Hidden in Plain Sight;

Recognising and growing the palliative care skills of allied health professionals.

A discussion document written by the
Allied Health Workgroup,
Te Whatu Ora – Health New Zealand
Te Waipounamu Regional Programme Office,
Aotearoa New Zealand.

October 2022

Te Whatu Ora
Health New Zealand

Te Waipounamu
Programme Office

Cover photo: *Weaving the threads of health.* Mary James

Allied Health Workgroup. (2022). Hidden in plain sight; Recognising and growing the palliative care skills of allied health professionals. Christchurch: Te Whatu Ora – Health New Zealand Te Waipounamu Regional Programme Office

Foreword

This report has been a long time coming. The personal motivation to initiate the project back in 2018 came from years of working alongside dedicated allied health professionals (AHPs) in the acute hospital environment. Their wealth of expertise often goes unrecognised and unappreciated. Every day I witness their dedication and professionalism and am ever grateful for their willingness to learn on the job, having often not encountered dying patients before in the course of their training or practice. Palliative care is challenging; the "standard" treatment may no longer be applicable or possible, requiring imagination and resourcefulness, teamed always with collaboration with the patient, their whānau and the wider healthcare team.

This work is formative; the first time in Aoteoroa New Zealand that AHPs have come together to articulate their role and place in working with those who are living with a life-limiting illness. It is collaborative, in that the Allied Health Workgroup (AHW) members, who came from eight distinct professional disciplines, were able to weave together their professional experiences, honouring both their similarities and their differences. It is also aspirational, signalling a pathway for those who wish to understand, recognise, and grow the palliative care skills of our allied health (AH) workforce in Te Waipounamu South Island and throughout Aotearoa.

The discipline-specific reports in this discussion document should serve as a starting point for AHPs who wish to further develop their skills, or furthermore, to work as part of a hospice or specialist palliative care service. Employers will also find the proposed palliative care competencies useful for developing job descriptions, career pathways, workplace education programmes, and individual development plans for their AH workforce. I am also hopeful that the main body of the work will provide a platform for change, to ensure that the AH workforce is developed and supported in the future, as an integral part of the palliative care system across Aoteoroa.

I am indebted to Jo Hathaway, Karla Poyner and all the AHW members for their diligence, persistence and enthusiasm. Jo and Karla had the unenviable task of keeping such a diverse and passionate group on task and supporting them to bring the discussion document to fruition. This has been a great project and I am confident that it will stand the test of time.

Dr Kate Grundy

Palliative Medicine Physician, Christchurch Hospital
Clinical Director, Canterbury Integrated Palliative Care Services
Chair, Waitaha Canterbury Clinical Ethics Advisory Group
Te Waipounamu/Waitaha Canterbury

Te Whatu Ora
Health New Zealand

Acknowledgements and limitations

A project such as this compelling brief of work does not present itself very often. It requires the vision and support of leaders in the health sector to set out the expectation, outcomes, and a plan to suit. Our appreciation is extended to Dr Kate Grundy for her stewardship and mentoring.

The Palliative Care Workstream (PCW) of the Te Waipounamu Regional Programme Office was able to draw together a wide range of AHPs, some working within the specialty, but all with a deep interest in palliative care. We thank the members of the PCW for their foresight, support and trust in us, the members of the AHW, to advance this important project. Whilst we share the commonality of being based throughout Te Waipounamu South Island, we trust that this work will have relevance for our colleagues throughout Aotearoa New Zealand.

What has bound us together as a workgroup from such diverse professional backgrounds has been our passion not only for our respective professions, but also to the evolving area of palliative care and ultimately the patients and their whānau that require these services. As a group, we are both humbled and inspired by them, their experiences, and the privilege they bestow on us in allowing us to share in their end-of-life care.

This discussion document was written by members of the AHW:

Karla Poyner **(Chair)**, Business Manager / Physiotherapist, Motus Ashburton
Jo Hathaway, **(Facilitator, Te Waipounamu Regional Programme Office)**, Registered Nurse
Karen Kennedy, Clinical Advisory Pharmacist Timaru and Palliative Care Workstream member
Janeen Richardson, Occupational Therapist, Nurse Maude Hospice
Mary James, Social Worker, Nelson Tasman Hospice
Dr Matthew McDonald, Clinical Psychologist / Allied Health Team Leader, Hospice Southland
Melody Chen, Pharmacist, Unichem Crisps Pharmacy, Christchurch
Nicki Kitson, General Manager - Hospice Marlborough, Occupational Therapy
Paula Hogg, Social Worker, Te Whatu Ora – Health New Zealand South Canterbury
Theona Ireton, Kaitiaki Oncology, Te Whatu Ora – Health New Zealand Waitaha Canterbury and Palliative Care Workstream member

Additional input was received from:

Alexandra Smedley, Speech Language Therapist, Te Whatu Ora – Health New Zealand Waitaha Canterbury
Major Clive Nicolson, Chaplain/Bereavement Support, The Salvation Army – Hospice Marlborough
Helen Brown, Dietician, Nurse Maude Hospice

AHPs belong to professional associations and/or regulatory boards that encompass a wide range of practitioners, some of whom work outside of the health sector. Hence, their professional standards and/or competencies are necessarily broad to accommodate the breadth of roles, responsibilities, and employment settings.

It is also important to note that the information in this document is based on korero with a multitude of our colleagues, education providers and regulatory bodies, within the limitations of timeframes and resources. Additionally, while many professionals with diverse expertise have contributed to this work, not all allied health voices are represented here.

Completion of this work was delayed by the COVID-19 pandemic. While every effort was made to ensure the accuracy of information when it was obtained (mostly during 2019), changes will have occurred in the interim, and readers are encouraged to seek the most current information directly from the service, organisation, or specialty they are interested in.

Contents

Foreword iii

Acknowledgements and limitations iv

Introduction 6

Background 7

Overview 9

Stage one: Identifying challenges 9

Stage Two: Available training options 10

Stage Three: Palliative care competence frameworks 14

Stage Four: Key findings and next steps 19

Key findings 19

Next steps 19

Conclusion 21

Bibliography 22

Appendix A: Discipline Specific Reports 23

Chaplaincy 23

Dietetics 29

Occupational Therapy 33

Pharmacy 39

Physiotherapy 65

Psychology and Counselling 78

Social Work 82

Speech Language Therapy 94

Appendix B: Definitions 107

Introduction

Although the most visible roles in the provision of palliative care services in Aotearoa New Zealand (NZ) are nursing and medical, the allied health (AH) workforce plays an integral part in enabling those with a life-limiting illness to live as well as possible. Just as it takes a village to raise a child, so too, it takes a full complement of the multidisciplinary team to provide holistic care to a person and their whānau. But when, and how, do allied health professionals (AHPs) develop their palliative care knowledge and skills? Although AHPs weave in and out of patients' care across their life span, there is currently little guidance on how they are trained and supported to deliver palliative and end of life care in NZ.

The Allied Health Workgroup (AHW) was established by the Te Waipounamu Regional Programme Office in December 2018. With support from the South Island Palliative Care Workstream (PCW) the AHW was tasked with evaluating the palliative care training and support that is currently available to AHPs throughout Te Waipounamu South Island. The workgroup also investigated ways that AHPs can be better supported to develop their palliative care skills and confidence.

This discussion document is formative, collaborative, and aspirational. It includes an overview of the project and details the four key stages of work undertaken by the AHW:

Stage one; Identifying challenges.
This included initial discussions with stakeholders to identify and summarise existing challenges and determine the direction of work.

Stage two; Training options.
This stage required the identification and evaluation of palliative care training, education, and support currently available to individual AH specialties in Te Waipounamu South Island. Discipline-specific summaries are included here with the full reports in Appendix A.

Stage three; Palliative care competence frameworks.
This involved an examination of existing international palliative care competencies for AHPs. Members proposed ways in which palliative care competencies could be developed for Aotearoa New Zealand, based on the Irish Palliative Care Competency Framework (Palliative Care Competence Framework Steering Group, 2014). Discipline-specific summaries are included here with the full reports in Appendix A.

Stage four; Key findings and next steps.
The key findings are identified along with proposed next steps.

Appendix A.
Detailed reports written by individual workgroup members for eight allied health professions:

Chaplaincy
Dietetics
Occupational Therapy
Pharmacy
Physiotherapy
Psychology and Counselling
Social Work
Speech Language Therapy

Background

In order to ensure a common understanding of the terms used in this document, we recommend readers refer to the New Zealand Palliative Care Glossary (Ministry of Health, 2015). Key definitions relevant to this discussion document are also listed in Appendix B.

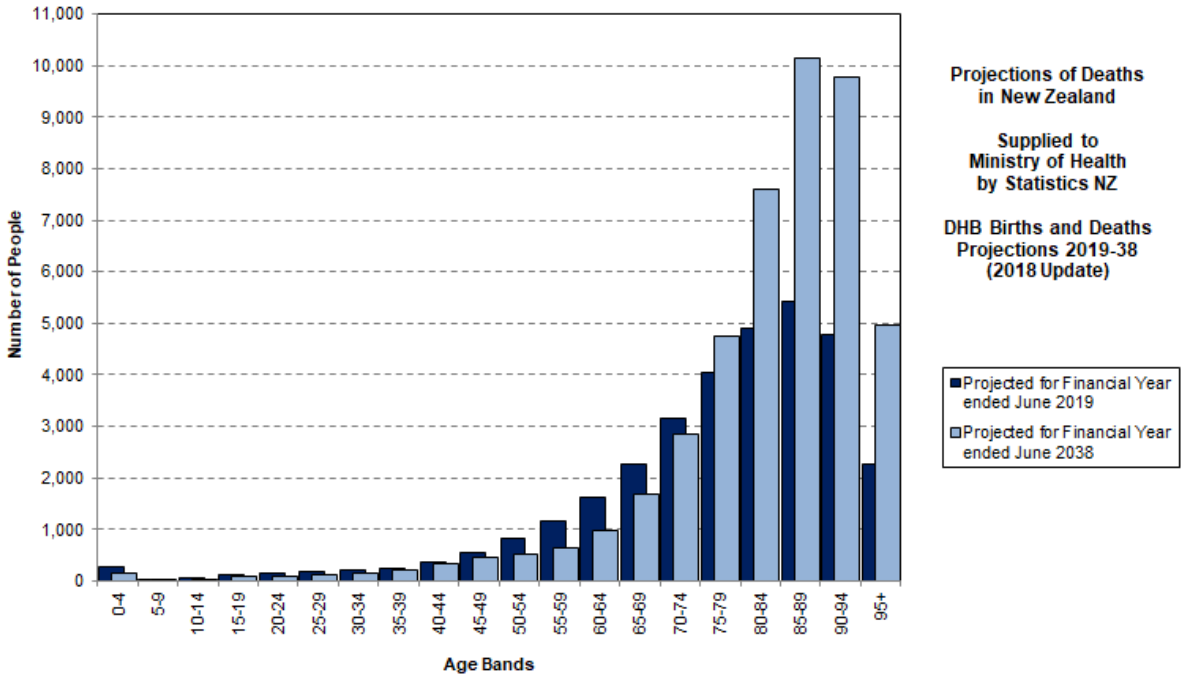
It is clear that AHPs are integral to the provision of palliative care. They have an important contribution to make and are vital to ensuring that current and future health service needs are met across all care settings. AHPs need to be well-trained, skilled, and supported to enable them to deliver high quality palliative care within an integrated health system that recognises the importance of timely, comprehensive, and holistic end-of-life care. Unfortunately, many AHPs enter the workforce feeling ill-prepared to provide end-of-life care, despite many of their skills being both transferable and highly valuable. Coupled with this, AHPs often struggle to access ongoing education and support opportunities tailored to their needs.

Advances in social and health care over recent decades in NZ have resulted in greater numbers of people reaching older ages than ever before. This inevitably leads to more people facing the end of their lives at older ages, and with more complex health needs, than previously.

As mentioned by McLeod & Atkinson (2019), Statistics NZ projected in their 2018 Update that deaths will increase from 32600 in 2019 to 45500 in 2038. Statistics NZ (2022) currently projects total deaths in NZ to increase from 36,400 in 2023 to 66,300 in 2073. In addition to the increasing number of deaths, there is also a dramatic increase projected in the average age of people at the time of their deaths (see Figure 1).

Figure 1

Projected deaths by age in New Zealand 2019 and 2038



Reprinted from Policy brief on place of care and time in the community at the end of life in New Zealand (p. 8), by H. McLeod and J. Atkinson, 2019.

Meeting the palliative care needs of this growing, and increasingly medically complex group will be a challenge for NZ. Ensuring that all members of the multidisciplinary health team are equipped to provide skilful care at the end of patients' lives, in all care settings, will be integral to maintaining the

sustainability of our health services and ensuring all patients and their whānau receive high quality and person-centred palliative and end-of-life care.

In this context, it was thought timely to put the allied health workforces' contribution to palliative care and their support needs under the spotlight. It is hoped that this work will inform health care providers to better understand the current situation and support meaningful change.

Equity considerations were paramount during this project. "You cannot be clinically competent if you're not culturally competent" (Riki Nia Nia, 2018, as cited by Te Tumu Whakarae, 2020).

The Ministry of Health's definition of equity is: *"*In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches with resources to get equitable health outcomes" (Ministry of Health, 2019, para.3).

Throughout this report consideration was taken to ensure Māori and other vulnerable groups were specifically considered, in recognition of the need to ensure that any opinions/recommendations do not exacerbate existing health inequities.

Overview

This section focuses on the process undertaken by the workgroup. It details the following four key stages:

Stage One:	Identifying challenges
Stage Two:	Training options
Stage Three:	Palliative care competence frameworks
Stage Four:	Key findings and next steps

Stage one: Identifying challenges

Once the AHW was established, the first task was to examine the brief given by the PCW and agree the project aims and scope. This translated into group discussions of possibilities and limitations and consultation with colleagues/stakeholders. Workgroup members identified many factors currently influencing the 1) role; 2) education and training; and 3) resources available to AHPs in Te Waipounamu South Island. These are summarised below:

Lack of clarity regarding the role of allied health in the provision of palliative care

- There is currently a lack of clarity regarding the role and contribution of AHPs in the provision of palliative care, especially in services that do not provide specialist palliative care. This may result in:
  - Further palliative care training and education not being recognised as needed or sought by individuals
  - Palliative care professional development and education not being prioritised by employers
  - Those who have completed further palliative care education may remain underutilised by team members who are unaware of the contribution they can make
- AHPs are often consulted too late in a person's care, or only when a crisis has occurred, as opposed to being part of routine planned care
- Many AHPs may not recognise the transferability of the skills they already have, the contribution they can make, or the palliative approach they are already providing to patients
- Few AHPs are employed in specialist palliative care services (e.g., hospices and hospital palliative care teams), and those that are working in specialist palliative care services are often in a lone role and/or working part-time
- Historically many AHPs were not included in patient care discussions or documentation, resulting in a culture of underrepresentation, and undervaluing of their skills and contribution
- There is a lack of published literature on the contribution and role of AHPs in palliative care, especially in Aotearoa New Zealand
- There can be variability in the education, training and/or practice pathways for some allied health specialties, leading to confusion about the skills they hold

Paucity of education and training opportunities designed specifically for allied health

- Many AHPs may not enter their professions with an awareness of, or interest in, palliative care. However, most will encounter people with life-limiting illnesses during their career
- Many undergraduate curricula for AHPs cover generic topics, of which palliative care may be only a minor component. Graduates may not appreciate when, and how, a palliative approach to care can be part of their day-to-day practice
- AHPs can undertake postgraduate programmes in palliative care in Aotearoa New Zealand however, these do not focus specifically on allied health practice, so individuals need to tailor the

papers to meet their own specialty and practice area. Discipline-specific postgraduate programmes in palliative care are available internationally

- Historically Health Workforce New Zealand (HWNZ) have not provided funding for AHPs to complete postgraduate education
- Most palliative care training for AHPs happens informally in the workplace (experiential learning, on-the-job training etc). It is often:
  - Ad hoc
  - Variable/inconsistent in quality and content
  - Dependent on the availability of workplace mentors, champions, or resource people
  - Unstructured (not necessarily underpinned by policies, competencies, professional development pathways/career progression plans or professional body guidelines)
- There are many good palliative care education and professional development opportunities that are available via various providers, but many have barriers to access/attendance including:
  - Requiring membership/employment with the host organisation (e.g., Pegasus workshops, HealthPathways, health Learn). Access is especially difficult for AHPs in private practice
  - Requiring physical attendance at an offsite location – often problematic due to the investment of time, travel and accommodation required (e.g., Hospice New Zealand Fundamentals of Palliative Care modules)
  - Many AHPs work part time and in lone roles making it difficult to gain release from their workplace or find cover for their case loads
- Many AHPs (and their employers) are not aware of the range and usefulness of the palliative care education that is available
- Currently there are no clearly defined career pathways for AHPs to develop their palliative care knowledge and skills and have these recognised by their employer

Limited access to palliative care practice resources for allied health professionals

- Resources are fragmented (and often replicated) across multiple services and sites. AHPs may not know of, or where, to look for palliative care resources relevant to their area
- The Palliative Care Handbook is a very useful and well-regarded resource, and freely available for download from the Hospice New Zealand website however, few AHPs are aware of this
- There are many established online palliative care special interest networks in Aotearoa New Zealand, and internationally, that are open to AHPs however, access to some networks is restricted to those who hold particular professional memberships or employment relationships
- However, recently a Palliative Care category has been added to Allied Healthways. This includes a definition of palliative care and details around assessment and management for AHPs. It also includes links with CareSearch to a series of clinical evidence summaries.

Stage Two: Available training options

In order to understand the readiness of AHPs to provide a palliative approach to care, the initial focus of the AHW was to undertake an inventory of the training, education, and support currently available to the allied health professions represented within the group. A preliminary investigation into undergraduate education was undertaken, extending to workplace/professional education opportunities and then postgraduate study for each discipline.

A summary of each investigation is included below with the detailed findings from this work contained in the respective **discipline-specific reports listed in Appendix A**. It is important to note that the information gathered was based on enquiries with as many colleagues and education providers as possible within the limitations of timeframes and resources available. Therefore, the information may be incomplete and will be subject to change over time.

Chaplaincy

Chaplains strongly embrace the pastoral and spiritual care of patients suffering with life-limiting illness and their whānau. However, it is essential that the chaplain holds a sound knowledge of the wider practice of palliative care. Due to the absence of formal palliative care chaplaincy training, learning on the job and building on a sound chaplaincy background is essential. The pathways into any chaplaincy role are many and varied and includes clergy ordination, Hospital, Military, and Industrial Chaplaincy training courses. All provide a background to chaplaincy however ongoing learning in palliative care is crucial with the availability of further education via the Hospice New Zealand Fundamentals of Palliative Care and the Hospital Chaplaincy course.

Dietetics

We were fortunate to gain dietetics input in the later stage of this project therefore prioritisation was given to a proposed set of competencies rather than a summary of the available training options for dietetics.

Occupational Therapy

Occupational Therapists, with their unique role supporting people to achieve their maximum independence in everyday activities, is synonymous with the focus of specialist palliative care, which by its very definition is focused on optimising an individual's quality of life until death. It makes sense then, that Occupational Therapy is one of the allied health professions that needs to be represented, in some way, in all specialist palliative care services.

The outcomes of this working group are seen as fundamental in raising awareness; continuing to reinforce and develop the role of Occupational Therapy in specialist palliative care. One of those outcomes has been to identify what emphasis, if any, is placed on palliative care in the training our Occupational Therapists in Aotearoa New Zealand. Simply, there is room for significant improvement in education and in recognising the essential role the profession has for people with life-limiting illness.

Undergraduate training programmes currently touch on palliative care and due to the foundational nature of their training curriculum, opportunities appear limited in both training institutions; AUT and Otago Polytechnic. However, for these institutions, there is a role to play to highlight the advanced practice roles available for occupational therapy practitioners. Currently those registered occupational therapists who gain further knowledge are doing so through workplace learning opportunities and limited 'generic' formal post graduate training programmes, however accessibility and cost do serve as a significant barrier.

Pharmacy

All pharmacists providing pharmacy services to patients, regardless of their work setting, will be providing care to palliative patients and their carers and/or whānau. Therefore, there are core palliative care competencies that undergraduate programmes need to be equipping our pharmacy undergraduates with. It is difficult for pharmacist undergraduate programmes to cover all areas at a depth that will enable specialised practice immediately upon graduation; particularly since in NZ undergraduate programmes are only graduating pharmacist interns, not fully registered pharmacists. Accordingly, palliative care undergraduate education for pharmacists covers some of the key concepts, but pharmacists wanting to provide specialist palliative care services or work as part of a specialist palliative care team will benefit from further palliative care education.

There are no pharmacist-specific postgraduate palliative care programmes offered through the Schools of Pharmacy at Otago and Auckland Universities that can prepare pharmacists working in or wanting to work in palliative care. However, the University of Auckland and University of Canterbury both offer a Postgraduate Certificate, Diploma and Master of Health Science that can be endorsed

with palliative care. Whilst not pharmacy specific, students are encouraged to focus on their own specialty area of practice and incorporate this into their learning. Pharmacists can also choose to study individual university papers pertaining to palliative care.

The Pharmaceutical Society of NZ (PSNZ) often is the first port of call for pharmacists seeking education packages, offering one palliative care resource for purchase, a self-directed learning Palliative Care Basic Practice update workbook which is a useful introduction to palliative care for pharmacists. For most community pharmacists, palliative care education after graduation is gained from Hospice NZ courses run by hospices or opportunistic single education sessions run by organisations such as Pegasus Health Pharmacist small group education.

Physiotherapy

There are a small number of physiotherapists working in specialist palliative care services however all physiotherapists will at times in their career contribute to the provision of palliative care. A 2019 workforce survey reported that 58% of physiotherapists with an annual practicing certification worked in private practice with 26% in hospital and health services. Training therefore needed to be available to those working in both the public and private sectors.

Palliative care education for undergraduates is present, however, it is not extensive at either Auckland University of Technology or Otago University School of Physiotherapy. There is no physiotherapy specific qualification in palliative care in New Zealand. Workplace education, monthly hospice education sessions and experiential learning are often the source of further education for those working in palliative care.

Barriers to accessing further training include cost and travel. Training that includes online modules and flexibility regarding time and location with online support groups are deemed to be attractive. Often positions in a specialist palliative care/Hospice setting are not full-time equivalents, therefore the cost of further training is high in relation to the remuneration for the position.

Psychology and Counselling

There are limited opportunities to develop skills and knowledge or even gain experience in the area of palliative care prior to becoming a registered practitioner. In regard to psychology undergraduate education at Otago University, palliative care is absent as a subject however grief and loss are recognised in introductory lectures. There are no specific psychology post graduate programmes in NZ however there are non-discipline specific palliative care post graduate qualifications.

Specific to counselling the Bethlehem Institute of Technology has a flexible programme that allows students with an interest in palliative care to tailor assignments to this interest. The University of Canterbury Master of Counselling programme allows 60 points to be completed from the Health Science Palliative Care papers.

A lot of learning about palliative care occurs in the work context via experiential learning with opportunities to upskill via Hospice NZ and HealthLearn resources.

Social Work

Health Social Workers work with a range of people with palliative care needs across community, hospital, and hospice settings. They are involved with palliative care at a generalist and specialist level. The core ethics of Social Work align with the principles of palliative care, and all Social Workers are familiar with providing holistic care from a strengths-based perspective. Social Workers are highly skilled in communication and working with whānau. Social Workers are familiar with working with

issues such as loss and grief as well as wider social issues. Social Workers assist whānau in navigating a place of care for patients with palliative care needs.

Specific palliative care training is often learned 'on the job'. All Social Workers are encouraged to attend the Hospice New Zealand Fundamentals of Palliative Care education sessions to support their knowledge when working with those who have palliative care needs.

For Social Workers working in Te Waipounamu, formal post-graduate interdisciplinary education is available via the University of Canterbury and is able to be focused on topics specific to palliative care Social Work. Efforts are currently being taken to include palliative care education into the new Te Pūkenga curriculum. To support palliative care Social Work practice, publication of palliative care Social Work research is readily available internationally and is an emerging field of practice in Aoteoroa.

Speech Language Therapy

Speech-language Therapists work with people with communication and swallowing disabilities in a wide range of settings across health and education. Speech-language Therapists can register with the NZSTA; a self-regulating body. The NZSTA keeps a register of all members. The private practice listing provides information about private practice Speech-language Therapists across the country including their specialist area of expertise.

Speech-language Therapy training is available through the current training institutes at Auckland University, Massey University and Canterbury University. Basic training in palliative care is available for all undergraduate and post-graduate students. Further training is available through web-based teachings, courses, and in-house training.

There is currently no clear career pathway for Speech-language Therapists wanting to specialise in the area of palliative care. Although basic education is provided in both undergraduate and post-graduate courses, there is a lack of further training opportunities, mentoring and recognition of this as a specialisation.

Summary of available training options

Overall, it was possible to identify several common themes in the palliative care training, education, and support available across these essential AH disciplines. These themes included:

- Informal / non-structured education pathways
- Little or no coverage in under-graduate courses of how to apply their professional skills to meet a palliative approach to care
- Ongoing education most often motivated by personal interest rather than professional imperative
- Limited choice for ongoing education and courses often delivered with a nursing or medical focus
- Little or no recognition in the workplace of advancing skills in palliative care
- Limited guidance on the skills required by AHPs to provide palliative care.

It was agreed by the AHW that the next step in this project should be an attempt to find existing competence frameworks for each AH discipline that support a structured approach to the development and recognition of palliative care skills from novice to expert.

Stage Three: Palliative care competence frameworks

Initially, members researched their own professional standards for evidence of competencies related to palliative care. However, the roles, responsibilities, and employment settings of the allied health workforce in NZ are diverse (e.g., some Social Workers are employed in non-health care settings) and regulated by separate discipline-specific professional associations and/or regulatory boards. Members found that the current professional standards and competencies that govern each allied health profession were often broadly defined, thereby offering little guidance on how best to apply their skills to the care of patients and their whānau facing end-of-life illness, and few mechanisms for planning, or gaining recognition of, palliative care skills development. In light of these challenges, the AHW hoped to find a common competence framework that could articulate each discipline's contribution to palliative care as well as a structured pathway for skills development.

Identifying palliative care competencies for allied health professionals

Initial research in to existing palliative care competencies involved researching key documents, sourced both nationally and internationally. With the aim of identifying those competencies that could be easily applied to AHPs in the NZ setting and used to inform a process of identifying the overlaps and gaps with existing NZ professional standards/competencies, competency documents from Ireland, Nova Scotia, British Columbia, and NZ were considered.

Ultimately the decision was reached to work with two key documents:

1. **Palliative Care Competence Framework** (Palliative Care Competence Framework Steering Group, 2014).

   This comprehensive and clearly laid-out framework from Ireland identified palliative care competencies for eight allied health professions (as well as medicine, nursing and midwifery and health care assistants):

Chaplaincy / Pastoral Care	Physiotherapy
Dietetics / Clinical Nutrition	Psychology
Occupational Therapy	Social Work
Pharmacy	Speech Language Therapy

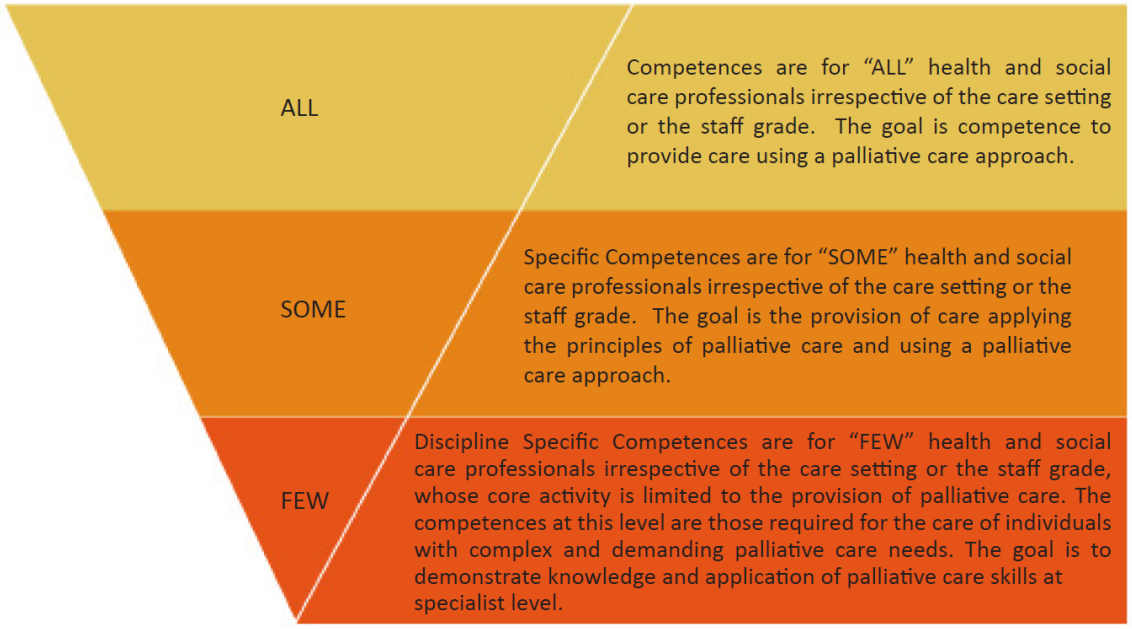
   Each disciple-specific set of competencies was divided in to six domains of competence:

   - Domain of Competence 1: Principles of Palliative Care
   - Domain of Competence 2: Communication
   - Domain of Competence 3: Optimising Comfort and Quality of Life
   - Domain of Competence 4: Care Planning and Collaborative Practice
   - Domain of Competence 5: Loss, Grief, and Bereavement
   - Domain of Competence 6: Professional and Ethical Practice in the Context of Palliative Care

Furthermore, each domain of competence was separated in to the All / Some / Few model of skill development (see Figure 2):

Figure 2

Competence Framework Model, Palliative Care Competence Framework, 2014



The All / Some / Few model helps AHPs to not only assess their current level of practice in palliative care, but also identify the additional skills needed to advance their practice, especially when working in a specialist palliative care setting such as a hospice or hospital palliative care team.

