

LIVING WELL, DYING WELL

A Strategy for a
Palliative Care Approach
– a Summary

2017 – 2020



In partnership with

LOWER NORTH ISLAND
Palliative Care Managed Clinical Network



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Foreword

This is a summary of the detailed Strategic Plan for a Palliative Care Approach document. This strategic plan represents the passion of the people, whānau, consumers and community leaders who have given it the highest level of importance for the future provision of palliative care services. It is a result of the collaborative effort of the Lower North Island Palliative Care Managed Clinical Network engaging with many stakeholders, including consumers, across Wellington, Hutt Valley and Wairarapa districts. There is no single author – we are all contributors and accountable to advancing a common vision through our individual and collective actions.

It sets the direction of palliative care in the sub-region to improve the experience for people, whānau and their communities. The document focuses on a palliative care approach and how to better understand and respond to people's needs.

This strategic plan is specifically aimed at meeting the needs of all people who would benefit from a palliative approach. Over the next couple of decades New Zealand will see a dramatic change in the patterns of life, disease, dying and death. There will be more people dying each year; people will be dying at older ages and with a range of more chronic conditions and frailty. This increasing and changing demand has wide reaching implications for our wider society and health system, but especially our palliative care system.

Services do an excellent job of providing specialist palliative care – and this plan supports sustaining specialist palliative care – but we need to do a much better job of providing coordinated and individualised care for the large and growing number of patients for whom a palliative approach would be beneficial. This group of patients, which is projected to increase by 60% in 2036, have not been in the forefront of our minds in planning palliative care services – and it is this group of patients whose needs this plan is principally intended to address.

The themes of the refreshed NZ Health Strategy (April 2016) were used to inform this strategy and are embedded in this document. People powered, care closer to home, value and high performance, one team and smart systems are all key drivers.

The ultimate goal of this palliative care strategy is for greater system integration that puts the patient and their whānau at the core of every decision that is made.

It represents a common consensus on a vision for palliative care across the sub-region and outlines the steps we need to take together to make that vision a reality. Members of the network will all use this document as a framework to engage more broadly with our colleagues and stakeholders to inform and implement change.

Adri Isbister

Project Sponsor,
Chief Executive, Wairarapa DHB

The Strategy

OUR VISION – TE AHO

'All people who require a palliative approach live well and die well irrespective of their condition or care setting'.

SEAMLESS AND HOLISTIC PATIENT CARE

Our palliative care system should be integrated with care and support right through from the time it is first identified that end of life is approaching, through the last days of life and into bereavement. Partnerships and integration between all service providers, volunteers, patients and whānau will create a seamless journey for patients. Communication, collaboration and sharing of resources are fundamental to addressing patient need and achieving efficiency.

SERVICE PROVISION IS BASED ON NEED

The majority of patients in need of palliative care are non-complex to moderately complex and their needs can, and will continue to be adequately managed by their primary palliative care provider. This may include indirect or direct (generally episodic) involvement of specialist providers. There are a relatively small proportion of patients with highly complex needs who require direct specialist involvement, similar to what occurs in most other health care specialties and subspecialties.

ONE INTEGRATED CARE TEAM

Each patient will have one virtual integrated inter-disciplinary care team who will ensure that the needs of the patient and their whānau are identified and met. Each patient will have an individualised palliative care plan which will encompass all settings in which the patient receives care. This care plan will identify all the key members that are directly involved in caring for the patient, as well as a designated lead palliative carer (LPC) and a palliative care facilitator (PCF). The LPC is responsible for clinical/medical oversight and the PCF is responsible for facilitating a range of services to meet need.

