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DISCUSSION PAPER

# ENDING WELL: THE URGENT CASE FOR ACCESSIBLE PALLIATIVE CARE

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DANIELLE VAN DALEN\*

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*All errors and omissions are the author's own.*

## *The paper in summary...*

Whether the cause is COVID-19 or something else, death is inevitable for all of us. A good death, however, is not. In spite of the care, expertise, and knowledge now available, bad deaths are unfortunately all too common for many New Zealanders.

Palliative care is an important ingredient for good end of life care—even when the person has complex medical issues or has struggled with significant pain. It is an approach that “prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”<sup>1</sup>

Studies have shown that palliative care can result in improved quality of life, an increased life expectancy and, due to lowered interactions with the hospital and admission process, can relieve financial costs on the healthcare system. One study found, for example, that “involvement from palliative care was associated with significantly lower hospital costs in the order of \$5000-8000 (Australian dollars) for all patient groups, but most particularly for non-cancer diagnoses.”<sup>2</sup>

For too many New Zealanders, however, good palliative and end of life care is out of reach.

As demographics change and New Zealand’s population ages the number of people struggling to access palliative care services is growing rapidly. In fact, studies project the need for New Zealand palliative care services to increase by half in the next 20 years, and almost double in the next 50 years.<sup>3</sup>

New Zealand’s health system is currently undergoing significant reform, through systemic changes as well as with the introduction of legalised assisted dying.<sup>4</sup> With these changes underway it is essential that palliative care services are not forgotten, but get the necessary attention and support so that all New Zealanders have the best opportunity for a good death.

This paper identifies **five key areas** where policy changes could improve access to palliative care services for New Zealanders:

- 1. Governance and strategy**—ensuring that strategies, plans, and data are relevant and up-to-date so that New Zealand’s services can best “meet rising demand for care.”
- 2. Public awareness**—increasing New Zealanders “death literacy,” or understanding of the dying process and care options available, so that families, whānau, and communities are equipped to support one another to the very end of life.
- 3. Training, support, and education**—increasing availability and enhancing training so that everyone who plays a role in caring for people at the end of life—whether that be specialist physician, primary carer, family, or whānau—feels equipped and able rather than distressed and unprepared.
- 4. Funding**—appropriate increases and targeting so that sufficient palliative care services are available and the need for surviving on “cakes and op shops” is reduced.
- 5. Accessibility**—increased and improved regional and cultural accessibility to palliative care services so that care is available for all New Zealanders.

## *Our recommendations in full:*

### **Governance and strategy:**

1. The Ministry of Health should evaluate the progress of the 2017 Palliative Care Action Plan's priorities and produce an updated Palliative Care Strategy and Strategy and Action Plan.
2. Parliament should maintain the All Parliamentary Group on Palliative Care and ensure information on its members and meetings are publicly available.
3. The Ministry of Health should collect and report consistent data on the provision and availability of palliative care services in New Zealand.

### **Public Awareness:**

4. Hospice New Zealand and the Ministry of Health should work together to promote public awareness of hospice and palliative care services in New Zealand.

### **Training, support, and education:**

5. The Government should mandate at least 72 hours of undergraduate palliative care training in the course of a medical or nursing degree as well as additional clinical practice.
6. The Government should mandate ongoing professional development in palliative and end of life care for every medical and nursing practitioner.
7. The Government should mandate palliative care training for all residential care staff.
8. The Government should allocate seed funding for a pilot programme to be developed that provides training and support for families, whānau, and caregivers.

### **Funding:**

9. The Government should increase targeted funding for providers of New Zealand's palliative care services.

### **Accessibility:**

10. The Government should prioritise palliative care training and support for medical practitioners based in regional New Zealand.
11. Specialist palliative care physicians should utilise technology to increase access to specialist palliative care in regional New Zealand.
12. The Ministry of Health should ensure access to specialist palliative care support as a minimum requirement for all New Zealand hospitals.
13. The Government, medical and nursing schools, and palliative care providers should work with important Māori stakeholders (such as Māori social service providers and local iwi) to listen, learn, and reduce cultural barriers to palliative care.
14. The Government should incentivise an increase in the Māori palliative care workforce.
15. All providers of palliative care should consider implementing the appropriate recommendations outlined in "Mauri Mate: A Palliative Care Framework for Hospices."
16. Palliative care providers should seek to fulfil the "six critical elements" of culturally sensitive palliative care services.

Death may be inevitable for all of us, but bad deaths don't have to be. Giving all New Zealanders access to high quality palliative care services must be a priority. Urgent changes are needed so that all New Zealanders—no matter their postcode or cultural background—have access to this care. The recommendations we outline are an important step toward overcoming rapidly increasing demographic challenges. Most importantly, however, these changes will ensure that every New Zealander has the best chance of a good death, when the time comes.

## 1. INTRODUCTION

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COVID-19 has brought death and dying into our living rooms in a way this generation has never experienced before. Images of overcrowded Intensive Care Units, burgeoning mortuaries, and an ever-growing death toll have been stark reminders of medicine's ultimate inability to stave off death. Whether the cause of death is COVID-19 or something else, death is inevitable for all of us. A good death, however, is not. In spite of the care, expertise, and knowledge now available, bad deaths are unfortunately all too common for many New Zealanders.

It has been said that the mark of a civilised society lies in how it cares for its most vulnerable members.<sup>5</sup> Palliative care is provided when a person is at their most vulnerable and has a life-limiting or life-threatening illness. Palliative care that is well resourced and available to all New Zealanders regardless of where they live, therefore, is essential to provide the best opportunity for a good death.

The case for palliative care is a key focus for this discussion paper, which begins with a brief discussion of what "normal" dying looks like. This is followed by a discussion about what palliative care is, who provides it, and the undeniable benefits (including its impact on quality of life, quantity of life, and financial cost). This is essential for understanding palliative care as more than a medical sub-specialty and instead, a fundamental service for caring for the wellbeing of New Zealanders. As best-selling author and surgeon Atul Gawande notes:<sup>6</sup>

*We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way.*

This paper reviews the gaps in the current provision of palliative care services that need to be addressed. The increasing needs of New Zealand's rapidly ageing population in particular, means that attending to the provision of, and access to, palliative care services in New Zealand has never been more important. Moreover, the significant changes in New Zealand health with the implementation of the End of Life Choice Act and the health system reforms further emphasise the need to ensure that palliative care is acknowledged as a crucial

component of healthcare. Failure to do so will result in increasing numbers of New Zealanders experiencing bad deaths in part due to a poorly prepared and under-resourced healthcare system.

This paper also outlines five key areas of the palliative care system that require amending to ensure that all New Zealanders have access to good palliative care: governance and strategy; public awareness; training; funding; and accessibility. These key areas cover the major systemic questions and concerns surrounding the provision of, and access to, palliative care in New Zealand and include a series of recommendations to address the gaps we currently see.<sup>7</sup> To ensure we all begin at the same place, we will first consider the process of normal dying.

## 2. NORMAL DYING

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Most people rarely consider what normal dying looks like. Conversations around death and dying generally focus on the things we're afraid of; the difficult, heart-wrenching and headline-grabbing stories that we're most likely to hear. As tragic as these stories are, they do not reflect the way that most people die. Any policy conversation about the nature of dying or care for people at the end of life requires a common understanding of what normal dying is like (bearing in mind that dying rarely feels "normal" for those witnessing it). One way to achieve this is through story.

Kathryn Mannix was a pioneer of palliative medicine, working in the specialty for over 30 years in the United Kingdom (UK). In 2018, her first book *With the End in Mind; Death, dying and wisdom in an age of denial*, was published and shortlisted for the Wellcome Book Prize.<sup>8</sup> Through a series of stories of her own experiences Kathryn outlines the process of normal dying in the hope of minimising the fear many people feel. The extract below is an especially compelling and important example of this. It allows the reader to learn alongside Kathryn as she, as a young doctor, listens to her superior explain dying to patient Sabine.<sup>9</sup>

*Sabine was delighted to see [our lead doctor]. He greeted her in French, and asked her permission to sit down. She sparkled and patted the bed, indicating where he should sit. [...]*

*'You have been worrying about what dying will be like, and whether it will be painful for you?'*

*'Yes,' she replied. I was startled by his direct approach, but Sabine appeared unsurprised.*

*'And you have been worrying that your courage may fail?'*

*Sabine reached for his hand and grasped it. She swallowed, and croaked. 'Oui.'*

*'I wonder whether it would help you if I describe what dying will be like,' he said, looking straight into her eyes. 'And I wonder whether you have ever seen anyone die from the illness that you have?'*

*If he describes what? I heard myself shriek in my head. [...]*

*'So let's talk about your illness,' said our leader. 'First of all, let's talk about the pain. Has this been a very painful illness so far?'*

*She shakes her head. He takes up her medication chart, and points out to her that she is taking no regular painkillers, only occasional doses of a drug for colicky pain in her abdomen.*

*'If it hasn't been painful so far, I don't expect it to suddenly change character and become painful in the future. But if it does, you can be sure we will help you to keep any pain bearable. Can you trust us to do that?'*

*'Yes I trust you.'*

*He continues, 'It's a funny thing that, in many different illnesses that cause people to become weaker, their experience towards the end of life is very similar. I have seen this many times. Shall I tell you what we see? If you want me to stop at any point, you just tell me and I will stop.'*

*She nods, holding his gaze.*

*'Well, the first thing we notice is that people are more tired. Their illness saps their energy. I think you are already noticing that?'*

*Another nod. She takes his hand again.*

*'As time goes by, people become more tired, more weary. They nod to sleep more, to boost their energy levels. Have you noticed that if you have a sleep during the day, you feel less weary for a while when you wake up?'*

*Her posture is changing. She is sitting up straighter. Her eyes are locked on his face. She nods.*

*'Well, that tells us that you are following the usual pattern. What we expect to happen from now on is that you will just be progressively more tired, and you will need longer sleeps, and spend less time awake.'*

*Job done, I think. She can expect to be sleepy, Let's go... But our leader continues talking.*

*'As time goes by,' he says, 'we find that people begin to spend more time sleeping, and some of that time they are even more deeply asleep, they slip into a coma. I mean that they are unconscious. Do you understand? Shall I say it in French?'*

*'Non, I understand. Unconscious, coma, oui.' She shakes his hand in hers to affirm her understanding.*

*'So if people are too deeply unconscious to take their medications for part of the day, we will find a different way to give those drugs, to make sure they remain in comfort. Consoler toujours. Yes?'*

*He must be about to stop now, I think. I am surprised that he has told her so much. But he continues, his gaze locked onto hers.*

*'We see people spending more time asleep, and less time awake. Sometimes when they appear to be only asleep, they are actually unconscious, yet when they wake up they tell us they had a good sleep. It seems that we don't notice we become unconscious. And so, at the very end of life, a person is simply unconscious all of the time. And then their breathing starts to change. Sometimes deep and slow, sometimes shallow and faster, and then, very gently, the breathing slows down, and very gently stops. No sudden rush of pain at the end. No feeling of fading away. No panic. Just very, very peaceful...'*

*She is leaning towards him. She picks up his hand and draws it to her lips, and very gently kisses it with great reverence.*

*'The important thing to notice is that it's not the same as falling asleep,' he says. 'In fact, if you are well enough to feel you need a nap, then you are well enough to wake up again afterwards. Becoming unconscious doesn't feel like falling asleep. You won't even notice it happening.'*

*He stops and looks at her. She looks at him. I stare at both of them. I think my mouth might be open, and I may even be leaking from my eyes. There is a long silence. Her shoulders relax and she settles against her pillows. She closes her eyes and gives a deep, long sigh, then raises his hand, held in both of hers, shakes it like shaking dice, and gazes at him as she says, simply, 'Thank you.' She closes her eyes. We are, it seems, dismissed.*

*The nurse, our leader and I walk to the office. Our leader says to me, 'That is probably the most helpful gift we can ever give to our patients. Few have seen a death. Most imagine dying to be agonising and undignified. We can help them to know that we do not see that, and that they need not fear that their families will see something terrible. I never get used to having that conversation, even though it always ends by a patient knowing more yet being less afraid.'*

*Then, kindly overlooking my crumpled tissue, he suggests, 'Shall we have a cup of tea?'*

While every death takes on a nature of its' own, medical specialists who regularly care for people at the end of life often explain that, like every birth, normal dying (as opposed to sudden, unexpected death) is a process with recognisable steps and stages. Normal dying, as explained by Sabine's doctor, is what the vast majority of people experience. Palliative care is the work of accompanying people through this process, providing care, relief of suffering in all its guises, support for both the individual and their family or whānau, as well as providing specialist care in those cases where there are complex needs and additional support is required.