2. **A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand** (Palliative Care Nurses New Zealand, 2014)

   This nursing-focused NZ framework sets out palliative care competencies within the four domains identified by the New Zealand Nursing Council:

   - Domain 1: Professional responsibility
   - Domain 2: Management of nursing care
   - Domain 3: Interpersonal relationships
   - Domain 4: Inter-professional health care and quality improvement

   There are two sets of competencies:

   1. Core palliative care competencies - for all Registered Nurses
   2. Specialty palliative care competencies - for Registered Nurses who work in a specialist palliative care setting (e.g., hospice or hospital palliative care team)

   Importantly, these competencies are applicable to the Aotearoa New Zealand context and provided a vital bicultural perspective which informed our work.

AHW members cross-referenced the applicable competencies found in the above two documents against the current NZ professional competencies and/or standards of their respective allied health disciplines. Members then proposed competencies for their identified gaps and proposals for

opportunities for improvement in the context of 'best fit' for practice in Aotearoa New Zealand. This work is summarised for each discipline below and the full **discipline-specific reports are listed in Appendix A**.

Chaplaincy

A set of competencies for chaplains or pastoral carers in palliative care is a very new concept in Aotearoa New Zealand and so we are grateful to be able to utilise the Palliative Care Competence Framework published by the All Ireland Institute of Hospice and Palliative Care [AIIHPC] in 2014. This has provided an excellent foundation from which to work from in order to draft a set of proposed competencies for use in palliative care in NZ.

Dietetics

The proposed set of competencies is based on the Palliative Care Competence Framework with recommended additions or modifications to reflect culture and practice in Aotearoa New Zealand.

Occupational Therapy

Underpinning practice for all Occupational Therapists in New Zealand are the threshold competencies and Code of Ethics set by the Occupational Therapy Board of New Zealand. These competencies for registration and practice for Occupational Therapists in Aotearoa New Zealand have been updated in 2022 and reflect the modern-day practice of the profession, inclusive of cultural competency. However, they are naturally foundational competencies and do not fully reflect the expectation of therapists practicing in advanced areas of clinical practice - such as specialist palliative care.

As a result of consultation with Occupational Therapy Board we elected to build on their competencies and to propose a set of supplementary competencies for our occupational therapy colleagues who choose to develop their career in this specialist area of health care. We strongly suggest that what we have proposed is used as inspiration, thought and discussion for the profession going forward, specifically in education, professional development, and clinical practice – key components of specialist practice.

Pharmacy

There is no specific palliative care competency framework for pharmacists in NZ that could be used to inform professional development and learning or undergraduate curricula or pre-registration programmes and thereby contribute to preparing pharmacists for delivery of palliative care services. The Pharmacy Council of NZ is the statutory authority that governs the practice of pharmacists and sets standards of competence for pharmacists which details the key competencies and behaviours expected of pharmacists. The document is broad-based by design so that it can be applied across a wide range of practice settings, but out of which should also fall the pharmacist specific competencies that are required in an individual practice setting.

There are two possible approaches to ensure competence standards for pharmacists in New Zealand better reflect the essential competencies required for pharmacist practice in palliative care. The first approach is to draft a specialty-specific palliative care competency framework for pharmacists, and the second is to add core competencies to the Competence Standards for the Pharmacy Profession that reflect the missing palliative care competencies.

With respect to the first approach, a draft Palliative Care Competency Standards Framework has been prepared. The pharmacy competencies in the Irish Palliative Care Framework have been used with the addition and/ or changing of some wording to reflect a NZ context.

Physiotherapy

The Physiotherapy Standards Framework describes the standard of ethical conduct, clinical and cultural competence that all registered physiotherapists must meet. This includes a series of minimal threshold competencies that physiotherapists must apply to their specific area of work, a code of ethics and professional conduct and a series of physiotherapy standards to be applied in specific situations.

When comparing the Physiotherapy practice thresholds in Australia and Aotearoa New Zealand (2015) with the Palliative Care Competence Framework it was first acknowledged they had different intentions. The former is generic and needs to cover all physiotherapists working in different fields of physiotherapy in the cultural setting of New Zealand. The latter is specific to physiotherapists working in palliative care and catered for three progressions of skill level as displayed previously in Figure 2.

The key differences were that the Palliative Care Competence Framework did cover grief, loss and bereavement which is not in the Physiotherapy Standards Framework, and it took communication to a higher and more specific level which is appropriate to palliative care. The Palliative Care Competence Framework was lacking the New Zealand specific cultural competencies due to its creation in Ireland.

It is unrealistic for the physiotherapy practice thresholds to alter due to its purposeful broad nature. It may however be practical to utilise the Palliative Care Competence Framework as an aspirational document used alongside and complimentary to the Physiotherapy practice thresholds with the addition of New Zealand specific cultural competencies. There may be merit in a palliative care physiotherapist practice standard much like the sports physiotherapist practice standard.

Psychology and Counselling

The Psychology profession in New Zealand is regulated by the New Zealand Psychologists Board. The board's role is ensuring the health and safety of members of the public using psychology services, making sure all psychologists meet the specifications of the Health Practitioners Competence Assurance Act 2003.

It is evident that the value of the allied health professions is becoming increasingly recognised in palliative care. Palliative psychology is an emerging field. Psychology has much to offer palliative care, especially considering the range of psychological concerns experienced by patients with a life-limiting illness. Considering the New Zealand context, the work of a psychologist can be generalist and varied with practitioners employed in many healthcare settings. A knowledge of palliative care will be important in all areas and advanced knowledge necessary for some roles, especially those in Hospice and Oncology services.

The proposed psychology competencies have been developed using the current Competencies for Registration as a Psychologist in New Zealand and a number of other competency and guideline documents.

Social Work

The professional body for Aotearoa New Zealand Social Workers is the ANZASW. The regulatory authority is the Social Work Registration Board (SWRB). Both bodies have a set of 10 practice standards or professional competencies that Social Workers are required to meet to maintain their professional practice. Whilst the competencies are slightly different, they are compatible with each other. A key document that underpins all Social Work in Aotearoa New Zealand is the Te Tiriti o Waitangi and this is written into both sets of professional competencies.

Palliative care Social Workers make up a small number of practitioners within the larger professional body of Social Workers. A Scope of Practice for Health Social Workers was produced by ANZASW in 2018, although this does not specifically address palliative care.

Whilst graduating Social Workers may have the generic skills to meet the competency required for providing generalist palliative care, they may not recognise they hold these skills, nor feel comfortable to work in this field of practice. There is a need for all Social Workers to attend palliative care education to develop and refine the skills needed to work with people who have a life-limiting illness.

The proposed competencies draw from the Palliative Care Competence Framework (Palliative Care Competence Framework Steering Group, 2014). The competencies that were missing from the Framework are predominantly based around cultural competence and the ability to work with tangata whenua.

Speech Language Therapy

The Scope of Practice forms one on the key foundation documents for Speech-language Therapists practising in New Zealand. It outlines the parameters for professional conduct, competency regulation and practice. It is not a description of level of education, experience, skill, or competency required to carry out those activities. A Speech-language Therapist does not typically work with all populations or practise in all contexts listed in this Scope. A Speech-language Therapist may only practice in areas in which they are deemed competent by their employer. Assessment of competency is made on the basis of education, training, and experience. Certain employment situations may necessitate that a Speech-language Therapist obtains further education or training in order to expand their personal scope of practice into new areas.

The Scope of Practice for Speech-language Therapists is quite generic to cover all areas of Speech-language Therapy. After graduation, Speech-language Therapists can specialise in different areas and further training is completed as required by their employer. The Irish Palliative Care Competency Framework outlines skills that are specific for Speech-language Therapists treating patients with life-limiting conditions. It is a comprehensive document covering all areas of Speech-language Therapy in regard to treatment of patients with life-limiting conditions. It could form the basis of a job description for Speech-language Therapists wanting to specialise in this area. The document will need to be reviewed by the NZSTA with special consideration of Te Tiriti o Waitangi.

Summary of Palliative Competence Framework

It should be noted that the proposed Framework and competencies are not intended to replicate or substitute the professional requirements of each professional association or regulatory board. Throughout this process, consultation has taken place (where possible) with each of the professional associations and/ or regulatory boards in the preparation of this discussion document. The proposed competencies are specific to the field of palliative care and intended to be complementary to the current requirements of our Professional Associations and/or Regulatory Boards.

The proposed Framework may be used as a tool in the development of job descriptions and roles by employers who are seeking to employ professional allied health practitioners new to palliative care. It may also work as a guide to assisting and supporting staff with professional and career development. It also allows allied health of varied disciplines a common resource.

Stage Four: Key findings and next steps

Following the identification of challenges, inventory of training options, review of professional standards and the development of proposed discipline-specific Palliative Care Competence Frameworks, the AHW has identified five key findings and proposed several possible next steps.

Key findings

The key findings of the AHW include:

1. Although the majority of AHPs will care for patients with life-limiting illnesses within their practice, most are underprepared to do so
2. There are limited education and training opportunities to support AHPs to provide quality palliative care. Few under-graduate programmes include palliative care modules and postgraduate programmes are dominated by nursing and medical approaches. Workplace training is largely ad hoc / informal, relies on scarce peer-support opportunities and can be difficult to access for AHPs working in private practice, lone roles or in part-time positions
3. The role and contribution of allied health in palliative care is poorly understood or recognised, both within allied health and the wider health workforce
4. There are currently no clearly defined Competence Frameworks or career pathways for AHPs in Aotearoa to formally develop their palliative care practice or be recognised for their advancing expertise. The proposed discipline-specific competencies developed by the AHW serve as a starting point to address this issue (see Appendix A)
5. Most of the palliative care practice resources available in Aotearoa are designed for nursing and medical practitioners. AHPs have a limited awareness of and/or poor access to these resources and very few include specific information for AHPs.

Next steps

Based on the work and key findings of the AHW, the proposed next steps include a multi-pronged approach to address current gaps in the understanding, training, support and recognition of AHPs providing care to patients with life-limiting illnesses. While these next steps are applicable to the health sector in general, many apply more specifically to specialist palliative care providers.

A. Increase understanding of the role and contribution of allied health in palliative care by:

- Supporting research within NZ that articulates the patient benefits of allied health input when receiving palliative care
- Generating multidisciplinary discussions of the complementary roles of each discipline
- Articulating the impact of various allied health roles on palliative symptom management
- Advocating for patients to be referred to allied health services early in their palliative diagnosis
- Ensuring allied health are included in multidisciplinary care planning meetings
- Including allied health perspectives in national palliative care policy documents

B. Improve palliative care education, training and support opportunities for AHPs by:

- Encouraging undergraduate programme providers to include palliative care modules and ensure students understand the skills that are transferable to palliative care. Course content can be tailored to discipline-specific Competence Frameworks at the ‘All’ level (see Fig.2, pg 13)
- Supporting AHPs working in primary palliative care settings to attend training. This may include sponsored placements where cost is a barrier and offering virtual attendance options. Course content can be tailored to discipline-specific Competence Frameworks at the ‘Some’ level

- Developing and distributing a 'toolbox' of available palliative care resources that AHPs can access independently, including postgraduate education options. Ensuring this is widely available to allied health forums and on appropriate allied health websites
- Ensuring AHPs new to working in specialist palliative care receive appropriate workplace supervision and mentoring, preferably by an experienced colleague within the same field of practice
- Encouraging postgraduate palliative care programme providers to specifically include allied health approaches in their course and assignment options as well as disciple-specific supervisors / mentors for allied health students when possible. Course content can be tailored to discipline-specific Competence Frameworks at the 'Few' level
- Identifying funding opportunities for AHPs to attend education and training programmes
- Supporting specialist interest groups for AHPs

C. Recognise AHPs advancing skills in palliative care practice by:

- Actively seeking input from AHPs in all palliative care professional forums, conferences and discussions
- Resourcing work to finalise the proposed Competence Frameworks for AHPs in Aotearoa, in collaboration with the appropriate allied health sectors
- Using Competence Frameworks in the workplace to support job descriptions, performance appraisals and career pathways / development plans for AHPs who would like to grow their skills, or specialise in caring for patients with life-limiting illnesses
- Ensuring remuneration policies for AHPs working in specialist palliative care recognise their advancing levels of competence

Consultation to achieve these next steps will be required. Key stakeholders will include allied health Regulatory Bodies, Professional Associations, Councils and Societies as well as wider discussions with a range of practitioners in the respective allied health fields of practice.

Conclusion

Allied health professionals (AHPs) are integral to the provision of quality palliative care; enabling those with a life-limiting illness to live as well as possible. Unfortunately, many AHPs enter the workforce feeling ill-prepared to provide end-of-life care and often struggle to access ongoing education and support opportunities tailored to their needs. Given the projected increase in the number of deaths in New Zealand (NZ) and the greater age at death leading to more complex health needs, it is important for the health sector to equip all health professionals to deliver palliative care. Our strength is in our people; AHPs should be prioritised alongside their medical and nursing colleagues.

The Allied Health Workgroup (AHW) were tasked with evaluating the palliative care training and support that is currently available to their allied health colleagues throughout Te Waipounamu South Island and investigating ways that AHPs can be better supported to develop their palliative care skills and confidence.

When identifying the general challenges currently faced by AHPs it was found that:

1. There is a lack of clarity regarding the role of allied health in the provision of palliative care
2. There is a paucity of education and training opportunities designed specifically for allied health
3. Allied health professionals have limited access to palliative care practice resources.

An investigation of the training, education, and support currently available to the allied health professions represented within the Workgroup found:

- Informal / non-structured education pathways
- Little or no coverage in under-graduate courses of how to adapt their professional skills to provide a palliative approach to care
- Ongoing education most often motivated by personal interest rather than professional imperative
- Limited choice for ongoing education and courses often delivered with a nursing or medical focus
- Little or no recognition in the workplace of advancing skills in palliative care
- Limited guidance on the skills required by AHPs to provide palliative care.

A review of international literature found palliative care competence frameworks for many allied health specialties. The AHW used these to develop proposed competence frameworks suited to practice in Aotearoa.

The proposed next steps for this work include:

1. Increasing the understanding of the role and contribution of allied health in palliative care
2. Improving palliative care education, training and support opportunities for AHPs
3. Recognising AHPs advancing skills in palliative care practice.

This discussion document is formative, aspirational and collaborative. It can be used as a starting point for AHPs who wish to further develop their skills, or furthermore, to work as part of a specialist palliative care service. Employers should find the proposed palliative care competencies useful for developing job descriptions, career pathways, workplace education programmes, and individual development plans for their allied health workforce.

The AHW acknowledge there are many other allied health disciplines that may not be as visible in palliative care or covered in this document but remain just as important. These AHPs work across our health system and will also intersect with patients and whānau at, or near, the end of life. We commend their dedication and expertise.

The Palliative Care Workstream (PCW) will disseminate this discussion document to the relevant professional bodies and allied health leaders and networks. We welcome all readers to join the dialogue.

Bibliography

McLeod, H., & Atkinson, J. (2019). *Policy Brief on Place of Care and Time in the Community at the End of Life in New Zealand*. ResearchGate. https://www.researchgate.net/publication/335405036_Policy_Brief_on_Place_of_Care_and_Time_in_the_Community_at_the_End_of_Life_in_New_Zealand

Ministry of Health. (2015). *New Zealand Palliative Care Glossary*. Wellington: Ministry of Health. https://www.health.govt.nz/system/files/documents/publications/new-zealand-palliative-care-glossary-dec15.pdf

Ministry of Health. (2019). *Achieving equity.* Ministry of Health. https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity

Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive

Palliative Care Nurses New Zealand. 2014. A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand. Wellington: Ministry of Health.

Statistics New Zealand. (11/9/2022). *National populations projections, characteristics, 2022 (base)-2073.* Statistics New Zealand. https://nzdotstat.stats.govt.nz/wbos/Index.aspx?DataSetCode=TABLECODE7586

Te Tumu Whakarae. (2020). *Te Mahi a Te Tumu Whakarae - Position Statement.* TAS. https://tas.health.nz/employment-and-capability-building/workforce-information-and-projects/te-tumu-whakarae/

Appendix A: Discipline Specific Reports

Chaplaincy

By Major Clive Nicolson, Chaplain/Bereavement Support, The Salvation Army – Hospice Marlborough

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Introduction and approach

The fundamental role of a Chaplain is to be involved in the provision of holistic care within the health community. Chaplains work collectively and collaboratively alongside other health care professionals to provide psycho-social/spiritual/pastoral services for patients and their whānau.

Chaplaincy in a palliative care setting does not differ significantly from other areas in healthcare. Chaplains strongly embrace the pastoral and spiritual care of patients suffering with life-limiting illness and their Whānau. However, it is essential that the Chaplain holds a sound knowledge of the wider practice of palliative care. Due to the absence of formal palliative care chaplaincy training, learning on the job and building on a sound chaplaincy background is essential. The pathways into any chaplaincy role are many and varied and includes clergy ordination, Hospital, Military and Industrial chaplaincy training courses. All provide a background to chaplaincy however ongoing learning in palliative care is crucial and the learning approaches listed below highlight areas that are available.

Current preparation and support to deliver palliative care

Palliative Care is a relatively new area of medicine however chaplaincy or spiritual support has been an integral part of the care of those who are dying and their families and carers for many centuries.

After speaking with a range of ordained Ministers who have worked as palliative care Chaplains, it seems that depending on when they undertook their training, this impacted on their exposure to palliative care. One priest spent 3 weeks at Mary Potter Hospice when it was in its infancy. Two other chaplains advised their training as ordained Ministers, tended to focus on funeral preparation.

The most that is currently offered in terms of training, is compulsory attendance at a Clinical Pastoral Education course. This is also offered to Chaplains in the hospital setting.

Existing local, national, and international resources

The following information represents the education opportunities available in the field of Chaplaincy/Pastoral Care locally, nationally or internationally as at November 2019:

Undergraduate Education

- Tertiary level Education in the form of Degrees in Theology or Religious Studies at all the major institutions in New Zealand.
- The number of programmes and institutions providing these programmes of study is not easily quantifiable.
- At time of this review has been limited research undertaken and this area of work requires further exploration.
- The pathways to chaplaincy are many and varied and include clergy ordination, Hospital, Military and Industrial chaplaincy training courses. Due to this minimum entry level, completion of the Palliative Fundamentals course and Hospital Chaplaincy course, with further chaplaincy training would be encouraged

Post Graduate Opportunities

- Post graduate opportunities in Chaplaincy are available through all the major tertiary institutions in New Zealand.

Workplace Education, Training and Support

- Once employed in specialist palliative care there are plenty of opportunities for education. However, these are often very medical and nursing focussed.
- DHB education and teaching does occur but is limited by the resources available i.e. Not every DHB has an inpatient SPC team.
- Advance Care Planning training – online module available

Baseline learning opportunities (readily available)

- Through Hospice New Zealand:
    - monthly Palliative Care Lecture series - focusses on the area of palliative care from a broad range of perspectives and lectures have been presented by AHPs
    - Fundamentals in Palliative Care Training Modules
    - Network Groups – annual 1- or 2-day workshops for a range of roles in palliative care for example Spiritual Support, Family Support
- The Palliative Care Handbook [9th edition 2019] – published in conjunction with Hammond Care in Australia. Provides good level of information around the symptomology and care of palliative care patients – no specific reference to the role that other professions have in supporting patients and their families although has chapters on quality of life and spirituality etc.
- healthLearn – online learning programme for health practitioners employed in South Island DHBs - includes palliative care modules.

<u>Proposed palliative care competencies</u>

A set of competencies for chaplains or pastoral carers in palliative care is a very new concept in Aotearoa New Zealand and so we are grateful to be able to utilise the Palliative Care Competence Framework published by the All Ireland Institute of Hospice and Palliative Care [AIIHPC] in 2014. This has provided an excellent foundation from which to work from in order to draft this set of proposed competencies for use in palliative care in NZ.

Due to time constraints around this work, consultation around these proposed competencies has been limited and we are appreciative of the time spent by Chris Donaldson Chaplain at Nelson Marlborough Health's Wairau Hospital for his input and advice in this project. It is acknowledged that further consultation within the sector and our colleagues working in chaplaincy, pastoral care or spiritual support is required.

Competencies marked in bold font denote recommended additions or modifications to the AIIPC competence framework to reflect culture and practice in Aotearoa New Zealand.

Proposed – Chaplaincy Competencies for Palliative Care
DOMAIN OF COMPETENCE 1

PRINCIPLES OF PALLIATIVE CARE

As a chaplain you should:

- **Demonstrate a holistic model of care for those with a life-limiting condition, encompassing the Māori philosophy of health and wellbeing – Te Whare Tapa Whā.**
- **Recognise the cultural uniqueness of individuals and their families/whānau and demonstrate the provision of sensitive and culturally appropriate care to those with a life-limiting illness.**
- **Demonstrate the ability to gain cultural support and assistance from appropriate sources if/when needed.**
- **Use appropriate mechanisms for monitoring own performance and competence.**
- Recognise that chaplaincy care is an essential element of holistic care for the person with a life-limiting condition and their family.
- Understand the nature of spirituality and recognise that everyone has a spiritual dimension and that for many people this may have a religious component.
- Assist the person with a life-limiting condition to discern their spiritual needs and create a safe space where they can name and address them.
- Recognise that the opportunity for human development, physical, emotional and spiritual, is an essential component of palliative care.
- Understand and appreciate that spiritual and emotional pain often results from a loss of meaning and unmet spiritual needs.
- Engage pastorally with persons who are experiencing spiritual distress and pain.
- Understand and appreciate that in some cases suffering can be seen as part of the normal process of living with the profound challenges of having a progressive illness, functional disability, and awareness of impending death.
- Demonstrate knowledge and understanding of the main world faiths, philosophies, beliefs, practices, cultures and traditions around life, illness, dying and death.
- Offer support and encouragement to the multidisciplinary team in order to promote wellbeing and self-care.
- Be committed to ongoing development, personally, pastorally and professionally.
- Be familiar with research in palliative care and use this to inform practice.
- Be familiar with family systems practice and its importance within the palliative care setting.
- Be committed, involved and take a leadership role in the delivery of spiritual and/or religious care within the context of a multidisciplinary team approach.
- Promote research and development of bereavement care, including audit of own practice.

DOMAIN OF COMPETENCE 2:

COMMUNICATION

As a chaplain you should:

Recognise and appreciate that the quality of pastoral presence is an essential component of spiritual care.

In the course of pastoral ministry, be fully attentive to the individual with a life-limiting condition and demonstrate the ability to connect and empathise with them.

Demonstrate sensitivity in pastoral conversations with patients, families and significant others.

Understand that the communication of information which changes the person's understanding of their situation and/or influences their decision-making or planning is an on-going process and not a single event.

Provide person-centred, family-focused chaplaincy care that understands and respects diversity in all its dimensions.

Use pastoral interventions and engage in pastoral conversations, which are age-appropriate.

Apply best practice in spiritual assessment and documentation to help determine and communicate interdisciplinary plans of care.

Recognise, understand and be sensitive to the significant changes in the person's condition when moving toward end of life and facilitate the individual, and their family to consider options for spiritual care and support.

Have the skill and capacity to engage respectfully and sensitively with patients around their beliefs, fears, hopes and uncertainties regarding death and afterlife.

Whilst respecting the individual's beliefs and wishes, ensure that spiritual and/or religious rituals and/or sacraments for end of life, are available.

Through spiritual accompaniment, help the individual with a life-limiting condition to make their final journey with dignity, peace and compassion, while also providing support to their family.

Demonstrate the ability to apply knowledge of the key physical, psychological and social principles in palliative care in order to communicate effectively with the multidisciplinary team.

Understand and practice appropriate principles of confidentiality in relation to matters of a private and sensitive nature.

Provide spiritually and culturally appropriate chaplaincy support during patient and family conferences and when participating in support groups.

Contribute to and support discussions between individuals, their families and staff members and recognise potential differences in decision making in the context of palliative care.

Understand how different styles of communication can be adapted and used to enhance communication in complex situations at end of life.

As part of the multidisciplinary team assist in the mediation of conflict in decision-making in the palliative care setting and work towards consensus building in care planning.

Support the multidisciplinary team, parents/guardians/families in sharing difficult or bad news, relating to illness or death, with children and vulnerable adults; facilitating direct supportive communication with them, where appropriate.

Anticipate and facilitate the distinctive needs of parents, families and colleagues in perinatal palliative care.

DOMAIN OF COMPETENCE 3:

OPTIMISING COMFORT AND QUALITY OF LIFE

As a chaplain you should:

Be able to help the person living with a life-limiting condition to feel assured that chaplains are capable of accompanying persons of all faith traditions, persons who profess no faith, persons whose lives are guided by a particular life philosophy.

Demonstrate an ability to assist members of the multidisciplinary team to understand the nature and importance of addressing the spiritual and religious needs of the individual and how these may impact on wellbeing.

Demonstrate an ability to assess the spiritual/religious needs of the person with a life-limiting condition and share as appropriate with the multidisciplinary team.

At the request of the individual with a life-limiting condition or their family liaise with the individual's parish clergy, faith group, spiritual companions/leaders and/or other community religious/spiritual and cultural resources.

In the context of your current role, support the team when considering the care and treatment options for the person with a life-limiting condition with due regard to the persons wishes.

Be able to recognise and at times anticipate the need to change and adapt the focus of pastoral care intervention at critical points during a life-limiting condition, supporting the person with a life-limiting condition and their family through times of transition.

Provide specialist pastoral care interventions based on continuing assessment of palliative and end of life care needs.

DOMAIN OF COMPETENCE 4:

CARE PLANNING AND COLLABORATIVE PRACTICE

As a chaplain you should:

Demonstrate an ability to assess, plan and communicate the spiritual needs of the patient to the multidisciplinary team.

Be aware and respect professional boundaries when offering and providing spiritual care to patients and when interacting with other members of the multidisciplinary team.

Demonstrate an ability to assess the need to seek professional consultation regarding the effectiveness of pastoral care and the appropriateness of referral to another professional care provider.

Facilitate referrals following spiritual assessment (e.g. referral to the patient's own faith representative if requested) and document appropriately.

Demonstrate an ability for effective engagement in multidisciplinary team meetings, highlighting and addressing spiritual issues and suggesting appropriate responses to identified spiritual need.

Work collaboratively with the person with a life-limiting condition, their family and other professionals, including attending family meetings, team meetings, mediating discussions and planning for future care.

Recognise that the person with a life-limiting condition may lose capacity to make decisions towards end-of-life.

Be able to facilitate and integrate collaborative processes and multidisciplinary relationships that respect the principles of holistic care within the wider health care institutional culture.

Demonstrate leadership in identifying spiritual/religious issues and facilitate the appropriate team response through family meetings involving other team members and services as appropriate.

Have the ability to articulate the unique professional role of chaplains as leaders in the provision of spiritual care.

Be able to quantify the benefits and measurable outcomes of pastoral care interventions through reflecting on expressed patient and family satisfaction.

Provide staff support and guidance around spiritual care issues by sharing professional knowledge and expertise regarding spiritual/religious issues in palliative care and at end of life, with the multidisciplinary team.

DOMAIN OF COMPETENCE 5:

LOSS, GRIEF AND BEREAVEMENT

As a chaplain you should:

Be able to articulate important spiritual, existential and emotional concepts for patients, families and significant others.

Work in partnership with parents, guardians and other family members in order to prepare and support children and vulnerable adults for the loss of loved ones.

Be able to provide appropriate spiritual care and emotional support to grieving persons of diverse cultural and religious traditions, and to persons with no affiliation to a faith tradition.

Be able to plan and lead appropriate rituals, suitable for the time of dying or after death, which offer hope and comfort to persons from a diversity of cultural and faith traditions, and to persons who represent a diversity of world views **or referral to the patient's own faith representative if requested.**

Be able to plan and lead services suitable for specific faith traditions, and ecumenical and interfaith services.

Demonstrate an ability to work in partnership with the patient's faith group/leaders and/or other community religious/spiritual and cultural resources to ensure that all sacramental, religious and faith based rituals are met in a timely and appropriate manner.

Demonstrate an understanding of the theories of loss, grief and bereavement.

Be culturally aware of nuances regarding pain, suffering, loss, complicated and anticipatory grief, and life review.
In the context of your current role as an ordained chaplain and appropriate to the faith tradition of the individual with a life-limiting condition, celebrate Mass and the sacraments of the Anointing of the Sick, Reconciliation and others as required.
In the context of your current role as an ordained chaplain and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith-based rituals, sacraments and ministry are met in a timely and appropriate manner.
Provide multidisciplinary team debriefing and support the development of self-care strategies for colleagues working in end of life care.

DOMAIN OF COMPETENCE 6:

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

As a chaplain you should:
Respect and uphold the dignity of the person who is receiving palliative or end-of- life care.
Respect and support the person with a life-limiting condition and their family to be treated with dignity throughout the course of illness, during the dying process, and after death.
Identify how one's feelings, attitudes, values and assumptions impact on pastoral ministry with the person with a life-limiting condition and their family.
To recognise and articulate challenging areas of ethical sensitivity and awareness in the hospice and palliative care arena.
Demonstrate maintaining one's integrity and authenticity in professional practice during the process of assisting others in moral and ethical care decisions, within a diverse and transitioning health care system and patient population.
Engage in reflective practice to promote greater self- awareness and ability to critically evaluate one's own practice within end of life care.
Utilise professional supervision to ensure best practice in end of life care and to meet organisational and professional requirements.
Participate in family meetings around ethical decision-making for patients and families honouring diverse ethnic, cultural, religious/faith tradition and philosophical world views.
Demonstrate leadership through advocating for on-going and continuous service development.
Be able to facilitate the discussion and resolution of ethical issues that may arise in palliative care.
Demonstrate an understanding of the process of quality improvement in the context of palliative care.
Communicate and advance the distinct contribution of pastoral care to palliative care.
Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research.

Next steps

Further consultation is required, especially with Chaplains in NZ and the following organisations:

- Interchurch Council for Hospital Chaplaincy - https://www.ichc.org.nz/
- Te Runanga Whakawhanaunga I Nga Hahi O Aotearoa (Māori Council of Churches)

Dietetics

By Helen Brown, Dietician, Nurse Maude Hospice

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Proposed palliative care competencies

Competencies marked in bold font denote recommended additions or modifications to the AIIPC competence framework to reflect culture and practice in Aotearoa New Zealand.