LED BY PRIMARY CARE

The general practice team will drive a palliative approach, and be well supported by the specialists within the Locality Palliative Care team, as well as responsive nursing, home based support and allied health services. A member of the general practice team will usually be the designated 'lead palliative carer' if the patient lives at home, and will often remain the first point of contact for patients and their whānau throughout their journey. They will ensure, in partnership with the palliative care facilitator, that the individualised Palliative Care Plan details the arrangements for medical care and support 24 hours/ 7 days a week. After hours care may be provided by health care professionals whose core role includes a 24 hours /7 days a week service.

SUPPORTED BY SPECIALISTS IN PALLIATIVE CARE

Primary care providers will have access to expert consultation and advice from Palliative Care Specialists. These specialists will work together to support a cluster of GP practices, ARC facilities, and other health care providers like District Nursing, depending on the population within the locality. These teams could include a gerontologist, a practice nurse with a special interest in palliative care, a gerontology nurse, allied health practitioners, nurse practitioner, clinical pharmacist, a palliative medicine specialist and nurse from the hospice community team. Their main role will be to make sure specialist knowledge is available for frontline workers. The specialists will indirectly, and at times directly, support primary providers in their locality with facilitating interdisciplinary review of palliative care patients, case reviews and educational support. Certain specialists within this locality support team will be contactable 24 hours/7 days a week.

CLEARLY DEFINED ROLES AND RESPONSIBILITIES

The new model of care will define and agree the roles and responsibilities of the various providers including the roles of the LPC and PCF. In our current models, assessment, coordination and service delivery are often carried out by different people or different organisations. Under the new model, these functions will be pulled together into one agreed assessment and planning process which will be synchronized by the same person to maximize the connectivity between services for patients. This will help facilitate improved communication, collaboration and sharing of resources to address need and achieve efficiency

Goals

The following outlines each step, and respective goal, of the pathway for the patient nearing the end of their life from the identification of their palliative care needs through to care after death (Rachael Addicott, 2010).



1. Patients and their whānau have early discussions as end of life approaches to ensure they make early informed choices about the what, where and how of care and support they receive (Self management)

Desired Outcomes

- Health professionals involved in palliative care are skilled in identifying people entering the end stage of their life and are well prepared at having timely discussions with patients and their whānau about the choices they have.
- Health professionals, patients and whānau are aware of all palliative care services and supports.
- Patients and their whānau are better prepared for their palliative care journey and have increased control and self-management over aspects of this journey.

Actions

1. Develop a method/pathway to support identification of people as their end of life approaches and implementation of lead palliative care model.
2. Implement individualised palliative care planning in primary care as a mechanism to identify and access services.
3. Promote the Health Navigator website as the basis for information to support patients, whānau throughout the journey including after death support.

Measuring success

- Increase in competence, capability and comfort of health professionals having early conversations with people and their whānau requiring palliative care
- Palliative patients and their whānau will have recorded early conversations about a palliative care approach to enable adjustment and planning of their lives, advanced care plan and goals of care.
- Patients and their whānau will have accessed information and support in relation to palliative care and satisfaction with journey start and choices.

2. Patients and their whānau receive coordinated assessment, care planning and review throughout their illness (Planning)

Desired Outcomes

- An individualised palliative care plan is developed in conjunction with the person and their whānau and is available to them and their health and care teams with an Identified lead palliative carer and linked to a palliative care facilitator to support co-ordination of the care
- Suitably experienced health professionals carry out comprehensive assessment of the palliative care needs of a person. The integrated care team can further contribute and develop this as needed.
- Review of a patient's health and care needs occur in a timely manner whenever the patient's condition changes, and the care plan is then updated
- Duplication of assessment and service provision is avoided and transition between services is safe and easy for the patient and whanau

Actions

4. Consolidate current assessment tools and processes across multiple providers into one agreed assessment tool that allows access to a full complement of services.
5. Implement a consistent palliative care pathway across all services within a district that supports service transitions and transfer of patients between services.