### 3. PALLIATIVE CARE

Caring for people at the end of life “has been seen as a special form of care for centuries.”<sup>10</sup> Dame Cicely Saunders, however, is appropriately credited with the establishment of modern hospice care through her work at St Christopher’s Hospice in London—an organisation established to care for people who are dying through a holistic model of care, based on the concept of “total pain.”<sup>11</sup> This revolutionary approach not only addressed the person’s physical symptoms, but also looked to “identify the multidimensional needs of patients and their families”, recognising that suffering “encompasses all of a person’s physical, psychological, social, spiritual, and practical struggles.”<sup>12</sup>

Balfour Mount, a Canadian surgeon who had worked with Saunders at St Christopher’s Hospice, coined the term “palliative care” because in French speaking Canada “the English word ‘hospice’ translated [to] ‘poor house’.”<sup>13</sup> Mount used the word palliative because “*palliate* originates from the Greek and translates as ‘to cloak.’”<sup>14</sup> This was considered acceptable because it suggested that the interventions of doctors providing palliative care “are meant to cloak or to prevent from seeing or experiencing pain or other suffering.”<sup>15</sup>

Today, hospices continue to work to deliver palliative care to those people who are nearing the end of life. The delivery of palliative care, however, is now also found in “the wider health-care system including hospitals, long-term care facilities, clinics, primary care settings, and personal residences.”<sup>16</sup> Originally hospice care focused on people with cancer diagnoses. Over time however, “the scope of palliative care [has extended] far beyond people with a diagnosis of cancer to include patients with other chronic life-threatening diseases.”<sup>17</sup>

This section will outline the palliative care approach, the people who provide palliative care—including the different types of care they provide—and the places where palliative care is received.

#### 3.1. The Palliative Care Approach

**Palliative care** is described by the World Health Organisation as:<sup>18</sup>

*an approach that improves the quality of life of patients (adults and children) and their families who are facing*

*problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*

Or, as described by the New Zealand Palliative Care Glossary:<sup>19</sup>

Palliative Care: 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, and
- 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 quality of life.

Palliative care is unique because it attends to the whole person—caring for their psychological, spiritual, and physical health as well as the wellbeing of their family and whānau to promote “a positive and open attitude toward death and dying,” ensuring the persons values and wishes are respected.<sup>20</sup> In practice, this means that a much broader attitude toward care is taken than solely providing medical treatment. This is sometimes referred to as caring for the patient’s “total pain” because while pain relief is an important part of the palliative care approach, caring for other causes of pain such as the emotional, psychosocial, and spiritual needs of the person and their family and whānau are also recognised as essential. That is:<sup>21</sup>

**Psychosocial care** includes the practical aspects of care such as financial, housing, and aids to daily living and overlaps with spiritual care. **Spiritual care** is less easy to define and is subjective and personal. It is generally assumed to include an individual’s beliefs, values, sense of meaning and purpose, identity, and for some people religion. It may also encompass the emotional benefits of informal support from relatives, friends, religious and community groups, and more formal pastoral care.

In New Zealand, similarities with the “total pain” approach in palliative care can be found in the Māori **te whare tapa whā** model of health. The model refers to the image of a house with four walls. If one wall is missing, or there is no connection with the *whenua* (land) as a foundation, the house will fall down. Thus, the model is based on four pillars:<sup>22</sup>

- *wairua* (spiritual well-being),
- *hinengaro* (emotional and mental health),
- *tinana* (physical well-being), and
- *whānau* (family, including extended family, and the wider social system).

As with the palliative care approach, *te whare tapa whā* acknowledges emotional, psychological and spiritual health along with the physical health of both the individual, whānau, and community.

### 3.2. Palliative carers

The practice of palliative care involves both specialist and primary healthcare professionals. The responsibilities and care provided by primary and specialist carers is different, dependent upon the needs and wishes of the patient, as well as the availability of care in that location. As outlined in the 2013 National Health Needs Assessment:<sup>23</sup>

*Specialist palliative care is palliative care provided by [healthcare professionals] 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 [such as hospices and hospital-based palliative care services].*

Specialist palliative care providers work exclusively with patients at the end of life, whether that be in the hospital, hospice, or community setting (or some combination of these). They focus on the complex cases that fall outside the expertise of primary carers, and provide advice and support to primary carers. Some specialist palliative care providers also teach and conduct research to further the speciality of palliative medicine.

**Primary palliative care** on the other hand,<sup>24</sup>

*is provided by all individuals and organisations that deliver palliative care as a component of their service, but whose substantive work is not the care of people*

*who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team.*

Primary palliative care providers then, can include:

- general practitioners (GPs),
- nurses (who have not specialised in palliative care),
- residential care assistants, and
- other medical specialists (e.g. oncologists).

Volunteers, communities, families, and whānau can also contribute to care as informal carers.

As stated by Professor Merryn Gott and colleagues, “only a minority of inpatients with palliative care need will receive specialist palliative care input with the majority receiving care from ‘generalist’ or ‘primary’ palliative care providers who have not received postgraduate education and training specific to palliative care management.”<sup>25</sup> Or, as the 2012 National Health Needs Assessment outlined “around 80 percent of people who die from a life-limiting or life-threatening condition will be cared for by a primary care provider, and around half of these people will be cared for in collaboration with a specialist palliative care service.”<sup>26</sup>

This desired “coordinated palliative care model”, where the workload is delineated between the primary and specialist palliative care providers allows “primary palliative care skills (skills that all clinicians should have) [to be distinguished] from specialist palliative care skills (skills for managing more complex and difficult cases) so that they can coexist and support each other.”<sup>27</sup> This model,<sup>28</sup>

*recognises the important role of the primary (also known as ‘generalist’ or non-specialist’) palliative care clinician, allows increased access to specialist care for those who need it, reinforces existing relationships, increases satisfaction and enhances the skills of all clinicians in palliative care, and potentially contributes to cost control by reducing the number of specialists routinely co-managing cases.*

Most importantly, without a “coordinated palliative care model”, “specialist palliative care clinicians [would be on their own and] never able to care for all patients with palliative care needs.”<sup>29</sup>

### *Advance Care Planning*

Advance Care Planning is an important element of end of life care. It is a process where a person discusses and records their care preferences and goals for the end of life with family and health-care professionals. The hope is that advance care planning will “ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”<sup>30</sup> How this information is recorded can “range from a documented collection of preferences and values to completion of a legally binding advance decision/directive to refuse treatment, or an appointment of an attorney to make decisions on the patient’s behalf.”<sup>31</sup> In New Zealand, the Health Quality and Safety Commission provide advice on advance care planning for both consumers and clinicians, including a guide and form that can be filled out.<sup>32</sup> Carers can later refer to these advance plans to determine the approach and make decisions about care and if the person does not have capacity to make their own decisions.<sup>33</sup>

### 3.3. Locations of palliative care

As noted above, palliative care can also take place in a range of healthcare settings, including hospices, hospitals, residential aged care facilities, and in the persons own home. The care received depends upon the needs and wishes of the patient and their family and whānau, as well as what services are available, and the place of care.

When asked, many people say that they would prefer to spend their last days in the comfort and familiarity of their own home. However, “despite policy initiatives to increase end-of-life care in the community, many older adults will die in hospital.”<sup>34</sup> Hospital palliative care teams play a crucial role in this environment by assisting with difficult decisions, (including “weighing up the risks and burdens versus benefits of treatment options”), supporting advance care planning, advising staff about symptom management, and helping to facilitate “the transition from active treatment to a palliative approach.”<sup>35</sup> It’s important to note, however, that not all hospitals provide this service, and in fact “some hospitals in New Zealand still have *no* specialist palliative care presence at all.”<sup>36</sup> As palliative specialists Kate Grundy and Willem Vink explain, “This is problematic and disappointing and has been allowed to happen because of the lack of a clear [Ministry of Health] directive for [District Health Boards] in this regard.”<sup>37</sup>

Most out-patient palliative care takes place in the person’s own home, supported by community nursing services, General Practitioners, and Hospice services. Residential

aged care facilities play a major role in providing primary care for the residents in their care, many of whom have quite complex needs.<sup>38</sup> Family members also play a significant role caring for their loved one at home with the support of the GP. As Geoffrey Mitchell from the University of Queensland points out, in these locations:<sup>39</sup>

*GPs are in an optimal position to evaluate and assess the needs of caregivers. GPs are usually the first point of contact for patients and their caregivers and generally have an established relationship with the patients with palliative care needs as well as having important contextual knowledge of the family and of the illness.*

## 4. THE CASE FOR PALLIATIVE CARE

In a healthcare system that focusses on a narrative of curing illnesses and injuries as a measure of success, palliative care is often overlooked. Through this narrative, death is seen as an extraordinary event that should be avoided at all costs, rather than something that can be anticipated and prepared for. As a result, referrals to palliative care are often delayed, denying the person, their family, and whānau the support they need.” In reality, the provision and availability of palliative care is much more important: to ensure those people with a life-limiting illness can live as well as possible for as long as possible, and then have as good a death as possible. In fact, palliative care has also been shown to increase life expectancy through improved quality of life, and studies suggest that rather than increasing health costs, palliative care can in fact reduce healthcare expenditure.<sup>40</sup> This section will discuss each of these points in turn.

### 4.1. Dying Well

As mentioned above, death and dying is something most people are reluctant to talk about in polite conversation. And yet, the nation-wide interest and conversation in the lead up to the 2020 referendum on the End of Life Choice Act centred on the desire for New Zealanders to have good deaths.<sup>41</sup>

Like pain, measuring a “good death” is variable and subjective. What one person considers a “good death” may, for someone else, be considered unacceptable. As a result, a conclusive definition of a good death is incredibly difficult, if not impossible, to determine. There are, however, consistent markers that can be identified as important features of good end of life care.

As the research of Jane Phillips and David Currow shows, “for the past 25 years, people with palliative care needs and their families have consistently reported what matters most to them in terms of end of life care.”<sup>42</sup> These things are:<sup>43</sup>

- effective communication and shared decision making,
- expert care,
- respectful and compassionate care, and

- trust and confidence in clinicians.

Academics Karen Steinhauser and Nicholas Christakis also found a series of themes considered important for a good death: “pain and symptom management, clear decision making, preparation for death, and completion,” as well as “contributing to others and affirmation of the whole person.”<sup>44</sup> Each are important facets of good palliative care.

Suzanne Rainsford, of Australia National University, and colleagues found that feeling safe and having high levels of trust in carers is essential to a good death.<sup>45</sup> Dying in a ‘safe place’, however, did not necessarily equate to dying at home.<sup>46</sup> When care needs are complex and trust and safety cannot be guaranteed “a home death is not essential for, and does not ensure a ‘good death.’”<sup>47</sup> In these situations in-patient hospice care, or if that is unavailable hospital based palliative care, can become a safe space.

People involved in the provision of palliative care have openly shared their belief that the availability of palliative care is a fundamental component of a good death—especially when the person has complex medical issues or has struggled with significant pain. A number of best-selling books written by palliative care specialists discuss the power of palliative care in a wide range of medical circumstances.<sup>48</sup> American palliative specialist Dr Ira Byock, for example, is the author of three books on death and dying and the urgent need for good palliative care to help manage difficult deaths.<sup>49</sup> As he states, “Dying is hard, but it does not have to be *this hard*.”<sup>50</sup>

All of these factors need to be taken into consideration, however, palliative care can play a central role in minimising the difficulty of dying.