Proposed – Dietetics/Clinical Nutrition Competencies for Palliative Care DOMAIN OF COMPETENCE 1:

FOOD, NUTRITION AND HEALTH EXPERTISE

As a dietician/clinical nutritionist you should:

- Apply knowledge of nutrition science and medical nutrition therapy for people in states of health and disease.
- Apply knowledge of sustainable food systems, food service management, food products and food preparation practices influencing nutrition and health.
- Apply knowledge of public health nutrition, including health equity, population monitoring and surveillance, community capacity building, and public health intervention planning, implementation and evaluation.
- Use appropriate interdisciplinary principles and frameworks to assess and identify client and stakeholder needs and to plan, implement, monitor, evaluate and adapt dietetic strategies.
- **Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems.**
- Assess the nutrient composition and/or nutritional quality of food products, composite foods, menus and food environments.
- Use appropriate dietary assessment methods to assess food and nutrient intakes of individuals and populations.
- Assess the nutritional status of populations and individuals in states of health and disease, using appropriate dietary, biochemical, anthropometric, physical / observed, clinical and historical data.
- Assess physical environments and economic, political and socio-cultural factors affecting client food choice and intake.
- Use knowledge of operational largescale food production and distribution systems transforming inputs to quality food that is safe, suitable, nutritionally adequate, culturally acceptable, practical, affordable and accessible.
- Access, plan, implement, monitor, evaluate and adapt food service systems to meet client and stakeholder needs.
- Demonstrate financial, technological and environmental literacy and optimise resources to provide safe, effective, efficient and sustainable food services.
- Identify and manage risks to food service systems.
- Apply public health principles, frameworks, theories and models to promote healthy socio-ecological systems.
- Identify, prioritise and advocate for structural interventions to address population food and nutrition needs.
- Identify and collaborate with key stakeholders from diverse settings to influence structural change.
- Assess, plan, implement, monitor, evaluate and adapt public health nutrition interventions to meet client and stakeholder needs and reduce health inequalities.
- Assist vulnerable communities to build their capacity for health promotion.

Proposed – Dietetics/Clinical Nutrition Competencies for Palliative Care

DOMAIN OF COMPETENCE 1:

- Apply clinical nutrition and medical nutrition therapy principles and models to client centred care across the lifespan.
- Analyse assessment data to identify nutrition diagnosis, prioritise problems and formulate goals in collaboration with client.
- Develop, implement, monitor, evaluate and adapt client-centred nutrition care plans based on assessment data and clinical reasoning.
- Prescribe, monitor and evaluate Special Foods (oral, enteral and parenteral products and approved nutrition-related medicines to optimise nutritional status.
- Maintain clear, accurate and appropriate records of the nutrition care process using standardised terminology.
- Contribute dietetic expertise, reasoning and judgement to interprofessional clinical teams, participating in shared decision making and implementation and evaluation of client-centred care.

For Dietitians whose core role is the provision of palliative care:

- **Demonstrate an advanced knowledge and understanding of the full spectrum of trajectories of life-limiting conditions and their impact on nutritional management when responding to complex and multidimensional care needs.**
- **Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of nutrition and dietary intervention and outcomes and service delivery in palliative care.**
- **Lead, facilitate and engage in further education, and audit in palliative care.**

DOMAIN OF COMPETENCE 2:

COMMUNICATION AND COLLABORATION

All Dietitians are able to:

- Assess peoples' communication needs and respond in the manner that is appropriate to their level of understanding, culture and preferred ways of communicating.
- **Be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.**
- Critically reflect on how their own personal values, beliefs and practices influence their communications.
- Respect Tikanga when communicating with Maori.
- Establish and maintain professional relationships that are characterised by trust, respect, empathy and cultural safety.
- Communicate evidence-based messages appropriately and responsibly utilising media, social media and other communication channels.
- Apply principles of behavioural psychology, counselling and learning to client-centred dietetic practice.
- Engage, motivate, empower and enable individuals, families / whānau and groups to achieve dietary behaviour and lifestyle goals.
- Demonstrate commitment to incorporating traditional Maori values, models of care and family / whānau support into Maori client-centred care.
- Communicate with clients at an appropriate health and food literacy level to support informed decisions.
- Engage, motivate, empower and enable employees and volunteers to provide quality food, nutrition and health services.
- Engage, motivate, empower and enable organisations to create health promoting environments.

- Apply principles of team leadership, teamwork dynamics and group processes to support collaborative practice and describe their own role and the roles of others within the team.
- Seek out, integrate and value the input and engagement of colleagues, clients and other stakeholders in shared decision making and designing, implementing and evaluating client-centred care / services.
- Demonstrate basic conflict resolution, mediation, advocacy, negotiation and assertiveness techniques.

For Dietitians whose core role is the provision of palliative care:

- **Demonstrate expertise as a mediator and advocate for the patient and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services.**
- **Provide support and counselling to the individual, their family and carers regarding irreversible weight loss and anorexia that may occur as end of life approaches.**

DOMAIN OF COMPETENCE 3:

MANAGEMENT AND LEADERSHIP

All Dietitians are able to:

- Apply management principles and skills to dietetic practice.
- Use effective management principles to develop and sustain a safe, effective, efficient, client-centred service.
- Contribute to strategic planning and understand its role in developing and improving services.
- Apply leadership principles within professional, legal and ethical frameworks.
- Identify organisational culture and its influences on professional leadership and practice.
- Encourage and support a safe environment for collegial professional practice and innovation.
- Identify problems and solutions and lead change to enhance professional practice.
- Demonstrate commitment to interprofessional and intersectoral practice.
- Advocate for the value dietitians bring to organisations and society.
- Encourage and support others to engage in personal and professional development activities for career growth and skill enhancement.

For Dietitians whose core role is the provision of Palliative Care:

- **Be able to facilitate discussion and resolution of ethical and legal issues in conjunction with the multidisciplinary team, individuals with life-limiting conditions and families that may arise in relation to artificial nutrition support in the palliative population.**
- **Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care.**
- **Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues.**
- **Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care.**

DOMAIN OF COMPETENCE 4:

PROFESSIONALISM

All Dietitians are able to:

- Critically reflect on professional practice.
- Maintain professional standards and responsibility (includes competence, professional conduct and fitness to practice).
- Evaluate self-performance and recognise and address limitations of professional knowledge, skills and abilities (including cultural competence).
- Demonstrate a commitment to lifelong personal and professional development and self-care.
- Identify and respect professional boundaries.
- Identify and assess health and safety risk and work with employers and employees to develop safe environments.
- Comply with legislation, statutory codes and professional / ethical frameworks for dietetic practice.
- Use appropriate procedures for informed consent.
- Maintain confidentiality, privacy and security of client information.
- Apply knowledge of New Zealand food, health and social systems.
- Critique and contribute to the development of New Zealand policies influencing food, nutrition and health systems.
- Advocate for the client within broader systems.
- Advocate for social justice and health equity for all groups including Maori.
- Contribute to the reduction of social and health inequalities.
- Apply Te Tiriti O Waitangi principles, Tikanga and Maori models of health (such as Te Whare Tapa Wha) to dietetic practice.
- Be culturally responsive to client values, beliefs, and practices in relation to food, nutrition and health.

DOMAIN OF COMPETENCE 5:

SCHOLARSHIP

All Dietitians are able to:

- Demonstrate evidence-based dietetic practice.
- Apply critical thinking principles and problem-solving techniques to dietetic practice.
- Conduct a comprehensive literature search, critically appraise and interpret research evidence, and consolidate findings.
- Implement, evaluate and develop evidence-based Practice guidelines and standards for dietetic practice.
- Audit and monitor adherence to standards.
- Conduct formative, process and impact / outcome evaluations to develop and monitor interventions and assess effectiveness.
- Use quality management principles to improve outcomes, systems and contribute to the evidence base.
- Apply relevant research principles, methodologies (qualitative and quantitative) and technologies to advance dietetic practice.
- Coordinate a nutrition, dietetic or interprofessional research project.
- Disseminate research findings to advance evidence-based nutrition and dietetic practice.
- Use technology and standardised terminology to retrieve, interpret, store, analyse and disseminate information.
- Evaluate and contribute to the development of user-centred technologies to enhance dietetic practice.
- Demonstrate knowledge of advancing technology and health informatics.

** The New Zealand Dietetics Competencies do not mention recognising common trajectories of life-limiting conditions*

Occupational Therapy

By Janeen Richardson, Occupational Therapist, Nurse Maude Hospice and Nicki Kitson, General Manager - Hospice Marlborough, Occupational Therapy

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Introduction and approach

Undergraduate and post graduate educational opportunities for Occupational Therapists in palliative care is of high importance. Occupational Therapists have a significant role in the provision of care for those who require a palliative approach because of the unique focus of the profession on promoting participation in meaningful life activities, including participation in life until death. *(The American Occupational Therapy Association, 2015; Occupational Therapy Australia, 2015; Occupational Therapy New Zealand-Whakaora Ngangahau Aotearoa, 2012).*

This scoping exercise has shown that prior to becoming a registered practitioner, there are limited opportunities to develop skills and knowledge or even gain experience in specialist palliative care. Input to this research has been sought from several stakeholders. This has included our academic colleagues at both training institutions for Occupational Therapists in Aotearoa New Zealand. Therefore, we are indebted to Stephanie Cox, Programme Leader, Occupational Sciences and Therapy at Auckland University of Technology, Dr Penelope Kinney (Head of School), Jackie Herkt (Academic Leader) and Professor Mary Butler, at School of Occupational Therapy, Otago Polytechnic, for the information they have provided and their feedback on our draft documents. We also consulted the group of Occupational Therapists working in a Hospice setting throughout Aotearoa New Zealand (HOT NZ group) as well as Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa (OTNZ-WNA); who have suggested further consultation with their Special Interest Group for oncology and palliative care. This is yet to be achieved.

We have also appreciated the input, advice and direction of Dr Mary Silcock, Professional Advisor for the Occupational Therapy Board of New Zealand. Mary, whilst not specifically representing the Occupational Therapy Board in our discussions, has brought a wider vision and regulatory context to our work which we have greatly valued and appreciated. As result, this consultation has framed our approach to the second phase of our work which has been the establishment of a proposed set of supplementary competencies, for Occupational Therapists to safely practice in a specialist role in palliative care. As some of these competencies are outside of the current scope of practice of occupational therapy, additional training and specific qualifications for occupational therapists will need to be provided to complement these. Over time, and as the role of Occupational Therapy in Specialist Palliative Care evolves and strengthens, we envisage that these competencies will need to be reviewed. Further, the development of a scope of practice for the role of a Specialist Occupational Therapist in Palliative Care may be an option. The objective of this would be to ensure that people receive safe, professional, and high-quality specialist palliative care.

Current preparation and support to deliver palliative care

Palliative care, as a subject, is touched on in both Aotearoa New Zealand undergraduate occupational therapy programmes (3-year programme) located in Dunedin (Bachelor of Occupational Therapy - Otago Polytechnic campuses in Dunedin and Hamilton) and Auckland (Bachelor of Health Science – Occupational Therapy Auckland University of Technology (AUT)). Students learn about grief, chronic life limiting conditions, and models of care that are congruent with specialist palliative care philosophy within bicultural Aotearoa New Zealand. The amount of time spent on palliative care in each curriculum differs and is somewhat dependant on the expertise or interests of the academic staff.

Unsurprisingly, the common theme for the profession of Occupational Therapy is that the majority of learning around specialist palliative care occurs in the work context (i.e., through experiential learning). This is certainly the case in Aotearoa New Zealand and internationally (Hammill 2017; Pearson, 2010). However, with the rising trend of the increased awareness about allied health roles in specialist palliative care and the expectation that therapists practising outside of specialist services have adequate skills and knowledge to practice effectively, there are now more formal and informal post graduate opportunities available. However, this does not negate the need to develop further opportunities in both undergraduate and postgraduate curriculums to prepare Occupational Therapists for this area of practice.

Formal post graduate opportunities in Aotearoa New Zealand are not specifically focussed on Occupational Therapy practice. They have a specialist palliative care focus and therefore can enhance a practitioner's skill, reflective practice, increasing understanding of the palliative approach; and its application to practice. Notwithstanding, these opportunities can be financially costly as it appears that there is no funding for allied health training and education that exists through Health Workforce New Zealand (HWNZ). In-house and other organisational training opportunities also exist, although is not always widely known to all Occupational Therapists who would benefit from access to them. These short courses are often online (for example, advanced care planning) and at very little or no financial cost to the individual or organisation.

The following information summarises the educational opportunities available to Occupational Therapists locally, nationally, or internationally as of February 2019:

Undergraduate Training (3-year programme)
Otago Polytechnic:
Students learn about grief, about chronic life limiting conditions, and about models of care that are congruent with specialist palliative care philosophy within bicultural Aotearoa. Third year students receive a one-hour lecture from an Otago Community Hospice staff member (Complex Cases course). This occurs at the discretion of the lecturer and the availability of staff.

AUT:
Students in the first semester of their first year of training undertake study through the School of Interprofessional Health Studies which brings together students and academic staff from different professions. There is one paper on death, dying and bereavement in that curriculum. Currently (2019) third year students have as part of their Clinical Reasoning, a case study that features a patient who is terminally ill however, the topic is set at the lecturer's discretion and so the content of the case study could be changed at any time

<u>Post Graduate Opportunities</u>
Otago Polytechnic & AUT: offer studies but nothing specific to Palliative Care at the time (2019)
University of Auckland: Post Graduate Certificate and Diploma in Health Sciences in Palliative Care. Not specifically available for Occupational Therapists
Canterbury University: Post graduate Certificate in Palliative Care

<u>Post Graduate Opportunities</u>
Flinders University Australia: Offers many levels of training however, there is a significant cost for Aotearoa New Zealand students as onsite campus attendance is required.

<u>Employment Opportunities</u>
District Health Board (DHB) education and teaching opportunities do occur but is limited by the resources available. i.e., not every South Island DHB has an inpatient Specialist Palliative Care team. So, if able, therapists can attend the limited number of study days or conferences on palliative care available.

When employed in a specialist palliative care setting, there are plenty of opportunities for education. However, these are very medical based, so not necessarily allied health/Occupational Therapy focused.

Baseline Learning Opportunities (readily available)

OTNZ-WNA:

- Special interest Group in oncology and palliative care (need to be a financial member of OTNZ-WNA to have access)
- Position statement in palliative care (under review)

Hospice NZ:

- Fundamentals of Palliative Care training modules
- Palliative Care Lecture Series
- Online resources
- Palliative Care Handbook

Health, Quality and Safety Commission

Advanced Care Planning training.

healthLearn

Available to organisations in the South Island only - contains four palliative care modules

Proposed Specialist Palliative Care Competencies for Occupational Therapists

The Occupational Therapy profession in Aotearoa New Zealand is regulated by the Occupational Therapy Board of New Zealand (OTBNZ). The board's role is to ensure the safety of consumers using occupational therapy services, by setting threshold competence standards, making sure all occupational therapists meet the specifications of the Health Practitioners Competence Assurance Act 2003.

It is evident that the value of the allied health professions including Occupational Therapy, is becoming increasingly recognised in palliative care. Whilst there are many shared core skills and competencies across the allied health professions, there are specific areas of specialised practice that an occupational therapist is best placed and most likely to be providing. In particular, the ability to facilitate the participation in everyday occupations/activities that continue to hold meaningful and purposeful value for people regardless of where they are in their illness trajectory.

Considering the Aotearoa New Zealand context, Occupational Therapists, particularly those in primary palliative care already use many components of the palliative approach in their practice, but these may not be explicit. Further education about this approach would be beneficial, recognising that it as a skill many therapists need to have at a new graduate level.

Very few Occupational Therapists are employed in specialist palliative care in Aotearoa New Zealand, the majority are employed in Hospice services but not all are in designated Occupational Therapy clinical roles. Careful consideration is needed to determine what defines specialist practice; ensuring the components of specialist practice are expected and demonstrated. These components are identified as: expert/advanced clinical practice, provision of formal and informal education, research, audit and development of best practice guidelines and service improvement and leadership (Palliative Care in Partnership, 2018; South Australia Health, 2015).

These proposed supplementary competencies have been developed using the recently released Occupational Therapy Board of New Zealand Competencies for Registration and Continuing Practice for Occupational Therapists (2022) for all Occupational Therapists in Aotearoa New Zealand. In addition, the following documents have also been used to guide the formation of these recommended specialist components of practice:

- Ministry of Health, (2012) *Resource and capability framework for integrated adult palliative care services in New Zealand*. http://www.moh.govt.nz
- New Zealand Palliative Care Nurses Competencies, A National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand (2014).
- Occupational Therapy Board of New Zealand (2015) Code of Ethics for Occupational Therapists.
- Public Health Agency Belfast. (2018). Management of symptoms in Palliative Care – The role of specialist practice care and allied health professional.
- Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive https://aiihpc.org/our_work/education/competence-framework/.
- South Australia Health (2015). Advanced Scope of Practice Framework: Occupational Therapy in Palliative Care.

Consultation with the following stakeholders has also taken place:

- Occupational Therapy Board of New Zealand
- Occupational Therapy New Zealand Whakaora Ngangahau (OTNZ-WNA)
- Hospice Occupational Therapy Group New Zealand
- Auckland University of Technology and Otago Polytechnic School of Occupational Therapy

Further consultation recommended:

- The Special Interest Group (SIG) group for Occupational Therapy and Palliative had not yet been consulted due to time constraints and would be greatly beneficial to do so.

As a result of consultation with the regulatory agency for Occupational Therapy in Aotearoa New Zealand - Occupational Therapy Board of New Zealand, additional competencies have been written and are proposed. The underlying expectation is that the current Competencies for Registration and Continuing Practice for occupational therapists are already being met by all therapists and so these proposed competencies are additional to practice, in role within palliative care at specialist level of practice. The full set of current Competencies of Registration are available through the Occupational Therapy Board of New Zealand website. Competencies-Handbook.pdf (otboard.org.nz)

Proposed – Occupational Therapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 1:

Applying whakaora ngangahau occupational therapy knowledge, skills and values

For All Occupational Therapists:

- Recognise a need for change in the goals of care at critical decision points in the course of a life-limiting condition and seek appropriate advice and support

For Occupational Therapists whose core role is the provision of specialist palliative care:

- Demonstrate expertise in the assessment of cognitive and functional capacity to enable individuals with life-limiting conditions to engage in occupations that are important to them and their whānau.
- Recognise the clinical indicators for deterioration (including palliative care emergencies) and the need to refocus intervention when critical decision making is required in a person's illness trajectory - setting realistic goals that are continually adapted to individuals need and expectations.
- Implement and evaluate interventions around non-pharmacological management of complex symptoms of disease to alleviate, and manage distressing symptoms, promote functional independence and quality of life.
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care.

- Demonstrate the use of advanced communication skills to engage in a variety of highly skilled, compassionate, and timely communications with individuals with life limiting conditions, their carers/family/whānau and members of the interdisciplinary team.
- Engage a high level of clinical expertise to educate and facilitate the person, their carers/family/whānau to adapt to fluctuating functional abilities, functional deterioration and death.

DOMAIN OF COMPETENCE 2:

Responsiveness to te Tiriti o Waitangi

For Occupational Therapists whose core role is the provision of specialist palliative care:

- Recognise the cultural uniqueness of individuals and their families/whānau and demonstrates the provision of sensitive and culturally appropriate care to those with a life-limiting illness.
- Recognition of the need for cultural support and assistance from appropriate sources to ensure communication is clear and culturally appropriate.
- Demonstrate an understanding of and implement strategies to reduce health disparities (economic, social and cultural) and health literacy barriers that exist for Māori and their whānau in palliative care.
- Demonstrate a holistic model of care (e.g. Te Whare Tapa Whā) for those with a life-limiting condition, encompassing the Māori world view and philosophy of health and wellbeing.
- Acknowledgement and understanding of loss and grief, Tangihanga and Tikanga best practice around death and dying for Māori.

DOMAIN OF COMPETENCE 3:

Developing and sustaining partnerships

For Occupational Therapists whose core role is the provision of palliative care:

- Act as an expert colleague, clinical resource and mentor for your occupational therapy and other colleagues practising in and anticipating practice in the area of specialist palliative care.
- Active contribution to policy development and strategic initiatives for the occupational therapy profession and/or the practice area of palliative care (Primary and Specialist) at a local, regional, and national level.
- Demonstrate advanced understanding of the roles of the wider interdisciplinary team, show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care and therapy outcomes for the individual and their whānau.

DOMAIN OF COMPETENCE 4:

Practising in a safe, legal, ethical, sustainable, and culturally competent way

For All Occupational Therapists:

- Actively and positively engage in clinical, professional and/or cultural supervision on a regular basis**.**

For Occupational Therapists whose core role is the provision of specialist palliative care:

- Demonstrate self-awareness of your own responses to communication challenges and remain in meaningful contact with individuals and whānau, even in the most complex, intense and dynamic circumstances.
- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice and service provision in the area of palliative care.

- Apply an advanced knowledge to issues related to practising in a safe, legal, ethical and culturally competent way.
- Actively and positively engage in clinical, professional and/or cultural supervision on a regular and ongoing basis.
- Employ strategies in own practice to manage perpetual loss and grief and to reflect on professional and personal development.

DOMAIN OF COMPETENCE 5:

Practicing responsively and upholding the occupational therapy profession

For Occupational Therapists whose core role is the provision of specialist palliative care:

- Hold advanced qualifications in occupational therapy practice and palliative care.
- Active and positive contribution through your membership of and involvement in, your professional organisation.
- Design and undertake palliative care service-related research, publishing articles in professional journals, collaborating with key stakeholders and practitioners.
- When required, provide clinical and professional supervision and peer review processes with your Occupational Therapy colleagues and other health practitioners.
- You act as an expert resource person for the development of the Occupational Therapy profession in the practice area of palliative care.

REFERENCES:

Hammill, K., Bye, R., & Cook, C. (2017). Workforce profile of Australian occupational therapists working with people who are terminally ill. *Australian occupational therapy journal*, *64*(1), 58-67. https://doi.org/10.1111/1440-1630.12325

Ministry of Health. (2017) Māori health models – Te Whare Tapa Whā. https://www.health.govt.nz

Occupational Therapy Australia (2015). Position Paper: Occupational therapy in palliative care. https://www.otaus.com.au

Occupational Therapy Board of New Zealand. (2022) *Competencies for Registration and Continuing Practice*. https://otboard.org.nz/

Occupational Therapy New Zealand/Whakaora Ngangahau Aotearoa. *(*2013*).* Occupational Therapy/Whakaora Ngangahau and End of Life and Palliative Care Position Statement 2013. https://www.otnz.co.nz

Pearson, D. (2010). End of life care: everyone's business. *British Journal of Occupational Therapy, 73*(7), 291. http://dx.doi.org/10.4276/030802210X12759925544227

The American Association of Occupational Therapy. (2015). The Role of Occupational Therapy in Hospice and Palliative Care Factsheet https://www.aota.org

Pharmacy

By Karen Kennedy, Clinical Advisory Pharmacist Timaru and Palliative Care Workstream and Melody Chen, Pharmacist, Unichem Crisps Pharmacy, Christchurch.

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Introduction and approach

Palliative patients have complex medical, spiritual, and physical needs that are best met by an integrated multi-disciplinary team (MDT) of health professionals working together to help improve the patients' quality of life. Pharmacists are an important member of this team with medications being a mainstay of treatment to help relieve symptoms of palliative conditions which may become increasingly burdensome towards the end of life. Large numbers of medications are often required, including the use of unlicensed or off label medications, different routes of administration and unusual formulations, all of which contribute to complex drug regimens and increased risk for side effects, medication error and medication management difficulties. Evidence shows that pharmacist interventions such as psychological support for the patient, the identification and prevention of medication issues, improved medication management by medication optimisation and patient counselling can have a positive impact on the patient including improved symptom control. *(Krzyżaniak et al, 2016)*

Pharmacists across the health system all interact with palliative patients or their whānau or carers: the community pharmacist, the clinical advisory pharmacist, the hospital pharmacist and pharmacists working in hospices or as part of a specialist palliative care service. Accordingly, all pharmacists need to be prepared appropriately at the undergraduate level so that after their internship year, they graduate with a core set of competencies that will enable them to appropriately deliver services to palliative patients, their carers and/or whānau, whatever their work setting.

Depending on their level of input into symptom management for palliative patients, pharmacists require increasingly advanced competencies for appropriate delivery of palliative services. While not always recognised by the multi-disciplinary team, pharmacists have a role to perform in palliative care that is far greater than just the supply and removal of medications for patients with life-limiting conditions. A strong, well-trained and integrated multi-disciplinary palliative care team across the health system that includes allied health will best enable the South Island to meet the palliative care needs of its current and future population.

It is with these thoughts in mind that this group started to look at the training that currently exists for the pharmacy profession at the undergraduate level, post-graduate level and work-based training, support and resources in regard to the specialty of palliative care and the role pharmacists can play in this area.

The Schools of Pharmacy at the Universities of Auckland and Otago were approached to ascertain palliative care content in the undergraduate and post-graduate programmes for pharmacy students, with thanks to Lynne Petersen, Academic Director of School of Pharmacy (Undergraduate Programme), University of Auckland; Lisa Kremer (Professional Practice Fellow) and Emma Smith (Professional Practice Fellow and lead for the Undergraduate Palliative Care module), University of

Otago, and Stephen Duffull (Professor and Associate Dean (Research, and Postgraduate), School of Pharmacy, University of Otago.

The NZ Palliative Care/Hospice Pharmacist email group was surveyed to understand how well their undergraduate programme had prepared them for the delivery of palliative care services, what palliative care postgraduate education they had undertaken and what workplace or outside organisation palliative care training, support and palliative care resources were available to them. In addition, the pharmacists were asked to identify any gaps and barriers that were negatively impacting how we currently prepare (educate and train) and support pharmacists to care for palliative patients in the South Island. Questions were emailed out via the convenor of the NZ Palliative Care Pharmacists email group and three responses were obtained with close alignment amongst the three responders. Community pharmacists in one South Island region were invited to provide input but there was no response. A pharmacist manager of one South Island Hospital Pharmacy was surveyed also. A Palliative Care Clinical Nurse Specialist (CNS) lead from one South Island Hospital was surveyed to understand what palliative care education, if any was provided to pharmacists in the region.

Ideally, it would have been useful to survey community and hospital pharmacists across the South Island for their input as well as undertake a survey of all South Island regions to understand what palliative care education, training and support is provided to pharmacists by Specialist Palliative Care Services to provide more detailed information across the South Island. However, the research undertaken is likely to have provided a reasonable snapshot of the current situation.

Current preparation and support to deliver palliative care

The following information details palliative care educational opportunities for pharmacists as at May 2019:

Undergraduate Training (4-year programme)

Bachelor of Pharmacy, Otago School of Pharmacy, Otago University

The Palliative Care curriculum for pharmacists at Otago School of Pharmacy is currently being revised and updated. It will be much more extensive and relevant than the previous Year 3 module i.e. the module will be run over two weeks compared to one lecture. It will include lectures and workshops with role plays and case studies pertinent to palliative care practice. It is anticipated that this new module will start end of September/ October 2019:

Week One – 4 lectures (Lecture 1. What is Palliative Care?; Lecture 2: Controlled Drug prescribing, Travelling and medication, gabapentinoids; Lecture 3. Food supplements, considerations and challenges of End of Life nutrition; Lecture 4. Bioethics and End of Life issues. The lectures will be followed by 2 workshops with practicals: 1. Law in Practice – approved meds & off label/licence; 2. Ethics in practice – end of life issues. The workshops will give a sense of the role of the pharmacist in palliative care, what they may be facing in clinical practice, how they may be interacting with patients and the multi-disciplinary team, practice queries they may have to answer, real life scenarios. There will be a formative mini objective structured clinical examination (OSCE) - examination – skills practical, which will be simulating what the student may face in real life. There will be role plays with coaching and feedback with one tutor per 3-5 students compared to one lecturer and 33 students.

Week 2. Lecture 1: Models of palliative care for Maori; Lecture 2: Te Ara Whakapiri; Lecture 3: Pain Management End of life – medicines, syringe drivers; Lecture 4: Core competencies for pharmacists – not defined yet; Lecture 5: Appropriate wound care management. The lectures will be followed by 2 workshops which a Palliative Care CNS will help with the development of. The content will be about the multi-disciplinary team (MDT) and roles; how pharmacists interact with the MDT, patient and whānau; how people end up in palliative care i.e. the different time frames/ trajectories for

COPD, cancer etc; and wound dressing. The workshops will follow the same format as Week 1 with role plays etc.

BPharm, School of Pharmacy, Auckland University

PHARMACY 411 Specifically named Palliative care content in University of Auckland

C&P Workshop: Aseptic workshop Palliative care Gp1 (2hrs); C&P Workshop: Aseptic dispensing palliative care Gp2 (2hrs); C&P Workshop: End of Life/Difficult Conversations Gp2 (2hrs); Oncology Lecture 8: Cachexia and the role of nutrition (1hr); Oncology Lecture 14: Palliative Care: philosophy, symptom control and role of the pharmacist (2hrs); Oncology Lecture 15: Māori perspectives on cancer and end-of-life care (1hr); Oncology Case management: Cases 7 & 8 Gp4 (2hrs); Case 7: Palliative Care in case of 82 year old with breast cancer (female); Case 8: Palliative Care in case of 76 year old with colon cancer (male).

NOTE: Some students in Part IV elect to go on placement for 2-week blocks within palliative care settings within hospital and some hospice settings in NZ. At Part IV of our programme, students experience 2 x 2-week blocks in specialised areas of pharmacy practice.

In addition to this, students have a day in the palliative care simulation as part of their Part IV Urgent & Immediate Patient Care Simulation week (UIPC IPL week). This involves students being taken through palliative care simulations about communication including whānau communication, MDT communication, handover information e.g. to a paramedic as well as drug treatment options and consideration of patient wishes.

This equates to a total of 19.5 hours of specific palliative care content in the programme.

In addition to course time dedicated specifically to palliative care key concepts, many of the skills and attributes that are required to successfully provide pharmacy services, including for people with life-limiting diseases and their whānau, are interwoven throughout the undergraduate course from year to year, and within the 5 different pharmacy 45- and 60-point courses that include integrated module content, rather than being left to the 4th year as in previous curricula. This includes concepts such as people skills, the ability to build rapport and develop relationships with patients and the multi-disciplinary team (MDT), complex communication skills in challenging situations and cultural competency. There is increasing complexity as students progress through the years of the programme and develop their clinical and professional skills.

