services provided. It incorporates treatments, programmes, policies, initiatives, benefits and entitlements that are provided for the person and their family/whānau/carers from the point when a life-threatening condition or illness is diagnosed until after the death, to include the care of the deceased person's body and care of their family/whānau/carers.

Hospice: is a philosophy of care; not only a building.

The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative care.

---

[7] Drawn from the New Zealand Palliative Care Glossary 2015: http://www.health.govt.nz/system/files/documents/publications/new-zealand-palliative-care-glossary-dec15.docx

[8] The wording has been adapted from the Gold Standards Framework.

[9] Based on the work of Hui et al 2014. Amended for New Zealand and with the Inclusion of Last Days of Life in consultation with a working group of the Palliative Care Council.

Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change (Hospice New Zealand 2015).

Last Days of Life: is the period when a person is dying. It is the period of time when death is imminent and may be measured in hours or days (Palliative Care Council 2015).

See also End of Life and the accompanying diagram.

Palliation: is alleviation of symptoms when the underlying medical condition or pathological process cannot be cured.

The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms, and is not necessarily limited to care provided for life-limiting and life-threatening conditions (Palliative Care Australia 2008).

The goal of palliation is to help a person feel more comfortable, and to improve quality of life. Palliation is a key goal of care for both end of life and palliative care.

Palliative Care:[10] is care for people of all ages with a life-limiting or life-threatening condition 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.

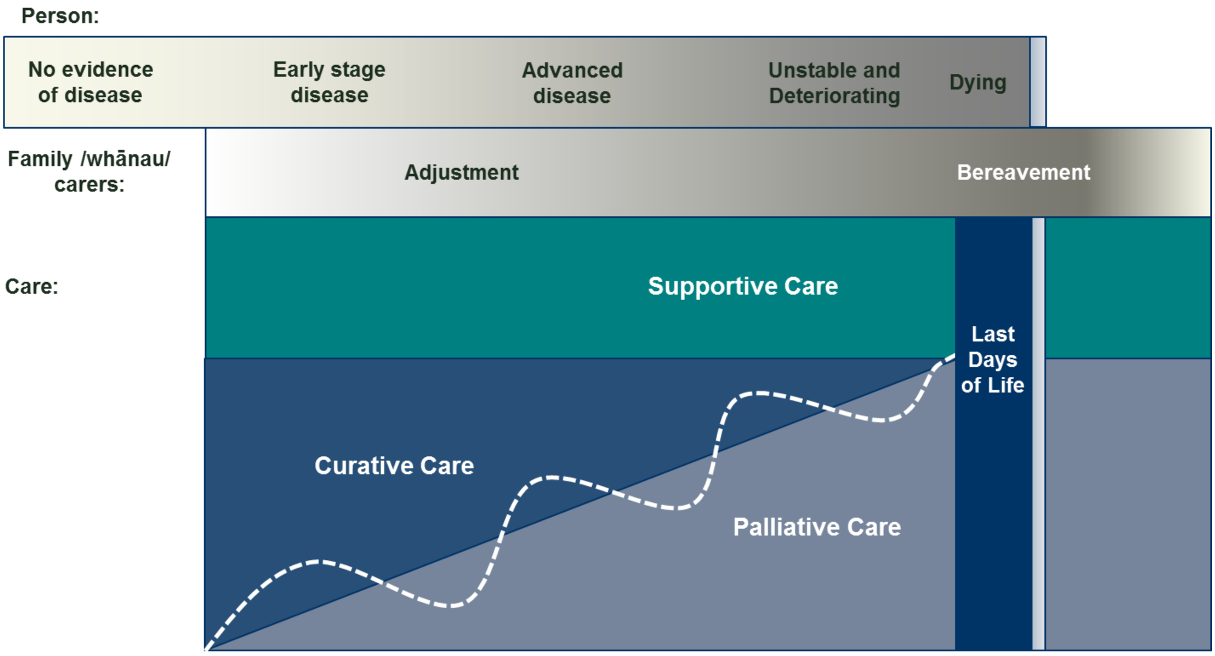
Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be located.

It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. This includes but is not limited to; Māori, children and young people, immigrants, those with intellectual disability, refugees, prisoners, the homeless and those in isolated communities (Palliative Care Subcommittee NZ Cancer Treatment Working Party 2007).

Figure 2: Adjustment, support and palliative care for adults



---

[10] This is the New Zealand specific definition of palliative care. See also Appendix A for the World Health Organization definition and subsequent clarification from the World Palliative Care Association.

Palliative Care Approach: an approach to care which embraces the definition of palliative care.

It incorporates a positive and open attitude toward death and dying by all service providers working with the person and their family, and respects the wishes of the person in relation to their treatment and care.

Palliative Care System: comprises specialist palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links between that tie together 'a system'. An interdisciplinary team approach to palliative care is one example of how such links can be developed and maintained.

Primary Palliative Care: is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team.

Primary palliative care is provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of people 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. 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.

Primary palliative care providers assess and refer people to specialist palliative care services when the needs of the person exceed the capability of the service.

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 the person and family/whānau.

See also Specialist Palliative Care and the accompanying diagram.

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 people have access to at least medical and nursing palliative care specialists (Palliative Care Subcommittee NZ Cancer Treatment Working Party 2007).

Specialist palliative care is delivered in two key ways:

- Directly – to provide direct management and support of the person and family/whānau where more complex palliative care need exceeds the resources of the primary provider. Specialist palliative care involvement with any person 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 resources of the primary team – this may be in any of the domains of care – physical, psychological or spiritual.
- Indirectly – to provide advice, support, education and training for other health professionals and volunteers to support the primary provision of palliative care.

Specialist Palliative Care Service: a team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.