### 4.2. Quality of Life

In spite of the difficulty of measuring a “good death”, research has increasingly linked good quality of life in patients diagnosed with cancer to early referral to palliative care services. Medical doctors Kate Rowland and Sarah-Anne Schumann, for example, found that change in quality of life was the primary outcome when comparing metastatic cancer patients who were referred early to palliative care with those who only received standard oncology care.<sup>51</sup> Another study compared cancer patients with early referral to palliative care

with those who received standard care and had similar findings. They state:<sup>52</sup>

*Most studies show that there is a deterioration in the quality of life over time, which is consistent with the results in the standard care group in our study. Despite similar cancer therapies in our two study groups, the patients assigned to early palliative care had an improved quality of life, as compared with those receiving standard care.*

As palliative medicine researchers Lukas Radbruch and Birgit Jaspers explain, “prevention and relief of suffering and improvement of quality of life are considered as central goals of palliative care.”<sup>53</sup> Therefore, while “adaptation takes time, and even experienced palliative care staff often underestimate the amount of time patients and caregivers need to adapt to a new situation”, quality of life at the end of life is very possible and even “patients with severe cognitive or physical impairments may report high quality of life, if they have had time to adapt their hopes and expectations to the present situation.”<sup>54</sup>

### 4.3. Life Expectancy

Patients receiving palliative care are generally deemed to be (approximately) within the last twelve months of life. Increasingly, however, studies are finding “evidence to suggest that palliative care not only enhances quality of life—in some cases, such as lung cancer and end stage breathlessness, it can even extend life.”<sup>55</sup> A 12-week study from the medical department at the University of Chicago, for example, compared patients with metastatic lung cancer referred to palliative care shortly after diagnosis with patients who received standard oncology (cancer) care. A key finding of the study was that patients with lung cancer who receive palliative care shortly after diagnosis live longer.<sup>56</sup> This finding is supported by a study from Massachusetts General Hospital which found that “patients receiving early palliative care had less aggressive care at the end of life but longer survival.”<sup>57</sup> Or as New Zealand based palliative specialists Kate Grundy and Willem Vink put it, “Palliative care teams have been shown to improve quality of life for patients with advanced cancer, and in a recent study, to extend survival.”<sup>58</sup>

### 4.4. Financial Cost

End of life care is expensive, especially when it includes hospitalisation. It is the period of time where a person is most likely to require medical care and intervention. “Estimates from the United States indicate that 25% of health-care expenditure is related to patients in their last year of life. In the United Kingdom, it is estimated that approximately 20% of hospital bed days are taken up by end of life care.”<sup>59</sup> Studies show, however, that palliative care can have a significant impact in reducing the financial cost of an individual’s healthcare at the end of life. An Australian study found that “involvement from palliative care was associated with significantly lower hospital costs in the order of \$5000-8000 (Australian dollars) for all patient groups, but most particularly for non-cancer diagnoses.”<sup>60</sup>

Reduced financial costs of palliative care are due to less interactions with the hospital, fewer hospital admissions, and less high-tech interventions. That is,<sup>61</sup>

*Research across high-income countries has consistently demonstrated that people who receive palliative care compared with those receiving usual care have less hospitalisations, shorter lengths of hospital stay, reduced use of intensive care units, and fewer emergency department visits. Cost savings from palliative care interventions occur across a number of settings including delivery at home, in hospital, and in residential aged care.*

A study from the United States also found that “an in-home palliative care programme” amassed “significantly lower costs [...] relative to the usual care control group.”<sup>62</sup> In fact “total costs were on average US\$7552 (at 2002 prices) lower for the in-home palliative care group over the study period, even after adjusting for a shorter survival period.”<sup>63</sup> The case for palliative care, therefore, is not limited to improved quality of life and increased life expectancy, but will also result in reduced health costs.

## 5. THE CONTEXT FOR PALLIATIVE CARE IN NEW ZEALAND

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Determining funding and changes to public health care is always an important and often difficult conversation. With a finite budget and so many different priorities to consider it is important to note why improvements to the palliative care system in New Zealand is an important conversation to be having right now. This section, therefore, will outline the current use and availability of palliative care in New Zealand and how this compares internationally, before outlining New Zealand's ageing population and correlating increased need for palliative care, the introduction of the End of Life Choice Act, and finally changes to the New Zealand health system. Considered together it becomes clear that amendments to New Zealand's palliative care system are not simply a good thing to do, but imperative.

### 5.1. A brief international comparison of New Zealand's provision of palliative care

In 2015 the Economist Intelligence Unit released the second edition of its Quality of Death Index.<sup>64</sup> The Index measures the quality of palliative care in 80 countries from around the world, basing rankings on income as a predictor of the availability and quality of services. With an overall rank of third (following the United Kingdom and Australia) New Zealand is described as having "excellent facilities and a qualified workforce."<sup>65</sup> While the 2020 instalment of the Index is due to be released and these rankings may shift, it is worth noting that the Index report also points out that "it should not be forgotten that for most countries—even those that occupy the highest ranks of the Index—much work remains to be done to ensure that those in need of care are not neglected."<sup>66</sup> For example, New Zealand has a lack of advanced palliative care trainee positions, an impending workforce shortage, and a variability in the provision of palliative care services throughout the different regions.<sup>67</sup>

Moreover, New Zealand's shifting demographics have led to increasing concerns about the capacity of palliative care for the growing number of people who will need it and the urgent need for changes to be made. Jane Phillips and David Currow discuss the Australian context, where palliative care receives significantly more government

funding to support service development than New Zealand, in the 2019 *Textbook of Palliative Care*.<sup>68</sup>

*The WHO has an aspirational goal that 80% of all people who die from cancer and 60-80% of people dying from HIV/AIDS should be seen by a palliative care service, but this is rarely achieved, regardless of the country's economic status. Even in a high-income country like Australia, with universal health coverage and where palliative care services are well developed, many people who would benefit from this type of care do not have access to it ... Without significant public policy reforms, reorientation of health care services and additional incentives to address the unmet palliative care needs of underserved populations, the situation will rapidly worsen.*

New Zealand's palliative care services, like Australia, might fare well when compared internationally. And yet, as we will discuss, due to unavailability, lack of awareness, inaccessibility, and low workforce capacity, many people do not receive the palliative care services they need.

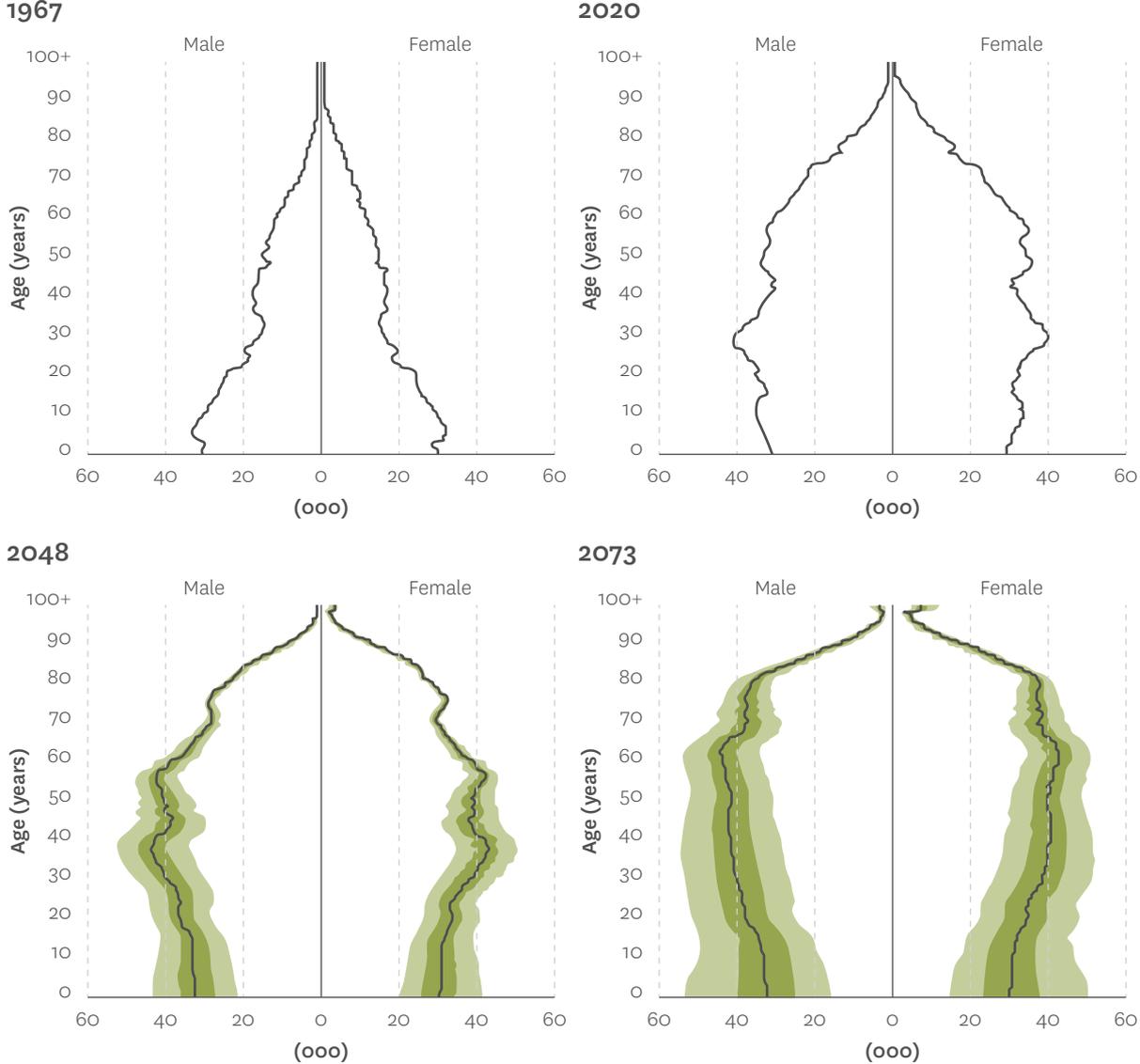
### 5.2. New Zealand's ageing population

It is no secret that, due to "declining fertility, the ageing of the baby boom generation and an increase in average life expectancy", New Zealand has an ageing population that is putting increasing pressure on the health system.<sup>69</sup> This means that in the coming years we will increasingly see New Zealand's demographic shift, with a rise in the population of those aged 65 and over, as well as those aged 85 and over. According to Statistics New Zealand:<sup>70</sup>

- In 2020 there were 88,000 people aged 85 and over,
- By 2048 their projections expect this number to more than triple to somewhere between 266,000 and 318,000 people, and
- By 2073 they expect this number to almost quadruple to somewhere between 348,000 and 513,000 people.

This significant shift in the population structure can be seen in the population pyramids below.

Figure 1: New Zealand Population Pyramids Historical and Projected 1967, 2020, 2048, & 2073



Source: Statistics NZ

The impact of this ageing population on palliative care needs is concerning and requires urgent attention. In 2011 a National Health Needs Assessment was conducted for palliative care in New Zealand. At that time there were already concerns regarding the increase in the number of adult deaths where palliative care may be of benefit.<sup>71</sup> The 2011 palliative care workforce service forecast projected that “the demand for palliative care services, and thus workforce, will increase slowly over the next ten years, but thereafter will increase more rapidly in line with the ageing population,” that “the number of deaths and palliative patients will nearly double by 2061,” and

that “the number of people requiring palliative care will increase by nearly 25% over the next 15 years and will be just over double that by 2061.”<sup>72</sup>

Updated assessments continue to support this estimate of palliative care need in New Zealand. In her 2016 report to the Ministry of Health, actuary and health economist Heather McLeod outlined comprehensive projections on the ageing population, deaths, and palliative care need over the next 50 years. In this work she expects “total deaths [to] rise from 30,300 a year in 2016 to 55,500 in 2068, an increase of 83%.”<sup>73</sup> From this, and (for this conversation) more importantly, “the need for palliative

care rises from 24,400 in 2016 to 46,700, an increase of 92%.<sup>74</sup> Over the next 20 years the projections are slightly less extreme—although still incredibly concerning—with “the number of deaths needing palliative care projected to increase from 24,680 in 2016 to 37,286 by 2038, an increase of 51.0%.<sup>75</sup> This 20 year increase, by region, is seen in Figure 2 below.