Auckland's School of Pharmacy also includes a pharmacist wellbeing thread that continues throughout their programme which ties in with the palliative care competency of keeping yourself and other members of your team safe as a provider of palliative care services. "Challenging Conversations" is also included as a topic and practiced within the Palliative care simulation day (UIPC IPL week) e.g. how do you talk to patients and their whānau at challenging times such as: These are the drugs to take home when someone is dying - how do you talk to the whānau? The Oncology module also covers information relevant to palliative care and wraps around and folds back on the wider set of skills and capabilities such as people skills introduced in Year 2 and 3.

Post Graduate Opportunities (NZ)

There are no specific pharmacist postgraduate palliative care courses offered through the Schools of Pharmacy at Otago and Auckland Universities.

Otago School of Pharmacy, Otago University

The Postgraduate Certificate in Clinical Pharmacy was revised and the new certificate was rolled out in 2019. The Postgraduate Diploma in Clinical Pharmacy is also being revised. While there is no specific palliative care content, there will be an option for pharmacists to focus on a specialty area and palliative care would fit in with this. The style of the postgraduate diploma will be more in keeping with general practice programmes where pharmacists will be doing work placements and

learning. Pharmacists working in this area will be asked to put up their hand for being a contact / provide work placements for pharmacists choosing this specialty area and to assist with the development of case studies and workshops.

Canterbury University have a palliative care endorsement of the Postgraduate Certificate, Diploma and Master of Health Science. These are generic palliative care papers which do have the ability to lead towards specific allied health fields: students are encouraged to focus on their own specialty area of practice and incorporate this into their learning.

Auckland University provides a Postgraduate Certificate, Diploma or Master of Health Science that can be endorsed with palliative care, but this isn't allied health specific. However, students are encouraged to focus on their own specialty area of practice and incorporate this into their learning.

Post Graduate Opportunities (International)

Flinders University, Adelaide, Australia – offers different professionals, including pharmacists, a Postgraduate Certificate, Diploma and Master of Palliative Care that can be completed by distance learning. This course was found to be excellent.

Employment Opportunities

Workplace education, training:

This is limited and variable.

- Depends on the importance the workplace places on pharmacist education in palliative care as well as available funding
- Depends on the availability of consultant access and training
- Depends on the availability of mentors and time
- Depends on the availability of palliative care education within the workplace
- Available education within the hospital setting may be tailored towards nursing and medical staff

Palliative Care Conferences E.g. Oceanic Palliative Care Conference.

Some pharmacists have been able to gain funding to attend overseas conferences to support their knowledge. Due to a limited education budget for pharmacists, this may not be accessible for many palliative care pharmacists who would need to fund their own attendance.

Medical Peer Review Group.

Two palliative care pharmacists at a hospice are on a Medical Peer Review Group where they discuss journal articles. This helps support their education/ clinical knowledge and keeping up to date with new evidence.

Baseline learning Opportunities (readily available)

Groups:

NZ hospice/ Palliative Care Pharmacist Email Group

Pharmaceutical Society of NZ (PSNZ)

Pharmacists can purchase a palliative care basic practice workbook for self-directed learning from the PSNZ website. This is a basic introduction to palliative care. The Palliative Care Best Practice Update Workbook has been revised in 2016 by specialist palliative care pharmacist Denise Hewitt. The following topics are covered in relation to palliative care: pain, nausea & vomiting, gastrointestinal, respiratory and central nervous system symptoms, skin conditions, syringe driver use, complementary and alternative medicines, total suffering. Throughout the workbook, there are self-marking case scenarios and exercises.

Hospice NZ:
-Foundations of Palliative Care training modules
-Palliative Care lecture series
-Online resources
-The Palliative Care handbook

Mercy Hospice Auckland
As part of the 10-learning package course of the HNZ Fundamentals of Palliative Care, Mercy Hospice in Auckland offers 5 learning packages in the course for pharmacists only. "The ESSENCE OF PALLIATIVE CARE" must be completed prior to any other sessions which include Pain & Other Symptoms; Pharmacology - many medications used in palliative care are used outside their normal approved use. This session provides a more in-depth look at the pharmacology aspects of palliative care to provide increased awareness and understanding about the medications commonly prescribed in palliative care and how these medications are used specifically with the palliative care patient; Last Days of Life and Communication Skills.

Arohanui Hospice
Arohanui Hospice (Palmerston North) has an education and research unit as part of its service. An education programme is provided by an interdisciplinary team and aims to share specialist palliative care knowledge, skills and experience with generalist providers and allied health teams. The Palliative Care Partnership provides training to community pharmacists.

Online information:
healthLearn -
Has three palliative care modules but these are not pharmacist specific:

- Fundamental Series: Palliative Care;
- Nursing Research Series Video Presentation: The Attitudes and Perceptions on Death and Dying in Hospital, of Adult Patients and Families Who Have Received Palliative Care;
- Palliative Care Study Day at Christchurch Hospital: illness trajectories, transitions, barriers and obstacles within palliative care, differing needs of patients in their terminal phase and symptom management in palliative care.

Goodfellow Unit (University of Auckland)
https://www.goodfellowunit.org/
As at May 2019, offers an online course in palliative care plus free podcasts and courses about palliative care that pharmacists can access on the internet. The available free webinars currently have no palliative care content.

CareSearch
Australian evidence-based online resource for all health professionals and patients. Good for review articles. NZ Pharmacists can sign up to receive regular Palliative Care Community Pharmacy updates which can be shared freely with others. The updates are a monthly bulletin for community pharmacists involved in the delivery of services to palliative care patients and their families. These updates provide practical up-to-date information relating to pharmacy and medicines management in the setting of palliative care to enhance pharmacists' interactions with other health providers, palliative patients and their families. They are based on critical review of available evidence. There are also back-dated newsletters and case studies with palliative care relevant information that are excellent.

Some palliative care pharmacists in NZ are using this online resource currently:
PCC4u: Palliative Care curriculum for Undergraduates http://www.pcc4u.org/
Australian-based. Free access.

Undergraduate Training

Pharmacist undergraduate education in New Zealand (NZ) is provided by two Schools of Pharmacy, at the University of Otago and at the University of Auckland. The undergraduate programmes for pharmacists are designed to provide a foundation of knowledge and core skills upon which pharmacists will build with experiential learning and continuing education, including post-graduate education, to meet the needs of their pharmacy practice.

All pharmacists providing pharmacy services to patients, regardless of their work setting, will be providing care to palliative patients and their carers and/or whānau. Therefore, there are core palliative care competencies that undergraduate programmes need to be equipping our pharmacy undergraduates with. It is difficult for pharmacist undergraduate programmes to cover all areas at a depth that will enable specialised practice immediately upon graduation; particularly since in New Zealand undergraduate programmes are only graduating pharmacist interns, not fully registered pharmacists. Accordingly, palliative care undergraduate education for pharmacists covers some of the key concepts, but pharmacists wanting to provide specialist palliative care services or work as part of a specialist palliative care team will benefit from further palliative care education that may include postgraduate education.

Historically, pharmacy undergraduate education contained very little or nothing in the way of palliative care content for pharmacy students, except for under the umbrella of oncology. This is reflected in the comments made by pharmacists working in palliative care who graduated 19 and 20 years ago who stated that their undergraduate training had no palliative care content and did not prepare them well for working in palliative care, requiring them to undertake postgraduate education.

Pharmacist roles have expanded and developed over the last 40 years, and undergraduate programmes have changed and developed to reflect the changing education requirements for pharmacy students. This process is ongoing with both Schools of Pharmacy having processes to ensure their undergraduate programmes are satisfactorily preparing their students for pharmacy practice and meeting the needs of their employers.

Reviewing the Undergraduate Programmes for Fitness of Purpose:

Both Schools of Pharmacy have recently revised their undergraduate palliative care programmes. For both undergraduate programmes, input for case studies and workshops is sought from palliative care specialists including pharmacists, nurses and doctors to ensure the material is relevant to practice.

With respect to how the Pharmacy Schools know whether the revised palliative care curriculum is meeting the needs of pharmacists and employers, the External Advisory Board has input into the curriculum. Sub-committees report to the Education Committee. Both Pharmacy Schools have close contact with the Assessment Centre and the EVOLVE Internship programme which can provide feedback from employers on whether pharmacy students are sufficiently prepared or whether there are any gaps in education that need to be filled by the undergraduate programme. Anecdotal student feedback is also received from students who have been on placement. Feedback is also provided by alumni/postgraduate students.

Post graduate Training

There are no pharmacist-specific postgraduate palliative care programmes offered through the Schools of Pharmacy at Otago and Auckland Universities that can prepare pharmacists working in or wanting to work in palliative care. However, the University of Auckland and University of Canterbury

both offer a Postgraduate Certificate, Diploma and Master of Health Science that can be endorsed with palliative care. Whilst not pharmacy specific, students are encouraged to focus on their own specialty area of practice and incorporate this into their learning. Pharmacists can also choose to study individual university papers pertaining to palliative care.

The disadvantage of these courses is that they are nursing based. One pharmacist, advancing her career in palliative care, wanted credibility from members of the MDT she worked with and postgraduate palliative care education, not an endorsement of a nursing-based degree. She completed the Masters of Palliative Care at Flinders University in Adelaide by distance learning and found this satisfied her requirements, as well as providing her with the credentials she wanted. Flinders University also offers a Graduate Certificate and Graduate Diploma in Palliative Care.

PSNZ, often the first port of call for pharmacists seeking education packages, only offers one palliative care resource for purchase, a self-directed learning Palliative Care Basic Practice update workbook which is a useful introduction to palliative care for pharmacists. For most community pharmacists, palliative care education after graduation is gained from Hospice NZ courses run by hospices such as Mercy Hospice or opportunistic single education sessions run by organisations such as Pegasus Health Pharmacist Small Group education (a Canterbury-based education programme that other regions can purchase).. They previously provided a session on "Dying Matters" in 2013 but due to a lack of new information, they are unlikely to be providing another session on palliative care in the near future.

These ad hoc training approaches are the mainstay for pharmacists wanting to upskill themselves in this area, in addition to skills and competencies gained from learning "on the job" if they happen to be working in a setting where palliative care is recognised and provided by the pharmacy either to the patients in their community or if they are working with aged-related residential care (ARRC) facilities that provide end of life services, or in a hospital or specialist palliative care setting.

<u>Support for Pharmacists Providing Palliative Care Services</u>

- Hospice Pharmacist networks e.g. Palliative Care/ Hospice Pharmacists Email Group.
  - Pharmacists working in palliative care may be put in touch with the convenor of this group by contacting PSNZ Practice and Support. Any palliative care practice questions are emailed to the convenor (Denise Hewitt who is based at Arohanui Hospice) who emails them to the group members who respond if they can provide information.
- Hospital Palliative Committees e.g. Nelson
- Hospice (local)
  - Local Hospices are a resource and support for pharmacists working with palliative patients but not all pharmacists may be aware of the support their local hospice may offer.
  - In Palmerston North, The Palliative Care Partnership (a partnership between Central PHO, Arohanui Hospice and General Practices) provides support and education for health professionals including pharmacists. Education is provided to community pharmacists and pharmacy technicians once a year. This is an excellent model that would be worth emulating in other regions.
- Palliative Care Specialist Services including local consultants/palliative care specialists, Palliative Care CNS's and allied health can be a source of support to pharmacists in all work settings.
  - Pharmacists working in specialist palliative care services appreciate support from the Palliative Care Specialists they work alongside.
- Oncologists
- Mentoring by other pharmacists working in palliative care. Hospital Pharmacists Association of NZ can provide a pharmacist mentor.

Evaluation of existing education, training and support

- **Undergraduate training**
  - Has historically been very limited or non-existent and pharmacists have not been well-prepared for providing palliative care services.
  - The revised palliative care module for the University of Otago School of Pharmacy undergraduate programme starting in late September /early October 2019 is much more comprehensive than the previous education provided to undergraduate pharmacy students with 2 weeks of lectures and workshops being dedicated to the topic compared to one lecture previously. The content is reasonably extensive and will better prepare pharmacists to provide palliative care services.
  - The University of Auckland undergraduate programme revised in 2017 has 19 hours dedicated to palliative care content covering important core palliative care competencies. In addition, the whole programme is interwoven with core competencies that are necessary for pharmacy practice across all areas as well as palliative care.
  - The revised palliative care content in both undergraduate programmes appears to cover many of the required core competencies and will provide a better foundation for preparing pharmacy students for delivering palliative care services. Core palliative care competencies addressing Loss and Grief, Caring for Ourselves, Spirituality and Advanced Care Planning will also be important palliative care competencies to impart to pharmacy students.
  - The undergraduate programmes are unlikely to completely prepare pharmacists for provision of palliative care services at a specialist level but may provide a core set of competencies for non-specialist palliative care services. If pharmacists are wanting to be involved with specialist palliative care services, postgraduate education will be necessary to enable competent and high-quality palliative care service provision. The level of postgraduate education required will depend on how involved the pharmacist is with symptom management.

- **Postgraduate training**
  - Is ad hoc for pharmacists and non-pharmacy specific. Available programmes cover the important palliative care concepts but within NZ, these are nursing-based Health Science degrees endorsed with Palliative Care which is off-putting to some pharmacists who have sought overseas qualifications through Flinders University. Nevertheless, pharmacists can complete these qualifications and tailor the learning to their professional practice with the content covering important palliative care concepts and competencies.
  - At the University of Otago School of Pharmacy, the Postgraduate Diploma in Clinical Pharmacy is currently being revised and will allow pharmacists the option of choosing a specialty which could include palliative care. Case studies and workshops supported by experienced pharmacists working in the specialty area, as well as work placements will support advanced learning. This is a good direction for pharmacists.
  - Flinders University in Adelaide provides an excellent alternative for pharmacists wanting a specific postgraduate palliative care qualification (certificate, diploma or masters) rather than a postgraduate qualification of Health Sciences endorsed with palliative care. Distance learning supports NZ pharmacists to undertake this programme, but there is significant cost involved and some on-campus requirements.

- **Workplace education, training and support:**
  - This is limited and variable.
  - Depends on the importance the workplace places on pharmacist education in palliative care as well as available funding.

- Some workplaces may not value palliative care education that is not pertaining directly to pharmacists i.e. some of the broader concepts that are essential to deliver high quality palliative care services that are not perceived as the pharmacist's specific role e.g. bereavement, spirituality.
- Depends on the availability of consultant access and training.
- Depends on the availability of mentors and time.
- Depends on the availability of palliative care education within the workplace and education that is at the right level and useful for pharmacists. Much workplace education is oriented towards nurses and doctors.

- **Other education:**
  - Hospice NZ education covers the main important concepts and is well-received but not all pharmacists are aware of its availability.
  - "Palliative Care Basic Practice Update Workbook" for self-directed learning that pharmacists can purchase from the Pharmaceutical Society of NZ l covers the main important concepts but is at a basic level.
  - The Goodfellow Unit: material is geared for doctors but there is useful learning for pharmacists. Not all pharmacists will be aware of this resource or learning material.

Barriers of existing education, training and support:

Ongoing education including postgraduate education is difficult to achieve:

- Lack of a defined palliative care competency framework and education pathway for pharmacists – pharmacists don't know which courses to select/ what would suit them best.
- Pharmacists have difficulty finding appropriate papers, degrees or knowing where to look. There is no advice on the PSNZ website regarding what postgraduate education pharmacists should take in palliative care.
- Cost
  - Papers, travel, accommodation, time off work.
  - Pharmacists don't seem to have access to Health Workforce NZ funding. Nurses apply to the DHB and get money from Health Workforce NZ for study days and can claim back their salary for attending the day.
  - Sometimes pharmacists may be able to obtain funding from other sources e.g. Genesis Oncology supported a palliative care pharmacist to go to a conference but there is a lot more funding available for medical staff e.g. under the Association of the Salaried Medical Specialists (ASMS) Multi-Employment Collective Agreement (MECA), $16 000 was available for education material for medical staff.
- Ease of access to courses outside main centres can be a barrier.
- Time available (when working full time and on call).
- Availability of cover to release time for courses.
- Lack of appropriate supervision in the workplace. Palliative care pharmacists advised that clinical supervision is difficult to find:
  - "Little clinical support available in hospital – Hospice will listen, then take over… the oncologists have been very supportive to me".
  - Lack of clinical supervision.
  - Lack of mentoring.
- Lack of defined roles for pharmacists working in palliative care (i.e. there is no defined career pathway for pharmacists in palliative care) as well as the lack of consistency across NZ (and SI) which may affect pharmacists' perception of the value in undertaking costly education if they are not able to put their learning into practice.
- Some workplaces may not value palliative care education that is not pertaining directly to pharmacists i.e. some of the broader concepts that are essential to deliver high quality palliative

care services that are not perceived as the pharmacist's specific role e.g. bereavement, spirituality.
    - One pharmacist commented that there is support for some areas of postgrad education within the workplace, but a lack of understanding by management that Palliative Care is more than just drugs and involves psychological, social, spiritual aspects.
    - One hospital funds PCF (Palliative Care Formulary) and would support some continuing education but only in pharmacy, rather than other areas of Palliative Care which are also needed.
- Lack of understanding that palliative care is not last days of life.
- Lack of support to update resources.
- Availability of suitable level of palliative care education in the workplace.
- Difficulty getting clinical experience after completing postgrad education.
    - A lack of processes for pharmacists newly trained in palliative care to gain clinical experience and maintain learned skills. This includes a place to work and the MDT understanding pharmacists add on value to palliative care other than medicine supply.
    - One pharmacist expressed concern she would lose the skills she had gained through postgraduate education because she was not being given the opportunity to apply her skills and knowledge: "There is a palliative care nurse in hospital for limited periods, and a consultant. They tend to interface with doctors and nurses and use pharmacy as a supply source, and a sign off for syringe drivers, rather than for clinical input. House officers and registrars do need clinical pharmacy support. I feel I will lose the knowledge I gained if I don't get more clinical work, with consultant supervision".
    - Hospices are not always ready to invest in pharmacists (employment is a barrier). Some smaller hospices are investing with small FTE's.
- Need a national body for palliative care. There is no over-arching body. Hospice NZ is a national organisation. There used to be a Palliative Care Council but it is no longer running.
    - There is a body called the Palliative Care Nurses of NZ (needed for pharmacists).
- More national guidelines to save replication and bring consistency at individual organisations would also be helpful.

<u>Existing local, national and international resources</u>

Local Resources:

- Local hospices can be useful resources of support and information for community and hospital pharmacists working with palliative patients. Pharmacists can access Hospice NZ education courses and lectures that are provided through local hospices. These courses and lectures are not always advertised to pharmacists and many pharmacists are unaware of their availability. The Hospice NZ breakfast lectures are great for specific topics.
- Specialist Palliative Care Services, including Hospital Palliative Care Specialists and Clinical Nurse Specialists (CNS's), can be used as a resource and support for community and hospital pharmacists. Palliative Care CNS's have an education component to their role, but education is not usually provided to pharmacists but could be. Arohanui Hospice in Palmerston North provides annual education to pharmacists and pharmacy technicians. South Canterbury Palliative Care CNS's currently have not provided education to local pharmacists but would be open to this if there was a particular, identified educational need.
- HealthPathways, including Canterbury, Nelson-Marlborough, Aoraki and Southern HealthPathways in the South Island, is a point of care tool, primarily for general practitioners, but is also able to be utilised by allied health, including pharmacists. Each HealthPathway is localised and updated using the Canterbury platform as a starting point but there can be a time delay for this to occur. There is a palliative care section that provides useful information that pharmacists can access with a Username and Password which is specific for each region. The Palliative Care section has a wide range of information including about medications used in palliative care, newly diagnosed palliative care patients, symptom control, access to the

Palliative care Handbook, syringe drivers and an opiate conversion guide. There are links to patient resources and to a Waitemata DHB Fentanyl Subcutaneous and Nasal guide.

National Resources:

- There is no national palliative care framework, pathway or set of competencies defined for palliative care pharmacists which is seen as a disadvantage by the AHW as well as some of the palliative care pharmacists who were surveyed.
- MoH Website:
  - Palliative Care and Maori Health Literacy Perspective (https://www.health.govt.nz/publication/palliative-care-and-maori-health-literacy-perspective)
  - Kia Mau te Kahu Whakamauru: Health Literacy in Palliative Care - https://researchspace.auckland.ac.nz/handle/2292/22569
  - https://researchspace.auckland.ac.nz/bitstream/handle/2292/22569/Health%2bliteracy%2bin%2bpalliative%2bcare%2breport%2bfinal.pdf?sequence=6
- Palliative Care Pharmacists in NZ are currently accessing some of the following resources, some of which are international:
  - The main and best resource is the British Palliative Care Formulary but it is expensive https://www.palliativedrugs.com/assets/pcf6/Prelims_PCF6.pdf
    - Can be accessed online via Medicines Complete – one pharmacist has access via Mercy Hospice subscription – this is usually accessed on a daily/weekly basis.
    - Nelson Public Hospital bought the PDF 2 years ago, but hasn't been updated.
  - Palliativedrugs.com for syringe driver survey database, bulletin board and donated documents. This is free but pharmacists must be registered to use it.
    - The Syringe Driver by Andrew Dickman and Jennifer Schnieder, 4th edition is essential for looking at syringe driver compatibility information (for nurses and pharmacists making the syringes). Cost is approx. $75 (NZD).
    - Regional HealthPathways with a dedicated section on Palliative Care, localised to the particular region. Free for health professionals such as GPs, practice nurses and pharmacists to access if they have a username and password.
    - Palliative Care Basic Practice Update Workbook, written by Denise Hewitt for Pharmacists (accessed by purchase from the PSNZ website) is an excellent but basic resource.
    - NZ Formulary – There is a chapter on Palliative Care and the formulary also references palliative care information in each relevant drug monograph.
    - Palliative Care Handbook
      - accessed free online via hospice.org.nz and on HealthPathways. The Hospice NZ breakfast lectures are great for specific topics.
      - Hard copies available.
    - International guidelines
      - Scottish Palliative Care Guidelines (free access)
    - Care Search (Adelaide)
    - European Association for Palliative Care (EPAC) - https://www.eapcnet.eu/
    - On line journals: Palliative Medicine, J Palliative Med
    - Cochrane
    - ANZCA – opioid conversion calculator, Developed by the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists.
      - An essential clinical tool: Simplifying the calculation of total oral Morphine Equivalent Daily Dose (oMEDD).Using evidence-based, conservative limits for opioids.· Utilising a "traffic light" opioid dose warning system to provide a new level of clinical caution. Useful links to further information and education about safe

opioid dosing.· Clear, simple and user-friendly format.· For prescribers and patients alike.

- NZ Wound Society

Overseas Resources

- Frameworks
  - Palliative Care Competence Framework Pharmacy 2014 –Ireland. Available from: https://aiihpc.org/wp-content/uploads/2016/02/Pharmacy-Complete-1.pdf Citation: Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive. An excellent document that could be adapted for NZ. Would need cultural aspects/ competencies specific to NZ to be included.
- A Paper: Krzyżaniak, Natalia & Pawłowska, Iga & Bajorek, Beata. (2016). An overview of pharmacist roles in palliative care: A worldwide comparison. Medycyna Paliatywna w **T**Praktyce. 10. 160-173. Available from: https://www.researchgate.net/publication/317126941_An_overview_of_pharmacist_roles_in_palliative_care_A_worldwide_comparison
  - This could be a useful resource to support the development of a pharmacist competency framework in NZ and to drive pharmacist roles as integral members of the palliative care MDT. While Australian palliative care pharmacists were included in the research, New Zealand palliative care pharmacists were not.
  - The literature identifies that there are differences in the types of palliative pharmacy practice between countries which may have varying levels of impact upon patient outcomes. As pharmacists can make significant contributions to palliative care, it is important to encourage the benchmarking of practice across different clinical settings and countries to promote a consistent equitable practice.
- Palliative Care Resources for Community Pharmacy (NHS Greater Glasgow and Clyde, Scotland): https://www.communitypharmacy.scot.nhs.uk/documents/nhs_boards/glasgow/NHSGGC_PCR_version_1.2_April_2014.pdf
  - This is an excellent palliative care resource that is specific to UK/ Scotland but could be used as a model for the development of a NZ resource for NZ community pharmacists but would require a new model of working and linking in with Hospice and specialist palliative care pharmacists. This resource was developed from an innovative palliative care pharmacy scheme that was designed to shift the balance of palliative care services away from the acute sector to a more financially sustainable community service. Pharmacist facilitators were aligned to community health care partnerships and worked with community pharmacists, increasing their awareness of palliative care medicines availability (an issue that prevents timely service delivery to palliative patients). The pharmacy facilitators were also tasked with providing quality information to support pharmacy practice as well as to improve the quality, safety and cost-effectiveness of prescribing. Evaluation of the original pilot found there was real potential to manage more people at home with palliative care needs rather than having them admitted to hospital in a crisis situation. The service was accordingly expanded. This included 10 pharmacy facilitators including pharmacists and pharmacy technicians working with 291 community pharmacies and the wider MDT primary care team to increase the awareness of the palliative care service offered by network pharmacies and to help improve access to palliative care medications out of hours. The aim of the roll-out was to improve the way palliative care services were provided through improved support for all community pharmacies; training to support staff in all community pharmacies being delivered; and improving care by promoting appropriate prescribing and dispensing of palliative medicines. The development of a palliative care resources folder for community pharmacy provides a single comprehensive source of quality palliative care information

for community pharmacy staff as well as GPs and district nurses. It also provides a framework to improve the quality and safety of prescribing and dispensing as well as practical advice to prevent delays in accessing specialised palliative care medication.

- Canadian Hospice Palliative Care Association
  http://www.chpca.net/professionals/pharmacists.aspx
  - The resources that were available to access were not pharmacy specific but may be due to the level of access that could be gained to the website. There were however, very good general resources for all professions. One in particular, was: "A Model to Guide Hospice Palliative Care. Based on National Principles and Norms of Practice": http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf in which there was the "Square of Care: A Conceptual framework" that made good sense. The Square of Care is a conceptual framework that reinforces how the process of providing care should address each of the domains/issues commonly faced by persons and families. The circle of care can use this tool to help identify issues and guide the essential steps of providing care during each therapeutic encounter. Each essential step in a therapeutic encounter can be expanded to include all the details needed to guide the process of providing care, including principles of practice for each essential step; norms of practice for each step; preferred practice guidelines for each issue; data collection and documentation guidelines for each issue. All of these details can be placed in the appropriate square in the grid created by the "Square of Care".
- Paediatric Hospice Palliative Care: Guiding Principles and Norms of Practice
  http://www.chpca.net/media/7841/Pediatric_Norms_of_Practice_March_31_2006_English.pdf
  - This followed a similar format to the previous (above) document.
- The Pan-Canadian Gold Standard for Palliative Home Care.
  http://www.chpca.net/media/7652/Gold_Standards_Palliative_Home_Care.pdf
  - Excellent standards. The one pertaining to pharmacists was:
    - Palliative home care teams have timely access to knowledgeable pharmacists who can advise on the use of pharmaceuticals in hospice palliative and end-of-life care. Canadians who receive end-of-life care in an acute care hospital have access to the services of clinical pharmacists with expertise in the administration of hospice palliative care pharmaceuticals. The same level of care is available to people receiving palliative home care. The hospice palliative care team includes a physician, nurse, psychosocial support and a clinical pharmacist with expertise in hospice palliative care. In addition, community pharmacists are required to have education on the use and management of pharmaceuticals in hospice palliative care. They are also linked with a clinical pharmacist on a hospice palliative care team who can provide support and advice. Jurisdictions work with the pharmacy profession to establish a consulting service with clinical pharmacists to support end-of-life care in the home.

Evaluation of existing resources:
Under the list of resources NZ Pharmacists are using (above), NZ Palliative Care Pharmacists' evaluation of the resources have been included when they have commented on this.

Essentially, the resources are good if one has access to them. There are sufficient resources available, but it is not about just relying on and following what is in resources: pharmacists need to get an adequate base of palliative care education first to be able to apply the information in the resources alongside the patient's individual situation and what is right for them as the patient sees it. One palliative care pharmacist commented: "After my first pharmacy degree, my focus was on monitoring for this, monitoring for that. After my Palliative Care degree, I understood that it was

much more about negotiating with patients and understanding where they were at, and just not relying on resources e.g. prednisone in the evening on an empty stomach was okay (doing it this way worked for the patient)". Palliative care Specialists/consultants can be a useful resource, but this can be a limited resource or not easily accessed by some pharmacists.

Barriers to resources being utilised:
The biggest barrier is the cost of resources which affects pharmacists' ability to access them e.g. the British Palliative Care Formulary and access for pharmacists to good quality compatibility information, i.e. The Syringe Driver book. The cost of resources and the cost to access them electronically, especially for small places, could be an increased barrier for workplaces wanting to fund this. There is also the need for resources to be updated especially if they are in hard copy and there is a cost to this. Not everyone has access to every resource recommended to be used by Palliative Care pharmacists. One palliative care pharmacist commented that access to journals was not funded by the workplace.

Pharmacists' awareness of available resources as well as an understanding of their respective usefulness can also be a barrier to resources being utilised.
Access to Palliative Care Specialists is variable and this is a barrier for pharmacists being able to utilise their knowledge and skills for practice and learning, and as a mentor, which is often required for post-graduate training.

Resource gaps:
- Equitable access to palliative care resources across different workplaces
- Access to ongoing consultant teaching
- Financial help for ongoing education
- Pharmacists being aware of the resources and their respective usefulness
    - A repository for available palliative care resources on the PSNZ website may assist with this

<u>Proposed palliative care competencies</u>
There is no specific palliative care competency framework for pharmacists in NZ that could be used to inform professional development and learning or undergraduate curricula or pre-registration programmes and thereby contribute to preparing pharmacists for delivery of palliative care services. The Pharmacy Council of NZ (established under the Health Practitioners Competence Assurance Act 2003) is the statutory authority that governs the practice of pharmacists. Amongst other responsibilities, it sets standards of competence for pharmacists which are detailed in the "Competence Standards for the Pharmacy Profession". This document details the key competencies and behaviours expected of pharmacists. The document is broad-based by design so that it can be applied across a wide range of practice settings, but out of which should also fall the pharmacist specific competencies that are required in an individual practice setting. (PHARMACY COUNCIL 2015) While the framework has been developed to be flexible and versatile, it is a dynamic document that may require periodic revision to ensure it reflects the broad competencies pharmacists require as pharmacist roles change and develop. It is in this context that it was important to see whether essential competencies that have been defined for pharmacists delivering palliative care services were appropriately reflected in the current "Competence Standards for the Pharmacy Profession" or whether the development of a "Palliative Care Competency Framework for Pharmacists" would better guide undergraduate curricula, pre-registration programmes and professional development.

