

National policies for adult palliative care in four countries

An evidence brief

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Abbreviations

GP general practitioner

NHS National Health Service

OECD Organisation for Economic Co-operation and Development

WHO World Health Organisation

Executive summary

Policy context

The Irish Programme for Government from June 2020 commits to publishing a new palliative care policy for adults by mid-2021, with the aim of ensuring the provision of high-quality, integrated, and accessible palliative care services for all patients. This will represent a major update of the 2001 policy – the *Report of the National Advisory Committee on Palliative Care*. The new policy will reflect increased demand for adult palliative care, the shift towards care in the community, the emphasis in Sláintecare on addressing geographic variations in the provision of both community and hospital palliative care services, and developments in international best practice. This evidence brief was commissioned by the Department of Health and will provide key inputs into the policy by describing national adult palliative care policies in four countries – Australia, New Zealand, Scotland, and the Netherlands.

Research question

This evidence brief addresses the following research question:

What approaches have been taken in Australia, New Zealand, Scotland, and the Netherlands to national policy for adult palliative care?

Defining palliative care

The national palliative care policies of all four countries included in this evidence brief are based on the WHO's definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, and spiritual.

Thus, like Ireland, these four countries aim to take a holistic approach to a person's experience of illness and dying by addressing their physical, psychological, social, and spiritual needs.

Methods

The four countries included in this evidence brief – Australia, New Zealand, Scotland, and the Netherlands – were chosen in close collaboration with the Department of Health. Only Organisation for Economic Co-operation and Development (OECD) member countries were considered, and countries with a population size similar to that of Ireland were prioritised.

This brief relied primarily on government publications, government websites, and country reports published by international organisations and independent agencies. In addition, relevant peer-reviewed journal articles were identified by an information specialist. Relevant data from the included sources were extracted and analysed.

Australia

In Australia, a distinction is made between palliative care provided in the community (in patients' homes or in residential aged care facilities) and care provided in hospitals (including hospices and dedicated palliative care wards). Australian national policy emphasises expanding the practice of specialist palliative care teams to support primary palliative care providers through consultative or consortium arrangements. The primary aim is to address inequities in access to care. Not everyone in Australia who needs palliative care can access it, particularly those living in rural areas, patients who are not identified as potentially benefiting from palliative care, and members of marginalised groups (including Aboriginal and Torres Strait Islander peoples; the LGBT+ population; migrants; people experiencing homelessness; and those living with disabilities).

In order to address these challenges, Australia's *National Palliative Care Strategy 2018* covers seven priority areas:

1. Understanding – “People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care.”
2. Capability – “Knowledge and practice of palliative care is embedded in all care settings.”
3. Access and choice – “People affected by life-limiting illnesses receive care that matches their needs and preferences.”
4. Collaboration – “Everyone works together to create a consistent experience of palliative care across care settings.”
5. Investment – “A skilled workforce and systems are in place to deliver palliative care in any setting.”
6. Data and evidence – “Robust national data and a strong research agenda strengthen and improve palliative care.”
7. Accountability – “National governance of this Strategy drives action.”

For each of the seven priorities, there are specific timeframes, accountable organisations, and relevant evaluation data at the national, state, and territory levels. The evaluation data will feed into the strategy's monitoring and evaluation plan.

Telemedicine is available across Australia for a range of medical services, including palliative care. A particularly innovative model of telehealth for palliative care has been developed by a group of researchers in Adelaide. In this model, community palliative care patients and their carers have structured video calls with practice nurse consultants, and patients and their carers enter their own data using the telehealth system. Data from wearable monitoring devices and self-reported data entered by patients and carers are monitored by an automatic system, and if a patient passes defined clinical thresholds the system alerts the nurse. Scheduled video call contacts are made in response to alerts, which lead to changes in care. An evaluation of the model found that patients were able to effectively use the technology to input their data, with the data being comparable with those collected during face-to-face assessments. Moreover, a majority of nurses reported that video calls were better than phone calls and similar to face-to-face consultations. The authors of the evaluation concluded that telehealth can increase equity in access to palliative care services, especially for those in rural areas, and that being able to consistently monitor symptoms led to a more efficient use of resources.

In response to COVID-19, Palliative Care Australia formed the Australian COVID-19 Palliative Care Working Group in March 2020 in order to respond to the impact of the virus on palliative and end-of-life care. The Working Group has produced documents on a range of topics, including how to project compassion through personal protective equipment and ensuring dignity for palliative care patients during the pandemic. It also releases a weekly newsletter containing editorials and updates on palliative care for COVID-19 patients.

New Zealand

In New Zealand, palliative care is delivered through an integrated approach in which both generalists and specialists provide care. Primary palliative care refers to palliative care provided in primary care, and includes care from GPs, pharmacists, physiotherapists, occupational therapists, social workers, and psychologists, among others. Specialist palliative care is provided by health professionals who have undergone specific palliative care training, and can be provided directly and indirectly through advice, support, training, and education.

New Zealand's Ministry of Health is currently focusing on developing a more person-centred system of palliative care. The emphasis is on respecting people's preferences; tailoring care to their needs; providing high-quality, future-proofed care; coordinating care; and supporting families and

communities. The *Palliative Care Action Plan* was published in 2017 and outlines five key goals of palliative care in New Zealand:

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

A key challenge in New Zealand is that palliative care services in rural communities have limited access to support from specialists. Indeed, a 2017 review of adult palliative care services highlighted inequities across New Zealand in access to palliative care specialists, specialist nurses, and GPs with palliative care expertise. In order to improve primary-level palliative care, the Ministry of Health is undertaking the following actions in the 2019–2025 policy cycle:

- Ensuring that palliative care is embedded within undergraduate and postgraduate healthcare training
- Rolling out new palliative care training programmes and guidance
- Scoping centralised online training resources and medical information
- Scoping evaluation processes for training initiatives in advance care planning and palliative care
- Revising referral guidance for specialist palliative care

Specific barriers that have been identified in terms of the integration of generalist and specialist palliative services include uneven access to information technology, inconsistent levels of funding, inconsistent criteria for referrals to specialist care, and inconsistencies in reporting. Enablers include shared electronic records, formal shared-care arrangements, and shared clinical management guidelines.

In response to COVID-19, Hospice New Zealand has produced a variety of documents for health professionals providing palliative care to COVID-19 patients, including several documents with guidance on communication tips and suggested scripts in response to a wide variety of potential questions from patients and families. Additionally, the Waikato District Health Board produced the *Palliative Care Pandemic Pack*, a tool developed by palliative care specialists that is aimed at enabling enhanced primary palliative care provision by a wider range of clinicians in the time of COVID-19.¹ It has been distributed to primary care providers, residential care facilities, and hospitals throughout the region. It provides succinct and specific resources to enable the rapid upskilling of clinicians with limited experience of palliative care.

Scotland

In Scotland, generalists and specialists deliver palliative and end-of-life care across a range of care settings. However, the Scottish Government has acknowledged that clarity about generalists' and specialists' differing roles and responsibilities is lacking. Moreover, many people who could benefit from palliative care do not receive it. In order to move towards a more structured system and to ensure equitable access to palliative care, the strategy for the 2016–2021 policy cycle aims to:

- Enhance identification of those who might benefit from palliative and end-of-life care
- Engage a broader range of health and social care professionals in the provision of palliative care
- Provide adequate training and ensure that staff feel supported
- Increase openness about dying, bereavement, and death
- Recognise the sources of support within communities that allow people to live and die well

-
- Increase the emphasis in research activities, improvement support programmes, and strategic plans on improved quality of, and access to, palliative and end-of-life care

The strategy outlines 10 commitments to achieve these objectives:

1. Support Healthcare Improvement Scotland to provide health and social care partnerships with expertise on improving the identification of those who could benefit from palliative care
2. Provide health and social care partnerships with strategic commissioning guidance on palliative care
3. Support the development of a new educational framework for palliative and end-of-life care
4. Support the further development of palliative care for young people aged 0–25 years
5. Support the establishment of the Scottish Research Forum in Palliative and End of Life Care
6. Support both personal and public discussion of death, dying, bereavement, and palliative care
7. Ensure that eHealth supports effective sharing of conversations around anticipatory care planning and end-of-life care
8. Support both clinical and health economic evaluations of palliative and end-of-life care models
9. Support improvements in data collection, analysis, and dissemination regarding palliative and end-of-life care demand, indicators, and outcomes
10. Create a new National Implementation Advisory Group to promote the implementation of these improvement actions

The strategy notes that it can be difficult for GPs to identify those in need of, or who could benefit from, palliative care. Qualitative research has also highlighted challenges in community palliative care, in particular in the following areas: sharing information across the National Health Service and across multidisciplinary teams; coordination and under-resourcing of district nurses; information technology; and cumbersome palliative care registers. Additionally, training is required to help professionals identify patients with non-malignant palliative care needs and to improve communication skills.

Regarding COVID-19, the *Scottish Palliative Care Guidelines* are available online as a living document that is regularly updated, and they contain extensive guidance for end-of-life care for COVID-19 patients. The website also publishes weekly bulletins on the latest research on palliative care and COVID-19. Notably, evidence from Scotland shows that individuals in hospital palliative care with COVID-19 spend a median of 2 days in palliative care, compared with a median of 5 days for all patients in Scotland who received palliative care in 2019.

The Netherlands

Dutch Government policy is based on the principle that palliative care is generalist care and should therefore be provided by any health professional, whenever necessary. As such, palliative care is not a distinct medical specialty in the Netherlands. Palliative care is largely provided at the primary care level with the GP as the lead provider. GPs in the Netherlands perceive palliative and end-of-life care as an integral part of their role, and all GPs have formal training in palliative care. District nurses also play a pivotal role in palliative care and receive formal training. There is a strong emphasis in the Netherlands on providing palliative care at home and dying at home when possible, and GPs and district nurses frequently conduct home visits.

The provision of palliative care as generalist care necessitates a strong system of specialist support. GPs and district nurses are linked with palliative care consultation teams – composed of providers with extensive experience in palliative care – from whom they seek advice and guidance. Notably, palliative care consultation teams do not directly take over patient care; the GP continues to be the lead provider. The Netherlands has also established a national palliative care help desk – a phone hotline for palliative care providers who need advice or support. The hotline is part of an effort to

expand support for GPs and district nurses, in order to address high levels of burnout that have been identified among primary care providers of palliative care.