The impact of this fast approaching and rapid increase in need for palliative care has significant implications—for the medical workforce, for hospitals, for residential care, for Hospices, and for society more generally. It will require a significant increase in the capacity of the health workforce to provide palliative care, a shift in approach so that hospitals and residential care facilities can appropriately provide sufficient palliative care, an increase in need for Hospice services, and greater awareness and support for communities, families, and whānau to care for loved ones at the end of life. In 2020, for example, Hospice New Zealand’s records show that they supported 10,374 people who died.<sup>76</sup> With 20-year projections (now just 17 years away) expecting 37,286 people will require palliative care services before death, our preeminent palliative care provider is a long way off.

As outlined in the Health Select Committee report on the petition of Helen Morgan,<sup>77</sup>

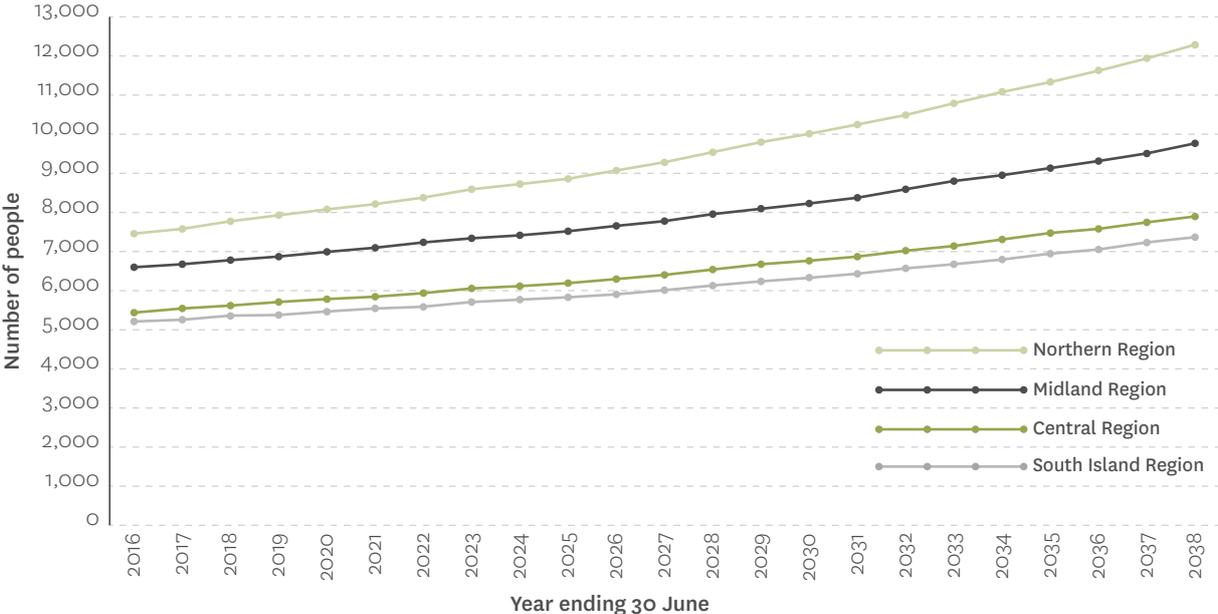
*More people are dying in their homes, either by choice or necessity. Home is often a person’s preferred place of death, particularly when they are supported by their family. More elderly people are also becoming in-home carers for others at the end of their life. The increase in people dying, and dying at home, puts more pressure on existing palliative care services. The ministry said there has been a move to supporting people at the end of life at home. However, it acknowledged that this shifts pressure onto families to manage complex issues.*

If New Zealand’s palliative and end of life care services are not sufficiently equipped to handle the coming “tsunami of people” in need described by the Health Committee, the consequence will be a rapid and significant increase in families and whānau overwhelmed by the care required as well as in the number of New Zealanders who experience a “bad death.”<sup>78</sup>

### 5.3. The End of Life Choice Act

Following an almost four-year parliamentary process followed by a referendum in the 2020 national election, the End of Life Choice Act comes into force on 7 November 2021.<sup>79</sup> This legislation will legalise euthanasia and assisted suicide in New Zealand, allowing medical practitioners to actively assist a person who fits certain criteria to die.<sup>80</sup> The introduction of this legislation

Figure 2: Projected Need for Palliative Care by Region, 2016 to 2038



Source: McLeod, The Need for Palliative Care in New Zealand

unavoidably impacts and will interact with the role of palliative care in New Zealand. Therefore, it is wise to be mindful of the implications in jurisdictions where similar legislation is already in practice and to ensure that palliative care is not forgotten in the midst of building something new.

Federal assisted dying legislation came into force in Canada in 2016.<sup>81</sup> In 2020 palliative care physicians outlined their concerns about the practice and impact of assisted dying legislation in Canada through an article published in the *World Medical Journal*.<sup>82</sup> They state that while assisted dying legislation “positioned euthanasia as a health care right” and therefore is “publicly funded and accessible to all Canadians”, palliative care has “not [been] afforded a similar status and there is no similar requirement for it to be funded and equitable to Canadians.”<sup>83</sup> They state that the introduction of assisted dying is taking away from palliative care resources and believe that the two practices should remain separate due to the distinct nature of their goals and procedures and therefore “it is in the best interest of patients, their families, and the teams themselves.”<sup>84</sup>

Concerns about the impact of legalised assisted dying existing alongside palliative care services are not unique to Canada. A recent study exploring the impact of assisted dying legislation on palliative care services in jurisdictions where it has been legalised (Flanders, Belgium; Oregon, USA; and Quebec, Canada) found there was “an overarching concern [of] a lack of public knowledge, recognition, and understanding of appropriate palliative care, as well as access to it.”<sup>85</sup> For example, participants from Oregon “expressed concern that palliative care was not given as much public attention as assisted dying, which distorted the reality on the ground in terms of the numbers opting for assisted dying versus those in receipt of palliative care.”<sup>86</sup> Moreover, in Flanders, Belgium “there were concerns raised that the current medical system allocated too little time and effort to the psychosocial and spiritual aspects of suffering, that palliative care was not always raised as an alternative, and that euthanasia increasingly rests on the principle of autonomy rather than being anchored in a holistic or beneficent practice of medicine.”<sup>87</sup>

Amidst these concerns, palliative care physicians continue to argue that the legalisation of assisted dying is unnecessary. They argue that the practice and provision of good palliative care can address the vast majority of

concerns and reasons for being assisted to die—so long as access to palliative care services is sufficient.<sup>88</sup>

While it is currently unclear exactly what impact of assisted dying legislation will have in New Zealand, the introduction of the End of Life Choice Act should not come at the cost of good palliative care. We know, for example, that assisted dying services in New Zealand will be fully-funded, while in contrast (and discussed further below) palliative care services remain partially-funded.<sup>89</sup> Policy makers now play an important role in ensuring that funding and accessibility of palliative care remain a priority for the New Zealand health system.

## 5.4. Changes to the New Zealand Health System

Changes to New Zealand’s health system bring an opportunity for prioritising palliative care services. In April 2021 significant reforms to New Zealand’s health system were announced by Minister of Health Hon. Andrew Little.<sup>90</sup> The White Paper discussing the reforms explains:<sup>91</sup>

*The case for reform of the New Zealand health system is clear. While the public health and disability system performs well overall by some measures, it has significant and persistent issues in delivering equity and consistency for all. An ageing population, advances in care and a growing burden from chronic disease mean that demand for health services will only grow over decades to come. There are indications that our health system is struggling to keep up with current demand, and that our workforce needs greater support to keep New Zealanders well for longer.*

This reform is about nationalising the health system so that “every hospital can look at a patient’s health needs from a national perspective. For example, if a patient requiring hip surgery can’t get an operation at their local hospital and there’s space for them somewhere else then they’ll be offered the option to go elsewhere.”<sup>92</sup> It includes the development of a new government organisation, Health NZ, to replace District Health Boards (DHBs) in the day-to-day management of the health system, the development of a new Māori Health Authority to “support the Ministry [of Health] in shaping system policy and strategy to ensure performance for Māori,” and to “work in partnership with Health NZ to commission care across New Zealand, ensuring that the

needs and expectations of Māori communities are also centred in design and delivery.”<sup>93</sup> Alongside this, the role of the Ministry of Health will be refocused to “stewarding the health system and providing advice to Ministers on health strategy and policy.”<sup>94</sup> The proposed legislation is currently working its way through the parliamentary process and Minister Little expects these changes to be introduced by July 1 2022.<sup>95</sup>

While the precise outworking and practical implications of these changes are currently unclear, it is clear that this is an opportunity for the Ministry of Health to revisit the role and importance of palliative care in the New Zealand health system, particularly in regard to the funding it receives to ensure equitable access to high quality palliative care services throughout New Zealand.

## 6. AREAS OF NEW ZEALAND'S PALLIATIVE CARE SYSTEM TO AMEND AND SOME RECOMMENDATIONS

Palliative care is a fundamentally important, yet often-overlooked component of healthcare that is under significant strain from increasing demand and workforce shortages. Significant changes to New Zealand's health system—both through the system changes and the introduction of the End of Life Choice Act—suggest that now is the time to address these issues to ensure palliative care services are accessible for all New Zealanders. We have identified five areas where policy changes could make a difference:

- Governance and strategy,
- Public awareness,
- Training, support, and education,
- Funding, and
- Accessibility.

Each of these categories is discussed below and outline a series of recommendations to amend the systemic issues they currently pose.

### 6.1. Governance and strategy

End of life care researchers Arno Maetens, Joachim Cohen and Richard Harding, explain the importance of “developing a palliative care policy.”<sup>96</sup> They explain that “a first essential element of a comprehensive approach [to public health] is to develop appropriate palliative care policies.”<sup>97</sup> They also recognise that this “policy can take many forms” including being “a stand-alone policy, part of a national health plan, or an element of a national NCD, HIV/AIDS, or cancer control strategy.”<sup>98</sup> New Zealand has the key markers of palliative care policy. However, with key documents not updated since 2001 or 2017 these are out of date, or as seen in the “Access to End of Life Palliative Care Bill” remain in a draft state.<sup>99</sup> Yet, as the 2015 Quality of Death Index explains “even in countries that have broad access to high-quality services, the interplay of policy, legislation and training remains critical if service provision is to meet rising demand for care.”<sup>100</sup>

#### 6.1.1. Strategy

In 2001 the Ministry of Health produced New Zealand's first Palliative Care Strategy. It casts a vision that:<sup>101</sup>

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

With an expected timeframe of 2000-2010, this Strategy was focused on establishing palliative care services in New Zealand and set “in place a systematic and informed approach to the future provision of palliative care services.”<sup>102</sup> It outlines nine key strategies:<sup>103</sup>

- Ensure access to essential palliative care services,
- Each DHB to have at least one local palliative care service,
- Develop specialist palliative care services,
- Implement hospital palliative care teams,
- Develop quality requirements for palliative care services,
- Inform the public about palliative care services,
- Develop palliative care workforce and training,
- Ensure that recommendations from the paediatric review are implemented, and
- Address issues of income support.

In 2017, the Ministry of Health released their findings on a Review of Adult Palliative Care Services in New Zealand followed by a supporting Palliative Care Action Plan to “provide a structured approach” in responding to the issues outlined in the review.<sup>104</sup> The Action Plan provides a practical approach to the five priority areas outlined by the Review, and outlines a series of actions the government will take to:<sup>105</sup>

- Respond to the voices of people with palliative care needs and their families and whānau,
- Ensure strong strategic connections,
- Improve quality in all settings,
- Increase emphasis on primary palliative care, and
- Grow capability of communities and informal carers.