Before this could be done, it was necessary to review other important New Zealand pharmacy competency documents that also support pharmacists in the delivery of pharmacy services. This

included the Pharmacy Council Statement on Cultural Competence 2010 (PHARMACY COUNCIL 2011) and the "Code of Ethics 2018 – Safe Effective Pharmacy Practice" (PHARMACY COUNCIL 2018).

It was also necessary to research existing local and international palliative care competency guidelines for AHPs, including for pharmacists. Out of the few that could be accessed, The Palliative Care Framework Competencies for allied health drafted by the Forum of Irish Postgraduate Medical Training Bodies (RYAN 2014) was agreed by the Allied Health Workforce to be the best one to compare current NZ pharmacist competencies against to see what our pharmacy palliative care competencies would look like. This was particularly liked because core palliative care domain competencies were split into competencies that "some", "all" and "few" AHPs would be required to have depending on their level of palliative care practice.

The Irish framework provided core competencies in palliative care whilst also detailing individual competencies for each health and social care discipline (RYAN 2014). As this framework was developed in Ireland, it did not reflect the desired cultural competencies for health professionals working in New Zealand. The "National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand" (PALLIATIVE CARE NURSES NEW ZEALAND 2014) was used alongside the Irish competencies to help determine appropriate cultural competencies for palliative care.

By comparing the pre-existing New Zealand competency standards for pharmacists with the Irish document, we were able to see what our current core competency documents already cover for our professional pharmacy practice and what additional palliative care specific competencies would need to be included to equip pharmacists wanting to work in this field.

After reviewing the above documents, it was found that our current NZ professional competency framework and associated documents provide sufficient guidance for pharmacists to practice at their scope of practice for registration and the annual renewal of this registration for broad core competencies, many of which could be adapted for pharmacy practice in palliative care. However, as they are not specialty-specific, there are some limitations to their usefulness for pharmacists wanting to specialise in a particular area such as palliative care as well for supporting professional development or informing undergraduate curricula.

In addition, some essential palliative care competencies did not appear to fit easily within the "Competence Standards for the Pharmacy Profession" or were not covered (See Appendix for a list of these), including competencies around loss, grief and bereavement; advanced care planning and caring for ourselves/personal well-being. Some of the advanced palliative care competencies detailed in the Irish competency framework that "few" pharmacists would demonstrate did not fit easily into the core competencies of the "Competence Standards for the Pharmacy Profession" particularly around leadership and strategic work at local, regional and national levels.

While not included in the Irish competencies or the NZ competencies, spirituality is another domain that is covered in Hospice NZ's "Fundamentals of Palliative Care" education as all people working with palliative patients and their carers and whānau, including pharmacists, have the opportunity to attend to the spiritual needs of the person in each encounter. This includes the person's need to be "heard" and need to be treated with dignity. Pharmacists are in a position to recognise spiritual distress and ensure this is recorded and addressed appropriately (HOSPICE NZ 2020). Competencies around this would be sensible to include but perhaps are considered to be covered under broad competencies for cultural competency.

There are two possible approaches to ensure competence standards for pharmacists in New Zealand better reflect the essential competencies required for pharmacist practice in palliative care. The first approach is to draft a specialty-specific palliative care competency framework for pharmacists, and the second is to add core competencies to the "Competence Standards for the Pharmacy Profession" that reflect the missing palliative care competencies.

A specialty-specific palliative care competency framework for pharmacists would ensure all the essential competencies for pharmacist practice in palliative care would be defined. It would also more easily inform pharmacists for their professional development as well as be used as a guide for job descriptions, performance review and to inform training and education requirements across all levels. In addition, it would more easily allow the public and other health professionals and members of the palliative care team to understand pharmacist palliative care competencies and for them to have confidence in the pharmacist's role.
A palliative care competency framework for pharmacists would be an excellent additional framework to be used alongside the "Competence Standards for the Pharmacy Profession". However, The Pharmacy Council of New Zealand has indicated they would not be interested in adding specialty-specific scopes of practice to their official documents yet as they feel they should focus on the broad core competencies rather than defining specialty competencies. They are, however, very interested to see what a specialty-specific competency framework for palliative care would look like but would be unlikely to endorse a competency framework that they had not prepared.

While Pharmacy Council is not currently interested in developing specialty-specific competencies, at the least, the addition of competencies around Loss, Grief and Bereavement, and advanced care planning should be considered for addition to the NZ competency standards as all pharmacists, regardless of their work setting will be engaging with people dealing with these things. Consideration of the development of an advanced practice competency framework for pharmacists, similar to Australia (ADVANCED PHARMACY PRACTICE FRAMEWORK STEERING GROUP 2012), may also be prudent to help capture some of the more advanced competencies required for palliative care pharmacists, especially those working at a strategic level locally, regionally or nationally. There are pharmacists working in other areas of pharmacy practice that may be working strategically also, and these core competencies would need to be broad enough to allow for this.

With respect to the first approach, a draft Palliative Care Competency Standards Framework has been prepared (see below). The pharmacy competencies in the Irish Palliative Care Framework have been used with the addition and/ or changing of some wording to reflect a NZ context. The nursing framework, "A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand" (PALLIATIVE CARE NURSES NEW ZEALAND 2014) has been used also for the addition of cultural competencies that were lacking in the Irish framework.

Proposed – Pharmacy Competencies for Palliative Care
DOMAIN OF COMPETENCE 1

PRINCIPLES OF PALLIATIVE CARE

As a pharmacist you should:

- Integrate the principles of palliative care into pharmacy practice
- Demonstrate knowledge and understanding of the trajectories of common life-limiting conditions
- Demonstrate knowledge of symptoms commonly experienced by people with life-limiting conditions and their treatments
- Understand the impact that a life-limiting condition has on a person, their family/whānau and wider community, and provide support to facilitate their own decision-making
- Demonstrate an ability to locate assess and interpret information about medicines used in palliative care
- Demonstrate an awareness of physical psychological social and spiritual needs of people with life-limiting conditions and understand how these may impact on their pharmaceutical care needs
- Demonstrate a holistic model of care for those with a life-limiting condition, encompassing the Māori philosophy of health and wellbeing – Te Whare Tapa Wha
- Recognise the cultural uniqueness of individuals and their families/whānau and demonstrate the provision of sensitive and culturally appropriate pharmacy services to those with a life-limiting illness
- Demonstrate the ability to gain cultural support and assistance from appropriate sources if/when needed
- Be able to provide individualised pharmaceutical care and support for people with life-limiting conditions and their family/whānau that promotes safety and independence while maintaining their quality of life
- Recognise and understand the changing pharmacological and pharmaceutical care needs of people with life-limiting conditions throughout the disease trajectory
- Be able to identify and actively respond to the medicines information needs of people living with life-limiting conditions and their family/whānau
- Be able to identify and actively respond to the medicines information needs of other health care professionals
- Demonstrate an understanding of the role of others in palliative care including allied health and specialist palliative care services in supporting health care professionals to provide a palliative care approach to persons with a life-limiting condition
- Maintain individual confidentiality privacy and autonomy throughout the disease trajectory.

Engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of a broad spectrum of life-limiting conditions and the associated symptoms and treatments
- Integrate the physical psychological social and spiritual needs of a person with life-limiting conditions into the provision of pharmaceutical care and pharmacy practice incorporating holistic models of health care, encompassing the Māori philosophy of health and wellbeing – Te Whare Tapa Wha
- Be able to identify and actively respond to medicines information needs of health care professionals and support the provision of evidence-based practice in a variety of care settings
- Demonstrate leadership in the delivery of palliative care provision in your local health care network
- Demonstrate leadership in the delivery of palliative care education in your local health care network.

Core role is the provision of palliative care, you should:

- Demonstrate an in-depth understanding of the full spectrum of life-limiting conditions the associated complex symptoms and treatments

Proposed – Pharmacy Competencies for Palliative Care
DOMAIN OF COMPETENCE 1

- Be able to identify and actively respond to complex medicines information needs of health care professionals and support the provision of evidence-based practice in a variety of care settings
- Demonstrate an in-depth knowledge of the use of specialist resources providing information about medicines used in palliative care and adapt this information for use in clinical settings
- Demonstrate leadership in the identification development and delivery of medicines-related palliative care guidance and policy
- Actively influence and promote strategic initiatives and policy development for palliative care services at local regional and national levels
- Demonstrate leadership in the development and delivery of palliative care education at a national level.
- Be able to lead facilitate and engage in audit and research in the field of palliative care in order to improve practice.

DOMAIN OF COMPETENCE 2

COMMUNICATION

- Be caring empathetic and sensitive to the needs and rights of people with life-limiting conditions when communicating with them their family/whānau and or carer(s) about medication issues, respecting individual and cultural differences while maintaining their dignity
- Recognise that individuals with life-limiting conditions have varying levels of health literacy and medication information should be delivered at an appropriate level for the person their family and carers
- Involve the person with a life-limiting condition's nominated representative, whānau or appropriate cultural services, where necessary, to better understand the person's cultural needs and assist the person's understanding, recognising also that shared decision-making involving whānau may be preferred
- Endeavour to ensure that the person with a life-limiting condition their family/whānau and carers understand the information they receive regarding medication
- Communicate recommendations regarding appropriate use of medicines to other health care professionals in order to inform decision-making about medications used in palliative care
- Understand the importance of communicating with health care professionals in various care settings to ensure the seamless delivery of pharmaceutical care to people with life-limiting conditions and their families.
- Demonstrate an understanding of the communication challenges that may arise in the context of engaging with people with life-limiting conditions
- Be able to utilise the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family/whānau carer.

Core role is the provision of palliative care, you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled empathic individualised and timely communication with individuals with life-limiting conditions their families/whānau and other health care professionals
- Demonstrate expertise in medicines management issues that individuals with life-limiting conditions may experience and communicate their needs and opinions to other health care professionals.
- Demonstrate expertise as a mediator and advocate for the individual with life-limiting conditions and the family/whānau in issues related to pharmaceutical care and decision making regarding pharmaceutical care
- Be able to facilitate the multidisciplinary teaching of communication skills with regards to pharmaceutical care.

DOMAIN OF COMPETENCE 3

OPTIMISING COMFORT AND QUALITY OF LIFE

a pharmacist you should:

- Understand the importance of the timely provision of medication for symptom control and disease management
- Demonstrate knowledge of treatment choices for symptoms experienced by people with life-limiting conditions and the pharmaceutical care issues associated with these treatments
- Demonstrate an ability to provide pharmaceutical care for the management of symptoms throughout the disease trajectory and at the end-of-life
- Demonstrate an ability to counsel individuals with life-limiting conditions and their families/whānau regarding the identification and management of common adverse effects of medications
- In the context of the scope of practice undertake individual-specific monitoring for medication therapy outcomes recommend alternative medicines or dosage forms identify duplicative medications identify medication omissions provide management strategies for interacting medications and provide advice regarding the prevention or control of medication related adverse effects
- Have an awareness that alternative treatments including traditional therapies like rongoa may be used by the person with life-limiting illness with potential for drug interactions
- Recognise and if appropriate respond to psychosocial issues or cultural factors which may impact on compliance and concordance with medications, including spiritual beliefs about the cause of the person's illness
- Demonstrate an ability to address and resolve any issues and concerns that the individual or family/whānau member may have about medications being used to treat symptoms at the end-of-life
- Demonstrate an awareness of factors relating to the dispensing and supply of medicines particularly unlicensed medicines off-label usage of medicines and expensive medicines
- Recognise when it is appropriate to refer the person with a life-limiting condition to other health care professionals.
- Demonstrate advanced knowledge and clinical application of pharmacological treatment options for symptoms in people with life-limiting conditions
- Provide expert advice on compatibility and stability when using multiple drugs being administered subcutaneously (SC) or intravenously (IV).
- Support and advise prescribers making decisions to modify the pharmacological management of co-morbidities
- Demonstrate expert knowledge and clinical application of pharmacological treatment options for the management of complex and non-complex symptoms in palliative care
- Be able to provide leadership expertise and guidance to colleagues on the pharmacological management of complex and non-complex symptom control strategies in individuals with life-limiting conditions.

DOMAIN OF COMPETENCE 4

CARE PLANNING AND COLLABORATIVE PRACTICE

As a pharmacist you should:

- Understand that in situations where a person lacks capacity to make decisions, decisions must be made in the best interests of the person in collaboration with the family/whānau and other members of the multidisciplinary team
- Demonstrate an ability to collaborate with individuals, family/whānau members, carers and other health care professionals in monitoring medicines used for symptom control at the end-of-life
- Demonstrate an ability to individualise pharmaceutical care to address the physical and psychosocial needs of persons with life-limiting conditions
- Demonstrate an ability to identify any potential medication safety risks and educate persons with life-limiting conditions and their family/whānau members on the correct use of medications used in palliative care and liaise with other health care professionals where appropriate
- Demonstrate flexibility in medication related care planning acknowledging that the persons priorities can alter with a change in their condition and disease advancement
- Demonstrate an ability to recommend strategies for medication recalls or medication dosage formulation shortages in order to avoid any disruption to care at the end-of-life
- Be able to provide advice to other health care professionals regarding commonly used difficult to source or expensive medications.
- Maintain professional development with regards to advancing knowledge and skills in palliative care
- Be able to provide advice to other health care professionals regarding specialised and difficult to source medications.
- Demonstrate an ability to collaborate with individuals, family/whānau members, carers and other health care professionals in designing implementing and monitoring a pharmaceutical plan for symptom control throughout the disease trajectory and at the end-of-life
- Demonstrate an in-depth understanding of medication related issues that may develop over the disease trajectory and plan accordingly
- Demonstrate an ability to perform a structured critical examination of prescribed medication in order to optimise the impact of medicines and minimise the number of medication related problems
- Demonstrate knowledge of the medication safety risks that arise with the use of medicines in palliative care and an ability to advise other health care professionals on methods to minimise the risk of harm to individuals
- Demonstrate the ability to collaborate with specialist palliative care teams and provide expert pharmaceutical care for people with life-limiting conditions with complex symptoms
- Demonstrate an ability to act as an expert clinical resource as required to generalist providers of palliative care with regard to the use of medicines in palliative care
- Be able to promote the safe use of medicines in palliative care by encouraging the reporting of errors improving medication use processes and developing and implementing medication safety strategies for high risk medications.

DOMAIN OF COMPETENCE 5

LOSS GRIEF AND BEREAVEMENT

As a pharmacist you should:

- Demonstrate an understanding of the impact a life-limiting diagnosis may have on an individual and their family/whānau
- Demonstrate understanding of normal and pathological responses to the diagnosis, prognosis of a life-limiting condition and an ability to address the immediate management of such responses
- In context of your role appreciate the needs of family/whānau and carers with regard to expression and management of grief
- Facilitate the safe efficient and traceable removal of drugs from the home of individuals with life–limiting conditions as required
- Reflect on experiences with persons with life-limiting conditions and bereaved family/whānau members to enhance professional practice.

DOMAIN OF COMPETENCE 6

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

As a pharmacist you should:

- Be aware of and act according to the Pharmacy Council of New Zealand Code of Ethics and its application to the care of people with life-limiting conditions
- Be aware of and act according to all legislation, regulations, codes of practice and standards which impact on the practice of pharmacy and the delivery of health and disability services in relation to the care of people with life-limiting conditions.
- Be aware of and act according to the Pharmaceutical Society of New Zealand Competency Standards for pharmacists
- Demonstrate an understanding of the difference between managing a life-limiting condition and providing end-of-life care
- Demonstrate an awareness of the importance of maintaining professional boundaries when working with individuals with life-limiting conditions.
- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations
- Demonstrate a commitment to working with pharmacy colleagues and other health care professionals to assess co-ordinate promote and improve medication safety in the context of palliative care.
- Demonstrate an ability to influence processes and behaviours that determines how medicines are used in palliative care at a national level.
- Demonstrate a commitment to working in partnership with health care managers and providers to assess coordinate promote and improve individual safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement and risk management in the context of palliative care
- Demonstrate a commitment to advancing palliative Care through the generation and application of knowledge and research
- Demonstrate leadership through advocating for continuous service development and professional practice

Next steps

- Current undergraduate education does not appear to teach pharmacy students core palliative care competencies on Loss, Grief and Bereavement; Spirituality and Advanced Care Planning. The modules may already be filled with competencies believed to be more critical for undergraduate learning. These competencies will need to be learned through Hospice NZ education programmes or through postgraduate education. Approaches could be made to the pharmacy undergraduate programmes to advise them of this gap and see whether it is possible for these competencies to be included in their palliative care programmes.
- There is no specific postgraduate training in palliative care through the Schools of Pharmacy in New Zealand. Extra education is therefore done ad hoc by pharmacists sourcing courses by a variety of providers.
- There is no advice on which courses would suit pharmacists best. There is no framework for pharmacist palliative care education, nor defined career pathway.
- There is no palliative care competency framework for pharmacists: What do pharmacists need to know? What should they be trained in?

We need to define a set of competencies for pharmacists so appropriate undergraduate and postgraduate education opportunities can be developed, and then what workplace training and support needs to be provided or undertaken. Competencies need to be defined for both generalist and specialist palliative care services provided by pharmacists e.g. Working in community pharmacy and providing pharmacy services to patients who are palliative living in the community or in ARRC; working in general practice and supporting GPs to prescribe for palliative patients; working in community pharmacy and providing a supply function to hospice and education; working in hospital and providing pharmacy services to palliative patients or working in hospice or providing hospice services.

Once the draft set of palliative care competencies have been defined, key pharmacy stakeholders should be consulted for feedback:

- **The Pharmacy Council of NZ**, which;
  - may consider adjustments to the existing Competency Standards if there are core palliative care competencies that are not reflected in the current standards.
  - is unlikely to endorse competencies they have not developed but the completed work may be a starting point for reflection on whether the current standards could be supported by discipline specific ones such as palliative care.

    Note: A palliative care specific competency framework is desired by pharmacists working in this area. They believe it would better support pharmacists working in this area to identify professional development and learning requirements and provide a consistent tool for standards in palliative care across all of NZ. The framework could be used to promote pharmacists' roles in palliative care and give confidence to members of the public and other members of the palliative care health team regarding pharmacists' involvement in the MDT and palliative care service delivery. It could be used to support job description development and performance reviews, in addition to help inform undergraduate curricula, pre-registration programmes and post-graduate education for pharmacists.

    The core competencies reflected in the current competence standards for pharmacists in New Zealand are expected to be built upon as a pharmacist progresses through their career. Australia has developed an Advanced Pharmacy Practice Framework as a pharmacist's competencies after years of experience and further education and training will be significantly different from that achieved at initial registration. The palliative care competencies required for delivery of specialised palliative care services, especially when a

pharmacist has a high degree of involvement with symptom control management for palliative patients near end of life, is likely to fit into an advanced pharmacy practice framework. It is timely to consider whether our current competence standards for pharmacists in New Zealand sufficiently capture competencies of advanced pharmacy practice.

- **Clinical Pharmacists' Association of NZ (CAPA),** which;
  - may want input into competencies for advanced pharmacy practice such as for provision of specialised palliative care services.

- **Pharmaceutical Society of New Zealand;**
  - Palliative care pharmacists would like a repository for information about available education and courses on palliative care, as well as a repository for palliative care resources. The development of palliative care career pathways and an associated palliative care education pathway with links to available education and resources on the PSNZ website would be useful. This could include desired palliative care competencies for pharmacists or if Pharmacy Council has no desire to endorse the proposed draft palliative care competencies for pharmacists, a link to the Irish Palliative Care competencies for pharmacists would be useful. Having a repository of palliative care resources, including online access that had been negotiated by PSNZ, may negate some of the equity issues regarding access to resources as well as ensuring currency of resources, especially for pharmacists working in smaller places.

  - Palliative care pharmacists are not included in the "Guide for Pharmacist Salary Banding in NZ" (PSNZ 2017). This document identifies pharmacists' existing and developing roles commensurate with required education, skills and responsibilities. The Guide reflects the range of salaries paid to pharmacists in differing roles in New Zealand and helps funders to appropriately recognise the value of the different and expanding roles, skill sets and education of pharmacists in the integrated healthcare model. PSNZ may wish to review and update this document to include palliative care pharmacists working across a range of work settings and in different degrees of specialisation and advanced practice. Their skill sets do not fit easily into this document. This may then support expanded pharmacist roles in palliative care being recognised as well as appropriate remuneration, which may encourage pharmacists to consider postgraduate training.

- **The Palliative Care/Hospice Pharmacist Email Group;**
  - The group expressed a wish to see the completed piece of work and wanted to feedback on our findings, conclusions and suggestions for moving forward, including our proposed palliative care competencies for pharmacists.
  - Note: We need to define pharmacist' contribution to palliative care and research maybe required to determine this:
    We do not know what roles NZ pharmacists are undertaking, what models of integrated palliative care are being used and what impact is being made on patient outcomes, or how this compares to overseas. Having this defined may help define what competencies are required, how we may better prepare pharmacists for their roles and how better patient outcomes may be achieved.
    Differences in the types of palliative pharmacy practice between countries have been identified in literature and may have varying levels of impact upon patient outcomes (Krzyżaniak 2016). "As pharmacists can make significant contributions to palliative care, it is important to encourage the benchmarking of practice across different clinical settings and countries to promote a consistent equitable practice" (Krzyżaniak 2016).
    Having roles defined may also support career pathway development and appropriate recognition by other health professionals, members of the palliative care MDT, employers

and the public. This in turn may encourage pharmacists to undertake postgraduate training in palliative care as they may see benefit for undertaking costly education.

- An education campaign promoting expanded pharmacist roles in palliative care along with what constitutes essential palliative care competencies for pharmacists may support better access to training opportunities for pharmacists, with employers having a greater understanding of these things and placing a greater value on pharmacists undertaking the training. This, along with evidence from research into different pharmacist roles and models of integrated palliative care may also create more job opportunities and placements to cement clinical training.
- Ensure pharmacists, especially those new to palliative care have access to mentors that can be set up through PSNZ. With respect to mentoring, The Irish Palliative Care Competence Framework for pharmacy indicated the importance of passing on the knowledge of palliative care from pharmacists who are working in the palliative care setting to other pharmacists, including those who may want to enter this specialty area, and also to other health professionals involved in the care of a palliative patient. As can be seen in our evaluation of current education and training available to pharmacists wanting to specialise in palliative care, the majority of the training available in New Zealand is through work or other organisations offering topical training when available. In this case, having pharmacist mentors who already work in the field can be an invaluable resource for those wanting to improve their understanding of this area.
- Investigate funding streams, including Health Workforce New Zealand, that may support pharmacist post-graduate education in palliative care to reduce cost as a barrier. With many employment agreements being governed by national agreements, there is a disparity in access to education funding within a DHB environment. This is difficult to resolve, however, DHB budgeting may allow for some flexibility to support palliative care education for pharmacists if it is seen as being valuable.
- Investigate the reasons why the NZ Palliative Care Council is no longer operational and whether or not a similar over-arching body is needed. Some palliative care pharmacists thought it would be beneficial to have this back.

References

- Advanced Pharmacy Practice Framework Steering Committee. An advanced pharmacy practice framework for Australia. October 2012. Available at: www.advancedpharmacypractice.com.au
- PSNZ. Guide for Pharmacist Salary Banding in NZ. [Internet]. [2017 Oct; Accessed: 20 Jan 2020]. Available from: https://www.psnz.org.nz/Folder?Action=View%20File&Folder_id=86&File=Salary%20Guide.pdf
- Hospice NZ. Fundamentals of Palliative Care. [Internet]. [Updated: 2020; Accessed: 21 Jan 2020]. Available from: https://www.hospice.org.nz/education-training/training-modules/
- Krzyżaniak, Natalia & Pawłowska, Iga & Bajorek, Beata. (2016). An overview of pharmacist roles in palliative care: A worldwide comparison. Medycyna Paliatywna w **T**Praktyce. 10. 160-173. Available from: https://www.researchgate.net/publication/317126941_An_overview_of_pharmacist_roles_in_palliative_care_A_worldwide_comparison
- Palliative Care Nurses New Zealand. 2014. A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand. Wellington: Ministry of Health. Available from: https://www.health.govt.nz/system/files/documents/publications/national-professional-development-framework-palliative-care-nursing-practice-nz-oct14.pdf
- Pharmacy Council of NZ. [Internet]. [Accessed: 19 Jan 2020; Updated Jan 2015] Available from: https://www.pharmacycouncil.org.nz/about-us/what-we-do/
- Pharmacy Council of NZ. Competence Standards for the Pharmacy Profession. [Internet]. [Updated: Jan 2015; Accessed Oct 2019]. Available from:

https://www.pharmacycouncil.org.nz/dnn_uploads/Documents/standardsguidelines/CompStds2015Web.pdf?ver=2017-02-20-104344-177

- Pharmacy Council of NZ. Statement on Cultural Competence. [Jan 2011; Accessed 12 Jan 2020]. Available from: https://www.pharmacycouncil.org.nz/dnn_uploads/Documents/standardsguidelines/Cultural%20Copetance%20statement%202010-%20web.pdf?ver=2017-02-20-105424-113)
- Pharmacy Council of NZ. Code of Ethics 2018 – Safe effective pharmacy practice. [Internet]. [Updated 2018; Accessed 21 October 2019] Available from: https://www.pharmacycouncil.org.nz/dnn_uploads/Documents/standardsguidelines/Code%20of%20Ethics%202018%20FINAL.pdf?ver=2018-03-04-215933-993).
- Ryan K, Connolly M, Charnley K, Ainscough A, Crinion J, Hayden C, Keegan O, Larkin P, Lynch M, McEvoy D, McQuillan R, O'Donoghue L, O'Hanlon M, Reaper-Reynolds S, Regan J, Rowe D, Wynne M; Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive. Available from: https://aiihpc.org/wp-content/uploads/2016/02/Pharmacy-Complete-1.pdf)

Addition

Competencies from the Irish Palliative Care Competency Framework that were not reflected in the NZ Competency Framework for Pharmacy Practice:

From under the Loss, Grief and Bereavement domain:

"Demonstrate an understanding of the impact a life-limiting diagnosis may have on an individual and their family"; "Demonstrate understanding of normal and pathological responses to the diagnosis/ prognosis of a life-limiting condition and an ability to address the immediate management of such responses"; "In context of your role, appreciate the needs of family and carers with regard to expression and management of grief "; "Facilitate the safe efficient and traceable removal of drugs from the home of individuals with life–limiting conditions as required" and "Reflect on experiences with persons with life-limiting conditions and bereaved family members to enhance professional practice".

From under the domain of Professional and Ethical Responsibilities:

"Demonstrate an understanding of the difference between managing a life-limiting condition and providing end-of-life care" and "Demonstrate an awareness of the importance of maintaining professional boundaries when working with individuals with life-limiting conditions".

From under the domain of Palliative Care Principles:

"Demonstrate knowledge and understanding of the trajectories of life-limiting conditions".

From under the domain of Communication:

"Understand the importance of communicating with health care professionals in various care settings to ensure the seamless delivery of pharmaceutical care to people with life-limiting conditions and their families"- There is nothing quite like this in the NZ competency standards, but it could fit under Competency M2.1 Communicate Effectively and/ or Competency O1.4 Deliver Quality And Safe Services).

From under the domain of Care Planning and Collaborative Practice:

"Understand that in situations where a person lacks capacity to make decisions, decisions must be made in the best interests of the person in collaboration with the family and other members of the multidisciplinary team"; "Demonstrate flexibility in medication related care planning acknowledging that the person's priorities can alter with a change in their condition and disease advancement" – this may fit under NZ Competency Standards: M1.1.1 Applies patient-centred care principles as the cornerstone of professional practice but there are no specific competencies referring to advanced care planning.

Some of the advanced palliative care competencies detailed in the Irish competency framework that "few" pharmacists would demonstrate did not fit easily into the core competencies of the "Competence Standards for the Pharmacy Profession" particularly around leadership and strategic work at local, regional and national levels.

This included competencies under the domain of Palliative Care Principles: "Demonstrate leadership in the identification, development and delivery of medicines-related palliative care guidance and policy"; "Actively influence and promote strategic initiatives and policy development for palliative care services at local regional and national levels" and "Demonstrate leadership in the development and delivery of palliative care education at a national level"; competencies under the domain of Professional and Ethical Practice: "Participate in the discussion and resolution of ethical dilemmas that may arise in palliative care" and "Demonstrate an ability to influence processes and behaviours that determines how medicines are used in palliative care at a national level".

Physiotherapy

By Karla Poyner, Business Manager / Physiotherapist, Motus Ashburton

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Introduction and approach

All physiotherapists working in Aotearoa New Zealand must adhere to the Physiotherapy Standards Framework. The Framework describes the standard of ethical conduct, clinical and cultural competence. It includes minimal threshold competencies that physiotherapists must apply to their specific area of work and specific standards for certain situations. Physiotherapy students in Aotearoa New Zealand exit their qualification at a level that meets this framework. Physiotherapists who have trained overseas who wish to gain New Zealand registration must follow a formal application process with the Physiotherapy Board of New Zealand to show they meet the Physiotherapy Standards Framework. Due to the nature of one framework for all, the competencies are generic, minimum standard thresholds and are not specific to palliative care. Each clinician must apply these standards to their area of practice. There are a small number of physiotherapists working in Specialist Palliative Care Services however by the definition of primary palliative care, the palliative care approach, and the palliative care system all physiotherapists will at times in their career contribute to palliative care.

Physiotherapists work in a variety of settings and will often have changes of clinical direction or geographical location over their career. When looking at the availability of education and resources we need to consider this to ensure education and resources are complementary to lifelong learning. It is uncommon for a physiotherapist to work in Specialist Palliative Care Services as a new graduate, as often people move into this field later in their careers. Data from the Physiotherapy Board Annual Report (2022) and online register states that there were 7556 registered physiotherapists and 14 'Physiotherapy Specialists'. 6038 of these 7556 registered physiotherapists hold an Annual Practicing Certificate (APC), those without an APC were predominantly working overseas. The report found 57% of physiotherapists worked in private practice and 27% in hospital and health services. This information is helpful as it shows that alongside providing resources for our physiotherapists working in hospital and health services, we have double that amount working in private practice. This is a large resource that may be utilised to contribute to servicing palliative care needs in peak moments or in more regional communities.