Ensuring equitable access to high-quality palliative care throughout the Netherlands has been a challenge, and the 2014–2020 policy cycle for palliative care involves five key actions that aim to address this:

1. The publication of the *Quality Framework for Palliative Care* in 2017 which describes the principles of palliative care in the Netherlands and provides detailed guidelines for providers. Its development was led by Palliatief (the Dutch national association of palliative care professionals) and the Netherlands Integrated Cancer Center. It is a living document that is available online, and it is regularly updated.
2. A €51 million investment from 2014–2020 in projects under four key areas of palliative care: healthcare innovation; coordination and continuity of care; patient and family participation in care choices; and public awareness of palliative care and of advance care planning.
3. Establishment of seven regional networks to improve local and national coordination in palliative care (and the development of a palliative care app for providers).
4. Establishment of a national Palliative Care Practice Team to support palliative care providers by addressing the challenges they identify in the organisation and funding of palliative care.
5. A public awareness campaign to promote conversations about palliative care and the end of life.

In response to COVID-19, a national expert group on palliative care in the time of COVID-19 has been established, consisting of academic and medical experts in palliative care from across the Netherlands. The purpose of the group is to share experiences of palliative care for COVID-19 patients and to address urgent issues. All findings and conclusions of the expert group are shared online. Additionally, a wide variety of resources for providers have been published, including a six-part series of training videos for doctors and nurses on providing palliative care for COVID-19 patients.

Conclusion

Our analysis of national palliative care policies in Australia, New Zealand, Scotland, and the Netherlands demonstrates that equitable access to palliative care on a national scale is dependent on community-based service delivery. Moreover, many people prefer to be cared for and die at home, and community-based palliative care makes this possible. It also allows the health workers who know patients most intimately – GPs and community nurses – to address their patients’ palliative care needs holistically. Yet, primary care providers, including out-of-hours GPs, must have the skills and confidence to support physical, psychological, social, and spiritual well-being. Therefore, GPs and community nurses ought to receive formal training in palliative care, both as part of their basic training and on an ongoing basis.

The provision of palliative care as primary care also necessitates a strong system of support. GPs and district nurses can be linked with teams of providers with extensive experience in palliative care, from whom they can seek advice and guidance. Additionally, support systems for informal caregivers are crucial, as they play a pivotal role in palliative care.

Clear guidelines and standards of care help all providers identify patients who would benefit from palliative care. Such guidelines ought to encourage providers to seek support whenever they feel they need it and to refer patients to other services as needed, including medical specialists, psychologists, social workers, and spiritual caregivers, among others. Referral to a wide variety of providers is crucial in order to holistically address all aspects of well-being.

As a global society, we are collectively facing the reality of illness and death more acutely than we have in a century. Palliative care was established as a field of medicine 50 years ago, and it has never been more important. Death is a universal experience, and palliative care is integral to our individual and collective well-being. The health system is the avenue through which people access palliative care. Yet, by addressing physical, psychological, social, and spiritual needs, palliative care enables the health system to improve all aspects of well-being.

1 Introduction

1.1 Policy context

The Irish Programme for Government from June 2020 commits to publishing a new palliative care policy for adults by mid-2021, with the aim of ensuring the provision of high-quality, integrated, and accessible palliative care services for all patients. This will represent a major update of the 2001 policy – the *Report of the National Advisory Committee on Palliative Care*. The new policy will reflect increased demand for adult palliative care, the shift towards care in the community, the emphasis in Sláintecare on addressing geographic variations in the provision of both community and hospital palliative care services, and developments in international best practice. This evidence brief was commissioned by the Department of Health and will provide key inputs into the policy by describing national adult palliative care policies in four countries – Australia, New Zealand, Scotland, and the Netherlands.

1.2 Research question

This evidence brief addresses the following research question:

What approaches have been taken in Australia, New Zealand, Scotland, and the Netherlands to national policy for adult palliative care?

1.3 Defining palliative care

The national palliative care policies of all four countries included in this evidence brief are based on the WHO's definition of palliative care:²

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial, and spiritual.

The WHO further clarifies that palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor to postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help families cope during the patient's illness and during bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling
- Enhances quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (such as chemotherapy or radiation therapy), and includes investigations needed to better understand and manage distressing clinical complications

2 Methods

The four countries included in this evidence brief – Australia, New Zealand, Scotland, and the Netherlands – were chosen in close collaboration with the Department of Health. Only Organisation for Economic Co-operation and Development (OECD) member countries were considered, and countries with a population size similar to that of Ireland were prioritised.

This brief relied primarily on government publications, government websites, and country reports published by international organisations and independent agencies. In addition, relevant peer-reviewed journal articles were identified by an information specialist. Relevant data from the included sources were extracted and analysed.

It is important to note that the section of the report on the Netherlands is significantly longer than the other three countries. This is because all policy documents from the Netherlands were only available in Dutch, and we translated these documents using Google Translate. We provided more detail about the Netherlands' policies so that policy-makers do not need to turn to the original Dutch documents. Additionally, the Netherlands was the only country of the four for which we were able to identify a national model of care for adult palliative care.

3 Australia

Australia has a regionally administered, universal public health insurance programme financed through a combination of general tax revenue and a government levy.³ Enrolment is automatic for citizens, and they receive free public hospital care and substantial coverage for physician services, pharmaceuticals, and other specific services. Approximately one-half of Australians have private supplementary insurance to pay for private hospital care, dental services, and other services not covered by the public system. The federal government pays a rebate towards this premium and charges a tax penalty on higher-income households that do not purchase private insurance.³ Australia ranks third in the OECD's Better Life Index, with 85% of adults reporting being in good health.⁴

While palliative care in Australia traditionally took place when treatment failed, as in many countries there has been a move towards providing palliation for longer periods, concurrently with therapies.⁵ The exact model of palliative care provision differs across Australia, with each state and territory having specified its own approach to providing palliative care-related services.⁵ The states and territories have different approaches to planning and delivering publicly funded services, different local delivery practices, and differently structured healthcare systems.⁵ They also have varying population density profiles and varying demands for particular types of services.⁵ For the purposes of the current report, we will focus exclusively on national policy in Australia, which guides state- and territory-level policies.

3.1 Definition of palliative care

Australia uses the WHO's definition of palliative care:⁶ (p4)

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, and spiritual.

3.2 Vision and objectives

Australia envisions a society in which people affected by life limiting illnesses get the care they need to live well.⁶ The first *National Palliative Care Strategy* in Australia was published in 2000, followed by the second *National Strategy* in 2010. Both strategies were produced at the national level and outlined agreed upon priorities and actions. The second strategy was reviewed in 2016 in consultation with service providers, clinicians, community organisations, policy-makers, and the public.⁶ The evaluation found that the strategy allowed for continuing expansion and improvement in the palliative care sector and recommended the creation of a further updated strategy, which was then published in 2018.

The *National Palliative Care Strategy 2018* was developed in consultation with more than 200 public, private, and not-for-profit organisations, health departments at the state and territory level, patients, and professionals involved in palliative care.⁶ Its overarching vision is that Australians have universal, equitable access to palliative care.⁶ This vision includes not only the individual, but also their family, carers, and friends. The aim of palliative care in Australia is to help people live as well as possible for as long as possible, while reducing both the physical and emotional distress of dying.⁶ Australia's *National Palliative Care Strategy 2018* is informed by six guiding principles:⁶

1. Palliative care is person-centred care
2. Death is a part of life
3. Carers are valued and receive the care they need
4. Care is accessible
5. Everyone has a role to play in palliative care
6. Care is high quality and evidence based

Person-centred care refers to putting the individual at the centre of their care and ensuring that they receive care that is responsive to their needs, wishes, and values.⁶ As palliative care is holistic care, it caters to the individual's physical, psychological and emotional, social, and spiritual needs, along with the needs of their carers and family members.⁶ Valuing and supporting carers is emphasised, as they tend to provide the majority of care and require bereavement support following the death of a patient.⁶

The Australian Strategy emphasises that making care accessible is essential to ensuring that care reaches underserved and marginalised groups. In Australia, these groups include Aboriginal and Torres Strait Islander peoples; LGBT+ people; migrants; those living in rural areas; people experiencing homelessness; and those living with disabilities.⁶

Multidisciplinary teams are also essential to palliative care in hospitals and in the community, in terms of both decision-making and capacity building.⁶ High-quality and evidence-based care is noted as necessary to ensure that people have access to reliable resources to aid their decision-making regarding their care. Having rigorous data on outcomes aids evaluation, and the most up-to-date research should inform processes.⁶

The Strategy also includes seven goals under the following headings:

1. Understanding
2. Capability
3. Access and choice
4. Collaboration
5. Investment
6. Data and evidence, and
7. Accountability.