These documents sit alongside mentions in a few other Ministry of Health produced strategies and action plans to make up New Zealand’s official strategy and policies regarding its palliative care services.<sup>106</sup>

The importance of strategies, action plans, and national policies for palliative care are recognised in health policy literature. In the 2015 Quality of Death Index “the presence and effectiveness of government policies” were one of the facets used to weight the quality of death and effectiveness of palliative care in different countries.<sup>107</sup> Therefore, while these documents should be viewed as important and a positive move toward progressing accessibility to palliative care for all New Zealanders, it is also important to note that despite significant demographic and medical shifts no new and updated palliative care strategy has been produced. Moreover, despite the Action Plan stating that it “focuses on the short term (2017-2018)”, and an expected timeline of 2001-2010 for the Strategy, neither an updated Action Plan nor an updated Strategy have been produced.<sup>108</sup>

***Recommendation 1: The Ministry of Health should evaluate the progress of the 2017 Palliative Care Action Plan’s priorities and produce an updated Palliative Care Strategy and Action Plan.***

Following a worldwide pandemic and demographics that have shifted since the writing of both the Palliative Care Strategy and Palliative Care Action Plan, it is important that both documents are revised by the Ministry of Health. The upcoming changes to the New Zealand Health System further date the current documents and provide an opportunity to revise for the coming challenges of providing palliative care in New Zealand. This work should begin by assessing the progress that has already been made to meet the priorities outlined in current policies and plans (in particular the 2017 Palliative Care Action Plan), and if these have not been met outline the barriers and potential solutions.

### *6.1.2. Parliament and legislation*

In August 2012, former Member of Parliament Maggie Barry announced “the formation of an All Parliamentary Group on Palliative Care.” It was “established in partnership with Hospice NZ and the palliative care sector [and] will be modelled on similar ones internationally, including the UK All Party Parliamentary Group on Dying Well.”<sup>109</sup> In her statement upon the formation of the group, the MP said that she “intends this to be a group that can work constructively, across party lines to focus on improving the quality of life for those with life-limiting conditions.”<sup>110</sup> With its founding member now a former Member of Parliament, it is unclear whether this group still exists, who its members are, and what it continues to do.

In April 2021 Parliament’s Health Committee released its report on the petition of Helen Morgan: Establish an in-home palliative care package.<sup>111</sup> The petitioner had cared for both “her mother and sister-in-law at the end of their lives” and found that there was a “lack of information and basic supplies” when caring for someone at home.<sup>112</sup> She requested “that the [Ministry of Health] create a comprehensive in-home palliative care pack to assist non-medically trained carers of people who die at home.”<sup>113</sup>

The Private Member’s Bill “Access to End of Life Palliative Care Bill”, owned by National party MP Simon O’Connor, currently sits in the Private Member’s Ballot awaiting an opportunity to be debated.<sup>114</sup> As outlined in the Bill’s explanatory note, it “aims to ensure the geographically equitable provision of professional, high-standard specialist palliative care and appropriate support services, regardless of whether they are provided at home, in a hospital, in a hospice, or in an aged care residential facility.”<sup>115</sup> As is also outlined in the Bill’s Explanatory Note, it is based on palliative care specialist and member of the United Kingdom’s House of Lords, Baroness Iora Finlay’s “Access to Palliative Care and Treatment of Children Bill.”<sup>116</sup>

Each of these parliamentary actions have the goal of positively impacting palliative care policy in New Zealand. Each of these actions, however, are also either stalled, remain in draft form, or have merely resulted in a formal encouragement for the Ministry of Health, DHBs, and Hospice New Zealand to support, equip and inform those people caring for loved ones at the end of life.<sup>117</sup> In contrast, public information on the UK parliament’s

All-Party Parliament Group on Hospice and End of Life Care members and meetings are regularly updated and the UK's "Access to Palliative Care and Treatment of Children Bill" is currently making its way through their parliamentary process.<sup>118</sup>

**Recommendation 2: Parliament should maintain the All Parliamentary Group on Palliative Care and ensure information on its members and meetings are publicly available.**

All Parliamentary Groups can be an effective tool of promoting a bipartisan issue, as well as ensuring that policy and parliamentary attention to the issue is maintained. With the forecasted increase in demand for palliative care, it is vital that this work continues regardless of whether an individual remains in office. Moreover, there should be publicly accessible information regarding the work of this group to reassure New Zealanders that our politicians do indeed care about all of its people through to the very end of life and into bereavement.

### 6.1.3. Data collection and reporting

Data collection and reporting is essential to the provision of sound public policy. It allows policy analysts and advisors to understand who they are writing policy for and the scope of the need. In 2011 and 2013, the Palliative Care Council of New Zealand released its first and second phase reports of "National Health Needs Assessment for Palliative Care."<sup>119</sup> The second of these reports, however, states that:<sup>120</sup>

*There appear to be a number of inconsistencies in how the survey questions were interpreted or how services defined different aspects of their service and staff. This occurred because there are currently no nationally consistent data definitions or dedicated collections for palliative care data. Data consistency was also affected by services using different data management systems, and some services had difficulties reporting the requested survey data because they did not have a specific patient database or were unable to easily extract the requested data.*

**Recommendation 3: The Ministry of Health should collect and report consistent data on the provision and availability of palliative care services in New Zealand.**

While the comments articulated in the National Health Needs Assessment are now nearly a decade old, the situation seems unchanged. The announced changes to the health system, however, present an opportunity to ensure that palliative care policy is best attending to the people and places that require it. Therefore, it is essential that part of this change to the health system includes the collecting and reporting of consistent data on the provision and availability of palliative care in New Zealand.

## 6.2. Public awareness

"All New Zealanders live well, stay well, get well."<sup>121</sup> This is the overarching theme of New Zealand's current health strategy. While this is a good goal for our public health system to aspire to, it ignores a key group of people who are cared for by the health system, and suggests an attitude that ignores dying and the end of life. As the London Royal College of Physicians said in a 2021 resource for end of life care, "This is an area where solutions require changes of attitude and culture. Death should not always be equated with failure, but rather as a natural process."<sup>122</sup> With a rapidly ageing population and an urgent need for an increase in the delivery of palliative care, a shift in attitudes towards dying is required.

A shift in this cultural attitude requires a healthy public conversation about dying and the end of life, which in turn will promote the supports and care available so that those people who need to access them are much more likely to do so.

The central message of Kathryn Mannix's book (mentioned above), *With the End in Mind*, is that we need to get better at talking about dying.<sup>123</sup> Her decades of experience in caring for patients at the very end of life highlighted to her the importance of having healthy conversations about death and dying because the more we hide death away, the less we understand what normal dying looks like, what we should and should not

be afraid of, and what good care looks like through the dying process. Kathryn is not alone in spreading this message. In fact, Hospice New Zealand produced a short animation describing normal dying to “support people to talk about it more, in the hope that they might worry about it less.”<sup>124</sup>

Encouraging conversation like this increases what experts call “death literacy”, or understanding of the dying process and ability to decide on the best care options. As Kerrie Noonan and colleagues explain, “People, and communities, with high levels of death literacy have context-specific knowledge about the death system and the ability to put that knowledge into practice.”<sup>125</sup> Due to the important role that communities, families and whānau often play in caring for loved ones through the dying process, death literacy is “essential for a public health approach to palliative care.”<sup>126</sup>

A 2012 study on New Zealanders’ awareness and knowledge of both palliative care and hospice services revealed that “for many, hospice is still perceived as a ‘place to die’ rather than as a philosophy of care and so people may not seek support from hospices until near the very end of their life.”<sup>127</sup> The study also considered how New Zealand compared internationally in its approach to promoting awareness and found:<sup>128</sup>

*Palliative Care Australia, the national peak body for palliative care has, over the last 13 years, held a National Palliative Care Awareness Week in an attempt to address a perceived lack of understanding and preparedness for death in Australia. In the UK, the Dying Matters Coalition encourages people to talk about death in general and about their wishes toward the end of life in particular.*

At the time the authors found that “No similar initiatives [were] available in New Zealand.”<sup>129</sup> Happily, in the years since, Hospice Awareness Week has been established, however, this is yet to reach the national level conversations seen in Australia and the UK. These kinds of public education campaigns are essential for altering the narrative around normal dying, the role of communities, and the supports available.

#### **Recommendation 4: Hospice New Zealand and the Ministry of Health should work together to promote public awareness of hospice and palliative care in New Zealand.**

Increasing public awareness and promotion of hospice and palliative care is essential. It ensures New Zealanders are aware of the dying process, care and support available, how to access it and are willing to stimulate conversations, and create opportunities to share personal values, goals and wishes in relation to end-of-life care. With their platforms, expertise, and access to government funding, the Ministry of Health and Hospice New Zealand should work together to develop public education campaigns that stimulate public dialogue and address peoples’ questions. This promotion could utilise Hospice Awareness Week for a large-scale national campaign, perhaps following the example of Daffodil Day and its promotion of the work of the cancer society or Dying to Know Day, an annual Australian campaign to “encourage people to start talking about death”.<sup>130</sup>

### 6.3. Training, support and education

In 2017 the Ministry of Health released a forecast of the palliative care workforce.<sup>131</sup> The workforce forecast included the following issues:<sup>132</sup>

- an aging workforce; recruitment and retention of palliative care medicine specialists,
- a shortage of general practitioners with an interest in palliative care,
- a shortage of nurses with specialist palliative care skills,
- confusion over advanced nursing practice in specialist palliative care across clinical settings, and
- a need to define and develop the role of allied health professionals within the multidisciplinary team.

Concerns for the sustainability and provision of a sufficient palliative care workforce have also been raised

by the Australian and New Zealand Society of Palliative Medicine. In a 2010 document outlining the “benchmark number of specialists in palliative medicine,” 1.0 full time equivalent (FTE) palliative medicine specialists per 100,000 people is considered the “minimum number of specialists for a reasonable provision of service.”<sup>133</sup> Following this measure “New Zealand has approximately half the Palliative Medicine Specialists it needs to service its population.”<sup>134</sup> Moreover, when the document was released “many of the currently practicing specialists [were] within 5-10 years of retirement.”<sup>135</sup>

With “the combination of decreasing numbers of specialists, reduced working hours, ageing population and access of all irrespective of diagnosis to palliative care means that the current shortages can only be exacerbated.” Currently there are not enough specialists to do the care, let alone the teaching.

These workforce issues, as outlined in the Palliative Care Workforce Service Forecast, emphasise the importance of further development of palliative care training for both specialist practitioners and primary carers.<sup>136</sup> In fact, as stated by Lis Heath (nee Latta) and Professor Rod MacLeod,<sup>137</sup>

*It is impossible to overemphasise the importance of palliative care education, particularly in light of the changing needs of a rapidly aging population with a high prevalence of non-communicable diseases. In order to be able to provide high-quality care at the end of life and avoid unnecessary suffering, the people who provide that care must be equipped with the necessary knowledge, skills, and experience to be able to do so.*

This section will consider the training and support of palliative care specialists and primary carers—namely: undergraduate medical and nursing students, current medical practitioners, specialist palliative care physicians, residential care staff, and family and whānau.

### 6.3.1. Undergraduate palliative care training

In 2017, the World Health Assembly’s resolution on palliative care called for:<sup>138</sup>

*all governments to ensure that palliative care education is provided at all levels of health professional training including undergraduate, graduate, postgraduate, and specialisation training. Practically this means that basic*

*palliative care curricula should be included in medical and nursing schools, additional course and practicums should be provided during residency and internships, continuing education should include palliative care, and a pathway for specialty or sub-speciality qualification should exist. Further, palliative care content should be included in social work, psychology, and chaplaincy education.*

In spite of this, New Zealand joins most other nations around the world with an undergraduate palliative care curriculum that continues to be insufficient. This is due to insufficient hours dedicated to formal palliative care teaching within the curriculum and minimal clinical experience for students.<sup>139</sup> An interesting parallel exists between birth and death in that while all New Zealanders will eventually die, not all will give birth, and yet undergraduate medical students will receive several weeks’ training in women’s health, compared to approximately one week in palliative and end of life care training across their six-year degree. As the London Royal College of Physicians has outlined, “in medical school curricula, great emphasis is placed on seeing a set number of births and engaging in other procedures—there should be an equivalent for end of life care training.”<sup>140</sup>

This gap also applies to undergraduate nursing programmes. “In a 2012 study that explored NZ nurses’ early experiences of patient death, few nurses felt their undergraduate education had prepared them well for this experience.”<sup>141</sup> Nurses work closely with patients and provide much of the direct patient care for people at the end of life, thus sufficient undergraduate palliative care education is essential in undergraduate nursing programs.