As mentioned earlier in the discussion document there is an upcoming challenge with an increase in number of deaths which are likely to be occurring at a later age in people with more co-morbidities and likely in Aged Residential Care (ARC). As physiotherapists, how well are we prepared to service this? Does our physiotherapy community have accurate knowledge of what palliative care is, what skills are required and the role of physiotherapy in palliative care? Are we supporting our physiotherapists currently working in this area? Do we have a career pathway for physiotherapists wanting to enter this area and progress to a higher level? Are we recognising and utilising our physiotherapists that are currently working at a high level in this field? Are we providing accessible resources to all of our physiotherapists who are at times providing palliative care?

One of the first findings with this project was that many physiotherapists working in private practice were unclear on definitions around palliative care. They understood the goal of palliative care and specialist palliative care but did not understand the palliative care approach nor the scope of those working in primary palliative care. They did not understand they were frequently contributing to a

palliative care approach. Once they understood the definitions then the topic became a lot more relevant. Those working in ARC and the hospital sector had a better understanding of definitions. As expected, those working in specialist palliative care had an in-depth knowledge and understanding of how the entire profession delivered at different levels. It is important as a profession that we do understand palliative care definitions (Appendix B) to increase awareness and support those moving into and currently working in this area. It is also worth noting in regional areas there may not be specialist services available and small number of physiotherapists may be servicing the entire community's needs.

This patient vignette can show how physiotherapists across multiple work environments are often working towards a palliative care system. A patient presents directly to a physiotherapist for pain relief due to low back pain, the physiotherapist refers to the GP due to concerns as to the cause of the pain. The patient undergoes further investigations and has a life limiting diagnosis. The patient is involved with specialist oncologist services and stays involved with physiotherapy to assist with pain management and mobility. Over the next few years, the patient receives physiotherapy services from those working in private practice, inpatient, and outpatient hospital departments and in ARC. At each point communication occurs between physiotherapists. These physiotherapists are also involved with family members and carers helping to give advice and education on appropriate transfers, equipment and avoiding injury.

Current preparation and support to deliver palliative care and existing local, national, and international resources

At an undergraduate level palliative care education is not extensive however it is present at both AUT and Otago University School of Physiotherapy.

At postgraduate level there were no physiotherapy specific qualifications in palliative care in New Zealand but opportunities for palliative care exist in Post Graduate Health Science qualifications at Canterbury and Auckland University. There is also a Post Graduate Certificate in Hospice Palliative Care at Whitireia by distance learning.

Flinders University in Australia have Post Graduate Qualifications in Palliative Care which are open to all health professionals with a bachelor's degree.

Workplace education occurs for those working in Specialist Palliative Services through the Hospice New Zealand Foundation training, this provides a condensed entry point without attendance fees if working within the hospice organisation. Physiotherapists were aware of the Hospice monthly breakfast education sessions which run through the whole country and is open for all to attend at set locations via teleconference and without fees.

Experiential learning occurred via clinical experience and informal discussions with Palliative Care Providers. Some Physiotherapists have worked well with developing mentors working in specialist palliative care services and an informal physiotherapy palliative care group had an inaugural meeting in Wellington May 2019. The purpose was to share research, education, build relationships and establish a peer group for those working in this area. Ten physiotherapists attended this with the hope that this becomes an annual event. This was publicised in the Physio Matters magazine with an invitation extended to interested physios to join the email group and future events. The purpose of the email group is to raise questions, problem solve and share information and resources.

External courses exist in manual handling which is relatively easy to access. Other education that was mentioned was Mary Potter Hospice which had some follow-on courses from the Foundations course

by offering Masterclasses in different topics for example, 'loss and grief' and 'the vulnerable brain and palliative care'. Lymphoedema courses were sourced through Physiotherapy New Zealand and external providers. Non-medication pain management in palliative care were mentioned. PINC/STEEL cancer rehabilitation courses are available for advanced cancer management for registered PINC/STEEL clinicians and palliative care education is part of the PINC/STEEL accreditation program. The limitation of this is that this is only available to already accredited PINC/STEEL providers or those undergoing accreditation education.

Barriers to access further training included cost and travel. Training that included online modules and flexibility regarding time and location with online support group were deemed to be attractive.

Online resources were often utilised as they were very accessible. Some examples are:

- The Hospice Palliative Care Handbook which can be downloaded off the hospice website. https://www.hospice.org.nz/resources/palliative-care-handbook/
- The Australian Allied Health Palliative Care (AAHPC) which is a free to join and sends out regular newsletters allowing communication between well over 400 members. They do not currently have a website but are looking into this. https://www.flinders.edu.au/research-centre-palliative-care-death-dying/partnerships-and-projects/australian-allied-health-palliative-care
- The Palliative Rehabilitation Facebook page is a closed group where members from all over the world can share information, ask questions, and communicate together. https://www.facebook.com/groups/110818868948811/
- Care Search is a website that is funded by the Australian Government Department of Health that has been accessible since 2008 and contains information for patient, family, support networks and health professionals around palliative care and has a regular newsletter. Many different organisations contribute to this website which has a Mission 'To ensure everyone receiving or providing palliative care has access to trustworthy evidence-informed information to support person-centred decision-making and the transition to palliative care.' There is an allied health section on this website. https://www.caresearch.com.au/
- Palliative Care curriculum for undergraduates is developed by the Australian Department of Health and is a palliative care online module for undergraduates. This promotes inclusion of palliative care education in nursing, medical and allied health education. This may be a useful resource for those entering a new setting for example ARC or wanting to recap some of the undergraduate education. This is an interactive website with learning modules specific to Australia. https://pcc4u.org.au/
- heathLearn is a website owned and maintained through the Canterbury District Health Board. Members of approved organisations can use this, and they are predominately rest homes and hospitals. There are 4 palliative care modules. https://www.healthlearn.ac.nz/
- The Association of Chartered Physiotherapist in Oncology and Palliative Care (ACPOPC) is a professional network aiming to provide peer support and networking opportunities for its members. New Zealand Physiotherapists are able to join for a fee of £30 GBP. https://acpopc.csp.org.uk/
- In the period between this data collection and report completion a category of Palliative Care was added to Allied Healthways Canterbury. This is a web-based information portal that supports allied health professionals with guidance for assessment and management of patients. This includes definition of palliative care and details around assessment, management and provides links with CareSearch which links to a series of clinical evidence summaries. Access is free and available to those working in public and private sector. https://canterbury.alliedhealthways.org.nz/LoginFiles/Logon.aspx?ReturnUrl=%2f

The following information represents the education opportunities available to Physiotherapists as of May 2019:

Undergraduate Training (4-year programme)

AUT were about to address palliative care in their curriculum refresh. At the time of this working group year one physiotherapy students had HEAL504: Lifespan Development and Communication, which covered "death, dying and bereavement". The required text was Shaw, S., Haxell, A., & Weblemoe, T., (2012). Communication across the lifespan. Melbourne, VIC: Oxford University Press. Chapter 9: Senior Years & Chapter 10: Dying, Grief and Bereavement. There was also a small amount of focus on death and dying in two of the physiotherapy-specific 3rd year papers.
Otago School of Physiotherapy include palliative care in the year 3 lecture series, and one lab: Hospice (often a Palliative Care Physician) provides one of the lectures. The students also get a lecture from an oncologist on management which includes palliative care, and in the lab they have a module on end of life/ a good death, and the role of the physiotherapist. The students may also have access to palliative care as part of their Year 3 and 4 clinical placements.

Post Graduate Opportunities (NZ)
Otago University & AUT School of Physiotherapy offer post graduate physiotherapy studies but not specific to Palliative Care.
Canterbury University have a palliative care endorsement of the Post Graduate Certificate, Diploma and Master of Health Science. These are generic palliative care papers which do have the ability to lead towards specific allied health fields.
Auckland University have a Post Graduate Certificate, Diploma or Masters in Health Science where to study palliative care, but this is not allied health specific.
Whitireia
Has a Post Graduate Certificate in Hospice Palliative Care which is taught by distance.

Post Graduate Opportunities (International)
Flinders University Australia – offers a post graduate certificate, diploma, and masters in palliative care.
Employment Opportunities
District health board education and teaching does occur but is dependent on the resources within each service. Not all hospitals have a specialist palliative care team.
When employed in specialist palliative care, there are opportunities for education for physiotherapists. However, these are frequently medical based and not specific to allied health. External courses in manual handling, lymphoedema, advanced cancer management and pain management are available.
Baseline learning opportunities (readily available)
Groups:
NZ informal palliative care interest group for physiotherapists - annual meeting and regular email contact. The inaugural meeting, with 10 physiotherapists, was held in 2019.

Hospice NZ:
Foundations of Palliative Care training modules, Palliative Care lecture series, online resources and Palliative care handbook.

Online information:
- healthLearn (has three palliative care modules)
- Care Search
- PCC4u
- ACPOPC

Newsletters/ communication:
AAHPC, Palliative Rehabilitation Facebook page.

Proposed palliative care competencies

When comparing the Physiotherapy practice thresholds in Australia and Aotearoa New Zealand (2015) with the Palliative Care Competence Framework it was first acknowledged they had different intentions. The former is generic and needs to cover all physiotherapists working in different fields of physiotherapy in the cultural setting of New Zealand. The latter is specific to physiotherapists working in palliative care and catered for three progressions of skill level as displayed in figure 1.

The tiered competencies in the Palliative Care Competence were applicable to physiotherapy in New Zealand. There was an 'all' category in which all physiotherapists should meet these competencies, a 'some' category designed for those with increased clinical engagement with people with life-limited conditions and a 'few' category for those physio's whose core role is the provision of palliative care. This seemed a practical system when considering the scope of practice of physiotherapy and the definitions of palliative care.

When comparing the two, the Physiotherapy practice thresholds were not specific enough in nature to be directly comparable to the Palliative Care Competence Framework however as mentioned previously this is not their purpose. The Palliative Care Competence Framework did cover grief, loss and bereavement which is not in the Physiotherapy Standards Framework, and it took communication to a higher and more specific level which is appropriate to palliative care. The Palliative Care Competence Framework was lacking the New Zealand specific cultural competencies due to its creation in Ireland.

The Palliative Care Competence Framework are categorised into 6 different domains:

- Principles of palliative care
- communication
- optimising comfort and quality of life
- care planning and collaborative practice
- loss, grief, and bereavement
- professional and ethical practice

The New Zealand Practice Thresholds in the Physiotherapy Standards Framework are in 7 roles:

- Physiotherapy Practitioner
- Professional and Ethical Practitioner
- Communicator
- Reflective Practitioner and self-directed learner
- collaborative practitioner
- Educator
- Manager/leader

A competency-based document could be helpful in creating job descriptions, defining scope of practice, guiding continual professional development, referencing in performance reviews, being able to see what entry level skills are required for palliative care and the progression of these skills to a higher level. The competencies in the Physiotherapy Standard Framework are minimum threshold competencies and are designed to be a set of generic competencies that all physiotherapists must adhere to in their specific area of work. Given this is an aspirational document there seems advantages of utilising the existing Palliative Care Competence Framework with the addition of additional cultural competencies as a document. Overall, the Palliative Care Competence Framework does align with our current Physiotherapy Practice Thresholds so utilising these competencies as a complimentary reference document may provide the physiotherapy and the palliative care community with a more specific document when required. It is not an attempt to act in place of the Physiotherapy Standards

Framework as this is a condition of being a registered physiotherapist, however it may give those working in Palliative care an additional resource and could be a complimentary document that links allied health working in Palliative Care. The main consideration is that cultural competency needs to be included in the Palliative Care Competence Framework. The Physiotherapy Standards section of the Physiotherapy Standards Framework are a set of specific standards for specific situations. This includes the Sports physiotherapist practice standard and the Cervical manipulation standard. These are revised by working groups and approved by the Physiotherapy Board with communication and consultation with all physiotherapists. It could be that there is scope for a Palliative Care specific standard.

Another way to go about this is to take components from the Palliative Care Competence Framework and request to the Physiotherapy Board that they are added to the Physiotherapy Standards Framework in the Physiotherapy practice thresholds. This would be adding competencies around 'grief, loss and bereavement' and more specific wording around communication. By doing this you would lose the tiered approach of the Palliative Competence Framework which is helpful for career pathways and loose the aspirational intent of physiotherapy in palliative care.

When looking at the tiered competencies in the Palliative Care Competence Framework this is not dissimilar to the Physiotherapy Board's tiered approach of Registered Physiotherapist, Advanced Practice Physiotherapist (APP) and Physiotherapy Specialist. To be awarded either the proposed APP or the Physiotherapy Specialist title the physiotherapist must proceed through a formal application and assessment process with the Physiotherapy Board. Physiotherapy Specialists are acknowledged as expert Physiotherapists who have advanced education, knowledge, and skills to practise within a specific area of clinical practice. The APP are acknowledged as having advanced knowledge, skills, and experience in a defined clinical area. As mentioned previously there is the differentiation of the protected title of Physiotherapy Specialist and a Physiotherapist working in a specialist service. At the time of information gathering there were no Physiotherapy Specialists working in palliative care however there are Physiotherapists employed in Palliative Care Speciality Services.

There may be barriers to Physiotherapists being awarded either an APP or Physiotherapy Specialist title including but not limited to access to post graduate programs, lack of financial assistance for tertiary education, financial cost of the application process, approved leave from work to study and the FTE requirements in an area (often there are budgetary constraints on FTE for Physiotherapists in Palliative Care). The Palliative Care Competency Framework may be a useful tool to acknowledge that the Physiotherapist is working at a high level when there may be barriers to proceeding with the board protected Physiotherapy Specialist or APP titles.

In summary the Palliative Care Competence Framework may be an aspirational document used alongside and complimentary to the Physiotherapy Framework Standard with the addition of Aotearoa Zealand specific cultural competencies. It is unrealistic for the Physiotherapy practice thresholds to alter due to its purposeful broad nature and the minimal threshold approach to the competencies. There is however scope to propose a Palliative Care physiotherapist practise standard with the use of the Palliative Care Competency Framework. These proposed competencies may provide support with job descriptions, scope of practice, continual professional development, performance reviews and carer pathways in palliative care.

The below suggested competencies come directly from the Physiotherapy Standards Framework 2018 and the Palliative Care Competency Framework although there are a few word changes and modifications of the Palliative Care Competence Framework to reflect the use in New Zealand. https://aiihpc.org/wp-content/uploads/2015/02/Palliative-Care-Competence-Framework.pdf

Suggested Physiotherapy Palliative Care Competencies

Cultural Competence

Please note: the below is directly taken from the cultural competence standard of The Physiotherapy Standards framework. https://www.physioboard.org.nz/standards/physiotherapy-standards/cultural-competence-standard

Cultural competence is a process of continuing self-development for the betterment of patients. As such, physiotherapists must demonstrate the appropriate awareness and knowledge, attitudes, and skills of cultural competence.

1. Awareness and knowledge

To work successfully with health consumers of different cultural backgrounds, a physiotherapist must demonstrate appropriate awareness and knowledge including:

- recognition that Māori and other cultures' definitions of health may involve multiple dimensions that extend beyond the physical and medical diagnoses
- an awareness and acknowledgement of their own limitations of cultural knowledge and an openness to ongoing learning and development
- an awareness of a patient's right to identify with any cultural parameters that they choose
- an understanding that patients may identify with multiple cultures
- an awareness that a patient's culture may have an impact on:
    - their perceptions of health, illness and disease
    - their access to health services
    - the delivery of health care practices
    - their interactions with medical professionals and healthcare systems
    - treatment preferences.

2. Attitudes

To work successfully with health consumers of different cultural backgrounds, a physiotherapist must demonstrate appropriate attitudes including:

- a preparedness not to impose their own values on patients
- a willingness to understand their own cultural values and beliefs and the influence these have on their interactions with patients
- a commitment to ongoing development of their own cultural awareness and practices including those of their colleagues and staff
- promote and actively support a culturally bias-free environment
- a willingness to appropriately challenge the cultural bias of individuals or health systems where this will have a negative impact on patients.

3. Skills

To work successfully with health consumers of different cultural backgrounds, a physiotherapist must demonstrate appropriate skills including:

- establishing a rapport with health consumers of other cultures, and respectfully inquire about the cultural background and beliefs of the patient
- identifying how a health consumer's culture might inform the physiotherapist-patient relationship
- identifying actions (conduct), which may be appropriate and inappropriate
- considering the health consumer's cultural beliefs, values, practices, and social rules in developing a relevant treatment plan for the patient
- including a patient's whānau, family and community in their physiotherapy care, where appropriate
- working cooperatively with individuals and organisations in a patient's culture

- working with other healthcare professionals to provide integrated culturally competent care
- reflecting on and improving their own practice to ensure equitable outcomes and demonstrating life-long learning in cultural competence
- Communicating effectively by:
  - recognising that communication styles of patients may differ from their own and modifying these as required
  - working with interpreters as required.
  - acknowledging any cultural dissimilarity when discussing a patient-centred treatment plan

The following is taken from the Palliative Care Competence Framework with some minor alterations to working to reflect the use in Aotearoa New Zealand. https://aiihpc.org/wp-content/uploads/2015/02/Palliative-Care-Competence-Framework.pdf

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 1

PRINCIPLES OF PALLIATIVE CARE

All Physiotherapists:

As a physiotherapist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand the impact of psychological responses to loss of role and functional independence, social stressors and the spiritual dimensions on the behaviour and decision making of individuals and families and take this into account when planning care
- Understand, recognise, and address the management of pathological responses to loss of role and functional independence, which may impact on behaviour and decision making of individuals and families, referring to specialist palliative care where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

Some Physiotherapists:

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate in-depth understanding of the full spectrum of trajectories of life limiting conditions in the context of your current clinical practice
- Undertake additional study relevant to the needs of individuals with life-limiting conditions to further knowledge and enhance application in practice.
- Be able to identify and engage in research that will lead to effective clinical practice.

Few Physiotherapists:

As a physiotherapist whose core role is the provision of palliative care you should:

- Demonstrate an advanced knowledge and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs.
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of therapy outcomes and service delivery in palliative care.
- Develop, facilitate, and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership, initiating strategies that will encourage colleagues to foster a caring environment that supports all levels of staff working in challenging situations with people with life-limiting conditions and their families

- Lead, facilitate and engage in further education and research in palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Be able to act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Physiotherapy Practice in Palliative Care.

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 2

COMMUNICATION

All Physiotherapists

As a physiotherapist you should:

- be able to assess the person's current understanding of his/her health, role, and functional status in the context of the person's life-limiting condition
- be able to communicate current functional status and likely progression in an accurate and compassionate manner, taking account of the individual's needs and wishes
- understand that the communication of information which fundamentally changes the person's understanding of their situation and/or influences their decision making or planning is an on-going collaborative process and not a single event
- be able to recognise and contribute to the management of potential conflict in decision-making in the palliative care setting.

Some Physiotherapists

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- demonstrate an increased level of confidence in utilising and modifying effective communication strategies to support the changing needs and wishes of individuals with life-limiting conditions and their families
- be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family.

Few Physiotherapists

As a physiotherapist whose core role is the provision of palliative care you should:

- demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised, and timely communication with individuals with life-limiting conditions, their carers and members of the multidisciplinary team
- demonstrate expertise as a mediator and advocate for the individual and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- demonstrate self-awareness of own responses and remain in meaningful contact with individuals and carers even in the most complex, intense, and changing circumstances
- be able to act as an expert that supports and facilitates multidisciplinary teaching of communication skills as these pertain to physiotherapy practice.

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 3

OPTIMISING COMFORT AND QUALITY OF LIFE

All Physiotherapists

As a physiotherapist you should:

- be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- recognise potentially reversible causes of physical deterioration and employ a palliative rehabilitation approach that is appropriate to promote optimal independence
- be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.

Some Physiotherapists

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a life-limiting condition.
- in the context of current scope of practice, be able to recognise and take appropriate action to address emergencies that may arise in palliative care (e.g., spinal cord compression)
- recognise and utilise non-pharmacological symptom management to promote comfort and quality of life
- demonstrate an ability to consider the benefits, burdens and risks of physiotherapy interventions and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- demonstrate the ability to manage decisions about withdrawing or withholding interventions, whilst recognising when to reengage if appropriate.

Few Physiotherapists

As a physiotherapist whose core role is the provision of palliative care you should:

- be able to apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- demonstrate advanced knowledge of individual clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- be able to act as an expert resource to other staff on the role of physiotherapy and rehabilitation in symptom management and optimising quality of life
- demonstrate knowledge to alleviate and manage distressing symptoms whilst attempting to maximise the individual's ability to function, to promote their independence and to adapt to changes that occur due to their life-limiting condition
- ensure that the emphasis of treatment is on physical performance and symptom management: expertise and advanced knowledge is required to identify the complex interplay of factors that impact on physical function
- have expert and advanced knowledge in the management of symptoms, functional changes and interventions which include but are not limited to function, exercise tolerance, respiratory care, fatigue, lymphoedema, neurological, orthopaedic, palliative rehabilitation and pain.

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 4

CARE PLANNING AND COLLABORATIVE PRACTICE

All Physiotherapists

As a physiotherapist you should:

- as a member of the multidisciplinary team be able to participate in key events in individual care, including family meetings
- demonstrate ability to recognise that the person with a life-limiting condition may lose capacity to make decisions towards end of life. In such circumstance's decisions must be made in the best interest of the person and follow Physiotherapy professional ethical guidelines in respect of decision making
- understand the importance of referral to palliative care teams for the management of the person with palliative care needs.

Some Physiotherapists

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- be able to work collaboratively and effectively within the inter-professional team and with other stakeholders to manage positive working relationships that will support the wellbeing of the individual and carer and promote individual centred care planning
- be able to facilitate individuals and their families towards active involvement in decision making and goal setting to support best outcomes and quality of life
- demonstrate flexibility in relation to care planning, acknowledging that an individual's priorities can alter with a change in their condition and disease advancement
- be able to facilitate discharge planning, carrying out in depth functional and risk assessments to facilitate the discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with life-limiting conditions and their carers
- be able to facilitate the individual to make an informed decision regarding place of care whilst identifying potential and actual risks in a supportive manner, and at all times keeping the team informed.

Few Physiotherapists

As a physiotherapist whose core role is the provision of palliative care you should:

- demonstrate expertise in developing therapeutic relationships with individuals/ families to assist their informed choices for care planning and therapy treatment options.
- be able to act as an expert clinical resource, as required, to generalist and other specialist providers of palliative care, role modelling advanced clinical skills when assessing and managing individuals with complex life -limiting conditions
- demonstrate advanced understanding of the roles of the wider multidisciplinary team (MDT), show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family
- demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation and functional levels
- be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care
- demonstrate an advanced level of clinical expertise and sensitivity in facilitating a safe, smooth, and seamless transition of care for individuals with complex discharge planning needs who choose to be cared for at home rather than in hospital or hospice
- create a holistic and person-centred plan that acknowledges the psychosocial impact of diminishing function and sets realistic goals that have to be continually adapted to individual need.

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 5

LOSS, GRIEF, AND BEREAVEMENT

All Physiotherapists

As a physiotherapist you should:

- have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues
- demonstrate greater sensitivity and engagement with the different stages of grief and loss, including loss of functional independence utilising this awareness to inform care planning and treatment interventions.

Some Physiotherapists

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- appreciate the nature of disenfranchised grief in individual, families and carers and appropriate methods of addressing this grief.

Few Physiotherapists

As a physiotherapist whose core role is the provision of palliative care you should:

- demonstrate advanced knowledge of the grieving process and reactions to actively support individuals and their families throughout the disease trajectory
- demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/ or referral to appropriate disciplines or agencies
- mentor and educate colleagues to understand the personal impact of loss, grief, and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis.

Proposed – Physiotherapy Competencies for Palliative Care
DOMAIN OF COMPETENCE 6

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

All Physiotherapists

As a physiotherapist you should:

- be aware and act according to the code of professional conduct of the Physiotherapy Board of New Zealand and adhere to the Physiotherapy Standards Framework.
- demonstrate an understanding of the difference between managing a life limiting condition and providing end of life care to an individual with a life-limiting condition.

Some Physiotherapists

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- participate in processes of clinical governance and quality assurance to maintain and improve clinical practice
- provide and participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations.

Few Physiotherapists

As a physiotherapist whose core role is the provision of palliative care you should:

- apply an advanced understanding of contemporary legal, ethical, and professional standards to the provision of quality palliative care therapy services

- lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- actively influence and promote strategic initiatives and policy development for palliative care services at local, regional, and national levels
- act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary, and residential care
- design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues.

Next steps

- I would recommend review of this document by the informal Physiotherapy Palliative Care group and circulation amongst the Physiotherapy community for feedback.
- Develop a resource where all available educational resources can be found. The aim being that a Physiotherapist can look at the Competencies and then directly target appropriate resources for specific education.
- Establish how to co-ordinate an online resource for all allied health which displays the discipline specific competencies and a link to resources.
- Assist in promotion of this via Physiotherapy New Zealand.
- Establish a resource of available financial support for further education in Palliative Care.

References

Ministry of Health. (2019). *Achieving equity.* Ministry of Health. https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity

Physiotherapy Board of New Zealand. (2022). *Physiotherapy Standards Framework*. Physiotherapy Board of New Zealand. https://www.physioboard.org.nz/standards

Physiotherapy Board of New Zealand. (2022). *Physiotherapy Board Annual Report 2022.* https://www.physioboard.org.nz/wp-content/uploads/2019/09/V6-Physio-Annual-Report-2019.pdf

Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive

Psychology and Counselling

By Dr Matthew McDonald, Clinical Psychologist, former Allied Health Team Leader, Hospice Southland

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within the available timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Current preparation and support to deliver palliative care

Palliative care is an important area of healthcare and a multi-disciplinary approach leads to the best outcomes for patients. Many different professions provide counselling support for patients with life limiting illness and their families, including psychologists, counsellors, and psychotherapists. The focus of this review has been psychology and counselling training; however, it is hoped that this review will serve as an example for all counselling related practitioners. This review exercise has shown that there are limited opportunities to develop skills and knowledge or even gain experience in the area of palliative care, prior to becoming a registered practitioner.

Palliative care, as a specific subject is absent from undergraduate training in psychology. However, at Otago University, grief and loss are recognised as important and touched on in introductory lectures. In undergraduate counselling training, Bethlehem Institute of Technology have a flexible programme that allows counselling students with an interest in palliative care to tailor assignments to this interest. University of Canterbury Master of Counselling programme allows 60 points (two papers) of course work to be completed from the Health Sciences Palliative Care papers. The university also offered lectures with the late Lois Tonkin, an expert in grief and loss. These lectures are now offered by other lecturers.

In terms of postgraduate psychology study, University of Otago, University of Waikato, University of Canterbury and University of Auckland **do not** offer specialist training in palliative care but do have components covering chronic illness and chronic pain. There are formal post graduate opportunities in New Zealand that are not discipline specific and have a palliative care focus, such as the Post-graduate Certificate, Diploma and Masters in Palliative Care.

Like other disciplines, a lot of learning about palliative care occurs in the work context (i.e. through experiential learning). There are opportunities for and courses to upskill through Hospice NZ and HealthLearn.

Training in palliative care depends on the interest of individual students and available opportunities for clinical placement in areas such as Oncology or Hospice. A gap between training and practice in palliative care remains which is a concern given that palliative care is a growing field. More exposure to the philosophy and practice of palliative care at both undergraduate and postgraduate levels is needed to better equip practitioners to practice safely with patients at the end of life. Practitioners are required to source their own training opportunities and extra post-graduate training options are limited. The University of Canterbury Master of Counselling Programme can be combined with University palliative care papers, thus providing an opportunity for students to undertake their supervised counselling placement in a palliative care setting.

Current preparation and support to deliver palliative care

The following section indicates the education opportunities available to students training to be Psychologists and Counsellors as at October 2019. This information is from discussions with recent students in programme or correspondence with programme co-coordinators. For this review attempts were made to contact all training institutions that may provide relevant programmes, however not all training institutions that were approached have provided information.

When psychologist and counsellors are employed within a hospice or specialist palliative care team, there are plenty of opportunities for education. However, these tend to be medically based.

Palliative care educational opportunities for psychologists (as at May 2019):

Undergraduate Training

- **University of Otago Psychology**, no formal education, grief mentioned in lectures
- **University of Otago -** education opportunities from other disciples e.g. previously offered an Anthropology paper - Death and Dying

Post Graduate Opportunities

- **University of Otago Clinical Psychology** - do not cover palliative care specifically. Assessment and treatment concerns for older person's health covered in a seminar series. Also seminars on chronic pain and chronic illness. Some students work directly with palliative care when working on their internship placements (e.g., oncology)
- **University of Auckland and University of Waikato** – **Clinical Psychology** - no formal education on palliative care. Some education on chronic pain conditions
- **Auckland University of Technology (AUT) - Counselling Psychology** - students receive training in a broad range of topics related to their scope of practice. Whilst we do not specifically cover palliative care, our students and graduates have worked successfully in related areas such as the Cancer foundation and Hospice
- **University of Canterbury** - **Postgrad Certificate and Diploma Courses in Palliative Care**

Post Graduate Opportunities (international)

- **Flinders University Australia –** offers many levels of training. However, there is a significant cost, as campus attendance is required.

Employment Opportunities

- DHB education and teaching does occur but is limited by the resources available. i.e., not every DHB has an inpatient Specialist Palliative Care team
- If able, practitioners can attend study days or conferences on palliative care but these are limited

Palliative Care educational opportunities for **counsellors** (as at May 2019):

Undergraduate Training

- **Bethlehem Institute of Technology (BIT)** - **Counselling** - common issues in Counselling paper – assignment, self-directed learning, practical placement in palliative care setting
- **University of Canterbury – Counselling** - previously held a series of lectures with Lois Tonkin on grief

Post Graduate Opportunities

- **University of Canterbury and BIT**- **Diploma and Masters in Counselling courses** – self-directed assignments allow student to tailor papers to palliative care focus
- **University of Canterbury** - **Postgrad Certificate and Diploma Courses in Palliative Care** Baseline learning opportunities for psychology and counselling

Hospice NZ

- Foundations of Palliative Care training modules
- Palliative Care lecture series
- Online resources

Health, Quality and Safety Commission
Advance care planning training. This is an excellent opportunity but needs to be funded

healthLearn
Available across the South Island; has three palliative care modules

Relevant Publications

Harris, R. (2012). *The reality slap: Finding peace and fulfilment when life hurts*. New Harbinger Publications.