Each goal is broken down by a key statement along with specific priorities:

1. Understanding

“People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care.”^{6 (p12)}

The priorities in this area include people being aware of the benefits and availability of palliative care, recognition of cultural beliefs, and building local capacity for palliative care.⁶

2. Capability

“Knowledge and practice of palliative care is embedded in all care settings.”^{6(p14)}

The priorities for this goal include all medicine, nursing, and allied health professionals being able to identify people's palliative care needs, both clinical and non-clinical service providers being able to discuss palliative care and to help people develop advance care plans, and meeting the bereavement needs of carers and family members.⁶

3. Access and choice

“People affected by life-limiting illnesses receive care that matches their needs and preferences.”^{6 (p16)}

This goal refers to equitable access for all groups, including marginalised groups (Aboriginal and Torres Strait Islander peoples, LGBT+ people, migrants, those living in rural areas, people experiencing homelessness, and those living with disabilities). These groups may face language barriers, may not reside close to palliative care specialists or generalists with experience of palliative care, or may be marginalised by the health system at large. The *National Palliative Care Strategy 2018* notes that in some instances, access and choice may be improved by telemedicine.⁶

4. Collaboration

“Everyone works together to create a consistent experience of palliative care across care settings.”⁶ (p18)

The priorities under this goal involve collaboration with people affected by life-limiting illnesses and engaging them in developing, implementing, and evaluating palliative care services. It also includes coordination between care settings as people transition from one setting to another, as well as communication between national, state, and local palliative care networks in order to improve consistency in care between jurisdictions.⁶

5. Investment

“A skilled workforce and systems are in place to deliver palliative care in any setting.”⁶ (p20)

The priorities within this goal include developing guidance for future workforce planning with a competency framework for palliative care, along with investment in and expansion of primary care and community-based palliative care. The *National Palliative Care Strategy 2018* highlights that technology can also support the delivery of palliative care.⁶

6. Data and evidence

“Robust national data and a strong research agenda strengthen and improve palliative care.”⁶ (p22)

The priorities in this area are to use data and research to inform improvements in the palliative care sector and, in the long term, to implement countrywide, population-level monitoring of palliative care services. The *National Palliative Care Strategy 2018* notes that without consistent data on outcomes and evaluations, it is difficult to know where to invest in, improve, and increase care.⁶

7. Accountability

“National governance of this Strategy drives action.”⁶ (p24)

The priorities for accountability include linking the governance structure for the *National Palliative Care Strategy 2018* with the Australian Health Ministers’ Advisory Council, annual reporting, and patient involvement in policy development.⁶

For each of the seven goals, there are specific time frames, accountable organisations, and relevant evaluation data at the national, state, and territory levels.⁶ The Strategy specifies that these plans will be reviewed after 5 years.⁶

The *National Palliative Care Strategy 2018* notes that a monitoring and evaluation plan will be developed to identify how progress on the priorities will be measured and reported.⁶ Outcomes, evaluation questions, indicators, data sources, and timeframes will be identified for each of the Strategy’s priorities. It is envisioned that this monitoring and evaluation plan will track the outcomes of the Strategy over a 5-year period. The *National Palliative Care Strategy 2018* notes that many of the required indicators are already available in existing datasets; however, the Strategy contains some aspirational priorities that will require the development of new datasets.⁶

3.3 Governance

A key finding of the 2016 evaluation of palliative care in Australia was the lack of formal governance and oversight structures, which was identified as a key barrier to consistent, high-quality palliative care across the country. This resulted in accountability being one of the seven key goals of the *National Palliative Care Strategy 2018*, as described in section 3.2.⁶ The focus of this goal is the establishment of a formal national governance structure with links to the Australian Health Ministers’ Advisory Council in order to ensure that palliative care is recognised and resourced as an integral component of the health system (while retaining the independence of states and territories to decide how best to invest in palliative care services). This governance mechanism will include people with lived experience of palliative care in order to ensure that the voices of people affected by life-limiting illnesses are considered in service and research development. The governance structure is also

responsible for the development of the implementation plan for the Strategy, as well as for reporting on progress made towards achieving the seven goals outlined in the *National Palliative Care Strategy 2018*. Moreover, it will provide a structural mechanism to support information sharing between the Commonwealth (which funds general practice and aged care services) and states and territories (which fund community, tertiary, and specialist services). The governance structure will also provide a platform for promoting the use of quality standards and accreditation processes and for dialogue and integration with other sectors, including aged care, disability, and social services.⁶

Additionally, Palliative Care Australia is the national association for palliative care in Australia, bringing together eight regional member groups involved in providing palliative care across the country. The association's work aligns with the 2018 Strategy's priorities. Its governance structure is made up of a board that is elected every 3 years, with representatives from universities and hospices, as well as patient representatives. The current board members of Palliative Care Australia hold the following positions:⁷

- Professor of Palliative Medicine
- Senior Research Fellow
- Representative from Laurel Hospice
- Representative from HLB Mann Judd (a financial and business consulting company)
- Representative from the Australian Centre for Health Law Research
- Social Worker
- Lived Experience Educator
- Patient representative

3.4 Model of care

Our search did not reveal any published documents providing a national model of care for adult palliative care in Australia akin to Ireland's *Adult Palliative Care Services – Model of Care for Ireland*. However, the *National Palliative Care Strategy 2018* outlines principles regarding palliative care (see section 3.2).

In Australia, there has been a focus on expanding the practice of specialist palliative care teams to support primary palliative care providers, often through consultative or consortium arrangements.⁵ Although palliative care can be provided to patients in a variety of settings, a distinction is commonly made between care provided in the community (in patients' homes or in residential aged care facilities) and care provided in hospitals (including hospices and dedicated palliative care wards).⁵ A key aspect of palliative care policy is addressing inequities in access to care. Not everyone who needs palliative care can access it, whether due to being a member of a marginalised group, living in a rural area, or not being identified as potentially benefiting from palliative care.⁶

Below, we describe the settings in which palliative care is provided in Australia, standards of care that have been established, and human resources for palliative care.

3.4.1 Care in the community

Community-based care includes palliative care provided at home, through primary care, or in residential aged care facilities, with care being provided by carers, family members, GPs, outreach services, and nursing and allied health professionals, among others.⁶ According to data from the Palliative Care Outcomes Collaboration, 44% of palliative care in Australia in 2016 was provided in the community.⁶ In order to be able to provide care at home and in the community, investment in resources and infrastructure in the community is a priority in the *National Palliative Care Strategy 2018*. The overall aim is to restructure the provision of palliative care from primarily metropolitan inpatient settings to the community.⁶

In 2015–2016, around 0.01% of all GP interactions were related to palliative care.⁵ Ninety per cent of these palliative care cases were older adults aged over 65 years, and 4.8% were aged under 55 years.⁵ Qualitative research undertaken with rural and urban Australian GPs examined barriers to, and facilitators of, the provision of palliative care.⁸ The GPs highlighted challenges related to lack of guidance and pathways for GP-led palliative care, time restrictions, the complexities involved in navigating doctor–family interactions during palliative care, and negotiating roles with the health system. Some of the GPs’ suggestions included using non-governmental organisations to provide transport services and fill voluntary support roles in order to aid GPs and families; accreditation for GPs for further education in palliative care; promoting palliative care as a subspecialty for GPs; and providing specialist-led mentorship in palliative care for GPs.⁸ Researchers have also noted that e-learning can help to increase generalists’ palliative care skills.⁹

3.4.2 Hospital-based care

The Australian Institute of Health and Welfare reports statistics on hospitalisations relating to palliative care.⁵ In 2017–2018, nearly 80,000 hospitalisations took place that involved palliative care, across both public and private hospitals. The majority of these (52.5%) involved patients aged over 75 years, and the average age was 73.5 years for hospitalisations involving palliative care. By comparison, the average age for general hospitalisations was 55.9 years. The proportion of palliative care provided in public hospitals was greater than in private hospitals, with 85.9% of palliative care hospitalisations occurring in public hospitals. Patients in public hospitals accessing palliative care have also been found to be more culturally diverse than those receiving care in private hospitals.¹⁰ This is important to consider, as resources are required to ensure that people from varying cultural backgrounds receive suitable and culturally appropriate care.¹⁰

3.4.3 Hospices

The meaning of the term ‘hospice’ has changed with time and hospices offer different services across Australia.¹¹ Hospice care can refer to specialist palliative care inpatient units, which can include freestanding facilities, as well as hospital-based wards offering a full range of specialist services. There are also some community-based freestanding hospices throughout Australia that provide some specialist services, including inpatient care.¹¹

Data on hospice care is limited to specialist palliative care units in public and private acute hospitals. In 2016–17, approximately 20% of public acute hospitals (133 out of 673) across Australia reported having a hospice care inpatient unit.⁵ There is regional variation in availability, with a greater proportion of public hospitals in major cities having a specialist inpatient unit (26.4%) than in regional (17.3%) or remote regions (19.1%). Of the 300 private acute hospitals, 24 have a specialist palliative care unit, with an average capacity of 281 beds each.⁵

3.4.4 Standards of care

Palliative Care Australia produced a set of standards aimed at specialists and those working in primary care, *Standards for Providing Quality Palliative Care for all Australians*.¹² The most recent (fifth) edition consists of nine standards:⁷

1. Initial and ongoing assessments incorporate the person’s physical, psychological, cultural, social, and spiritual experiences and needs.
2. The person, their family, and carers work in partnership with the team to communicate, plan, and set goals of care, and to support informed decisions about the care plan.
3. The person’s family’s and carers’ needs are assessed and directly inform provision of appropriate support and guidance about their role.
4. The provision of care is based on the assessed needs of the person, is informed by evidence, and is consistent with the values, goals, and preferences of the person as documented in their care plan.

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5. Care is integrated across the person's experience in order to ensure seamless transitions within and between services.
 6. Families and carers have access to bereavement support services and are provided with information about loss and grief.
 7. The service has a philosophy, values, culture, structure, and environment that supports the delivery of person-centred palliative care and end-of-life care.
 8. Services are engaged in quality improvement and research to improve service provision and development.
 9. Staff and volunteers are appropriately qualified, are engaged in continuing professional development, and are supported in their roles.

Standards 1–6 are the enablers of high-quality care; standards 7–9 are governance standards. The full document outlines how the health service can reach these standards and maps these standards to the *National Safety and Quality Health Service Standards*.⁷ The *National Safety and Quality Health Service Standards* document was produced by the Australian Commission on Safety and Quality in Health Care, and the current edition consists of eight standards in healthcare to protect patients: clinical governance; healthcare-associated infection; medication; communication; blood management; acute deterioration; partnering with consumers; and comprehensive care.¹³

The Australian Commission on Safety and Quality in Health Care also produced a consensus document for palliative care aimed at generalists, including clinicians in acute care settings, health service managers, training providers, and policy-makers, among others. The consensus statement includes 10 'essential elements', 5 of which centre on processes of care and 5 of which are organisational prerequisites.