Overcrowding of the curricula is a common and reasonable argument for the minimal hours of palliative care education. As Director of Palliative Care at Townsville Hospital, Queensland Will Cairns, and Director of Post-graduate Studies—Nursing at Queensland University of Technology Patsy Yates state “if the care of people with degenerative and progressive diseases [such as Alzheimers or multiple sclerosis] is an essential facet of practice, rather than just a skill to be learned, then palliative care must be integrated throughout the curriculum.”<sup>142</sup> Moreover, with limited access and availability of clinical experience options available, it is not possible to simply increase students’ clinical exposure to palliative care

services. Therefore, all healthcare professionals need to be familiar with how to integrate a palliative care approach in their practice, so this can be modelled for students in all healthcare settings.

***Recommendation 5: The Government should mandate at least 72 hours of undergraduate palliative care training in the course of a medical or nursing degree as well as additional clinical experience.***

Increasing and mandating the minimum time students spend interacting with palliative care in their undergraduate training will ensure that they are much better prepared to appropriately care for many of their patients. Moreover, greater interaction with palliative care in undergraduate courses will likely increase the number of students choosing to specialise in palliative care, therefore also reducing the impact of an ageing sub-specialty, workforce shortage, and ageing population. EDUPALL, an Erasmus project to develop an undergraduate palliative care curriculum has recommended a minimum of 72 hours undergraduate palliative care training in addition to clinical experience—perhaps in a local hospice or with a hospital-based palliative care team.<sup>143</sup> Ideally, more than 72 hours of undergraduate palliative care training would take place, however, this should be a mandated minimum requirement for every New Zealand medical school.

### *6.3.2. Palliative care training and support for all medical and nursing staff*

While New Zealanders may not be very good at talking about dying, a consistent prognosis is that every New Zealander will eventually die. In fact, a 2013 census carried out at Auckland City Hospital indicated that 20% of hospital inpatients met the criteria for palliative care need.<sup>144</sup> As a result, throughout their career all medical and nursing staff – no matter their area of specialisation and expertise – will have patients that require palliative care and a primary carer.<sup>145</sup> To ensure every New Zealander has access to good palliative care all medical and nursing staff require sufficient training and education.

As discussed above, not all patients will have the complex needs that require specialist palliative care. Moreover, specialist “palliative care professional skills are scarce, and in many cases, the best strategy is to use these to encourage other care professionals to adopt a palliative care approach.”<sup>146</sup>

Providing good and appropriate palliative care can be complex and so training and support are required. In fact, “education and training has been cited as crucial for helping generalists develop the skills required to identify and address needs and the confidence to introduce a palliative approach or seek specialist input, thus ensuring patients have timely access to the appropriate level of support.”<sup>147</sup> A 2018 study by the London Royal College of Physicians reports that while “conversations around prognosis, palliative care and end of life care [...] are important for improving patient experience” “many physicians still find these conversations difficult.”<sup>148</sup> Research from New Zealand produced similar results, with findings showing that “despite increased education and teaching in palliative care, junior doctors still report that this is the area in which they feel most unprepared and which causes them the greatest distress.”<sup>149</sup>

One attempt to better support medical and nursing staff in their role as primary palliative carers was through the Liverpool Care Pathway (LCP), “an integrated pathway approach to the care of people who are dying... developed in the United Kingdom in the 1990s.”<sup>150</sup> The LCP aimed to support primary carers with guidance through materials and training on “comfort measures, anticipatory prescribing of medications, discontinuation of interventions no longer necessary, psychological and spiritual care, and care of a dying person’s family/whānau, both before and after the person’s death.”<sup>151</sup> In 2005 the LCP was introduced in New Zealand, however, less than ten years later “an independent review of the LCP in the United Kingdom identified a number of problems with the model, and recommended that it be replaced by individual care plans for each individual patient.”<sup>152</sup> The LCP “seemed to work well in settings where it was operated by well-trained, well-resourced, and sensitive clinical teams. But when used without much attention, as a tick box exercise, it runs the risk of not showing enough respect to patients.”<sup>153</sup> The pathway was eventually discontinued in the UK and, after conducting a local review, New Zealand promptly followed suit.<sup>154</sup>

The UK responded to the failures of the LCP with the Gold Standard Framework (GSF), with the same intention of improving primary palliative care with a “three-step approach based on early identification, better assessment of clinical and personal needs, and focused planning and coordination.”<sup>155</sup> In New Zealand, the GSF indicators have been used to help inform guidelines about when to refer a patient to specialist Hospice and palliative care services.<sup>156</sup> These indicators are intended to assist non-palliative specialists with early identification of patients who would benefit from palliative care, as research shows this is likely to have better long-term results.<sup>157</sup>

The downfall of the LCP also resulted in the Ministry of Health’s development of “Te Ara Whakapiri: Principles and guidelines for the last days of life” to outline “the essential components and considerations required to promote quality care at the end of life for all adults in New Zealand.”<sup>158</sup> It was not developed as “a care plan in itself but serves as a foundation document for all policies and procedures concerned with care at the end of life and for all education initiatives.”<sup>159</sup> The corresponding “toolkit” was developed to “enrich and support delivery of end of life care throughout the country” by helping health care professionals to “make regular assessments that include reflection, review and critical-decision making in the best interest of the person they are caring for.”<sup>160</sup> If high-quality palliative and end of life care is to be provided by primary carers, however, there is a need for improved education and support about how to integrate a palliative approach to patient care.

Ongoing education, with support from specialist palliative care providers plays an important role in equipping healthcare practitioners with the knowledge, skills, and attitudes to be able to provide a high standard of care for all people nearing the end of life, whether they work in surgery, oncology, an emergency department, or residential care. A doctor interviewed for the Economist Intelligence Unit’s 2015 Quality of Death Index explained that “if everyone has palliative care in their basic education, then no one will come out not understanding pain management, how to communicate with patients and families or that psychological, social and spiritual care are part of palliative care, not an optional extra.”<sup>161</sup>

Better palliative training and support for all healthcare professionals allows for a delineation of services, with specialist palliative care providers caring for those people with the most complex needs, while ensuring promoting equitable access to primary palliative care for all New Zealanders.

### *Poi*

Poi (Palliative Outcomes Initiative) is a programme funded by the District Health Board with clinical teams from the local hospices working across the city “to help develop palliative care skills and capacity within residential care and general practice through free packages of coaching and training.”<sup>162</sup> Established by the specialist Hospices of Auckland, having recognised the need for ongoing palliative care training and support for medical practitioners and residential carers,<sup>163</sup> the programme aims to enable clinicians to identify patients with palliative care needs, develop a palliative care plan, and deliver primary care.<sup>164</sup> Their 2020 results show the impact of having a palliative care plan with 83% of people in the Poi programme who lived longer than a month after the development of a palliative care plan not using ambulance or hospital services, only 3% of people in the Poi programme dying in hospital, and only 17% of people in the programme with a palliative care plan using the Emergency Department.<sup>165</sup>

**Recommendation 6: The Government should mandate ongoing professional development in palliative and end of life care for every medical and nursing practitioner.**

To increase workforce capacity and help address the increase in demand for primary palliative care, all medical and nursing practitioners should undergo regular training in palliative and end of life care after their initial qualifications. This will improve confidence, knowledge and skills to provide care alongside an awareness of their role and connection points with specialist palliative physicians. This professional development should also include training in Advance Care Planning, Referral Criteria for Palliative Care Services, and use of Te Ara Whakapiri Principles and Guidance for End of Life Care.

### 6.3.3. Specialist palliative care training

In New Zealand, specialist palliative care training is delivered by the Royal Australasian College of Physicians. The general path to qualifying for this role will follow years of undergraduate study at medical school as well as training in hospitals around New Zealand, and finally, three years of specialisation and qualification resulting in a Fellowship with the Australasian Chapter of Palliative Medicine.<sup>166</sup> This program is nationally-funded and includes a minimum of six months working as a palliative medicine registrar in hospital palliative care to “develop skills in an acute setting.”<sup>167</sup>

### 6.3.4. Palliative care support for additional primary carers

Primary carers such as residential care staff and family and whānau, play an increasingly important role in the provision of palliative care, and should be appropriately supported to do so. This section will consider each group in turn.

#### **Residential Care Staff**

Care assistants in aged residential care facilities play a vital role in caring for residents with complex needs. As the population ages and the demand for residential care increases, the need for care assistants will also grow.

To do this well they require training and support, and yet “unlike their registered nurse colleagues, most care assistants have no formal work-related qualifications”, and “largely rely on their instincts to guide them when caring for people who are dying.”<sup>168</sup> As acknowledged by former Member of Parliament Ruth Dyson at a speech to the 2004 Residential Care NZ Conference, “it is well-recognised that despite the best efforts of many service providers, care workers have for years been undervalued, under-paid and in many cases under-trained for work that is becoming increasingly demanding.”<sup>169</sup> Since then some movement has been made in this space with the nationwide “Fundamentals of Palliative Care” course established by Hospice New Zealand, however, as outlined by Lis Heath and Jean Ross:<sup>170</sup>

*What is concerning is those care assistants who do not access palliative care education. There needs to be significant effort made by policy-makers, aged care facility managers and hospice services to consider how best to meet the need for palliative care education for all care assistants.*

**Recommendation 7: The Government should mandate palliative care training for all residential care staff.**

The Government should require all residential care staff to receive basic palliative care training so that all carers feel equipped to provide the best possible care, understand when to interact with medical practitioners and specialist palliative care services. This training could include the Hospice New Zealand “Fundamentals of Palliative Care” course. All residents should also have a clearly documented Advance Care Plan on admission to the facility.

#### **Family and Whānau**

Significant primary care is also often provided by family and whānau. When “faced with the need to care for seriously ill relatives [this group] also need practical hands-on training in caregiving making it possible for loved ones to remain in the place they call home.”<sup>171</sup> Hospice staff and palliative care specialists play an important role in providing this training, teaching skills

## Violet

Australian social enterprise Violet has seen the need for training and support for caregivers of people at the end of life. By providing “free services, programs and resources to anyone in the community who is caring for someone in the last stage of their life (in either an informal or formal role)”, “the Violet Initiative exists to reduce regretful outcomes in the last stage of life for Australians, their caregivers and their families.”<sup>173</sup>

Recognising that caregivers often slip through the gaps for support until after someone has died and they are in the bereavement process, Violet pays particular attention to supporting this group. To achieve this, Violet trains and supports volunteer Guides who have all had firsthand experience caring for a loved one through the process of dying, to support those caregivers via a series of phone conversations. These will cover concerns like the role of the caregiver, advocating for a loved one, self-care, support and assistance available or necessary, end of life wishes and conversations, and whether they know what lies ahead. There is a wide variety of needs and opportunities for support, and “Violet Guides have supported callers through family conflict, helped them prepare for difficult but necessary conversations and checked in on their mental and emotional well-being.”<sup>174</sup>

specifically needed to care for their loved one and providing support right through to the bereavement period. While a number of groups and organisations exist to provide bereavement support for caregivers, Australian social enterprise Violet is unique in its specific provision of support, training, and by providing a space for questions via volunteer guides and phone consults for those families caring for someone in the final stage of life.<sup>172</sup>

***Recommendation 8: The Government should allocate seed funding for a pilot programme to be developed that provides training and support for families, whānau and caregivers.***

The approach and work of the Violet Initiative is unique and valuable, but not currently available in New Zealand. Establishing an organisation like this would provide personalised support for many New Zealanders coping with and caring for loved ones at the end of their life. An approach of care “for the community, by the community” is likely best provided by a community-based, not-for-profit organisation, however, the Government could play an important role in providing the seed funding for a pilot programme.