Sage, N., Sowden, M., Chorlton, E., & Edeleanu, A. (2013). *CBT for chronic illness and palliative care: A workbook and toolkit*. John Wiley & Sons.

Strada, E. A. (2017). *Palliative Psychology: Clinical Perspectives on an Emerging Specialty*. Oxford University Press.

The Palliative Care Handbook - available for free download from Hospice NZ website

<u>Proposed palliative care competencies</u>
The Psychology profession in New Zealand is regulated by the New Zealand Psychologists Board. The board's role is ensuring the health and safety of members of the public using Psychology services, making sure all Psychologists meet the specifications of the Health Practitioners Competence Assurance Act 2003.

It is evident that the value of the allied health professions is becoming increasingly recognised in palliative care. Palliative psychology is an emerging field. Psychology has much to offer palliative care, especially considering the range of psychological concerns experienced by patients with a life limiting illness, including co-morbid anxiety, depression, complicated grief reactions (Strada, 2018). Considering the New Zealand context, the work of a Psychologist can be generalist and varied with practitioners employed in many healthcare settings. A knowledge of palliative care will be important in all areas and advanced knowledge necessary for some roles, especially those in Hospice and Oncology services.

These proposed competencies have been developed using the current Competencies for Registration as a Psychologist in New Zealand and the following documents have been used to guide the formation of the recommended competencies for palliative care:

- Palliative Care Competence Framework; Ireland guidelines. (2014)
- Core Competencies for the Practice of Psychology in Aotearoa New Zealand
- Psychologist's Code of Ethics for Psychologists working in Aotearoa New Zealand
- Management of symptoms in Palliative Care – The role of specialist practice care and allied health professional (2018)
- New Zealand Palliative Care Nurses Competencies, A National Professional Development Framework for Palliative Care Nursing in Aotearoa New Zealand (2014)
- Strada, E. A. (2017). *Palliative Psychology: Clinical Perspectives on an Emerging Specialty*. Oxford University Press.

Consultation with stakeholders:

- NZ Psychologists Board: The Psychologists board advised that as Palliative Psychology is not a registered scope of practice, guidelines can be developed to assist clinicians working in that field without a requirement for board endorsement
- NZ Psychological Society and New Zealand College of Clinical Psychologists

Proposed – Psychology Competencies for Palliative Care

ALL

As a psychologist you should:

Ensure your practice is compliant with NZ code of ethics and all core competencies for your scope of practice. Refer to;

- Core Competencies for the Practice of Psychology in Aotearoa New Zealand
- Psychologist's Code of Ethics for Psychologists working in Aotearoa New Zealand

SOME

As a psychologist with increased clinical engagement with people with life-limiting conditions you should:

- Understand the impact that a life-limiting condition has on a person, their family/whānau and wider community, and provide support to facilitate their own decision-making
- Provide adequate explanation and support to those with a life-limiting illness and their families/whānau, facilitate informed decision-making regarding proposed plan of care
- Assess the person's subjective experience and meaning of their illness trajectory
- Recognise dying as a normal process in life
- Have an awareness of the psychological aspects of life-limiting conditions and potential mental health needs arising from these
- Be aware of the importance of empathic and responsive relationships between those experiencing life-limiting conditions and their health care team
- Demonstrate an understanding of palliative care issues, which may impact on subsequent interactions with individuals and their families
- Recognise cultural differences and an awareness of cultural models and grief practices for tangata whaiora [Māori clients]

FEW

As a psychologist whose core role is the provision of palliative care, you should:

- Be aware of the role of specialist palliative services in supporting staff when providing a palliative care approach to a person with a life-limiting condition
- Maintain a thorough understanding of psychological theories of death, dying and living with life-limiting conditions
- Provide leadership in the psychology of palliative care by contributing to the knowledge base of society via talks, conferences, media
- Demonstrate proficiency in using validated assessment tools to diagnose and differentiate between ego-syntonic sadness and mental health issues such as; anxiety, depression and Post Traumatic Stress Disorder
- Formulate and deliver a broad range of evidence-based therapeutic interventions to people with life-limiting conditions and their family members who present with increased stress vulnerability and/or complex grief responses

Next steps

- Continued development of resources to guide AHPs in their palliative care work and in providing online access to these resources
- Continued consultation with key stakeholders such as Hospice NZ and tertiary education providers regarding promotion of allied health workforce and development of education.

Social Work

By Mary James, Social Worker, Nelson Tasman Hospice and Paula Hogg, Social Worker, SCDHB

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Current preparation and support to deliver palliative care

Professional Social Work education in Aotearoa New Zealand is focused on providing generic skills and abilities to prepare students for a wide range of employment opportunities. Thus, the opportunity for many Social Workers to be exposed to palliative care during their first professional Social Work qualification is limited. It is only when a student has field education experience as part of their study that they may develop skills and knowledge specific to palliative care. This will often continue with their academic work during that year's study. Social Work programmes at Otago University, the University of Canterbury and the University of Auckland offer a paper on grief and loss.

The Aotearoa New Zealand Association of Social Work (ANZASW) is the professional body for Social Workers whose purpose is to support Social Workers and advocate for the profession. In contrast, the Social Work Registration Board (SWRB) is the statutory regulator with the primary purpose of protecting the public by ensuring Social Workers are competent to practice. From 27 February 2021, it is mandatory that all Social Workers are registered practitioners with SWRB.

In 2018 a Health Social Work Scope of Practice document was published as a joint collaboration between the National District Health Board (DHB) Health Social Worker Leaders Council and ANZASW. The Health Social Work Scope of Practice document provides an overview of the role, scope, contribution and evidence base of Social Work practice in the health care field, although this does not specifically address palliative care.

The Health and Disability Commissioner Act 1994 No 88 in Section 2(1) Interpretation, has the following definitions:

Health practitioner

a. has the same meaning as in section 5(1) of the Health Practitioners Competence Assurance Act 2003[1]; and
b. includes-
    (iv) a Social Worker within the meaning of the Social Workers Registration Act 2003

Under section 2 of the Health and Disability Commissioner Act 1994, Authority is defined: "has the same meaning as in section 5 of the Health Practitioners Competence Assurance Act 2003; and includes the Social Workers Registration Board established by section 97 of the Social Workers Registration Act 2003".

Many palliative care Social Workers do their main learning through experience on the job. This includes attending workplace education and training. It also includes study days, guest speakers, and Healthlearn which has four modules Social Workers can access. Hospice New Zealand offer specialist lectures every month via teleconference. They have developed some education programmes which

[1] The Health Practitioners Competence Assurance Act (HPCA) defines as health practitioner as "a person who is, or is deeme

include Fundamentals of Palliative Care and Standards of Palliative Care that are delivered by local hospices. Hospice New Zealand offer a biannual conference and annual network meetings specific to occupational groupings. Local hospices offer inhouse education programmes although these do tend to be more generic in nature.

Post graduate post professional qualification education for Social Workers interested in palliative care is offered by the University of Canterbury, the University of Auckland and Te Pūkenga-Whitireia New Zealand. These papers are generic in nature, yet the topics cater to palliative care Social Workers. They extend to Masters and PhD level qualifications.

Internationally palliative care literature for Social Workers can be accessed via journals and books. Online modules are available from www.caresearch.com.au at no charge. Flinders University in Australia also offer online educational modules. The voice of palliative care Social Workers from New Zealand in the published literature is minimal and needs nurturing and development.

A barrier to post graduate study is access to funding as historically palliative care Social Workers have not had access to Health Workforce funding via local DHBs. BNI offer a scholarship programme for allied health employees that is administered by Hospice New Zealand. Most hospices offer financial assistance for their staff to engage in post graduate study, however the level of financial support may vary between hospices.

The biggest gap in education for Social Workers interested in working in palliative care is the lack of focus on health Social Work; in particular principles of palliative care, psychological and spiritual care, having difficult conversations, advanced communication, advance care planning, end of life decision making, self-care, the needs of unwell people and their family/whānau as they approach end of life, and recognising that unwell people are deteriorating.

For those palliative care Social Workers who live and work near a training organisation, encouragement is given to build professional relationships with their local provider and offer opportunities to give professional talks, or meet other educational needs including workplace experience.

Some of the documents that guide palliative care Social Work include:

- Altilio, T. & Otis-Green, S. (Eds) The Oxford Textbook of Palliative Social Work. (2011) Oxford University Press, New York

- ANZASW Code of Ethics (2019) https://anzasw.nz/wp-content/uploads/ANZASW-Code-of-Ethics-Final-1-Aug-2019.pdf

- ANZASW Health Social Work Scope of Practice (2018) https://anzasw.nz/wp-content/uploads/NZ-Health-SW-Scope-of-Practice-Final-24-April-2018.pdf

- Gamondi, C., Larkin, P. & Payne, S. Core competencies for palliative care Social Work in Europe: An EAPC paper. (part 1). European Journal of Palliative Care. (2013) 20(2) p.86-96. https://www.eapcnet.eu/DesktopModules/EasyDNNNews/DocumentDownload.ashx?portalid=0&moduleid=1207&articleid=376&documentid=47

- Gamondi, C., Larkin, P. & Payne, S. Core competencies for palliative care Social Work in Europe: an EAPC White Paper (part 2). (2013) 20(3) p.140-145. https://www.eapcnet.eu/DesktopModules/EasyDNNNews/DocumentDownload.ashx?portalid=0&moduleid=1207&articleid=376&documentid=47

- Palliative Care Competence Framework (2014) Palliative Care Competence Framework. Dublin: Health Service Executive. https://aiihpc.org/our_work/education/competence-framework/

- The Role of Social Workers in Palliative, End of Life and Bereavement Care https://www.apcsw.org.uk/resources/social-work-role-eol.pdf

- SWRB Code of Conduct (2016) https://swrb.govt.nz/for-the-public/code-of-conduct/

Proposed palliative care competencies

The professional body for Aotearoa New Zealand Social Workers is the ANZASW. The regulatory authority is the SWRB. Both bodies have a set of 10 practice standards or professional competencies that Social Workers are required to meet to maintain their professional practice. Whilst the competencies are slightly different, they are compatible with each other. A key document that underpins all Social Work in Aotearoa New Zealand is Te Tiriti o Waitangi and this is written into both sets of professional competencies.

Palliative care Social Workers make up a small number of practitioners within the larger professional body of Social Workers. A Scope of Practice for Health Social Workers was produced by ANZASW in 2018, although this does not specifically address palliative care. Neither ANZASW nor SWRB are looking to develop competencies specific to palliative care Social Work. Both bodies have been consulted in the development of these competencies and expressed a willingness to 'cast their professional eye' over the competencies that are written below.

These competencies draw from the Palliative Care Competence Framework (Palliative Care Competence Framework Steering Group, 2014). Whilst graduating Social Workers may have the generic skills to meet the competency required for providing generalist palliative care, they may not recognise they hold these skills, nor feel comfortable to work in this field of practice. There is a need for all Social Workers to attend palliative care education to develop and refine the skills needed to work with people who have a life limiting illness. The competencies identified as 'some' and 'few' are aimed at those Social Workers who wish to develop their skills and work in specialist palliative care.

All competencies in this section have been assessed alongside the New Zealand SWRB Core Competency Standards. The competencies that were missing from the Framework are predominantly based around cultural competence and the ability to work with tangata whenua. These have been taken directly from the Social Work Registration Board Core Competency Standards 1,2 and 3 and are documented in Domain 1.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 1

COMPETENCE TO PRACTISE SOCIAL WORK WITH MAORI AND DIFFERENT ETHNIC AND CULTURAL GROUPS IN AOTEAROA NEW ZEALAND

As a Social Worker who is competent to practice Social Work with Māori you should:

- demonstrate knowledge of the Treaty of Waitangi, te reo Māori and tikanga Māori;
- articulate how the wider context of Aotearoa New Zealand both historically and currently can impact on practice;
    - Te Rangatiratanga: Maintain relationships that are mana enhancing, self-determining, respectful, mindful of cultural uniqueness, and acknowledge cultural identity.
    - Te Manaakitanga: Utilise practice behaviours that ensure mauri ora with a safe space, being mana enhancing and respectful, acknowledging boundaries and meeting obligations.
    - Te Whanaungatanga: Engage in practice that is culturally sustaining, strengthens relationships, is mutually contributing and connecting, and encourages warmth.

As a Social Worker working with different ethnic and cultural groups in Aotearoa New Zealand you should:

- acknowledge and value a range of world views including divergent views within and between ethnic and cultural groups;
- understand that culture is not static but changes over time;
- demonstrate awareness and self-critique of their own cultural beliefs, values, historical positioning and how these impacts on their social work practice with their clients from other cultural backgrounds;
- critically analyse how the culture and social work approaches and policies of their employing organisation may compromise culturally safe practice;
- demonstrate knowledge of culturally relevant assessments, intervention strategies and techniques;
- engage with people, groups and communities in ways that respect family, language, cultural, spiritual and relational markers.

As a Social Worker who is competent to work respectfully and inclusively with diversity and difference in practice you should:

- demonstrate knowledge of diversity between and within different cultures, including ethnicity, disability, social and economic status, age, sexuality, gender and transgender, faiths and beliefs;
- demonstrate sufficient self-awareness and is able to critically reflect on own personal values, cultures, knowledge and beliefs to manage the influences of personal biases when practising;
- respectfully and effectively communicate and engage with a diverse range of people.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 2

PRINCIPLES OF PALLIATIVE CARE

Palliative care aims to improve the quality of life of people with life-limiting conditions and their families, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement.

Indicators

As a health care professional, you should:

- understand and be able to describe the meaning of the term 'life-limiting condition'
- understand and be able to apply the principles of palliative care that affirm life, offer people with life-limiting conditions a support system to help them live as actively as possible until death with optimal quality of life and help families cope during illness
- understand the significance of the physical, psychological, social and spiritual issues that affect people with life-limiting conditions and their families throughout the continuum of care
- demonstrate the ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person and her/his family
- provide empathetic care to individuals with life-limiting conditions and their families, with clear regard to the individuality of each person
- show a commitment to one's own continued professional development and learning and facilitate the learning and development of others, in order to improve care for those with life limiting conditions and their families
- show a commitment to developing self-care strategies and to attending to any impact that working with people facing life-limiting conditions and their families may have on you.

SOCIAL WORK

ALL

As a Social Worker you should:

- understand and recognise common trajectories of life-limiting conditions
- understand the impact that psychological responses, social stressors and spiritual dimensions to loss may have on the mental health and decision making of the person with a life-limiting condition and their family and take this into account when planning care
- take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

SOME

As a Social Worker with an added level of engagement with people with life-limiting conditions you should:

- identify and address the specific barriers which impact on people with life-limiting conditions and their families' ability to access and utilise palliative care
- support the multidisciplinary team to reflect on and manage the influence of their own values and practice on individuals and families facing life-limiting conditions, within the context of your role
- advocate for responsive services for people with life-limiting conditions and their families.

FEW

As a Social Worker working primarily with people with life-limiting conditions you should:

- understand and recognise significant changes at end of life and help individuals and their families plan appropriately
- demonstrate leadership in the development and delivery of palliative care policy and provision
- be able to recognise the potential for extending the ethos and practice of palliative care beyond formal health care settings, and work to build the capacity of communities and promote social inclusion
- demonstrate leadership in the development and delivery of palliative care education
- lead, facilitate and engage in research in the field of palliative care in order to improve practice

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 3

COMMUNICATION

Effective communication is essential to the application of palliative care principles and to the delivery of palliative care. Communication is particularly important where bad news has to be relayed, when difficult decisions regarding treatment continuance and/or cessation are to be made and where the communication needs of the person with a life-limiting condition and their family. Communication is also important where circumstances are ambiguous or uncertain and when strong emotions and distress arise. Specific consideration should be given to communication as a method of:

- Supporting and enabling therapeutic relationships with the person with a life-limiting condition and her/his family
- Ensuring that the person and her/his family understand and participate in decision-making regarding care to the extent that she/he is able to and wishes to be involved
- Enabling inter-professional teamwork.

Indicators

As a health care professional, you should:

- understand the essential role communication plays in palliative care
- understand the different types of communication e.g. verbal, non-verbal, visual, written, and interpersonal interaction (either one-to-one or with a group or team)
- demonstrate the ability to communicate effectively with the person with a life-limiting condition, their family and the interdisciplinary team in order to establish, maintain and conclude a therapeutic relationship
- demonstrate the ability to communicate effectively with individuals and families from diverse cultures and different backgrounds, using professional interpreters where necessary and/or assistive communication technology where necessary
- be able to modify your own communication style to facilitate communication with individuals with a range of communication impairments or seek facilitation in this area if required.
- understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, clarifying statements, inviting questions
- demonstrate an ability to be attentive to the person through careful listening to help the person and their family feel they have been heard
- support individuals (or parents in the case of children and minors) to make informed decisions regarding the level of information they wish to receive and want to share with their family
- act as an advocate for the person and their family to ensure appropriate and timely palliative care intervention.

SOCIAL WORK

ALL

As a Social Worker you should:

- Be able to assess the person's current understanding of their health status

- In the context of your current role, be able to support colleagues to address questions regarding diagnosis and likely prognosis in an empathic manner, taking account of the person's needs and wishes
- Understand that the communication of information which changes the person's understanding of their situation and/or influences their decision-making or planning is an on-going process and not a single event
- Contribute to and support discussions between individuals, their families and staff members and recognise potential differences in decision making in the context of palliative care
- Support people with life-limiting conditions to adjust to illness and to understand its potential impact on their welfare and that of their families
- Understand the different styles of communication which can be adapted and used to enhance communication in complex situations at end of life.

SOME

As a Social Worker with an added level of engagement with people with life-limiting conditions you should:

- Support people with life-limiting conditions, their families and health care professionals to use developmental and age appropriate communication with children and vulnerable adults
- Assist in the mediation of conflict in decision-making in the palliative care setting and work towards consensus building in care planning
- Support Parents/Guardians/Families in sharing difficult or bad news, relating to illness or death, with children and vulnerable adults; facilitating direct supportive communication with them, where appropriate.

FEW

As a Social Worker working primarily with people with life-limiting conditions you should:

- Communicate the Social Work role and demonstrate leadership in relation to complex and high risk cases which may arise in palliative care, identifying appropriate interventions that may be of help, from within the service or from other agencies
- Explore and engage with issues of a private and sensitive nature which may arise when caring for a person with life-limiting condition, offering support and guidance to colleagues in managing these situations.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 4

OPTIMISING COMFORT AND QUALITY OF LIFE

Individuals with life-limiting conditions and their families can be affected not only in physical, but also in psychological, social and spiritual ways. Optimising comfort and quality of life for the person with a life-limiting condition and her/his family is a dynamic process that involves anticipating, acknowledging, assessing and responding to a range of symptoms and needs in a proactive and timely manner in order to prevent and relieve suffering.

Indicators

As a health care professional you should:

- Understand how the palliative care approach can enhance the assessment and management of symptoms
- Understand the significance of anticipating and responding to the needs of people with life limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner
- Exhibit an ability to apply a range of assessment tools to gather information

- Be able to evaluate non-complex interventions and propose alternative actions if deemed necessary
- Demonstrate professional awareness of the scope of, and benefits of timely, and appropriate access to specialist palliative care services
- Recognise the importance and benefit of multidisciplinary working in optimising comfort and enhancing the quality of life of the person with a life-limiting condition and her/his family
- Recognise the ways in which people with life-limiting conditions and their families can be engaged in self-management of their condition.
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible.

SOCIAL WORK
ALL
As a Social Worker you should:

- Engage in psychosocial assessment with a person with a life-limiting condition and recognise the role of palliative care in enhancing that person's care
- Demonstrate an ability to analyse appropriate knowledge and information to inform decision making in end of life care
- Recognise how the changing nature of symptoms can impact on the life of the person with a life-limiting condition and their family
- Be able to recognise that there can be practical, social and cultural aspects of the dying process
- Be able to recognise and address the socio-economic impact of a life-limiting diagnosis on the individual and their family and possess a knowledge of supports and interventions which may ease economic and social distress
- Provide therapeutic interventions based on assessment or refer on where appropriate.

SOME
As a Social Worker with an added level of engagement with people with life-limiting conditions you should:

- Recognise how disease progression may impact on the capacity of the person with a life-limiting condition to engage in meaningful discussion
- Support families with complex relationships in order to facilitate the on-going provision of care, whilst prioritising the wishes of the person with a life-limiting condition, where appropriate
- In the context of your current role, support the team when considering the care and treatment options for the person with a life-limiting condition and with due regard to the persons wishes.

FEW
As a Social Worker working primarily with people with life-limiting conditions you should:

- Be able to recognise and at times anticipate the need to change and adapt the focus of social work intervention at critical points during a life-limiting condition, supporting the person with a life-limiting condition and their family through times of transition
- Provide specialist therapeutic interventions based on going assessment of palliative and end of life needs.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 5

CARE PLANNING AND COLLABORATIVE PRACTICE

Care planning in palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families. It involves assessing need, promoting and preserving choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory. Care planning

ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting conditions should be helped to engage with care planning to the extent that they are able to and wish to be involved. The concerns of families and carers should be taken into account as part of this process.

Indicators

As a health care professional you should:

- Recognise the impact of a life-limiting condition on the person and her/his family and be able to provide support in order to help the individual to adapt to the changes in her/his condition
- Recognise the impact of a life-limiting condition on the person and her/his family's mental health and coping mechanisms and be able to provide support in order to help the individual to adapt to the bereavement and loss
- Appreciate the roles, responsibilities and professional boundaries of individual members of the interdisciplinary team
- Understand the collaborative relationship between the person with life-limiting conditions, the health care professional, the family and all the other agents of care involved with the person and the family in order to develop an individualised and coherent plan of care to assist the person and the family to attain realistic goals and outcomes in all care settings
- Collaborate effectively with others as a member or leader of a multidisciplinary team
- Be able to identify priorities or concerns for the individual with a life-limiting condition and their carers, taking account of the individual's coping strategies and how the person perceives their diagnosis
- In the context of professional scope of practice be able to critically evaluate outcomes of interventions against established standards and guidelines
- Demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the person, the family and the range of professionals and agencies involved.

SOCIAL WORK

ALL

As a Social Worker you should:

- Work collaboratively with the person with a life-limiting condition, their family and other professionals, including co-ordinating family meetings, team meetings, mediating discussions and planning for future care
- Recognise that the person with a life-limiting condition may lose capacity to make decisions towards end-of-life
- In situations where a person lacks capacity to make decisions, the Social Worker acts as an advocate for the person and/or their family/carers and within their current Code of Professional Conduct and Ethics
- Understand the centrality of relationships for people, based on the theories of attachment, separation, loss, change and resilience
- Identify and coordinate the input of multiple care agents to support a range of differing care needs of people with life-limiting conditions, their carers and families at end of life.

SOME

As a Social Worker with an added level of engagement with people with life-limiting conditions you should:

- Share professional knowledge and expertise regarding psychosocial issues in palliative care and at end of life, with the multidisciplinary team or with colleagues
  Support and advise the multidisciplinary team to interpret, use and access relevant policy, legal and administrative processes during times of illness, loss and bereavement, within the context of your current role.

FEW

As a Social Worker working primarily with people with life-limiting conditions you should:

- Carry out bereavement risk assessment in collaboration with the family and multidisciplinary team
- Demonstrate leadership role by drawing on in-depth psychosocial assessment and integrating multiple sources of knowledge and experience in order to contribute to care planning
- Demonstrate leadership in identifying complex psychosocial issues and facilitate the appropriate team response through family meetings involving other team members and services as appropriate
- Demonstrate leadership in the development and maintenance of effective relationships with health care providers, managers of services and the public in the context of palliative care.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 6

LOSS, GRIEF AND BEREAVEMENT

Dealing with loss, grief and bereavement for the person themselves, their family and the professionals who care for them is intrinsic to palliative care provision. Most people manage their loss by combining their own resources with support from family and friends. However, a minority of people are at risk of developing complications or difficulties in their grieving. Professionals using the palliative care approach have an important role to play in supporting bereaved people by providing information and support to all and by identifying those who require bereavement therapy or counselling.

Indicators

As a health care professional, you should:

- Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced
- Recognise the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief
- Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family
- Demonstrate an ability to engage with a person who is experiencing loss in the context of professional scope of practice and/or role
- Assist the family to access bereavement information and support at a level that is appropriate to their needs
- Understand the personal impact of loss, grief and bereavement and recognise your own loss responses and engage in activities that maintain your resilience on an on-going basis
- Possess a level of self-awareness that prevents your own experiences of loss from negatively impacting on the person with a life-limiting condition or their family.

SOCIAL WORK

ALL

As a Social Worker you should:

- Work in partnership with parents, guardians and other family members in order to prepare and support children and vulnerable adults for the loss of loved ones and refer on where appropriate
- Facilitate the person with a life-limiting condition and their carers to express their thoughts and feelings relating to illness and loss
- Be able to recognise that there are a variety of psychological responses to diagnosis and illness
- Demonstrate an understanding the theories of loss, grief and bereavement.

SOME

As a Social Worker with an added level of engagement with people with life-limiting conditions you should:

- Provide supports and interventions to carers and families after the death of a loved one, as appropriate
- Demonstrate knowledge of available networks and supports across a range of family needs into bereavement
- Provide bereavement support in individual and group settings, with referral to other agencies, where appropriate.

FEW

As a Social Worker working primarily with people with life-limiting conditions you should:

- Understand and share knowledge of theories and research evidence relevant to loss and bereavement including anticipatory grief and risk indicators for complicated grief
- In the context of your practice setting provide multidisciplinary team debriefing and support the development of self-care strategies for colleagues working in end of life care
- Provide bereavement risk assessment and counselling in individual or group settings, with referral on to other agencies, where appropriate
- Provide expert guidance on adult and childhood grief within complex family situations
- Promote research and development of bereavement care, including audit of own agency practice and forge appropriate links with external agencies.

Proposed – Social Work Competencies for Palliative Care
DOMAIN OF COMPETENCE 7

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

The goal of health care is to help people sustain health that is essential to their well-being. However, there comes a time when specific treatments or interventions may be futile or overly burdensome. Integrity in palliative care practice refers to the importance of respecting the person's values, needs and wishes in the context of a life-limiting condition. It guides all health care professionals to reflect on the relationship between their contribution to a person's care and the necessary contributions of other professionals. Professional and ethical practice is about considering how best to provide continuing and integrated care to people as their health care needs change in the course of life limiting conditions.

Indicators

As a health care professional, you should:

- Work within your current Code of Professional Conduct and engage ethically, knowledgably and respectfully with other disciplines.
- Recognise and respect your professional responsibility to care for people with life-limiting conditions and their families to ensure their comfort and dignity
- In the context of your current professional role establish collegial partnerships and in the context of palliative care contribute to the professional development of students, peers, colleagues and others through consultation, education, leadership, mentorship and coaching
- Use the resources available in the context of providing appropriate care to the person with a life-limiting condition
- In the context of professional scope of practice and/or role anticipate and demonstrate the ability to address potential ethical issues that may be encountered when caring for the person with a life-limiting condition and her/his family such as: Do Not Attempt Resuscitation Orders, withdrawal and withholding of treatment, use of artificial hydration and feeding, palliative sedation and requests for euthanasia
- Be able to establish and respect people's wishes about their care and options/ preferences. This includes:

- Recognising people's right to make informed decisions to refuse additional treatment(s)
- Seeking, responding to and implementing people's preferences about where they are cared for (e.g. in their own homes) if this is practicable
- Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen
- Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service delivery

SOCIAL WORK
ALL
As a Social Worker you should:
- Engage in reflective practice to promote greater self- awareness and ability to critically evaluate one's own practice within end of life care.

SOME
As a Social Worker with an added level of engagement with people with life-limiting conditions you should:
- Utilise supervision to ensure best practice in end of life care and to meet organisational and professional requirements
- Have a commitment to anti-oppressive practice in relation to end of life care and service delivery
- Raise awareness within the multidisciplinary team of the factors or practices which may be considered oppressive.

FEW
As a Social Worker working primarily with people with life-limiting conditions you should:
- Demonstrate a commitment to working in partnership with health care managers and providers to assess, coordinate, promote and improve individual safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research
- Demonstrate leadership through advocating for on-going and continuous service development
- Facilitate appropriate engagement of service users in the development of palliative care services
- Be able to facilitate the discussion and resolution of ethical issues that may arise in palliative care
- Communicate and advance the distinct contribution of social work to palliative care.

<u>Next steps</u>
As already stated, the following next steps are offered for consideration for the continued development of palliative care Social Work:
- For all Social Workers employed in the health sector to attend palliative care education, especially the Fundamentals of Palliative Care
- Increased access to funding for palliative care education (including post graduate study) for all Social Workers employed in the health sector
- For palliative care Social Workers to develop relationships with their local training organisation/ institution to offer education about palliative care Social Work
- For encouragement and practical support for palliative care Social Workers to undertake research and publish their findings
- For the inclusion of palliative care Social Work and other allied health professions to be included in a meaningful way into Te Whatu Ora Health New Zealand palliative care policy documents
- For ongoing consultation with ANZASW, SWRB and educational providers/ institutions

Speech Language Therapy

By Alexandra Smedley, Speech Language Therapist, CDHB

Disclaimer: the following information is based on initial enquiries with as many colleagues and providers as possible within our timeframes and resources. It will therefore be incomplete in parts and subject to change over time. Proposed competencies have not been ratified or endorsed, they are offered as a basis for further discussion and development.

Introduction and approach

Speech-language Therapy training provides us with expertise in areas that are important in palliative care. Speech-language Therapists can provide patients with ways to communicate when speech or voice is lost due to illness or treatment. They are skilled in the use of alternative and augmentative communication. They can provide guidance to families and carers when communication becomes difficult due to speech or language difficulties. Speech-language Therapists can assess if patients are able to comprehend written or spoken language ensuring that patients are able to make informed decisions around their care.

Speech-language Therapists also assess patient's ability to eat and drink safely. For patients with life limiting conditions, it is important that Speech-language Therapists consider quality of life and this requires a more considered approach. Conversations with the person with a life limiting condition, their families/whānau and the wider team are needed, and this requires counselling skills and knowledge of legal and ethical issues. While these areas form part of our general training, special considerations are needed for patients with life limiting conditions.

