# Contents

- Foreword ..................................................................................................................................... 3
- Acknowledgements ...................................................................................................................... 3
- Glossary ........................................................................................................................................ 3
- Executive Summary ...................................................................................................................... 4
- Background .................................................................................................................................. 4
  - What is palliative care? .................................................................................................................. 4
  - Who should access palliative care? .............................................................................................. 5
  - Who provides palliative care? ...................................................................................................... 5
  - How do we respond to palliative care need? ................................................................................ 5
  - What is the national, regional and local context? ......................................................................... 6
  - The population serviced by this Strategy .................................................................................. 8
- Aims and principles .......................................................................................................................... 8
- Strategy goals and objectives ......................................................................................................... 10
- This applies to: .............................................................................................................................. 11
- Implementing this Strategy ............................................................................................................ 15
- Appendix 1: Auckland District Health Board Localities ............................................................... 16
- Appendix 2: The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand ........................................................................................................ 17
Foreword

The development of the Auckland DHB Palliative Care Strategy 2015 - 2018 is informed by the Auckland DHB palliative care’s sector views, national and international research, and the stakeholders’ consultation, including primary and aged residential care sectors, and funding and planning, Auckland and Waitemata DHBs. This Strategy will guide further development of integrated palliative care services across the Auckland DHB district.

Acknowledgements

Many thanks to the members of the Adult Palliative Care Governance Group, health professionals and organisations who contributed their time and shared their knowledge, experience and thoughts; their contributions have been immensely valuable and are greatly appreciated.

Glossary

APCGG - Adult Palliative Care Governance Group
ARPCOG - Auckland Regional Palliative Care Operations Group
Auckland DHB – Auckland District Health Board
DHBs – District Health Boards
MoH – Ministry of Health
RCF - Resource and Capability Framework
WHO - World Health Organisation
Executive Summary

New Zealand faces the challenges of an ageing population and increasing demand for many services, including palliative care. In the Auckland DHB district the number of people 65 and over will double from 50,000 to approximately 96,000 by 2034. The constrained health funding and increasing demand for palliative care necessitate strategic development and robust planning of palliative services across the Auckland DHB district to meet the future population need.

The Adult Palliative Care Governance Group (APCGG) developed the Adult Palliative Care Strategy during 2015. This group includes representatives from community and specialist palliative care services, allied health, primary and aged residential care, and Planning, Funding & Outcomes, Auckland and Waitemata DHBs. The aim of the Strategy is to achieve culturally appropriate, timely and high quality palliative care, which is responsive to patient and whānau need, regardless of diagnosis, prognosis or care setting.

The Strategy is based on the concept that for many people the need for palliative care can be appropriately met by their generalist multi-disciplinary team in close collaboration with specialist palliative care services.

The Strategy will guide further development of an integrated palliative care service model across the district, within the available funding and resources, to ensure the best possible quality of life for people in advanced illness and end of life, and for their whānau.

Background

What is palliative care?

The WHO¹ (2002) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, emotional and spiritual. In applying the WHO definition, New Zealand also takes into account the fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection².

¹ World Health Organisation definition of palliative care (2002)
² NZ Palliative care: a working definition. Palliative Care Subcommittee, NZ Cancer Treatment working party (2007)
Who should access palliative care?

Palliative care should be available to all people with a life limiting illness independent of diagnosis. Palliative care is applicable at any time during the illness trajectory, months or even years before death and should be provided in response to need rather than prognosis.

Who provides palliative care?

Palliative care is integral to the work of all health professionals regardless of their clinical setting or client group. Palliative care is provided in the community, in people’s homes, in aged residential care facilities and in acute hospitals. The majority of palliative care is provided by the patient’s usual care providers such as general practice teams, district nurses, hospital services, residential care staff and patient’s whānau.

Specialist palliative care is provided by most hospice services and hospital palliative care teams. In the Auckland DHB district specialist palliative care is provided by Mercy Hospice Auckland and the Auckland City Hospital Palliative Care Team. These services are staffed with people who have been specifically trained in palliative care providing an interdisciplinary level of service provision.

How do we respond to palliative care need?

The development of a dynamic approach to care provision, based on the concept that for many people the need for palliative care can be appropriately met by their usual care provider, forms the foundation of this strategy. The level of need or complexity can be used to classify patients into three groups, as illustrated in Figure 2. Complexity refers to the capacity of the generalist provider to meet the needs of the patient and family rather than the complexity of the illness.

Figure 2: Three levels of patient need
Group A: the largest group, comprises patients whose needs are able to be met by their usual care providers, and these patients do not need to access specialist palliative care. However, skills to recognise unmet palliative care needs and how to access specialist palliative care services are required by all clinicians involved in the care of patients in this group.