## 6.4. Funding

New Zealand has a universal health system that is publicly funded to ensure care is available to anyone who needs it. This includes palliative care services offered by specialist teams in hospitals or primary carers within the public health system. Publicly provided palliative care of this nature was encouraged by a Dr Sheila Payne, emeritus professor at the International Observatory on End of Life Care, who contributed to the Economist Intelligence Unit’s 2015 *Quality of Death Index*. She argued that “to cope with future demand, countries need to embrace the public health model of palliative care and extend palliative care into a broad range of healthcare services.”<sup>175</sup> Dr Payne is not alone in thinking this. Palliative specialists Jane Phillips and David Currow explain that:<sup>176</sup>

*At the macro level, there is an expectation that palliative care is integrated into all aspects of a country’s national health care financing and health system’s structures (i.e. primary and community care, aged and acute care). However, this requires all countries to fund the delivery of palliative care and ensure that everyone who requires it has access.*

In April 2020 New Zealand’s Cabinet approved a funding increase of \$5 million per year to “sustain access to Hospice Specialist Palliative Care.”<sup>177</sup> This increase in financial support for palliative care is significant and a

positive step. It is unlikely, however, to result in the “move towards palliative care for all, in any beds that people are in” that Dr Payne desires.<sup>178</sup> Unlike assisted dying which will be fully funded under the End of Life Choice Act, palliative care services remain partially funded.<sup>179</sup> With a growing population of people aged 65 and over, and stresses already apparent in New Zealand’s provision of palliative care services, targeted funding for New Zealand Hospice services neither removes their need to continue fundraising, nor does it attend to hospital based palliative care services.<sup>180</sup> In fact, news reporting from October 2020 explained that hospice receives about \$78 million in government funding, but with \$155 million required to cover costs each year a further \$77 million is fundraised to make up the shortfall.<sup>181</sup> This is supported by the Hospice New Zealand website which states:<sup>182</sup>

*Everything hospice provides to patients, family and whānau is provided free of charge. As an essential health service provider, hospices receive the majority of their funding from Government; but we do need community support to fundraise the gap between funding and the cost of care. Each year we must raise more than \$77 million nationally through a variety of fundraising activities.*

As New Zealand’s largest provider of specialist palliative care, the same news report suggests that hospice services are the only specialist healthcare service that balance their books with charitable donations and fundraising.<sup>183</sup> Palliative care leaders have described this as surviving on “cakes and op shops.”<sup>184</sup> While I would never expect a surgeon to fundraise for their salary, the true cost of this approach is much bigger. First, fundraising for this amount of money requires a coordinated approach, taking time, focus, and—ironically—money away from the core work of caring for people at the end of life and raising awareness about palliative care. Second, while Hospice New Zealand is the overarching membership organisation, the 33 local hospices around New Zealand are responsible for their own fundraising which results in inconsistent funding.<sup>185</sup> Areas like Ponsonby in Auckland are much more likely to have the financial ability to support their hospice well than, for example, areas of Northland.

An increased need in palliative care will result in a corresponding increased need in funding for palliative care. While any additional funding is positive, there is clearly a need for more. As Stephen Connor of the

Worldwide Hospice Palliative Care Alliance explains, “[t]he ultimate test of whether palliative care is effectively implemented in a country is the willingness of governments to reallocate funding to palliative care, especially in non-hospital settings.”<sup>186</sup> If the government is to take both palliative care services and provision of the best possible care for all New Zealanders right through the end of life and into bereavement seriously then increasing funding, both to New Zealand hospice providers and others working to deliver palliative care services, is an important step forward. Moreover, as discussed above, funding for palliative care services is a likely to result in reduced healthcare costs for people at the end of life.

**Recommendation 9: The Government should increase targeted funding for providers of New Zealand’s palliative care services.**

To continue and strengthen New Zealand’s public health approach to palliative care it is essential that sufficient and targeted funding is available to provide this. Changes to the New Zealand health system are an opportunity to make this a priority. These measures should include:

- Dedicated funding to ensure all New Zealand hospitals have provision for palliative care services,
- Targeted increased funding for Hospice services in areas that struggle to reach sufficient fundraising goals, and
- Overall increased funding for Hospice services so that, rather than costing communities \$77 million in donations each year, palliative care services are free and universally available in New Zealand.

### *The last 1000 days*

Professor Brian Dolan and Lynda Holt developed #Last1000Days and the Today Model “to help draw attention to where and how time is wasted [in hospitals], to reinforce the positioning of patient’s time as the most important currency in health care and to create a sense of urgency.”<sup>187</sup> They argue that time is often wasted in hospitals, which for people in the last 1000 days of life is especially costly. Their model recognises that:<sup>188</sup>

*As nurses, doctors, therapists or other people involved in the patients’ journey through the health system, we strive to do the best by patients on a daily basis. Sometimes we fall short because we are paying attention to the wrong thing – the system and processes we are used to, the way things are currently done and the time scales we have come to accept. By putting patients’ time at the centre of everything, by making it our most important currency, we create a new value system that enables us to pay attention to different things – the things that may get in the way of the care we want to give.*

## 6.5. Accessibility

For many New Zealanders palliative care is not accessible. This is either due to the limitations of access in more isolated and rural areas, or to cultural barriers to palliative care services. This section will consider each of these issues in turn.

### 6.5.1. Rural Accessibility

Many people want to die at home.<sup>189</sup> In fact, dying at home is often tied to how we understand a good death. Yet, for many New Zealanders where they die, as well as the palliative and end of life care they receive prior to death, is dictated by where they live. For those people living in central Auckland or other major centres around New Zealand, for example, palliative and hospice care is generally available. In more remote areas, however, accessibility to good palliative care is less likely to be available.<sup>190</sup>

As outlined in a recent Health Select Committee report, “End of Life care varies by DHB. Variables include whether in-home services, such as bedding, beds, dressings, and other supplies are provided. The [Ministry of Health] acknowledged that variance between DHBs means end of life care at home is not consistent across the country.”<sup>191</sup> This variance isn’t solely an issue for palliative care, and in health policy is colloquially referred to as the “postcode lottery.”<sup>192</sup> That is, those people with a Central Auckland postcode have access to a very different level of care compared to those people with a regional New Zealand postcode.

While this issue isn’t specific to palliative care, it can certainly be seen in the provision of palliative care throughout New Zealand. On the South Island’s West Coast, for example, there is no Hospice building or staff – rather, the Buller West Coast Home Hospice Trust works “to accumulate, manage and distribute funds to support families on the West Coast financially to care for their loved ones with a life limiting illness and are in the palliative stage.”<sup>193</sup> According to the Hospice New Zealand website this means that they:<sup>194</sup>

- “provide support with the free hire of equipment”,
- “work alongside [the] District Health Board to plan Palliative Care for Cancer patients”, and
- “sponsor health professionals with training programmes”, but
- “have no patient contact” themselves, rather taking “requests for assistance from District and Palliative Care nurses.”

While the availability of this service is better than nothing, studies show that people who live in rural areas and require specialist palliative care but have limited choices for that care must either go without or travel long distances to seek “care outside their community” removing the “choice on the location of their death.”<sup>195</sup>

As most people do not have specialist needs, primary carers are obviously pivotal to the provision of good rural palliative care.<sup>196</sup> The need for sufficient training of primary palliative carers in rural areas with limited specialist palliative care available is, therefore, essential.

This allows carers to cater to “the uniqueness of rural communities and the concern that their end of life care programs cannot be modelled after urban counterparts.”<sup>197</sup> Moreover, creative use of technology can be a powerful tool in supporting isolated primary carers or patients with more complex needs. Telenursing, or the use of technology to provide nursing care, for example, has been found to be useful—especially when the ability to travel was limited.<sup>198</sup> In fact, health policy academic Donna Wilson and colleagues suggest that:<sup>199</sup>

*Telehealth could assist local assessment and treatment of pain or symptoms. Urban palliative/hospice care centres should also reach out through traveling clinics, satellite offices, on-call telephone consultations or high-tech options to ensure specialist care and continuing education for rural end of life care through funding websites or other programs.*

**Recommendation 10: The Government should prioritise palliative care training and support for medical practitioners based in regional New Zealand.**

As discussed above, training and support for medical practitioners providing primary palliative care to people in regional New Zealand is essential. This is especially important for those people in rural and remote areas where providing palliative care focused professional development for this group should be a priority.

**Recommendation 11: Specialist palliative physicians should utilise technology to increase access to specialist palliative care in regional New Zealand.**

COVID-19 brought significant challenges to the health care profession, including determining how best to care for patients when unable to travel or meet in person. In the process of determining how best to overcome these challenges technology has proven to be a powerful tool.<sup>200</sup> Transferring this knowledge to the provision of palliative care in rural New Zealand will allow those people who had previously struggled to meet with specialist providers to have more opportunities to receive

care. Moreover, this approach will provide primary carers with increased access to support and guidance from specialist palliative services. In fact, studies show that approaches like “teleconsultation” can “support multidisciplinary care” as communication between primary and specialist carers is increased.<sup>201</sup> The Royal Australasian College of Physicians should assist palliative care specialists in this shift and the Government should ensure sufficient funding of technology infrastructure to enable greater service delivery.

**Recommendation 12: The Ministry of Health should ensure access to specialist palliative care support as a minimum requirement for all New Zealand hospitals.**

While many people would prefer to die at home, the hospital remains a primary place of death for New Zealanders.<sup>202</sup> It is important then, that specialist palliative care services are available in all New Zealand hospitals. This is not currently the case but if it was, we would see increased access to palliative care and a higher standard of care, alongside fewer bad deaths. Dedicated palliative care units in UK hospitals “have led directly to an increase in home death rate, a reduction in deaths in the acute setting, and better integration of community, hospital, and palliative care unit teams facilitating admissions and discharges and have raised the profile of palliative [care].”<sup>203</sup> While the number of small and regional hospitals around New Zealand mean that it is probably not feasible to have a specialist palliative care team in every hospital this would be the preference, and if not access to specialist support and advice is essential.

### 6.5.2. Cultural Accessibility

Limited accessibility of palliative care in New Zealand does not only apply to those people living in rural and isolated areas. As discussed above, hospice care and the palliative approach were first established in the United Kingdom and thus by design is western in its approach. While palliative care specialists are careful to provide

appropriate care for the needs of all New Zealanders, whatever their ethnicity or cultural background, research shows that around the world “indigenous populations are among those least likely to receive adequate [palliative care] services.”<sup>204</sup> Inequitable access to care is endemic throughout the healthcare system.<sup>205</sup> When considering systemic issues of access to palliative care in New Zealand, however, it is essential that cultural accessibility is included.

New Zealand’s ageing population is also reflected in the Māori population, and will result in an increased need for cultural accessibility to palliative care services. As outlined in a 2018 Māori and Palliative Care Report:<sup>206</sup>

*The proportion of Māori deaths relative to the total deaths in New Zealand is expected to remain fairly constant over the next 30 years (10.9% by 2038), however, the Māori population is projected to grow beyond 1 million by 2038. A significant feature of this period is the increasing age at which Māori will die. This may mean an increase in the prevalence of diseases associated with old age, such as dementia, amongst Māori warranting further consideration for the type and appropriateness of palliative care services and supports required in the future by Māori who are dying and their whānau.*

These concerns are not limited to Māori. A study on “addressing palliative care for Pacific populations in Aotearoa/New Zealand” notes that “44% of all deaths among Pacific populations occur among those under the age of 65 years.”<sup>207</sup> As the authors note “this raises the importance of not only having culturally appropriate palliative and end-of-life care services but also ensuring services take account of the younger age at death of Pacific populations.”<sup>208</sup>

When considering systemic issues of access to palliative care in New Zealand, therefore, we must include cultural accessibility. As a result, this section will consider some of the barriers to cultural accessibility of palliative care in New Zealand, before outlining some opportunities and recommendations for overcoming these barriers.

### **Barriers to cultural accessibility**

Cultural differences in the understanding of, and attitude toward, death and dying can result in significant barriers to accessing palliative care for some New Zealanders.