The processes of care refer to how palliative care should be delivered:¹⁴

1. Patient-centred communication and shared decision-making
2. Teamwork and coordination of care
3. Components of care
4. Use of triggers to recognise patients approaching the end of life
5. Responses to concerns

The organisational prerequisites relate to structural requirements for appropriate and high-quality delivery of palliative and end-of-life care:¹⁴

1. Leadership and governance
2. Education and training
3. Supervision and support for interdisciplinary team members
4. Evaluation, audit, and feedback
5. Systems to support high-quality care

Recent research by Bloomer *et al.* evaluated audit data from one private and one public hospital in Melbourne, using the five essential elements of the processes of care from the Australian Commission on Safety and Quality in Health Care as their conceptual framework for successful end-of-life care.¹⁰ They identified gaps in all five elements in both hospitals. Although the elements are only recommendations and are not mandated, the authors suggested that the elements should be operationalised to bring standards of care in line with practice.¹⁰

3.4.5 Human resources

As populations age and demand for palliative care increases, workforce planning is required in order to plan for the competencies that will be required.⁶ The *National Palliative Care Strategy 2018* states

that strategic workforce planning supports each of the outlined goals.⁶ The palliative care workforce in Australia comprises various health professionals, including GPs, specialist palliative medicine physicians, nurses, other specialists, health support staff, and volunteers.⁵ In order to qualify as a specialist palliative medicine physician in Australia, doctors must complete 3 years of postgraduate training under the supervision of a palliative care physician. This training can be in adult or paediatric specialist palliative care. Having completed this training, specialists are qualified to work across Australia and New Zealand. Another route to training in palliative care is the Clinical Diploma in Palliative Medicine; however, this is not accredited. For nurses, there are a number of routes to specialisation, including master's programmes and postgraduate certificates.⁵ In 2017, there were 249 specialist palliative medicine physicians employed in Australia, most of whom worked in hospital settings, and there were 3,340 palliative care nurses, which is around 1.1% of all nurses employed in Australia; most of these nurses were women.⁵ There are also many volunteers and community organisations involved in this sector.

3.5 Key performance indicators

The Palliative Care Outcomes Collaboration is a health information system and national evidence hub for palliative care funded by the Australian Government Department of Health.¹⁵ It was established in 2005, and it uses five clinical tools to measure outcomes in palliative care across Australia.¹⁵ Approximately 130 service providers contribute data on outcomes to the Collaboration on a voluntary basis, and there is data available for over 250,000 people.¹⁵ The program is a collaboration of four universities, led by University of Wollongong's Australian Health Services Research Institute.¹⁶ The data is viewed at three levels:¹⁶

1. The patient-level includes demographic information
2. The episode-level describes the setting where the palliative care is provided and where the patients dies
3. The phase-level data includes data on the patient's clinical condition.

The data collected measures the palliative care phase, the patient's pain, functional status, their symptoms, and activities of daily living.¹⁶ The five clinical tools used are:

- Palliative Care Phase¹⁷
- Palliative Care Problem Severity Score¹⁸
- Symptom Assessment Scale¹⁹
- Australia-modified Karnofsky Performance Status scale¹⁸
- Resource Utilisation Groups – Activities of Daily Living¹⁸

The palliative care phases are categorised as stable, unstable, deteriorating, terminal, and bereavement.¹⁷ The Palliative Care Problem Severity Score records the clinician's assessment of problems over a 24-hour period (pain, other symptoms, psychological/spiritual, family/carer).¹⁸ The Symptom Assessment Scale measures patient distress due to difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue, and pain.¹⁹ Australia-modified Karnofsky Performance Status scale is a clinician rated assessment of performance relating to activity, self-care, and work over a 24-hour period.¹⁸ The activities of daily living measures dependency for bed mobility, toileting, transfers, and eating.¹⁸

The data produced by the Palliative Care Outcomes Collaboration program is used to inform policy formation and decision making and for benchmarking across services and states. Notably, it has led to improvements in service delivery across Australia.¹⁶ The program is being replicated internationally, including in Ireland.^{16 20}

3.6 Trends in demand for palliative care

According to the Palliative Care Outcomes Collaboration dataset from 2018, there were 57,221 episodes of palliative care that year, half of which took place within inpatient settings.⁵ This represented 42,613 patients accessing specialist services from 133 service providers. For the vast majority (94.2%) of patients, palliative care commenced on either the day they were ready, or the day after. More than three-quarters (77%) had a diagnosis of cancer. The median age of palliative care patients in 2018 was 72.0 years. In terms of socioeconomic status, areas of relative deprivation or disadvantage accounted for around one in seven episodes (combining both inpatient and community settings).⁵

In Australia, by 2066, approximately one-quarter of the population will be aged over 65 years.⁶ Time series analysis on hospitalisations has shown that between 2013–2014 and 2017–2018, the demand for palliative care increased by 16.9%, and the demand for end-of-life care increased by 48.2%.⁶ Palliative Care Australia has predicted that more than 200,000 people will die annually in Australia by 2030.²¹

3.7 Interface between adult and children's palliative care

Australian palliative care policy documents do not clarify how children are supported in the transition from children's palliative care services to adult palliative care services. In terms of children's palliative care, Australian Government policy states that end-of-life and palliative care for children and young people aims to help them live as well and fully as possible.²² Any child or young person who has a serious, complex, or life-limiting illness can receive palliative care. Children and young people with life-limiting conditions can use a range of different palliative care services, including community-based support agencies and disability support services. The services provided by paediatric palliative care teams include: specialist care; assistance in accessing services; sibling support; counselling and emotional support; bereavement support; networking activities; and support from trained volunteers. There is a strong emphasis on support for family members, particularly in helping parents make decisions about their child's care.²²

3.8 Telemedicine

Telemedicine is available across Australia for a range of medical services, including palliative care.²³ An evaluation of a palliative telehealth service in Adelaide found that telecare and telemonitoring is a feasible model of palliative care service delivery in community settings.²⁴ In this evaluation, community palliative care patients and their carers had structured video calls with practice nurse consultants, and patients and their carers could enter their own data using the telehealth system. Data from wearable monitoring devices and self-reported data entered by patients and carers were monitored by an automatic system. If the data showed that a patient passed a threshold on the assessments, an alert was triggered which led the practice nurse consultant to schedule a video conference, a home visit, or a case conference online. The study found that patients were able to effectively use the technology to input their data, with the data being comparable with those collected during face-to-face assessments. Moreover, nurses reported that video calls were similar to (22.3%) or better/much better than (65.2%) phone calls, and similar to (63.1%) or better/much better than (27.1%) face-to-face consultations. The authors concluded that telehealth has potential to increase equity in access to palliative care services, especially for those in rural areas, while also allowing resources to be redirected to those most in need within the community. Being able to consistently monitor symptoms for changes rather than fire-fighting in a crisis was also found to lead to a more efficient use of resources.²⁴

3.9 Funding and costs

Funding allocations for palliative care services in Australia are distributed primarily through public third-party entities, and there is little reliance on charitable funds or out-of-pocket payments to generate revenue. There is no national model for how palliative care services are funded. Instead,

dedicated palliative care budgets are distributed using different models across states and territories. Notably, an important advantage of dedicated budgets is that having predictable funding streams can promote long-term service planning and development.²⁵ Hospital-based palliative care services are funded through each state's funding arrangements. In Victoria, for example, the system of activity-based funding for hospitals means that additional hospital admissions can generate additional funding (within the overall budget limits for hospital funding). Similarly, the payment model for hospital-based services in New South Wales aims to ensure that resource allocation reflects differences in patients' needs and characteristics, not just the volume of services provided.²⁵ However, because community-based services are only funded through site-specific budgets, there is no additional funding for providing care to more people.²⁶ This mixed system of activity-based and non-activity-based funding incentivises hospital-based care over community-based services.²⁶ It is important to note that any measures aimed at reducing hospitalisations for people with palliative care needs will need to take the funding model into consideration.

A study of health care utilisation and expenditure in the last 180 days of life for elderly Australians with and without a history of cancer found that younger, community-based patients and those with a history of cancer had higher costs.²⁷ Costs near the end of life were primarily driven by hospitalisations, irrespective of cancer history. Overall, those dying in residential care settings incurred about half the costs of those who died in hospital. Notably, a relatively low proportion of decedents received hospital-based palliative care services, just 14.7% among those with cancer and 3.1% for non-cancer patients. Similarly, few people were admitted to hospice, with only 4.1% among the cancer cohort and about 0.5% for those without cancer.²⁷

3.10 Response to COVID-19

In response to COVID-19, Palliative Care Australia formed the Australian COVID-19 Palliative Care Working Group in March 2020 in order to respond to the impact of the virus on palliative and end-of-life care.²⁸ This Working Group includes representatives from the following groups:²⁸

- Australian Department of Health
- Australian and New Zealand Society of Palliative Medicine
- Palliative Care Nurses Australia
- CareSearch
- The Australasian Chapter of Palliative Medicine of the Royal Australasian College of Physicians
- End of Life Directions for Aged Care
- Paediatric Palliative Care Australia and New Zealand, and
- caring@home

The Working Group has produced documents and resources on a range of topics, including how to project compassion through personal protective equipment and ensuring dignity for palliative care patients during the pandemic. It also releases a weekly newsletter containing editorials and updates on palliative care for COVID-19 patients.

4 New Zealand

New Zealand has a long history of being a progressive country. In 1903, it became one of the first countries in the world to have a full Ministry of Health headed by a cabinet minister, and universal healthcare in New Zealand dates back to 1938. It is currently one of the highest-performing countries in the OECD's Better Life Index, with 88% of New Zealand's 4.9 million residents self-reporting good health.⁴

New Zealand has achieved universal health coverage through a primarily publicly funded system.²⁹ The national government sets an annual budget and benefit package, the majority of which is funded through general taxation. Services covered by public funding include inpatient care, outpatient care, mental health services, long-term care, and prescription drugs. Twenty district health boards oversee the planning, purchasing, and provision of health services at the local level. Patients pay copayments on some services and products, and approximately one-third of the population has private insurance to fund the cost of copayments and services that are not covered by the public system.²⁹

Healthcare in New Zealand is strongly influenced by the Māori concept of health, in which the following four pillars of health are seen as being of equal importance:³⁰

- Taha tinana (physical health)
- Taha wairua (spiritual health)
- Taha whānau (family health)
- Taha hinengaro (mental health)

This model has been used as a framework in many areas of health, including palliative care. This is exemplified in the 2017 document *Te Ara Whakapiri: Principles and guidance for the last days of life*, which guides adult palliative care for all New Zealanders, not just those who are Māori.³⁰

4.1 Definition of palliative care

New Zealand has adapted the WHO's definition of palliative care to its national context, and defines palliative care as follows:³¹ (p5)

Care for people of all ages with a life-limiting illness which aims to: 1) optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual, and cultural needs and 2) 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 should be available wherever the person may be. It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.