Group B: these patients require episodic access to specialist palliative care services, although these patients continue to have their care managed by their usual care providers in a shared care model.

Group C: is the smallest group. The needs of these patients are unable to be met by their usual care providers and are likely to require ongoing support from specialist services in partnership with the patients usual care provider.

What is the national, regional and local context?

The New Zealand Government developed the New Zealand Palliative Care Strategy in 2001. The strategy was supported by the Ministry of Health (MoH) Nationwide Service Specification for Palliative Care Community Services in June 2001. The service specification provided DHBs with the minimum requirement for palliative care services that should be provided for their populations. The MoH is undertaking a review of the specification. The
specification is to be re-tabled for endorsement by the General Managers Planning & Funding, Auckland and Waitemata DHBs once the request for a new outpatient non-clinical follow-up code is included in the specification.

The MoH commissioned development of the Resource and Capability Framework (RCF) for integrated adult palliative care services in New Zealand (Appendix 2). The RCF was developed in 2013 in close collaboration with the sector and with guidance from the MoH’s Palliative Care Advisory Group. The development of the RCF was based on a role delineation approach, which involves differentiating services by their level of complexity. The framework supports consistent access to integrated palliative care across the country.

In 2006 the Adult Palliative Care Governance Group was established. This group developed 13 initiatives including the Palliative Care Network, improved information sharing through access to existing IT systems (such as CONCERTO) for MHA, the development and implementation of a last days of life care plan and the development of the Primary Care Palliative Care programme in partnership with the Primary Health Organisation, ProCare. In addition, the group commissioned Needs Assessment and Recommendations for Service Development, 2008, which has been used to guide the development of palliative care services through to 2013. The second key document, Palliative Care Education Strategy, 2010-15 outlined a coordinated district wide approach to education across the district. Further work is needed to implement this strategy.

For a period of time the APCGG was in abeyance however in October 2014 the group reconvened with a mandate from senior management to oversee the strategic development of palliative care services across the district. This group includes representatives from community services and hospital palliative care services (specialist and non-specialist), allied health, primary care and Planning, Funding & Outcomes, Auckland and Waitemata DHBs. This group has been instrumental in developing this strategy and will be involved in the development of a work plan to support its implementation.

Governance for the Auckland Regional Palliative Care Operations Group (ARPCOG) had been provided under the Northern Regional Cancer Network. This alignment stopped in early 2014 as the Cancer Network reviewed their governance structure. The ARPCOG has written to the Auckland DHB senior management team requesting support for a new regional palliative care collaboration which will provide a forum to address those activities that would more efficiently be addressed regionally.
The population serviced by this Strategy

The Auckland DHB district is broken down into nine geographical board areas. Auckland DHB has recently committed to developing service provision models within localities which align with the nine geographical areas (Appendix 1). The goal of this approach is to put local communities at the heart of health service planning and delivery, and better coordinate and integrate health services at the local level. This will allow individuals, whānau and communities to take greater control over their lives to maximise their health.

Auckland DHB has an ethnically diverse population of approximately 478,000 Auckland DHB (2015)\(^3\): with 8.3% Māori, 11% Pacific, 29% Asian and 52% European/Other. Over 40% of our population were born overseas and we have one of the highest non-English speaking areas in NZ with over 100 different languages spoken. We are a relatively young population with 10% aged over 65 years and over, compared with 12% of the NZ population.

Auckland population is expected to grow to 610,000 by 20343. The Maori population is projected to grow by 14%. Auckland’s Asian population is projected to grow by 60% by 2034, against an overall growth of 31% for the DHB. In 2033, Asian people will make up 36% of the population of Auckland DHB.

By 2034 the number of people 65 and over will double from 50,000 to approximately 96,000, making up 16% of our population.

Aims and principles

The aim of this strategy is to achieve appropriate, timely and high quality palliative care, which is responsive to patient and family need, regardless of diagnosis, prognosis or care setting. We aim to provide “palliative care without walls”, based on needs not on location.

In order to achieve this we must work towards:

- Empowering communities
- Collaboration, integration and partnership between all services resulting in seamless delivery of care
- Raising the awareness of advanced care planning and palliative care supports and services amongst the Auckland DHB population
- Enhancing understanding of the services available for those with palliative care needs
- Ensuring that all health care providers have the necessary skills and knowledge to provide palliative care with the support of specialist services where needed

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\(^3\) Auckland DHB Health Needs Assessment (2015)
• Keeping the patient experience at the centre of service design
• Delivering high quality services that ensure health equity for all including Māori.