Measuring success

- Patients identified as palliative will have one comprehensive palliative care assessment/care plan/goals of care with an identified lead palliative carer and palliative care facilitator for their palliative care
- The patients care team of interdisciplinary health professionals will have access to and be able to contribute to the assessment/care plan/goals of care and subsequent reviews
- Patients do not have assessment duplicated by different services but different services contribute to one assessment and transitions between services feels seamless to the patient and their whānau

3. Patients and their whānau experience equitable and seamless care through coordinated service provision (Integration)

Desired Outcomes

- Palliative care provision that is equitable across the whole of the population that the health systems serve
- Palliative care professionals and services that are aware of and address service access disparities for their local population
- Palliative care services that collaborate between primary, secondary and specialist services with a named lead palliative care professional co-ordinating service provision
- Palliative care that is well co-ordinated and seamless for the patient and their whānau
- Māori and Pacific services that are integrated with other services

Actions

6. Implement a local single point of service facilitation to access a wide range of comprehensive wrap-around palliative care services.
7. Establish and implement locality palliative care specialists and case collaboration models to create a clear and formalised way of working across the palliative care system.
8. Implement shared care planning across the 3 districts and enable access to all relevant health providers.

Measuring success

- Single point of service facilitation in each district is implemented
- Patients have equal access to palliative care services across all parts of the community, whatever their ethnicities and socio economic situations
- Palliative care system is responsive to different cultural need across the population
- Palliative care services and provision is coordinated and seamless for patients and their whānau
- Providers of palliative care have integrated systems and processes with robust communication

4. Patients and their whānau experience high quality services in different settings (Quality)

Desired Outcomes

- A workforce with capability and capacity to deliver high quality palliative care across the whole of the health and care system
- Palliative care education and resources that are available to all professionals, carers and community across the sub-region
- Standardised high quality palliative care practice
- System wide clinical governance, quality framework and monitoring processes utilised in palliative care
- Sustainable and skilled workforce across the whole of health

Actions

9. Complete a sub-regional workforce plan that considers the current gaps and future workforce requirements of medical, nursing and the allied health workforce. Such a plan would identify ways in which the workforce across the sub region could best leverage off each other's skills and expertise, and work together to strengthen the workforce capacity and capability.
10. Develop and implement a sub-regional workforce training and professional development programme based upon evidence based practice and quality measures to include:
 - Clinical skills and prescribing management
 - Cultural perspectives for end of life
 - End of life recognition, planning and conversations for health professionals across the system
 - Specialist partnership staff working in primary care settings
 - Informal carers, volunteers and Kaiawhina
11. Establish a system wide network/service level alliance in each district to oversee local implementation of the strategy
12. Implement nationally agreed quality standards and increase the visibility of palliative care quality indicators in accountability arrangements, as proposed in the draft service review (Ministry of Health, June 2016). These would include:
 - A regional platform for the exchange, comparison and benchmarking of patient focussed best practice between providers and linked to clinical governance.
 - Linkages to education and research in palliative care.
13. Implement a patient/whānau satisfaction survey following initial referral/planning and the VOICES (Views of Informal carers – Evaluation of Services) survey to establish a baseline of consumer experience and measure improvement over time.

Measuring success

- Curriculum and development programme for health professionals within primary and specialist palliative care providers across the palliative care system is in place and utilised
- Specialist services/primary provider partnership agreements in place and utilised
- Active palliative care clinical governance, quality framework and standards monitoring are in place
- Patients and whānau report a 'good death' in satisfaction surveys

5. Care in the last days of life is comprehensive, with good symptom control, is in the most appropriate setting in the company of whānau and/or friends (Last days of life)

Desired Outcomes

- Health professionals across the health systems recognise the transition of the patient towards the last days of life and are able to communicate this to the patient, whānau, carers and the wider health team occurs in a skilled manner
- Care provision is comprehensive and supportive for the end of life phase in the most appropriate and preferred place for the patient and their whānau
- Patients and their whānau are treated as individuals, with dignity and respect and given emotional support throughout the end of life phase
- Whānau and carers are well informed, have their needs supported, included in decisions and supported to provide physical care if they wish.