Speech-language Therapists are in an ideal position to manage many aspects of communication and swallowing difficulties that patients with life limiting conditions can experience. Current undergraduate and postgraduate programmes offer basic training in palliative care, but there is no consistent approach for palliative care education between the different training institutes and there are limited opportunities for specialist training in palliative care.

Many Speech-language Therapists learn about treatment for patients with life limiting conditions as part of their workplace setting and often it is in those settings that Speech-language Therapists may seek further education. These are available through further training at the workplaces, e-learning portals, websites and through Hospice.

Current preparation and support to deliver palliative care

The New Zealand Speech-language Therapists' Association (NZSTA) is the national professional body of Speech-language Therapists in New Zealand https://speechtherapy.org.nz/about-slt/. Speech-language Therapy courses are currently available through Auckland University, Massey University and Canterbury University, both as Bachelor and Master Programmes. These programmes are subject to the NZSTA Programme Accreditation Framework. Please note that Speech and Language Therapy and Speech and Language Pathology are interchangeable to reflect international terminology. Overseas-trained Speech and Language Therapists or Speech and Language Pathologists are required to get approval from the NZSTA to become members of the NZSTA.

Training Provider	Undergraduate	Postgraduate	NZSTA accreditation
University of Canterbury	Speech and Language Pathology with honours – 4-year programme	Master of Speech and Language Pathology – 2-year postgraduate programme	yes
Massey University	Bachelor of Speech and Language Therapy with honours – 4-year programme		yes
University of Auckland		Master of Speech Language Therapy Practice – 2-year postgraduate programme	yes

The responses from the above training providers were as follows: At an under-graduate level, Universities offer basic training in palliative care for all students. Typically, this includes: what is palliative care across the age span; self-care; basic counselling skills; challenging conversation skills; working with the multidisciplinary team; roles and responsibilities; risk feeding; end-of-life; power of attorney; and ethics.

Therapists who specialise in palliative care can take specialist courses through training institutes or through their workplaces. There is also an e-learning module available through the NZSTA.

Existing local, national and international resources

At an under-graduate level, Universities offer basic training in palliative care for all students.

Online courses on palliative care that have been recommended:

- http://www.pcc4u.org/ Palliative care curriculum from Australian University for Undergraduates working in health, patient stories, self-evaluations etc.
- https://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life. This is a very detailed resource from the NZ MOH with guidelines/flowcharts

Health Learn: There are two courses available for CDHB staff

https://www.healthlearn.ac.nz/course/search.php?search=palliative+care

- Fundamental Series: Palliative Care
- Palliative Care Study Day at Christchurch Hospital

NZSTA e-learning module available for Speech Language Therapists:

https://speechtherapy.org.nz/about-slt/

- Module one (currently available)
- Module two (in preparation)

Risk Feeding Guidelines:

- https://flexiblelearning.auckland.ac.nz/speech-science-dysphagia-education-hub/6/files/riskfeedingguideline_post-endorsement.pdf
- These are guidelines available to support health professionals when eating and drinking has been assessed as being unsafe

Organisations that provide training/resources:

- Dove Hospice – Auckland based
- Hospice New Zealand

Proposed palliative care competencies

The NZSTA is the national professional body governing Speech-language Therapists in New Zealand. We abide by professional standards, which include the Principles and Rules of Ethics and the NZSTA Scope of Practice. We also adhere to the principles of the Treaty of Waitangi and the Maori philosophy of health and wellbeing – Te Whare Tapa Wha.

I have reviewed the Irish Palliative Care Competency Framework 2014 and have found it to be a very comprehensive document that would complement the current professional standards for Speech-language Therapists. I have only made minimal changes to reflect considerations that are unique to New Zealand and these changes are in italics.

Reference:
Palliative Care Competence Framework Steering Group. (2014). *Palliative Care Competence Framework*. Dublin: Health Service Executive

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 1

PRINCIPLES OF PALLIATIVE CARE

Palliative care aims to improve the quality of life of people with life-limiting conditions and their families*/whānau*, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement.

Indicators
As a health care professional, you should:

- Understand and be able to describe the meaning of the term 'life-limiting condition'
- Understand and be able to apply the principles of palliative care that affirm life, offer people with life-limiting conditions a support system to help them live as actively as possible until death with optimal quality of life and help families*/whānau* cope during illness
- Understand the significance of the physical, psychological, social and spiritual issues that affect people with life-limiting conditions and their families*/whānau* throughout the continuum of care
- Demonstrate the ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person and her/his family/*whānau*
- Provide empathetic care to individuals with life-limiting conditions and their families*/whānau*, with clear regard to the individuality of each person
- Show a commitment to one's own continued professional development and learning and facilitate the learning and development of others, in order to improve care for those with life-limiting conditions and their families*/whānau*
- Show a commitment to developing self-care strategies and to attending to any impact that working with people facing life-limiting conditions and their families*/whānau* may have on you.

SPEECH AND LANGUAGE THERAPY
ALL
As a speech and language therapist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand the impact of psychological responses to multiple loss including loss of social participation, social stressors and the spiritual dimensions on the behaviour and decision making of individuals with life-limiting conditions and families*/whānau* and take this into account when planning care
- Understand, recognise and address the management of pathological responses to multiple loss, social participation and functional communication which may impact on behaviour and decision-making of individuals with life-limiting conditions and families, and refer individuals and/or their families*/whānau* to specialist palliative care where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the role of specialist palliative care services in supporting staff when providing a palliative care approach to the person with a life-limiting condition.

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate in-depth understanding of the full spectrum of trajectories of life-limiting conditions in the context of your current clinical practice
- Undertake additional study relevant to the needs of individuals with life-limiting conditions to enhance application in practice
- Be able to identify and engage in research that will lead to effective clinical practice.

FEW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate an advanced knowledge, and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of therapy outcomes and service delivery in palliative care
- Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations with people with life-limiting conditions and their families/*whānau*.
- Lead, facilitate and engage in further education and research in palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Speech and Language Therapy Practice in Palliative Care.

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 2

COMMUNICATION

Effective communication is essential to the application of palliative care principles and to the delivery of palliative care. Communication is particularly important where bad news has to be relayed, when difficult decisions regarding treatment continuance and/or cessation are to be made and where the communication needs of the person with a life-limiting condition and their family*/whānau*. Communication is also important where circumstances are ambiguous or uncertain and when strong emotions and distress arise. Specific consideration should be given to communication as a method of:

- Supporting and enabling therapeutic relationships with the person with a life-limiting condition and her/his family*/ whānau*
- Ensuring that the person and her/his family understand and participate in decision-making regarding care to the extent that she/he is able to and wishes to be involved
- Enabling inter-professional teamwork.

Indicators

As a health care professional, you should:

- Understand the essential role communication plays in palliative care
- Understand the different types of communication e.g. verbal, non-verbal, visual, written, and interpersonal interaction (either one-to-one or with a group or team)
- Demonstrate the ability to communicate effectively with the person with a life-limiting condition, their family and the interdisciplinary team in order to establish, maintain and conclude a therapeutic relationship
- Demonstrate the ability to communicate effectively with individuals and families*/whānau* from diverse cultures and different backgrounds, using professional interpreters where necessary and/or assistive communication technology where necessary
- Be able to modify your own communication style to facilitate communication with individuals with a range of communication impairments or seek facilitation in this area if required
- Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, clarifying statements, inviting questions
- Demonstrate an ability to be attentive to the person through careful listening to help the person and their family*/whānau* feel they have been heard
- Support individuals (or parents in the case of children and minors) to make informed decisions regarding the level of information they wish to receive and want to share with their family
- Act as an advocate for the person and their family*/whānau* to ensure appropriate and timely palliative care intervention

SPEECH AND LANGUAGE THERAPY

ALL

As a speech and language therapist you should:

- Be able to assess the person's current understanding of his/her health, role and functional FEDS (feeding, eating, drinking and swallowing) and communication status in the context of the person's life-limiting condition
- Be able to optimise effective communication for the person with a life-limiting condition who presents with receptive and/or expressive speech and language impairment, cognitive-communication difficulties, and/or alaryngeal communication, accessing expertise in assistive communication when appropriate
- Be able to educate and facilitate members of the multidisciplinary team in optimising effective communication with the person with a life-limiting condition who presents with receptive and/or expressive speech and language impairment, cognitive-communication difficulties, and/or alaryngeal communication

- Be able to communicate current functional status in relation to communication and disorders of FEDS and likely progression in an accurate and compassionate manner, taking account of the patient's needs, wishes and possible changes in communicative function
- Understand that the communication of information which fundamentally changes the future of the person living with a life-limiting condition is an on-going collaborative process and not a single event
- Recognise and contribute to the management of potential conflict in decision-making in the palliative care setting.

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- Demonstrate an increased level of confidence in demonstrating, utilising and modifying effective communication strategies including the use of assistive communication, to support the changing needs and wishes of individuals with life-limiting conditions and their families*/ whānau*
- Be able to facilitate assessment of decision-making capacity in individuals with communication or cognitive-communication impairment
- Be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family */whānau.*

FEW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised and timely communication with individuals with life-limiting conditions, their carers and members of the interdisciplinary team
- Demonstrate expertise as a mediator and advocate for the patient and the family*/whānau* to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- Demonstrate expertise as a mediator and advocate for the patient and family*/whānau* with regard to decision making related to initiating, withdrawing or withholding artificial hydration and nutrition as a consequence of advanced oropharyngeal dysphagia
- Demonstrate self-awareness of own responses to communication challenges and remain in meaningful contact with individuals and carers even in the most complex, intense and changing circumstances
- Be able to act as an expert that supports and facilitates multidisciplinary teaching of communication skills, as they pertain to speech and language therapy practice including but not limited to the management of individuals with receptive and and/or expressive language impairment, cognitive-communication difficulties and/or alaryngeal communication.

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 3

OPTIMISING COMFORT AND QUALITY OF LIFE

Individuals with life-limiting conditions and their families can be affected not only in physical, but also in psychological, social and spiritual ways. Optimising comfort and quality of life for the person with a life-limiting condition and her/his family*/whānau* is a dynamic process that involves anticipating, acknowledging, assessing and responding to a range of symptoms and needs in a proactive and timely manner in order to prevent and relieve suffering.

Indicators

As a health care professional, you should:

- Understand the significance of anticipating and responding to the needs of people with life-limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner
- Understand how the palliative care approach can enhance the assessment and management of symptoms
- Exhibit an ability to apply a range of assessment tools to gather information
- Be able to evaluate non-complex interventions and propose alternative actions if deemed necessary
- Recognise the importance and benefit of multidisciplinary working in optimising comfort and enhancing the quality of life of the person with a life-limiting condition and her/his family*/whānau*
- Recognise the ways in which people with life-limiting conditions and their families*/whānau* can be engaged in self-management of their condition.
- Demonstrate professional awareness of the scope of, and benefits of, timely and appropriate access to specialist palliative care services
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible.

SPEECH AND LANGUAGE THERAPY

ALL

As a speech and language therapist you should:

- Be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- Be able to recognise potentially reversible causes of functional deterioration in the patient's FEDS and communication abilities, identifying adaptive or compensatory strategies and /or employing a palliative rehabilitation approach that is appropriate to promote optimal independence and safety in these areas
- Be able to assess caregivers' skills and need for skill training and support, to assist with safe swallow techniques within the context of life-limiting condition.
- Promote and educate carers on optimising effective communication with the individual who presents with communication or cognitive-communication impairment
- Be able to help the person with a life-limiting condition and their family/*whānau* to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to recognise critical junctures in care and thereby identify a need for change in the focus of care and treatment goals in the course of a life-limiting condition
- Be able to recognise and access multidisciplinary expertise and non – pharmacological interventions to support the management of symptoms including fatigue, dyspnoea, secretion

management and anxiety that can impact on safe and/ or pleasurable engagement in FEDS, communication activities and quality of life

- Demonstrate increased awareness of the impact of multiple loss (e.g. communicative autonomy, ability to eat/drink), when formulating relevant and realistic treatment programmes appropriate to the needs of the individual with a life-limiting condition
- Be able to recognise the need to seek expertise in seating and other equipment which may promote autonomy in communication and enhance safety and independence in eating, drinking and swallowing in the individual with a life-limiting condition within the hospital and/ or home environment.
- Demonstrate an advanced ability to consider the benefits, burdens and risks of speech and language therapy interventions (including instrumental assessment) in individualising management for each person living with a life-limiting condition
- Demonstrate the ability to manage decisions about withdrawing or postponing speech and language therapy intervention, while recognising when to reengage if appropriate.

FEW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Be able to apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- Demonstrate advanced knowledge of patient clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- Through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- Be able to act as an expert resource to other staff on the role of speech and language therapy and rehabilitation, in symptom management and optimising quality of life
- Be able to identify the psychosocial impact of diminishing communication and/or swallow function as a consequence of life-limiting condition providing timely person-centred modifications to facilitate continued social participation
- Demonstrate expertise in facilitating individuals and their families to identify personally significant functional communication activities and empowering continued participation through supported conversation and total communication approaches
- Demonstrate expert knowledge of the impact of pain, dyspnoea and other symptoms on swallow function and/or communication performance, utilizing compensatory and palliative rehabilitation approaches to alleviate symptoms, and optimise effective, pleasurable and safe participation in these activities
- Be able to access MDT expertise in the pharmacological management of secretions, dyspnoea and anxiety which may impact upon safe and/or pleasurable engagement in eating drinking, swallowing and/or communication

Demonstrate expertise in assessing individuals with life-limiting conditions for assistive communication technology, outlining recommendations for devices/modifications that will promote communicative autonomy for the individual within their environment.

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 4

CARE PLANNING AND COLLABORATIVE PRACTICE

Care planning in palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families*/whānau*. It involves assessing need, promoting and preserving choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory. Care planning ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting conditions should be helped to engage with care planning to the extent that they are able to and wish to be involved. The concerns of families*/whānau* and carers should be taken into account as part of this process.

Indicators

As a health care professional, you should:

- Recognise the impact of a life-limiting condition on the person and her/his family*/whānau* and be able to provide support in order to help the individual to adapt to the changes in her/his condition
- Recognise the impact of a life-limiting condition on the person and her/his family*/whānau on* mental health and coping mechanisms and be able to provide support in order to help the individual to adapt to the bereavement and loss
- Appreciate the roles, responsibilities and professional boundaries of individual members of the interdisciplinary team
- Understand the collaborative relationship between the person with life-limiting conditions, the health care professional, the family*/whānau* and all the other agents of care involved with the person and the family*/whānau* in order to develop an individualised and coherent plan of care to assist the person and the family to attain realistic goals and outcomes in all care settings
- Collaborate effectively with others as a member or leader of a multidisciplinary team
- Be able to identify priorities or concerns for the individual with a life-limiting condition and their carers, taking account of the individual's coping strategies and how the person perceives their diagnosis
- In the context of professional scope of practice be able to critically evaluate outcomes of interventions against established standards and guidelines
- Demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the person, the family*/whānau* and the range of professionals and agencies involved.

SPEECH AND LANGUAGE THERAPY

ALL

As a speech and language therapist you should:

- As a member of the interdisciplinary team be able to participate in key events in patient care, including family meetings
- Demonstrate the ability to recognise and promote the importance of communication, supporting the individual's ability to make and communicate decisions in all ways possible
- Demonstrate ability to recognise that the person with a life-limiting condition may lose communicative competency to make decisions towards end of life. In such circumstances decisions must be made in the best interest of the person and must adhere to speech and language therapy professional ethical guidelines in respect to decision making
- Understand the importance of referral to the specialist palliative care team for the management of complex needs.

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to work collaboratively and effectively within the inter-professional team and with other stakeholders to manage positive working relationships that will support the wellbeing of the patient and carer and promote patient centred care planning
- Be able to facilitate individuals and their families*/whānau* towards active involvement in decision making and goal setting to support best outcomes and quality of life
- Be able to collaborate with the multidisciplinary team to ensure that information regarding care decisions and consent is accessible to the individual's level of cognitive–communication capacity
- Be able to optimise the ability of individuals with communication or cognitive-communication difficulties to be involved in decisions and consent processes regarding their care, including enabling the individual to understand the information provided, to identify the consequences of making a care decision and to communicate his/her decision
- Be able to collaborate with the individual and their family*/whānau* to agree individualised goal-based treatment programmes that are person centred and responsive to the changing needs of the individual with a life-limiting condition
- Demonstrate flexibility in relation to care planning, acknowledging that a person's priorities can alter with a change in their condition and disease advancement
- Be able to facilitate discharge planning, carrying out in depth swallowing and communication assessments and risk assessments to facilitate the discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with life-limiting conditions and their carers.

FEW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate expertise in developing therapeutic relationships with individuals/families/ *whānau* to assist their informed choices for care planning and therapy treatment options
- Be able to act as an expert clinical resource, as required, to generalist and other specialist providers of palliative care, role modelling advanced clinical skills when assessing and managing individuals with complex life-limiting conditions
- Demonstrate advanced understanding of the roles of the wider multidisciplinary team, show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family*/whānau*
- Demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation and functional communication ability
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care
- Demonstrate an advanced level of clinical expertise and sensitivity in facilitating a safe, smooth and seamless transition of care for individuals with complex communication, cognitive-communication and FEDS needs who choose to be cared for at home rather than in hospital or hospice.

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 5

LOSS, GRIEF AND BEREAVEMENT

Dealing with loss, grief and bereavement for the person themselves, their family/*whānau* and the professionals who care for them is intrinsic to palliative care provision. Most people manage their loss by combining their own resources with support from family/*whānau* and friends. However, a minority of people are at risk of developing complications or difficulties in their grieving. Professionals using the palliative care approach have an important role to play in supporting bereaved people by providing information and support to all and by identifying those who require bereavement therapy or counselling.

Indicators

As a health care professional, you should:

- Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced
- Recognise the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief
- Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family/*whānau*
- Demonstrate an ability to engage with a person who is experiencing loss in the context of professional scope of practice and/or role
- Assist the family/*whānau* to access bereavement information and support at a level that is appropriate to their needs
- Understand the personal impact of loss, grief and bereavement and recognise your own loss responses and engage in activities that maintain your resilience on an on-going basis
- Possess a level of self-awareness that prevents your own experiences of loss from negatively impacting on the person with a life-limiting condition or their family/*whānau*.

SPEECH AND LANGUAGE THERAPY

ALL

As a speech and language therapist you should:

- Have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues
- Demonstrate sensitivity and engagement with the different stages of grief and loss, including multiple loss related to role and functional independence in communication and swallowing, utilising this awareness to inform care planning and treatment intervention

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to appreciate the nature of disenfranchised grief in individuals, families/*whānau* and carers and appropriate methods of addressing this grief.

FEW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate advanced knowledge of the grieving process and reactions to actively support individuals with life-limiting conditions and their families throughout the disease trajectory
- Demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/or referral to appropriate disciplines or agencies.
- Mentor and educate colleagues to understand the personal impact of loss, grief and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis

Proposed – Speech Language Therapy Competencies for Palliative Care DOMAIN OF COMPETENCE 6

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

The goal of health care is to help people sustain health that is essential to their well-being. However, there comes a time when specific treatments or interventions may be futile or overly burdensome. Integrity in palliative care practice refers to the importance of respecting the person's values, needs and wishes in the context of a life-limiting condition. It guides all health care professionals to reflect on the relationship between their contribution to a person's care and the necessary contributions of other professionals. Professional and ethical practice is about considering how best to provide continuing and integrated care to people as their health care needs change in the course of life-limiting conditions.

Indicators

As a health care professional, you should:

- Work within your current Code of Professional Conduct and engage ethically, knowledgably and respectfully with other disciplines
- Recognise and respect your professional responsibility to care for people with life-limiting conditions and their families*/whānau* to ensure their comfort and dignity
- In the context of your current professional role establish collegial partnerships and in the context of palliative care contribute to the professional development of students, peers, colleagues and others through consultation, education, leadership, mentorship and coaching
- Use the resources available in the context of providing appropriate care to the person with a life-limiting condition
- In the context of professional scope of practice and/or role anticipate and demonstrate the ability to address potential ethical issues that may be encountered when caring for the person with a life-limiting condition and her/his family such as: Do Not Attempt Resuscitation Orders, withdrawal and withholding of treatment, use of artificial hydration and feeding, palliative sedation and requests for euthanasia
- Be able to establish and respect people's wishes about their care and options/ preferences. This includes: Recognising people's right to make informed decisions to refuse additional treatment(s)
- Seeking, responding to and implementing people's preferences about where they are cared for (e.g. in their own homes) if this is practicable
- Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen
- Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service delivery

SPEECH AND LANGUAGE THERAPY

ALL

As a speech and language therapist you should:

- *Comply with any requirements for membership to the NZSTA – New Zealand Speech-language Therapist's Association*
- *Be aware of and act according to the NZSTA Principles and Rules of Ethics and NZSTA Scope of Practice*
- *Recognises the cultural uniqueness of individuals and their families/whānau and demonstrates the provision of sensitive and culturally appropriate care to those with a life-limiting illness*
- *Demonstrates a holistic model of care for those with a life-limiting condition, encompassing the Māori philosophy of health and wellbeing – Te Whare Tapa Wha*
- Demonstrate an understanding of the difference between managing a life-limiting condition and providing end of life care to an individual with a life-limiting condition

- Be aware of the limitations of role, practice and expertise in end of life decision making related to artificial hydration and/or nutrition as a consequence of severe oropharyngeal dysphagia in advanced life-limiting condition, referring to relevant specialist palliative care expertise as appropriate.

SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice
- Provide and participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations.
- Use recognised ethical, legal and professional frameworks to guide speech and language therapy intervention in end of life decision making related to initiating/withdrawing/withholding artificial hydration and/or nutrition as a consequence of severe oropharyngeal dysphagia in advanced life-limiting condition.

FEW

As a speech and language therapist whose core role is the provision of palliative care you should:

- Apply an advanced understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care services
- Lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- Actively engage in building the evidence base to support interventions with persons with a life-limiting condition, in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care.

Next steps

Speech-language Therapists training provides basic education for working with patients with life-limiting conditions. Ideally the training should be consistent through all training institutes. This would allow Speech-language Therapists from new graduate level to build on their knowledge with more in-depth learning from recommended sources.

Collaboration with the training institutes and the NZSTA Programme Accreditation Committee would ensure the training provided is the same across all training institutes and complies with the standards of the NZSTA. There is already an e-learning module on palliative care on the NZSTA website and this should be made available for all Speech-language Therapists working in this area. Furthermore, a list of workplace training could be made available for Speech-language Therapists working in palliative care. The identification of suitable mentors and creation of Special Interest Groups would support Speech-language Therapists specialising in palliative care.

Appendix B: Definitions

The following selection of definitions were taken directly from the New Zealand Palliative Care Glossary (Ministry of Health, 2015), in alphabetical order.

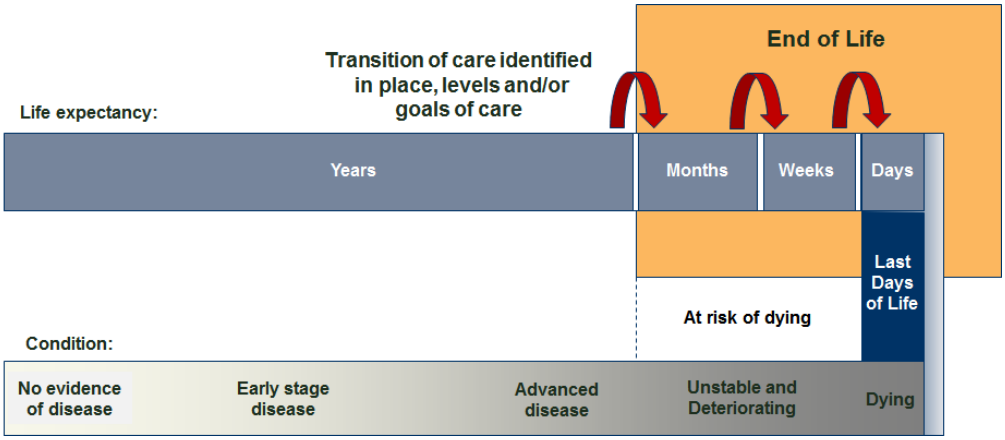
End of Life: is that period of time prior to death but the duration can never be precisely defined in advance (National Gold Standards Framework Centre 2011).[2]

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[3]



Last Days of Life: 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).

Multidisciplinary team: a team that consists of a mix of health care disciplines.

Team members share common goals, collaborate and work together in planning and delivery of care. Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists,

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

[3] 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.

physiotherapists, dieticians, volunteers, pharmacists, or care assistants (Palliative Care Australia 2008).

Palliative Care:[4] 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.

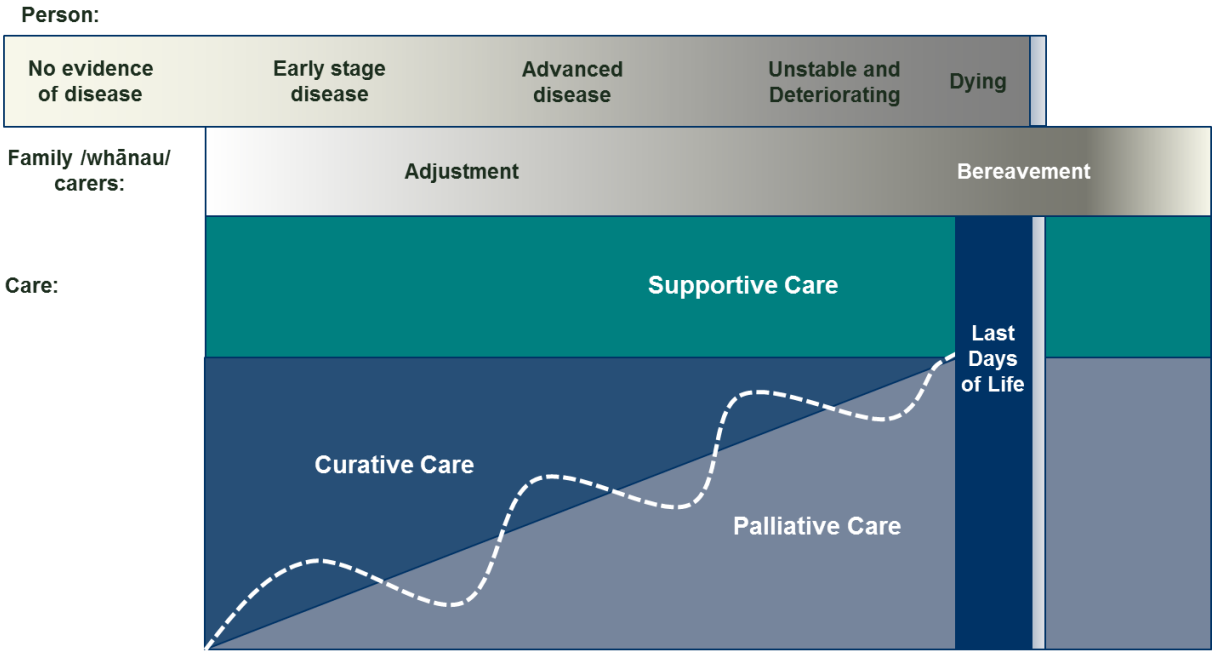
Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

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



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

[4] 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.

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.

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.

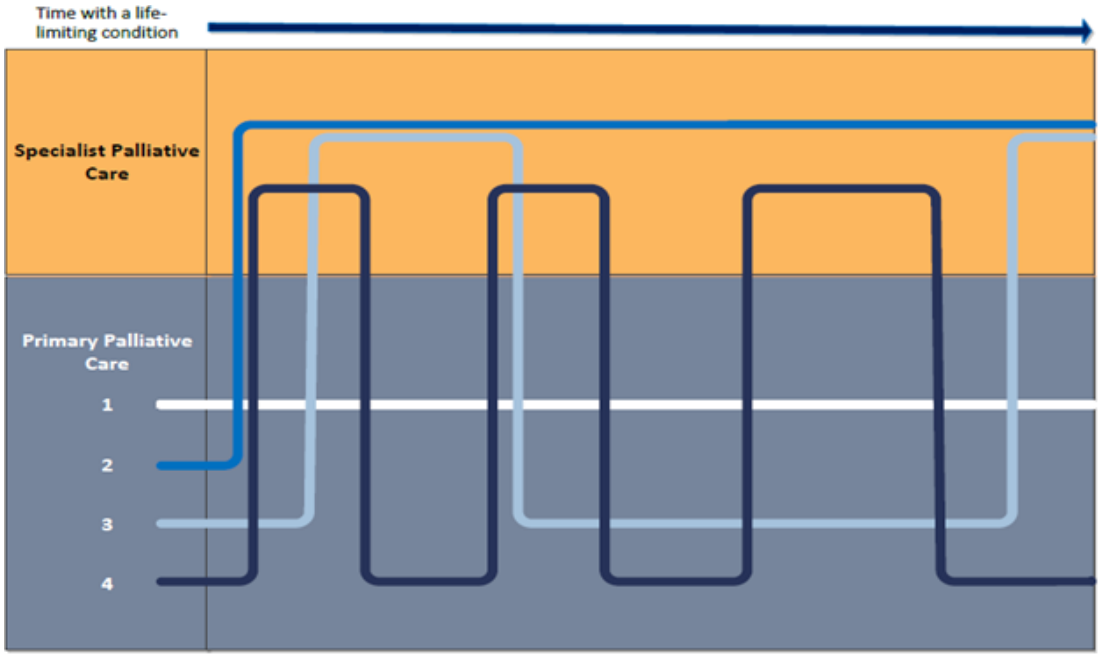
Specialist Palliative Care: is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

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.

Figure 3: The relationship between primary palliative care and specialist palliative care



In Figure 3, episodes of care meet the needs of the person, family /whānau/ carers, depending on the expertise and experience of the primary palliative care providers. Four examples are illustrated.

1) All care is provided by the primary palliative care providers with no input required from specialist palliative care services.

2) Care is provided by specialist palliative care for the duration of the illness with little or no input from primary palliative care providers.

3) Initial involvement from specialist palliative care to guide a plan of care with re-referral during the deteriorating phase or during the last days of life.

4) Multiple episodes of specialist palliative care involvement during times of increased need/complexity, not necessarily during the last days of life.

3) and 4) are examples of the ways in which care may be provided intermittently by specialist palliative care in combination with primary palliative care. Continuity of care is provided by the primary palliative care provider(s).

Whānau: extended family, family group, a familiar term of address to a number of people. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members (Moorfield 2015).