The guiding principles of the Auckland DHB strategy are:

• Compassion is an ethical imperative.
• Health equity is an integral component of a high quality Palliative Care Service.
• Social and cultural diversity adds value and must impact on the provision of appropriate palliative care.
• Strengthening community capacity is key to ensuring that where possible palliative care is provided within the community.
• The individual with a life limiting illness, their family and whānau comprise the unit of care.
• The majority of palliative care is provided by the patient’s usual care providers and where needed supported by specialist palliative care services.
• An integrated palliative care framework using a ‘hub and spoke’ approach emphasises the role of both primary palliative care providers and specialist palliative care services and ensures a sustainable and comprehensive palliative care service.
• Where ever possible there will be a regional approach to service development and innovation.
• The allied health workforce is an integral component of providing good palliative care.
• The entire care pathway recognises that dealing with loss and bereavement is a major component of care.
• Quality palliative care responds to needs across all domains including clinical, psychological, spiritual and social.

Enablers of an integrated approach include:

• Formalised shared-care arrangements between providers
• Use of consistent care pathways and shared clinical management guidelines and IT systems
• Telehealth services to support virtual working for palliative care specialists
• Coordinated 24 hour access to an appropriate level of care including specialist palliative care
• Development of culturally appropriate, competent, accessible and responsive services
• Strong links to whānau, hapu, Iwi and Whānau Ora providers
• Clarity of roles and responsibilities, underpinned by formal agreements
• Clear and systematic purchasing framework based on needs across the pathway
• Education and training for non-specialist palliative care providers
• Shared communication and IT systems accessible by all service providers.

Strategy goals and objectives

Goal 1: To provide integrated and seamless patient, family and whanau focused care for all people with a life limiting illness regardless of diagnosis, prognosis or care setting
This applies to:
• specialist services provided by Mercy Hospice Auckland and the Auckland City Hospital Palliative Care Team
• all other healthcare providers involved in the care of patients with palliative care needs and their families.

Objectives

• Develop a service model that utilises the Framework for integrated adult palliative care services and a ‘hub and spoke’ approach which supports patient centred care
• The service model will be responsive to the needs of all cultures, including Maori
• Explore, develop and implement a lead provider model which will provide clinical leadership and governance across the continuum of care
• To develop and implement a shared information platform that supports a clinical record accessible to all health professionals involved in providing care across the hospital-community interface
• To develop a single point of entry to the suite of palliative care services that is effective in identifying those who require specialist palliative care when they need it
• To ensure equity of access to palliative care no matter the location of the patient in Auckland District
• To integrate palliative care services and staff within the locality model of service delivery to ensure integration of services is maximised with primary care, aged care and other community providers
• Develop palliative care models of service delivery that support aged care services to deliver care and avoid unnecessary admissions of those at end of life
• To work with primary care services in order that urgent care options are planned for and available for those with palliative care needs
• To develop an after-hours service for specialist palliative care services including hospice and hospital based services
• To identify an appropriate core data set and process for consumer feedback that can be implemented to collect information to monitor and benchmark appropriate quality indicators for palliative care provision

• To improve psychosocial supports available to those with palliative care needs as part of the pathway of care.

**Goal 2:** To empower our community to care in the best way possible for those affected by life limiting illness, and death

**This applies to:**

• all those living in the Auckland DHB district and those outside the district who are served by Auckland DHB health providers

• the Auckland City communities, especially those affected directly and indirectly by life limiting illness

• education providers involved in training health practitioners at undergraduate, graduate and postgraduate levels

• organisations and individuals that provide palliative care services and support including primary care teams, district nursing and allied health teams, hospital teams, hospices, aged care facilities and not for profit organisations involved in patient and caregiver support

• those involved in the funding and planning of health and community services.

**Objectives**

• To establish and resource a steering group to oversee the implementation of the Palliative Care Education Strategy

• To improve palliative care knowledge, skills and behaviours of health professionals, non-clinical staff and volunteers across generalist care settings

• To ensure the education focusses on holistic palliative care across all domains meeting the needs of all providers and patients and their whānau

• To provide appropriate education and training for nurses, doctors, pharmacists and allied health professionals (both specialist and non-specialist palliative care) within a framework of workforce planning, and informed by population based needs analysis

• To maximise educational opportunities through enhancing collaboration, inter-professional networking and liaison amongst those working in palliative care

• To increase involvement in palliative care research across Auckland, nationally and internationally
• To facilitate the development and delivery of high quality, culturally appropriate educational interventions and materials that reflect best educational, subject discipline and palliative care practice

• To support advanced care planning in communities and across all health care services, to encourage patients and their families/whanau to feel in greater control of their care plan as they reach the end stages of their lives

• To promote awareness and discussion of issues relating to dying, death and end of life care across our communities; and identify ways of building community resilience to support people with life limited illness

• Wherever possible utilise a co-design approach to service development and innovation

• To ensure appropriate engagement with Maori in the development and implementation of new models of care.
Goal 3: To develop a sustainable palliative care workforce inclusive of all care providers that is responsive to the needs of patients and their families

This applies to:

- generalist health care workforce including: general practice teams, aged residential care staff, hospital staff, district nurses, and other community based services
- specialist palliative care workforce including Mercy Hospice Auckland and the Auckland Hospital Palliative Care team.