A paper by Elizabeth Johnston Taylor and Shirley Simmonds on the perspectives of Māori on hospice care, for example, shows that barriers to palliative care for indigenous communities include:<sup>209</sup>

*unfamiliarity with what hospice care involves, perceptions of hospices as a place in which to die that costs a lot of money, language barriers, gatekeeping physicians who assumed that members of these groups would prefer not to use hospice services, and fear of discrimination from the predominantly white hospice clinicians.*

They explain:<sup>210</sup>

*Traditionally, for example, many Māori believe that it is spiritually important to die and be buried at one’s ancestral home. Bodies are typically returned to this location if the deceased did not die there. Extended family and friends gather for 3 to 5 days to mourn the deceased at the local meeting house. Those who mourn talk, and even joke or sing, to the deceased to bring closure to their relationship. Mourners may sleep in the large meeting house where the deceased person is lying. At the end of the mourning period, the deceased person is buried.*

*Tikanga*, or traditions and customs, do not only take place after the death but flow right through the dying process. As a result, “perception among many Māori that ‘there are no options given to whānau who want to look after their own’” can be a significant barrier.<sup>211</sup> Moreover, hospitals that are generally unable to cater to large whānau who want to be with their loved one through this process—which can include eating *kai* (food), singing *waiata* (songs), and carrying out other spiritual and cultural ceremonies and practices together—can be a barrier to accessing palliative care services. Additionally, while Māori are diverse and have a variety of experiences and perspectives, study results have found:<sup>212</sup>

*[f]or Māori, there were specific financial costs associated with cultural customs at end of life. Manaakitanga (hospitality, generosity, kindness) of the ill person/turoro and manuhiri (visitors) for example, required not only excellent care of the ill and dying person but also of those who visited them before death.*

Perception of palliative care as *Pākehā* with a lack of Māori presence in most services “undermines Māori confidence

in the ability of hospice and other palliative care service providers to deliver culturally competent care that will meet their needs.”<sup>213</sup> As a result, research has shown a preference for “by Māori for Māori” approaches and “service delivery that involved provision by Māori.”<sup>214</sup> With a “long-standing and enduring under-representation of Māori in the palliative care workforce” it is clear that systemic shifts are necessary.<sup>215</sup>

Important progress has been made by groups like Hospice New Zealand to overcome barriers for Māori. As academic Shaouli Shahid and colleagues note:<sup>216</sup>

*Hospices in New Zealand have tailored their services to meet the needs of Māori patients by increasing flexibility, partnering Māori hospice staff with both non-Indigenous staff and primary health care providers, working closely with families, creating physical space for large families to visit, and regular communication between multiple agencies.*

For Hospice New Zealand this progress is most clearly represented in “Mauri Mate: A Māori Palliative Care Framework for Hospices” (See Appendix for more details).<sup>217</sup> This framework was launched in 2020 with the goal of developing “guidelines for hospices, so adult Māori receive access to good palliative care.”<sup>218</sup> It outlines both barriers for cultural accessibility, recommendations for overcoming these barriers, and a roadmap for moving forward.<sup>219</sup>

Again, these barriers can be found in other New Zealand minority groups. For example, while there are limited studies on the palliative care needs of Pacific populations in New Zealand, there are some studies on palliative care that include Pacific participants. These:<sup>220</sup>

*report challenges in access and utilisation of palliative care including: lack of awareness of the role of hospice and palliative care services, language barriers and differences in cultural norms and values. Pacific populations are also more likely to reside in socioeconomically deprived areas with worse access to a variety of health services, including palliative care.*

It is essential that these different barriers are addressed.

### **Opportunities for overcoming barriers to cultural accessibility**

*Te Whare Tapa Wha* Model of Māori health is recognised as being highly compatible with the palliative care approach.<sup>221</sup> This model recognises that health should not solely focus on the individual’s physical health, but like a house that requires four walls to hold up the roof, it recognises that an individual’s health must be held up by other important aspects. These aspects, or pillars, are *wairua* (or spiritual well-being), *hinengaro* (or emotional and mental health), *whānau* (including extended family and the wider social system) and *tinana* (or physical health and well-being).<sup>222</sup> Margaret Cottle and colleagues from Unitec Institute of Technology in Auckland have shown how a hospice service was able to adopt *Te Whare Tapa Wha* model into its’ service delivery and increase Māori and Pacific peoples use of that hospice.<sup>223</sup>

*They worked with a Hui (weekly local gathering) to make significant changes to that hospice service, including reallocating staff time, rearranging the physical space, and re-orienting the management format. They made efforts to ensure clear and regular communication between all parties.*

In an article outlining key features of palliative care service delivery to indigenous populations in Australia, New Zealand, Canada, and the United States, Shaouli Shahid and colleagues found that in the models that attempted to deliver culturally sensitive palliative care services there were six critical elements:<sup>224</sup>

1. Community engagement,
2. Education and training,
3. Culturally safe service delivery strategy,
4. Flexible organisation / program structure,
5. Patient-centred care, and
6. Quality service delivery.

### *Te Ipu Aronui*

Te Ipu Aronui is a collection of online stories and information “to support Māori whānau (families) to provide care to adults and kaumatua (older people) at the end of life.”<sup>225</sup> Having collected these stories through the Pae Herenga study, Dr Tess Moeke Maxwell is very aware of their power “to show the different ways whānau manaaki provide care.”<sup>226</sup> The website also “provides practical information and recommendations to help health and palliative care services and professionals to be equity driven”, and “aim[s] to signal to health providers what education, training, resources, skills and Māori community collaborations are needed to support the cultural values practices and protocols of kaumatua, whānau manaaki, hapū, and iwi.”<sup>227</sup>

***Recommendation 13: The Government, medical and nursing schools, and palliative care providers should work with important Māori stakeholders (such as Māori social service providers and local iwi) to listen, learn and reduce cultural barriers to palliative care.***

To ensure that all New Zealanders, whatever their cultural background or affinity, are able to access palliative care services everyone involved in New Zealand’s palliative care services should take up the opportunity to learn from and work with community groups and stakeholders to ensure they are providing culturally accessible services. This will assist in both meeting the obligations of *te tiriti o Waitangi* “to work collaboratively with Māori to provide the best care and outcomes for Māori patients/tūroro and whānau” as well as in removing barriers.<sup>228</sup>

***Recommendation 14: The Government should incentivise an increase in the Māori palliative care workforce.***

The Ministry of Health’s 2014 Palliative Care and Māori from a Health Literacy Perspective document recommends providing “incentives and funding to encourage Māori palliative care workforce development at all levels and in a variety of roles. This should encompass professional development in health and literacy for Māori already in the palliative care workforce, including those based with Māori community organisations.”<sup>229</sup> A limited Māori workforce

continues to be a barrier to culturally accessible palliative care in New Zealand and therefore the need for this recommendation remains.

***Recommendation 15: All providers of palliative care should consider implementing the appropriate recommendations outlined in “Mauri Mate: A Māori Palliative Care Framework for Hospices.”***

The recommendations outlined in Mauri Mate range from “develop[ing] specific information packs” to build awareness and understanding of palliative care services, through to “develop[ing] staff training (for all health professionals) on cultural safety and cultural competency with supporting resources that describe Māori diversity, Māori preferences and hospice resources.”<sup>230</sup> (See Appendix for full list of recommendations.) These recommendations cover a much larger reach of barriers to be overcome than is possible for this paper, and the implementation of many of these recommendations is a necessary step toward greater cultural accessibility of New Zealand’s palliative care services.

**Recommendation 16: Palliative care providers should seek to fulfil the “six critical elements” of culturally sensitive palliative care services.**

The six elements are as follows:<sup>231</sup>

- Community engagement,
- Education and training,
- Culturally safe service delivery strategy,
- Flexible organisation / program structure,
- Patient-centred care, and
- Quality service delivery.

## 7. CONCLUSION

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Death may be inevitable for all of us, but bad deaths don't have to be. Giving all New Zealanders access to high quality palliative care services must be a priority. Currently, excellent care is available for some, but not all. Urgent changes are needed so that all New Zealanders—no matter their postcode or cultural background—have access to this care.

Government, Parliament, the Ministry of Health, training institutions, residential care facilities, and healthcare practitioners all have a role to play. Together, they must:

- update strategy, legislation, and policy to ensure New Zealand remains an international leader of palliative care services,
- increase public awareness and death literacy to reduce fear and increase awareness of the supports available,
- improve and enhance the training and support for current and future healthcare practitioners, residential care staff, and everyone providing care at the end of life so that all primary carers are confident in their roles and responsibilities,
- provide appropriate increases in funding to support development of specialist palliative care services, and
- increase and improve both regional and cultural accessibility to palliative care so that neither remain a barrier.

Each of these changes is essential for overcoming the rapidly increasing demographic challenges, and are well placed in the opportunities that changes to the New Zealand health system bring. Most importantly, however, these changes will ensure that every New Zealander has the best chance of a good death, when the time comes.

## 8. APPENDIX: MAURI MATE RECOMMENDATIONS<sup>232</sup>

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### **Ngā Whānau Kanorau, Ngā Wheako Kanorau: Diverse Whānau, Diverse Experiences**

- Hospices develop care plans that are informed by and record the support needs and preferences of care of Māori patients and whānau.
- Care should be taken to respectfully note differences between patients and whānau and describe how the differences are resolved where possible or managed when not resolved.
- Care plans should be kept up to date over the course of the palliative care journey.

### **Ngā Pārongo: Information**

- Hospices develop specific information packs:
  - Designed and tested with Māori patients and whānau
  - Delivered by hospice staff describing palliative care services
  - Introduce key concepts for the palliative care journey
  - Useful up to date contact details, assistance or entitlements, and how to access these
  - Further information or vignettes drawn from real case studies is likely helpful in resources conversations within whānau and with hospice staff about the palliative care journey and cultural customs at the end of life.

### **Te Haumarū Ā-Ahurea me te Mātanga Ā-Ahurea: Cultural safety and cultural competence**

- Hospices develop staff training (for all health professionals) on cultural safety and cultural competency with supporting resources that describe Māori diversity, Māori preferences and hospice resources, that will meet the needs of Māori patients and whānau.

### **Rongoā Māori**

- Further research is encouraged and developed regarding the use of rongoā rākau and rongoā practice in palliative care, noting the guidelines published by Whakaue Research Centre on their website.

### **Te Manaaki Haumanu: Clinical Care**

- Hospices specifically enquire and engage with Māori patients and whānau about their intentions, preferences or needs in respect to tikanga Māori. This should be recorded in the care plan and should be visible to the patient and whānau.
- Hospices specifically discuss the opportunity to support cultural practices.
- Hospices care plans are informed by and record the support needs and preferences of care of Māori patients and whānau. Care should be taken to respectfully note differences between patients and whānau and describe how the differences are resolved where possible, or managed when not resolved. This needs to be kept up to date over the course of the palliative care journey.
- That given the strong Māori preference for care to remain in the home, hospices evaluate and assess their data and their day and community programmes to identify what type of services are being accessed by Māori whānau and what changes might be required.
- As assessment, audit and patient or whānau feedback processes have been largely developed with a mainstream focus, that:
  - Alternative consumer-feedback, or quality audit processes be developed and trialled to capture targeted Māori views of hospice service
  - A cultural audit tool be developed to assess fully the hospice service to identify gaps, service change and training needed to improve the hospice service.

**Ngā Hiahia Motuhake: Special care needs**

- That programmes and initiatives that are intended to support caregivers be monitored, reviewed and assessed, to identify whether Māori patients and whānau are accessing such programmes and how they are being viewed by Māori.

**Te Ohu Mahi Haumanu: Clinical workforce**

- Hospices develop workforce training development plans that include training on the Treaty of Waitangi (with a focus on health) for all hospice health professionals and available to all staff and volunteers.
- Hospices develop staff training on cultural safety and cultural competency, with supporting resources, that describe Māori diversity, Māori preferences and hospice resources, that meet the needs of Māori patients and whānau.
- Hospices continue to support advanced communication training around the 'difficult' conversations around death and dying—not only providing courses for their own staff but providing opportunities for their health colleagues across the sector.
- Hospices develop specific resources to support improved awareness of, and knowledge about palliative care services, how to access services and entitlements.
- Hospices develop specific training for all staff to use these resources in engaging with Māori patients and whānau.
- Hospices regularly collect and reflect on feedback from Māori patients and whānau about information on palliative care services, access to palliative care services and entitlements. This information can also assist to highlight issues for training.

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