4.2 Vision and objectives

New Zealand's Ministry of Health envisions a health system in which people who are dying, and their loved ones, who could benefit from palliative care services have timely access to high quality care that is culturally appropriate and provided in a coordinated way.³² There is a special emphasis on developing a person-centred system of palliative care, helping people make informed choices about their care and about the end of life.³² The focus is on respecting people's preferences; tailoring care to their needs; providing high-quality, future-proofed care; coordinating care; and supporting families and communities.³³

The following principles guide the provision of palliative care in New Zealand:³¹

- Providers should acknowledge a holistic Māori model of health and well-being in palliative care, encompassing physical health, psychological health, spiritual health, and family health.
- Providers should respect the rights of patients as detailed in the Code of Health and Disability Services Consumers' Rights.
- Generalist palliative care should be available throughout the course of a life-limiting illness, rather than simply at the point of diagnosis or prognosis.
- The level of palliative care support required for any individual and their loved ones is dynamic and varies during the course of illness (and into bereavement).
- Depending on need, the involvement of specialist palliative care may be episodic or continuous.
- The patient's primary care team provides continuity of care throughout their illness.
- Care should be available wherever the patient is – be that home, hospital, residential care, or hospice.
- Palliative care is centred on the patient and their loved ones.
- Palliative care services acknowledge the diverse cultural beliefs, values, and practices of patients and their loved ones in New Zealand society.
- Care needs to be flexible enough to adapt to changes in society, disease and illness, and individual and societal expectations regarding palliative care.

New Zealand's most recent national palliative care strategy was published in 2001,³⁴ however, the 2017 document *Te Ara Whakapiri: Principles and guidance for the last days of life*, which represented a significant update to the strategy, was published following a review of adult palliative care.³⁰ The vision within the 2001 strategy was that "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 co-ordinated way".^{34 (p7)} Nine goals were outlined in order to achieve this:³⁴

1. Ensure access to essential palliative care services
2. Each district health board to have at least one local palliative care service
3. Develop specialist palliative care services
4. Implement hospital palliative care teams
5. Develop quality requirements for palliative care services
6. Inform the public about palliative care services
7. Develop the palliative care workforce and training
8. Ensure that recommendations from the Paediatric Review are implemented
9. Address issues of income support

The 2001 strategy was influenced by the Liverpool Care Pathway from the United Kingdom. An independent review of the Liverpool Care Pathway conducted in 2013 found that as a one-size-fits-all model, it did not integrate individual differences in care needs. Therefore, along with the United Kingdom, New Zealand moved away from the Liverpool Care Pathway.³⁰ In 2008, the Palliative Care Council was established and was charged with exploring a new approach to palliative care. This Council established the Last Days of Life Working Group, composed of experts in palliative care, palliative medicine, palliative nursing, gerontology, general practice, and aged residential care.³⁰ The aim of the Working Group was to integrate the findings from the review of the Liverpool Care Pathway into palliative care in New Zealand by finding contextually appropriate ways to address

individual differences in palliative care needs. The Working Group focused on identifying best practice and commissioning research with families of people who had experienced palliative care.³⁰

In 2016, a review of adult palliative care services in New Zealand built on the Working Group's findings and identified priority areas to improve the quality of, and access to, care.³² Providing equitable access to palliative care services across New Zealand was identified as a key challenge, with variations in access based on geographical location, population group, and disease.³⁵ As a result of this review, the *Palliative Care Action Plan* was published in 2017, and it outlines five key goals of palliative care in New Zealand:³⁶

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

In addition to the *Palliative Care Action Plan*, the Ministry of Health also published the document *Te Ara Whakapiri: Principles and guidance for the last days of life* in 2017 (hereafter referred to as the *Principles and guidance* document).³⁰ It outlines the essential components of providing equitable access to high-quality adult palliative and end-of-life care in New Zealand.³⁰ Its development was based on a review of national and international literature, and it has been endorsed by key professional health organisations in New Zealand.³⁰ It outlined the following principles of palliative care:³⁰

- Care is person-centred
- The workforce providing care is the right workforce
- Communication is clear and respectful
- Services providing care to people in their last days of life are integrated, and move with the person
- Services are sustainable
- Services are nationally guided and supported in order to improve consistency and reduce unacceptable variation in access, including for geographic reasons
- Access to resources and equipment is consistent nationally

Several tools for providers of palliative care were published alongside the *Principles and guidance* document:

- *Care in the last days of life* – a baseline assessment and care-after-death checklist
- *Ongoing care of the dying person* – for care planning in healthcare settings
- *Home care in the last days of life* – for care planning in the patient's home
- *Recognising the dying person flow chart*
- *Medical management planning – general principles* – a list of principles for general medical management planning
- *Bereavement risk assessment tool*
- *Discharge checklist* – for people going home to die, and
- *Symptom management guidelines* – flow charts covering pain; agitation; delirium and restlessness; nausea and vomiting; excessive respiratory tract secretions; and dyspnoea/breathlessness.

Additionally, two documents were published for patients and their families alongside the *Principles and guidance* document:

- *When death approaches*
- *Dying at home*

4.3 Governance

The Governance Group for the implementation of the *Principles and guidance* document comprises:³⁰

- The Director of Palliative Care in Arohanui Hospice
- A palliative medicine specialist
- A senior analyst for the Palliative Care Council
- A palliative medicine physician
- The Chief Executive of a hospice
- The Chief Executive of Hospice New Zealand
- A clinical nurse practitioner with expertise in palliative care

4.4 Model of care

Our search did not reveal any published documents providing a model of care for adult palliative care in New Zealand akin to Ireland's *Adult Palliative Care Services – Model of Care for Ireland*. However, principles and guidance regarding palliative care at the end of life have been published, as described below.

4.4.1 Assessment of need

A baseline assessment is the first step in providing care, as outlined in the document *Principles and guidance for the last days of life*.³⁰ This involves either diagnosis of a life-limiting illness or recognising when someone is dying and in need of end-of-life care. Early identification of the last days of life allows the family and the individual some time to prepare themselves and allows the medical team to prioritise the person's comfort. When death is imminent, the lead health practitioner needs to be identified. For patients at home, this will be the person's GP, and in acute settings it will be the person's consultant. The lead health practitioner is not necessarily a palliative care specialist, but they should have 24/7 access to specialist advice and support. A secondary health practitioner should be identified as well, in order to ensure continuity of care in case the lead is not available. An assessment then takes place in order to identify the person's physical care needs and symptom management needs. These needs can be identified through documented conversations with the patient and their family. The patient's current and anticipatory medication is then reviewed. The health practitioner should then assess the person's preferences for care, documenting their preferences to allow a natural death, whether the person has an enduring power of attorney, and whether they have an advance care plan or advance directive. The patient's preferences for after their death should also be documented.

The patient's cultural needs also need to be addressed. In New Zealand there are specialised cultural supports available for Māori and Pasifika peoples. Cultural differences and traditions can inform people's wishes regarding the end of their life.

If the dying person wishes, they should be provided with food and fluids, and health practitioners should provide information to their family on the risks and benefits of continuing to provide nutrition. Equipment to support the person's care needs should be provided, examples of which include equipment for continuous subcutaneous infusion, sliding sheets, or pressure-relieving mattresses. If

the dying person has a cardiac device, a conversation must be held about whether and when to deactivate it. The person and their family should also be able to access information on support and facilities available to them, e.g. car parking, kitchen facilities, sleeping spaces within the hospital, chaplaincy services, after-hours services, and advice on emergency scenarios.³⁰

Practitioners should create an individual care plan and assess this plan on an ongoing basis.³⁰ Moreover, practitioners should have ongoing conversations with the person's family regarding the patient's condition and their needs.³⁰ Communication around the person's changing condition is important not only for the patient themselves but also for their family. These conversations can be difficult, and practitioners should be supported through education, training, and guidance from those with more experience in palliative care.

Upon the patient's death, practitioners need to verify death as quickly as possible in order to allow for funeral and legal arrangements to proceed.³⁰ The family and deceased person should have their wishes and preferences followed where possible and should be able to discuss their spiritual, religious, and cultural needs. If the person has died in an institutional setting, ideally there should be a private space for the family to grieve. Palliative care organisations provide families with information on next steps, including funeral arrangements and bereavement supports.³⁰

4.4.2 Integration of care

Primary palliative care refers to palliative care provided in primary care, and includes care from GPs, pharmacists, physiotherapists, occupational therapists, social workers, and psychologists, among others.³² Primary palliative care is supported through an integrated approach with specialist palliative care teams.³⁵ Specialist palliative care is provided by professionals who have undergone specific palliative care training, and can be provided directly and indirectly through advice, support, training, and education.³²

Palliative care service integration is promoted by both the *Healthy Ageing Strategy* and the *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand*.³² Integration across general and specialist services is key to improving service planning and delivery.³² As part of the 2016 review of adult palliative care services, district health boards across New Zealand self-assessed how their services managed integration.³² This assessment showed that many district health boards reported high levels of integration and collaboration across specialist and generalist services.³² In some examples, larger hospices acted as local hubs for specialist services within a district health board. Many districts have palliative care networks that operate alongside cancer networks or older people's networks. The *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand* promotes a hub-and-spoke approach to palliative care, with specialist services acting as the hub and satellite services acting as the spokes.³⁵ The hub-and-spoke model represents one level of specialist and high-quality care available to all, through various providers.³⁵

However, the review also found that isolated communities had more instances of community palliative care services operating with limited access to support from specialists.³² Although the number of palliative care specialists per head of population for the country as a whole is adequate as per the Australian and New Zealand Society of Palliative Medicine's mandated ratios, there are inequities in regional access.³² Across the 20 district health boards in New Zealand, there is wide variation in population density. As a result, there is not an adequate population base for specialised services across the whole country. Six regional networks of specialist care centre around Auckland, Hamilton, Palmerston North, Wellington, Christchurch, and Dunedin. These areas have specialist palliative care centres that coordinate with local oncology services.³⁷ However, outside of these areas, there is variation in access to palliative care specialists, specialist nurses, GPs with palliative care expertise, and Māori health workers.³²

The review also noted that the ageing population means that more people will need access to palliative care. Moreover, the palliative care workforce is also ageing; many members of the current workforce are aged over 55 years.³² In addition to focusing on increasing the capacity and capabilities of generalists in the community, the Ministry of Health anticipates that the country's reliance on

informal care is likely to increase, which will require additional supports for family carers and volunteers as they take on more complex roles.³²