Actions

14. Ensure a wide range of responsive and comprehensive service options exist, including 24 hours/7 days a week carer, specialist, nursing and medical support, and psycho-social support for those patients and their whānau in the last days of life.

Measuring Success

- End of life transition moments are recognised, documented and well communicated.
- Health professionals feel well prepared and supported for patient's end of life care
- End of life care is resourced appropriately
- Support for a patient's whānau through the end of life phase is appropriate for them

6. Whanau experience high quality care after death (After death support)

Desired Outcomes

- Due care and attention is provided to the patient and their whānau after death
- Bereaved whanau, formal and informal carers will have access to good quality information about the practical steps they need to consider and where to access emotional support if required.

Actions

15. Implement culturally appropriate bereavement support services and enable equitable access for those in need of support after death

Measuring Success

- Bereaved whānau have appropriate and accurate information about the post death requirements.
- Formal, and informal carers and whānau are aware of and able to access bereavement support.

Summary of Strategic Goals: Desired Outcomes, Actions and Measures

All people with life limiting conditions live well and			
Triple Aim		Improve health & equity for all population	
New Zealand Health Strategy		People powered	Closer to home
Goals	Patients and their whānau have timely identification that end of life is approaching, early discussions to ensure they make informed choices about what, where and how they receive care and support	Patients and their whānau receive coordinated assessment, care planning and review through their palliative care journey	Patients and their whānau experience equitable and seamless care through coordinated service provision
Desired Outcomes	1. Self management • Health professionals are skilled in identifying people entering the end stage of their life & are well prepared for early discussions with patients and their whānau • Health professionals, patients and whānau are aware of all palliative care services and supports • Patients and their whānau are better prepared for their palliative care journey and have increased control and self-management over aspects of this journey.	2. Planning • An individualised palliative care plan is developed and is available to them and their health and care teams with an identified lead palliative carer and linked to a palliative care facilitator • Suitably experienced health professionals carry out comprehensive assessment of the palliative care needs • Review of a patient's health and care needs occur in a timely manner whenever the patient's condition changes and care plan updated • Duplication of assessment and service provision is avoided and transition between services is safe and easy for the patient and whānau	3. Integration • Equitable services across the whole of the population that the health systems serve • Palliative care professionals and services are aware of and address service access disparities • Palliative care services collaborate between primary, secondary and specialist services with a named lead palliative care professional co-ordinating service provision • Well co-ordinated and seamless care for the patient and their whānau • Māori and Pacific services that are integrated with other services
Actions	1. Develop a method/pathway to support identification of people as their end of life approaches 2. Implement individualised care planning in primary care as a mechanism to identify and access services 3. Promote the Health Navigator website as the basis for information to support patients, whānau and carers throughout the journey including after death support.	4. Consolidate current assessment tools and processes across multiple providers into one agreed assessment tool that allows access to a full complement of services 5. Implement a consistent palliative care pathway across all services within a district that supports service transitions and transfer of patients between services	6. Implement a local single point of service facilitation to access a wide range of comprehensive wrap-around palliative care services 7. Establish and implement locality palliative care specialists and case collaboration models to create a clear and formalised way of working across the palliative care system 8. Implement shared care planning across the 3 districts and enable access to all relevant health providers
Measures	• Increase in competence, capability and comfort of health professionals having early conversations with people and their whānau • Palliative patients and their whānau have recorded early conversations to enable adjustment and planning of their lives, an advanced care plan and goals of care with a palliative focus. • Palliative patients and their whānau will have accessed information and support in relation to palliative care and satisfaction with palliative care journey start and palliative care choices.	• Patients have one comprehensive palliative care assessment/care plan/goals of care with an identified lead palliative carer and palliative care facilitator for their palliative care • The patient's care team will have access to and be able to contribute to the assessment/care plan/goals of care and subsequent reviews • Patients do not have assessment duplicated by different services but different services contribute to one assessment and transitions between services feels seamless to the patient and their whānau	• Single point of service facilitation in each district is implemented • Patients have equal access to palliative care services across all parts of the community, whatever their ethnicities and socio economic situations • Palliative care system is responsive to different cultural need across the population • Palliative care services and provision is coordinated and seamless for patients and their whānau. Providers of palliative care have integrated systems and processes with robust communication