Objectives

- Define the roles and accountabilities of the workforce across the sector
- Support the workforce to work to its full capacity and capability within the model of care
- Support staff to deliver sustainable services through appropriate staff support and debriefing for those working within palliative care groups and services
- Enhance the role of allied health professionals within palliative care services, identify gaps in service provision and address these in partnership with funding and planning teams
- Support the development of training posts across medicine, nursing and allied health to ensure the specialist workforce is equipped to meet the growing needs of the population
- Support the development of advance training post in palliative medicine as advocated by Health Workforce NZ
- Support staff in providing culturally appropriate services working effectively with non-English speaking service users, carers and interpreters
- Actively support the development of a regulated Māori palliative care workforce.
Goal 4: To influence the development of palliative care at a national and regional level

This applies to:

- all specialist palliative care providers
- all other health care providers involved in providing palliative care
- Planning, Funding & Outcomes team, DHBs.

Objectives

- To support the development and endorse the business case for a regional forum
- Identify and communicate issues that are best addressed at a regional level using the regional forum
- Work with local, regional and national organisations to support the integration of palliative care across clinical settings and service providers.
- Advocate for and influence the development of national initiatives relating to palliative care
- Set the expectation that all people receiving palliative care and their whānau will have equitable access to high quality services.
Implementing this Strategy

In implementing this Strategy, Auckland DHB is committed to the development and implementation of a lead provider model that supports the integration of systems and processes across the continuum of care. The Strategy emphasises the role of the patient’s usual care provider and the specialist provider in providing sustainable and comprehensive palliative care to meet the needs of the Auckland DHB population. The Strategy recommends that patients receive care which is based on need rather than diagnosis, prognosis or place of care. In order for the generalist-specialist model of care to be effective, the generalist workforce needs to be supported to provide palliative care for the majority of people with a life limiting illness. This means there is likely to be an increase in the acuity and complexity of patients seen by specialist palliative care services. In addition specialist services will need to increase their support and education of generalist providers influencing indirectly the care of all patients with a life limiting illness and their family.

The role of the Adult Palliative Care Governance Group is pivotal to the successful implementation of the Strategy and the overseeing of the various steering groups, some of which are already fully embedded in current service provision such as the Last Days of Life Steering Group and the Palliative Care Network. While other steering groups such as the Palliative Care Education Group has yet to be established. An action plan will be developed by the Adult Palliative Care Governance Group to ensure the timely implementation of this strategy.

Implementation of the Strategy has implications for existing service configuration and service planning, including opportunities to:

- identify current and future population need and map this against existing services
- develop and implement a lead provider model to achieve an integrative model of service delivery across the care continuum
- promote collaborative links between all providers of palliative care and integration across specialist palliative care providers
- develop agreed referral criteria which reflects the best use of a service in order to meet population needs
- determine palliative care workforce configuration and new models of care delivery
- ensure the contribution of the allied health workforce is included in the development of future models of care
- align local service development with regional and national initiatives in palliative care to ensure connected, seamless and streamlined well planned care models
• develop performance improvement, monitoring and accountability mechanisms that ensure services achieve equitable access to high quality palliative services for all, including Māori.

Appendix 1: Auckland District Health Board Localities
Appendix 2: The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand

The framework that was agreed by the Ministry of Health following stakeholder consultation is presented in figure 1.

Figure 1: Framework for integrated adult palliative care services

The patient, family and whānau are at the centre of the framework, with the primary carer providing the first level of care. In many cases the primary carer is a family member who takes the general role of coordinating and delivering care and supporting the patient. The primary carer as a family and whānau member is both a provider of care and a recipient of supportive care.
The primary care provider (for example, general practice teams, district nurses and residential care staff) works in an ‘integrated approach’ with secondary care providers, specialist palliative care services.

Specialist palliative care services will provide care in response to individual patient and/or family need. The provision of this care will be assessed as being greater than that which can be provided by the usual care providers. Care may be episodic or sustained depending on the needs of the patient, family and whānau.