Barriers that have been identified in terms of the integration of generalist and specialist palliative services include uneven access to information technology, inconsistent levels of funding, shortages and uneven distribution of palliative care specialists in medicine and nursing in rural areas, inconsistent criteria for referrals to specialist care, and inconsistencies in reporting.³² Enablers include shared electronic records, formal shared-care arrangements, and shared clinical management guidelines.³⁵

4.4.3 Primary-level palliative care

Palliative care is led by specialists in New Zealand. The Ministry of Health has identified the need to increase support for primary-level palliative care.^{32 36} The medium-term actions that are being implemented from 2019 to 2025 to achieve this include:³⁶

- Ensuring that palliative care is embedded within undergraduate and postgraduate healthcare training
- Rolling out new palliative care training programmes and guidance
- Scoping centralised online training resources and medical information
- Scoping evaluation processes for training initiatives in advance care planning and palliative care
- Revising referral guidance for specialist palliative care

The longer-term action (2025–2030) is to assess the impact of minimum service expectations and target primary palliative care strategies.³⁶

The Ministry of Health has highlighted the importance of increasing the capabilities of communities and informal carers.^{32 36} The *Palliative Care Action Plan* acknowledges the importance of informal carers in allowing people to stay at home for as long as possible.³⁶ Short-term goals (2017–2018) in this area included defining carer groups, assessing technologies that could support carers, assessing gaps in workforce development for the community support workforce, and assessing the needs and contribution of volunteers.³⁶ Medium-term goals for 2019 to 2025 are to roll out new development and training programmes for carers and introduce technologies to help carers.³⁶ In the longer term (2025–2030), the goal is to assess the impact of training and development on community capability and target community development strategies.³⁶

4.4.4 Hospital-based care

Hospital-based palliative care teams play two key roles: they ensure that patients can access the support they need; and they support staff in caring for patients nearing the end of life. In order to meet demand for hospital-based palliative care, a number of system-level goals are identified in the *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand*:³⁵

- Sufficient capacity
- Appropriate referrals
- Continuity and coordination of care
- Best practice is followed
- Palliative care meets the needs of the patient, their family, and whānau

4.4.5 Hospices

There are currently 33 hospice services in New Zealand.³⁸ Hospice New Zealand produced *The Palliative Care Handbook* covering symptom management, psychosocial well-being, spirituality, and pharmacopoeia in hospices.³⁹ Hospice New Zealand also produced the document *Standards for Palliative Care 2019*, which guides hospice care.⁴⁰ The standards outlined are as follows:⁴⁰

-
1. Assessment of needs
 2. Developing the care plan
 3. Providing care
 4. Supporting and caring for the family, whānau, and carers
 5. Transitions within and between services
 6. Grief support and bereavement care
 7. Culture of the organisation
 8. Quality improvement research
 9. Staff qualifications and training

Mauri Mate is a recent document for hospices that addresses palliative care for Māori people.⁴¹ It consists of a framework, a road map, and a literature review, all aimed at improving end-of-life experiences in hospices for the Māori population.⁴¹

4.5 Key performance indicators

Unfortunately, key performance indicators regarding national palliative care outcomes in New Zealand were not available in the published literature.

4.6 Trends in demand for palliative care

In 2019, approximately 34,260 people died in New Zealand³² (the latest data in Ireland are from 2018, with 31,116 deaths⁴²). By 2045, the annual number of deaths in New Zealand is expected to rise to 45,000, and by 2068, it is projected to reach 55,000.³² The age profile will also change, with half of those dying over the age of 85 years by 2037.³² Moreover, projected increases in comorbidities over time will make palliative care needs increasingly complex.³²

4.7 Interface between adult and children's palliative care

Palliative care policy documents from New Zealand do not clarify how children are supported in the transition from children's palliative care services to adult palliative care services. Palliative care services for children and young people are provided on a significantly smaller scale and through a different set of services.³⁰ Specialist paediatric palliative care is provided in collaboration with formally trained or experienced paediatric healthcare professionals based either in the community (e.g. GPs or district nurses) or in hospitals.³¹ Home is the preferred location for palliative care for children and young people; however, it is recognised that some children and young people spend long periods of time in tertiary hospitals far from their primary care team.³¹

4.8 Telemedicine

A 2018 survey of telehealth activities across the district health boards in New Zealand reported relatively few examples within palliative care services.⁴³ Active services were limited to two district health boards – Canterbury and Northland. In Canterbury, palliative care services use videoconferencing to conduct some follow-up appointments, facilitate multi-disciplinary meetings, and deliver educational sessions. In Northland, videoconferencing is used for clinician-to-clinician communication and educational sessions. An initiative was also piloted in the West Coast region, encompassing cardiology, oncology, and palliative care services. The interactions and services facilitated through videoconferencing included some follow-up visits, clinician-to-clinician meetings, and nurse clinics. No evaluations were identified regarding the implementation of these programmes or associated outcomes.⁴³

4.9 Funding and costs

In New Zealand, many district health boards do not fund palliative care as a separate service; instead, funding is integrated into the general healthcare budget allocated to district health boards.³² Services are paid for through block contracts based on historical allocations, rather than activity- or patient-based characteristics.²⁵ The proportion of government funding for the running costs of inpatient specialist palliative care units and hospices is capped at 70%.^{25 2017 #66} Palliative care services are not funded through out-of-pocket payments, but there are charges for primary care and prescriptions. The Ministry of Health has noted that the 2015 budget provided NZ\$24.1 million to support innovative palliative care services in primary care, community, and residential aged care facilities.³²

4.10 Response to COVID-19

Hospice New Zealand has produced a variety of documents for health professionals providing palliative care to COVID-19 patients:⁴⁴

- *Communication for all health care professionals – COVID-19*
- *Phone consultations – COVID-19*
- *Communications tips for all stages – COVID-19*
- *Giving serious news – COVID-19*
- *Goals of Care – COVID-19*
- *Symptom control for COVID-19 patients*
- *Managing symptoms at end of life without a Syringe Driver*
- *ICU end of life guidelines for COVID-19*
- *How to tell children someone has died*
- *Supporting children when a family member dies during COVID-19*
- *End of Life Nursing Considerations – COVID-19 Patients*

Additionally, the Waikato District Health Board produced the *Palliative Care Pandemic Pack*, a tool developed by palliative care specialists aimed at enabling enhanced primary palliative care provision by a wider range of clinicians in the time of COVID-19.¹ It has been distributed to primary care providers, residential care facilities, and hospitals throughout the region. It provides succinct and specific resources to enable the rapid upskilling of non-specialist palliative care clinicians. The pack contains an information sheet outlining key considerations with respect to the provision of palliative care, along with specific guidance for clinicians regarding medical management. Advice is also provided regarding stock supply of core consumables and medications to facilitate timely symptom control measures. Core competencies are outlined, specifically relating to the insertion of subcutaneous lines and maintenance of infusions. Staff are directed to guidelines and resources to aid in conducting goals-of-care discussions, pre-emptive prescribing, and identifying the dying patient. Direct links to online resources and standard departmental palliative care guidelines are provided, and consideration is paid to the needs of healthcare providers and the enhanced risks of vicarious trauma and moral distress in this situation. Concise clinician guidance has been developed regarding key symptom management concerns for those dying from COVID-19-related illness. The intention of the tool is that other regions throughout New Zealand will adapt it to their context. The authors note that “it is clear that the core expertise of specialist palliative care, in providing leadership, compassionate wisdom, and clinical skill, would serve our populations well as we face the COVID-19 challenge collaboratively”.^{1 (p20)}



5 Scotland

The National Health Service (NHS) in Scotland provides healthcare services free at the point of care to the entire population of 5.5 million. Population density across Scotland is relatively low.⁴⁵ NHS Scotland consists of 14 territorial boards, 7 special NHS boards, and 1 public health body.⁴⁶ Territorial boards are responsible for the protection and improvement of their populations' health and the delivery of front-line healthcare services. Special NHS boards support territorial boards by providing important specialist and national services.⁴⁶ Services are paid for through general taxation, and most providers are employed directly by NHS Scotland, although most GPs are independent contractors, as are some other providers, including dentists, community pharmacists, and opticians.⁴⁷ Many practitioners and specialists offer both NHS-funded and private services.⁴⁷

Palliative care has been recognised as a medical specialty in Scotland since 1987.⁴⁵ In Scotland, generalists and specialists deliver palliative and end-of-life care across a range of care settings. However, the Scottish Government has acknowledged that clarity about their differing roles and responsibilities is lacking.⁴⁸ Moreover, many people who could benefit from palliative care do not receive it.⁴⁸

5.1 Definition of palliative care

The Scottish approach to palliative care aligns with the WHO's definition of palliative care by taking a holistic approach to a person's experience of dying and aiming to meet their physical, psychological, social, and spiritual needs.⁴⁸ Palliative care in Scotland aims to reduce the pain and suffering experienced by a patient when dying, while increasing the quality of life of both the patient and their family.^{48 49}

5.2 Vision and objectives

The Government of Scotland is currently implementing a 5-year plan (2016–2021) to enhance provision of palliative care: the *Strategic Framework for Action on Palliative and End of Life Care*.⁴⁸ Scotland's vision in that plan is that by 2021, everyone in Scotland who needs palliative care will have access to it, irrespective of their diagnosis, location, age, gender, socioeconomic background, care setting, or proximity to death. The Strategic Framework aims to address inequities in the delivery of palliative care in Scotland at both the individual and group level. Examples of individual-level inequities include those based on age, religion, or sexual orientation, while groups such as the Traveller community, prisoners, and people with non-cancerous life-limiting conditions also face challenges in accessing palliative care.⁴⁸

The specific aims of the 5-year plan are to ensure that:⁴⁸

- People have timely and relevant conversations, preferably before a crisis occurs, to plan for future possible decline in health and suitable care at the end of life, and people are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems, and processes within health and social care services that empower staff to exercise their skills and provide high-quality, person-centred care.
- People understand the importance of high-quality palliative and end-of-life care.