die well irrespective of their condition or care setting

Improve quality, safety & experience of care

Best value for health system resources

Value and high performance

One team

Smart systems

High quality sustainable services are delivered	Care in the last days of life is comprehensive, with good symptom control, is in the most appropriate setting in the company of family and friends	Whānau experience quality care after death
4. Quality	5. Last days of life	6. After death support
- A workforce with capability and capacity to deliver high quality palliative care across the whole of the health and care system - Palliative care education and resources that are available to all professionals, carers and community - Standardised high quality palliative care practice - System wide clinical governance, quality framework and monitoring processes utilised in palliative care - Sustainable and skilled workforce across the whole of health	- Health professionals recognise the transition towards the last days of life & communicate this in a skilled manner - Care provision is comprehensive and supportive for the end of life phase - Patients and their whānau are treated as individuals, with dignity and respect and given emotional support throughout the end of life phase - Whānau and carers are well informed, have their needs supported, included in decisions and supported to provide physical care if they wish	- Due care and attention is provided to the patient and their whānau after death - Bereaved whānau, formal and informal carers will have access to good quality information about the practical steps they need to consider and where to access emotional support if required.
9. Complete a sub-regional workforce plan that considers current gaps and future workforce requirements 10. Develop and implement a sub-regional workforce development programme 11. Establish a system wide governance group in each district to oversee local implementation of the strategy 12. Implement nationally agreed quality standards and increase the visibility of palliative care quality indicators 13. Implement a patient/whānau satisfaction survey and the VOICES survey to establish a baseline of patient/whānau experience and measure improvement over time	14. Ensure a wide range of responsive and comprehensive service options exist, including 24 hours/ 7 days a week carer, specialist, nursing and medical support, and psycho-social support for those patients and their whānau in the last days of life.	15. Implement culturally appropriate bereavement support services and enable equitable access for those in need of support after death
- Curriculum and development programme for health professionals within primary and specialist palliative care providers across the palliative care system is in place and utilised - Specialist services/primary provider partnership agreements in place and utilised - Active palliative care clinical governance, quality framework and standards monitoring are in place - Patients and whānau report a good death in satisfaction surveys	- End of life transition moments are recognised, documented and well communicated - Health professionals feel well prepared and supported for patient's end of life care - End of life care is resourced appropriately - Support for a patient's whānau through the end of life phase is appropriate for them	- Bereaved whānau have appropriate and accurate information about the post death requirements - Formal and informal carers and whānau are aware of and able to access bereavement support

Next Steps – Implementing the strategy

Achieving the future vision for palliative care across the sub-region will involve a period of evolutionary change over the next five years. Despite the gaps and barriers of the current palliative care system there are some pockets of effective integration and partnership working in each district. The implementation plan will build on this and expand it across services to achieve further integration and enhance the coordination of palliative care services.

Implementation will be achieved through local or sub-regional alliancing arrangements which will be responsible for driving agreed actions to improve the patient and whānau journey. These will ensure clinically-led service development and implementation is within a “best for patient, best for system” framework. The alliances are also expected to build on the work currently underway to implement new Hospice initiatives.

In order to ensure a stable and enduring transition to the future model, it will be important to protect the gains and relationships that have already been made in developing this strategy. The sector is motivated and committed to the coordinated change that is needed as we, locally, regionally and nationally, face the challenge of the increasing and changing nature of future demand for palliative care.



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