The strategy's specific objectives are to:

- Enhance identification of those who might benefit from palliative and end-of-life care
- Engage a broader range of health and social care professionals in the provision of palliative care
- Provide adequate training and ensure that staff feel supported

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- Increase openness about dying, bereavement, and death
 - Recognise the sources of support within communities that allow people to live and die well
 - Increase the emphasis in research activities, improvement support programmes, and strategic plans on improved quality of, and access to, palliative and end-of-life care

The Government's commitments within this document include working with stakeholders to:⁴⁸

1. Support Healthcare Improvement Scotland to provide health and social care partnerships with expertise on improving the identification of those who could benefit from palliative care
2. Provide health and social care partnerships with strategic commissioning guidance on palliative care
3. Support the development of a new educational framework for palliative and end-of-life care
4. Support the further development of palliative care for young people aged 0–25 years
5. Support the establishment of the Scottish Research Forum in Palliative and End of Life Care
6. Support both personal and public discussion of death, dying, bereavement, and palliative care
7. Ensure that eHealth supports effective sharing of conversations around anticipatory care planning and end-of-life care
8. Support both clinical and health economic evaluations of palliative and end-of-life care models
9. Support improvements in data collection, analysis, and dissemination regarding palliative and end-of-life care demand, indicators, and outcomes, and
10. Create a new National Implementation Group to promote the implementation of these improvement actions.

In order to deliver these aims, several supports have been put in place. These include GB£3.5 million in additional funding for 2016–2021 to support implementation of the strategy; a set of implementation plans for local improvements; and national monitoring and evaluation of quality improvement activities.⁴⁸

As part of the Strategic Framework, a National Implementation Group is to be established.⁴⁸ This group will oversee the development of a new educational framework; establish ways of sharing learning and improvements across Scotland; support the development of locally owned improvement and implementation plans; and provide an annual report that will outline outcomes delivered. The Implementation Group will report to the National Advisory Group for Palliative and End of Life Care and will contain some members of the Palliative and End of Life Care Stakeholder Group (see section 5.3 for a full list of members of the Stakeholder Group). Members of the Implementation Group include representatives from:

- Scottish Government
- Western Isles Integration Joint Board
- NHS Lothian
- Alzheimer Scotland
- University of Glasgow
- NHS Greater Glasgow and Clyde
- St Columba's Hospice
- Marie Curie Scotland
- Healthcare Improvement Scotland
- Convention of Scottish Local Authorities

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- NHS Education for Scotland
 - Children’s Hospice Association Scotland
 - Scottish Children and Young People’s Palliative Care Network
 - Scottish Social Services Council
 - Care Inspectorate
 - Royal College of Nursing
 - NHS Forth Valley

Data, evidence, and research are core components of the Scottish Government’s palliative care strategy.⁴⁸ The strategy has resulted in the establishment of the Scottish Research Forum in Palliative and End of Life Care, which aims to fortify research coordination and knowledge exchange across Scotland.⁵⁰ The Forum is composed of researchers, policy-makers, health and social care professionals, and health service managers.

The *Strategic Framework for Action on Palliative and End of Life Care* (2016–2021) was also developed based on available evidence. A review was commissioned by the Health and Sport Committee in 2016 which looked at 308 papers published on palliative care in Scotland between 2006 and 2015.⁵⁰ The review authors found that most studies were descriptive studies as opposed to intervention and implementation studies.⁵⁰ The papers described services and settings, physical symptoms, experiences and needs, psychological or psychosocial issues, education and training, coordination, methodology and assessment, quality of life, carers, bereavement, and methods of identifying people who would benefit from palliative care. Many of the articles included in this review formed the evidence base for the Strategic Framework.⁵⁰

5.3 Governance

The Scottish Parliament has a Cross-Party Group on Palliative Care.⁵¹ The Secretariat for this group sits in the Scottish Partnership for Palliative Care. The Cross-Party Group on Palliative Care contains Members of the Scottish Parliament, along with representatives from palliative care groups and the public.⁵¹

In Scotland, governance of palliative care care is the responsibility of the National Implementation Advisory Group and the Palliative and End of Life Care Stakeholder Group. The National Advisory Group is made up of the following clinical, academic, and government representatives:⁴⁸

- Healthcare Quality and Improvement Directorate, Scottish Government
- Scottish Children and Young People’s Palliative Care Network
- Regional NHS Scotland health boards
- Integrated Joint Board Chief Officer Group
- NHS Education for Scotland
- Independent adult hospices
- Scottish Care
- Care Inspectorate
- Healthcare Improvement Scotland
- Convention of Scottish Local Authorities
- Palliative Care and End of Life Care Stakeholder Group
- Scottish Government

The Palliative and End of Life Care Stakeholder Group includes representatives from the following organisations:⁴⁸

- Alzheimer Scotland
- Marie Curie Scotland
- Marie Curie Expert Voices
- Children’s Hospice Association Scotland
- University of Glasgow
- Scottish Health Council
- NHS Education for Scotland (Bereavement)
- NHS Education for Scotland (Spiritual Care)
- Neurological Alliance of Scotland
- Age Scotland
- Scottish Non-Malignant Palliative Care Forum
- Carers Trust Scotland
- Association of Hospice and Palliative Care Chaplains
- Scottish Older People’s Assembly
- General Medical Council Scotland
- Association of Palliative Care Social Workers
- Scottish Palliative Care Pharmacists Association
- Health and Social Care Alliance Scotland
- Scottish Partnership for Palliative Care
- Children’s Hospice Association Scotland Young Adult’s Council
- Royal College of Nursing
- Scottish Children and Young People’s Palliative Care Network
- Scottish Care
- Macmillan Cancer Support

5.4 Key performance indicators

In 2013, Healthcare Improvement Scotland developed a set of four high-level indicators for palliative and end of life care services in Scotland.⁹¹ The indicators are intended to measure delivery of person-centred, safe, and effective healthcare, and to promote improvement in care. They are outlined below, and further details regarding how each indicator is measured are available in the report *Palliative and end of life care: indicators*.⁹¹

- *Indicator 1 - Increase in the number of people with palliative and end of life care needs who are identified.* This indicator measures 1) the proportion of people with cancer who are on a palliative care register and 2) the proportion of people with a long-term condition other than cancer who are on a palliative care register.
- *Indicator 2 - Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan.* This indicator measures 1) the proportion of people with cancer

who have an electronic palliative care summary and 2) the proportion of people with a long-term condition other than cancer who have an electronic palliative care summary.

- *Indicator 3 - Increase in the number of electronic palliative care summaries accessed.* This indicator measures the proportion of people who have had their electronic palliative care summaries accessed.
- *Indicator 4 - Place of death.* This indicator is a proxy measure of whether people's preferences for place of death are achieved; it assesses 1) the proportion of people who die in hospital and 2) the proportion of people who die in their usual place of residence

Additionally, Scotland's current 5-year plan (2016–2021) to enhance provision of palliative care includes a commitment to "support improvements in...indicators and outcomes".^{48 p2}

5.5 Model of care

Our search did not reveal any published documents providing a model of care for adult palliative care in Scotland akin to Ireland's *Adult Palliative Care Services – Model of Care for Ireland*. However, NHS Scotland has published its core principles regarding palliative care as well as clinical guidelines. In 2014, *Caring for people in the last days and hours of life* was published, and it outlined the principles the should underly palliative care in Scotland.⁵² These guidelines replaced the United Kingdom's palliative care guidelines, the Liverpool Care Pathway, which was phased out in Scotland 2014.^{53 54} *Caring for people in the last days and hours of life* centres on four principles relating to communication, decision-making, the patient's needs, and the needs of families and carers.⁵²

- Principle 1 – Prioritising timely, sensitive, and informative communication in a person's care. This includes ensuring that the family knows which lead clinician is responsible for the person's care and how to contact the team responsible for their care.
- Principle 2 – Multidisciplinary decision-making about a person's care and their diagnosis of dying, along with a multidisciplinary plan for the management of their condition.
- Principle 3 – Recognising the physical, social, spiritual, and psychological needs of the person, and treating them with dignity and respect. The multidisciplinary team should agree individualised goals of care and review these every day, including the person's preferences regarding their place of care and resuscitation status. The outcome of any intervention should be recorded. Key symptoms should be assessed, and interventions should be documented. When these symptoms are resistant to interventions then aid should be sought from the specialist palliative care team.
- Principle 4 – Considering the well-being of the person's carers and family as part of bereavement care. Staff can ensure this by listening to the family's concerns, explaining the death certificate, providing information packs, and having supportive conversations with the family before and after the person's death.

Additionally, a review of the Liverpool Care Pathway, which also focuses on the end of life, highlighted three specific issues that needed to be addressed, and as a result the Scottish guidelines provide specific guidance on these issues:⁵²

1. Hydration and nutrition in the last few days and hours of life – People should be supported to eat or drink, if they are able and choose to do so. If a change in preference occurs, it should be recorded and documented. A drip can sometimes cause a build-up of fluid in the lungs and body, and this possibility should be communicated to the family.
2. Acknowledging the uncertainty of a diagnosis of dying – Dying involves uncertainty, and the decision to proceed with or finish an intervention can be fraught. It is important to be led by the dying person's wishes, while addressing any symptoms and their psychological, social, and spiritual needs. Communication and monitoring are essential for dealing with uncertainty.
3. Communication between people and families, and between staff – Sensitive and timely communication with the person and their family is key. Providers should be kept aware of the

person's condition, the likelihood of their condition changing, the wishes of the person and their family, and the agreed goals of care.

NHS Scotland published the *Scottish Palliative Care Guidelines* in 2014 as a living online document that is regularly updated. It has extensive clinical guidelines for palliative care for individuals with a range of symptoms.⁴⁹ The guidelines are aimed at both specialists and generalists. The guidelines are overseen by a development group, composed of representatives from all NHS Scotland jurisdictions, Marie Curie Scotland, and hospices. The symptoms addressed in the guidelines include:⁴⁹

- Anorexia/cachexia
- Bowel obstruction
- Breathlessness
- Constipation
- Cough
- Delirium
- Depression
- Diarrhoea
- Hiccups
- Mouth care
- Nausea and vomiting
- Pruritus
- Sweating
- Weakness/fatigue

There is also specific guidance on alternatives to regular medication normally given via a syringe pump, end-of-life care guidance when a person is imminently dying from COVID-19, and out-of-hours handover.⁴⁹

5.5.1 Integration of care

In Scotland, palliative care is delivered through a mix of specialist and non-specialist services⁵⁵. Palliative care service integration is central to the Strategic Framework and is promoted through a commitment to supporting the development of strategic commissioning plans specific to palliative care services. Strategic commissioning encompasses the funding, planning, and oversight of health and social care services. Development and evaluation of commissioning plans are managed by the 31 Health and Social Care Partnerships (referred to as Partnerships) throughout Scotland. The Partnerships have been formed to commission and deliver integrated health and social care services. Strategic commissioning of palliative care must assess and plan for needs across four domains: physical, psycho-emotional, social, and spiritual. Partnerships are also advised to regard palliative care as encompassing all illnesses at all times (i.e. from diagnosis to bereavement) in all settings.⁵⁵

Specialist palliative care services provide direct care but also provide clinical advice and out-of-hours support to other services delivering palliative care.⁵⁵ Specialist services tend to be well-integrated within the communities they serve and provide a range of education and training support for community-based primary palliative care providers.⁵⁵

In Scotland, collaboration and continuity of care are made more efficient by the Key Information Summary outlined in the *Scottish Palliative Care Guidelines*.⁵² This is an online record that can be accessed by members of the community care team such as GPs, district nurses, and emergency care providers. While the Key Information Summary (KIS) is a general medical record and can be used for non-palliative patients, there is a portion of the record entirely dedicated to palliative practices and

the patient's care plan. The KIS is useful for this form of collaboration, allowing all teams across settings to access important information regarding the patient, such as relevant contact details, medication, allergies, desired care plans, and detailed information entered by specialists such as cardiologists and oncologists. The patient may also consent to enter their position regarding cardiopulmonary resuscitation in their record.⁵² Work to include KIS data in all linked data sets is ongoing with the aim of access across all settings by 2021.⁵⁵

5.5.2 Care in the community

Community-based palliative care includes palliative care provided at home or in care homes through primary care services including carers, family, GPs, and community nurses.⁵⁵ The Scottish Government is focusing on delivering integrated care within the community and supporting people to remain at home.⁵⁵

A recent paper suggests that while Scotland is an exemplar for other countries in terms of specialist palliative care services, coverage by specialist palliative home care teams is suboptimal.⁵⁶ The authors found that population coverage for this service was 72%, with around 7.1 home care teams per million people. Recommendations from the European Association of Palliative Care regarding specialist palliative care service capacity suggest there should be about 10 palliative home care teams per million people to ensure high-quality care.⁵⁶

The Strategic Framework notes that it can be difficult for GPs to identify those in need of, or who could benefit from, palliative care.⁴⁸ The Palliative Care Directed Enhanced Service initiative is used by many Scottish GPs to help identify potential patients for palliative care.⁵⁷ Analysis of data from this tool in 2012-13 found that patients with cancer were more frequently identified for palliative care than those with a non-malignant condition. Through qualitative analysis of that dataset, some challenges in community palliative care were identified in the following areas: sharing information across the NHS and across multidisciplinary teams; coordination and under-resourcing of district nurses; information technology; and cumbersome palliative care registers. The authors also noted that training is required to help professionals identify patients with non-malignant palliative care needs and to improve communication skills.⁵⁷

5.5.3 Hospitals

Around 48% of deaths occur in hospital in Scotland.⁴⁵ Scotland has 27 hospital support teams providing specialist palliative care support and advice for patients, families, and clinical staff. Every health board in Scotland has at least one hospital support team, and population coverage is 100%. The support teams also offer other services including formal and informal education.⁴⁵

5.5.4 Specialist palliative care inpatient units

Inpatient units refer to facilities with beds allocated specifically for patients with specialist palliative care needs. These beds can be in hospices, hospitals, or nursing homes.⁵⁶ Figures from 2016 indicate that Scotland had 23 specialist palliative care inpatient units, with a total of 349 beds. This represents about 85% population coverage using the European Association of Palliative Care's consensus statement on specialist palliative care service capacity. In 2015, there were 16 hospices, providing 240 of the palliative care inpatient beds available across Scotland.⁵⁶

5.6 Trends in demand for palliative care

The population of Scotland is currently more than 5 million people. In 2016, 56,728 people died, one-third of whom were aged over 85 years.⁵⁸ Annually, more than 200,000 people in Scotland are impacted by the death of a loved one.⁴⁸ The Government estimates that 80% of people who die could benefit from palliative care.⁴⁸ Analyses examining trends in expected death rates in Scotland estimate that 65,757 people will die in 2040, with the proportion of people who die aged over 85 years increasing from one-third to 45%. Given these projections, changes will be required in workforce and capacity planning for palliative care. In particular, primary care professionals (district nurses, GPs, and social care staff) will need support.⁵⁸

The Strategic Framework acknowledges that in order to provide holistic and high-quality palliative care, professionals must have appropriate knowledge and training in standards of care.⁴⁸ Currently, both specialists and generalists face difficulties accessing training in palliative care.⁴⁸

5.7 Interface between adult and children's palliative care

Palliative care policy documents from Scotland do not clarify how children are supported in the transition from children's palliative care services to adult palliative care services, beyond noting that palliative care for children and young people covers those up to age 25. Approximately 2,200 children and young people die in Scotland each year,⁵⁹ and most end-of-life care for children in Scotland is currently delivered in the hospital environment.⁴⁸ The Scottish Children and Young People's Palliative Care Executive formed after the publication of *Living and Dying Well: a national action plan for palliative and end of life care in Scotland* in 2008, because the 2008 action plan did not explicitly address the challenges of palliative and end-of-life care for children and adolescents. The Strategic Framework for 2016–2021 includes the improvement of palliative care services for children and young people as one of its 10 commitments: "We will support children and families by promoting the further development of holistic palliative care for the 0–25 year age group, recognising that many of their needs may differ from those of adults."⁴⁸ (p12) This commitment includes the establishment of a research forum that will provide a platform to share emergent examples of good practice and experience of what works, for whom, and why, thereby facilitating knowledge exchange, informing evidence-based decision-making, and driving quality improvement in palliative care for children and young people.

Additionally, since 2019, NHS Scotland has led a dedicated paediatric palliative care network – the Paediatric End of Life Care National Managed Clinical Network – which supports children and adolescents aged up to 25 years with life-limiting illnesses.⁵⁹ The aim is to improve access to, and support the delivery of, high-quality, patient-centred end-of-life care for this age group, regardless of location, age, or ethnicity.

5.8 Telemedicine

In response to COVID-19, Children's Hospice Association Scotland pivoted its paediatric hospice services to telemedicine.⁶⁰ The move from face-to-face care to telemedicine had been planned prior to the pandemic, but the COVID-19 outbreak in February 2020 expedited this process. The organisation has provided hospice services for children with life-limiting illnesses in Scotland since 1995. It is charity-funded with an annual budget of GB£20 million, and it employs 200 people and receives support from 800 volunteers.⁶⁰

In early 2020, the Children's Hospice Association Scotland set up a pandemic task force to advise on how to move from face-to-face to online service provision. As the number of hospice beds was reduced from eight per hospice to three in order to facilitate physical distancing, the move to online service provision was imperative. In order to implement this change, a senior leadership team came together. From late March 2020, the virtual hospice came into being a year earlier than had been planned in the Children's Hospice Association's strategy for 2020–2023.⁶⁰

The senior leadership team launched a suite of online support services. The services that were converted included clinical check-ins ('kindness calls'), bereavement and spiritual support, government benefits maximisation, clown doctors, and events. New services were also brought online: virtual appointments, volunteer check-ins ('friendship calls'), letter writing, small-group drop-ins, and virtually delivered activities, including crafts, baking, and storytelling.⁶⁰

There were some issues with technology during the roll-out process. For example, NHS Scotland provides a free video conferencing medical service platform called NHS Near Me/Attend Anywhere which the online services relied on, and some participants had trouble adapting to the NHS's secure platform. There were also issues with connectivity in rural areas in Scotland.⁶⁰

5.9 Funding and costs

There was very limited information in the literature regarding funding for palliative care in Scotland.⁶¹ Notably, an inquiry on palliative care by the Scottish Parliament's Health and Sport Committee in 2015 required all regional health boards to report their expenditures on palliative and end of life care. However, they found that the response and quality of information received was mixed. In particular, several health boards could not separate out general palliative care expenditure from other areas of spending.⁶¹

5.10 Response to COVID-19

The *Scottish Palliative Care Guidelines* contain extensive guidance for end-of-life care for COVID-19 patients.⁴⁹ There is guidance on treatment of breathlessness, cough, respiratory secretions, terminal delirium/agitation/restlessness, pyrexia, and pain. The website also publishes weekly bulletins on the latest research on palliative care in the context of COVID-19.⁴⁹

6 The Netherlands

The Netherlands is a small but very densely populated country.⁶² It ranks second in the OECD's Better Life Index, with 76% of adults self-reporting that they are in good health.⁴ It has a statutory health insurance system, with universally mandated private insurance provided through a national exchange, which is heavily regulated by the Government.⁶² This system of managed competition was introduced in 2006 and represented a major reform of the health system, which had previously consisted of a mix of public and private care, with sharp inequities between the two.⁶²

In the Netherlands, access to GPs is universal and free at the point of service, as is healthcare for children aged under 18 years.⁶² Registration with a GP is not required; however, most citizens are registered with one whom they have chosen, and patients can change GPs without restriction.⁶³ Primary care is strong in the Netherlands, with GPs providing a broader service profile relative to many other countries in the European Union.⁶² There is a gatekeeper system for individual access to healthcare; as in Ireland, patients must be referred to specialists by their GP.⁶⁴ Patients pay out of pocket for specialist care and for inpatient hospital visits up to a maximum annual total of €385, with the remainder of the cost covered by the individual's insurance (which is subsidised for those with low incomes).⁶³

The Netherlands' per capita health expenditure is among the highest in Europe.⁶² However, there have also been significant improvements in performance since the 2006 reform: essential health services are now easily accessible to the entire population, waiting times have decreased over time, and improvements in length of stay and prescription of generics are indicative of increases in efficiency.⁶² Some analyses suggest costs are now levelling out after a period of sharp increase, due to increasing reliance on district nurses to meet demand.

Palliative care in the Netherlands is largely provided at the primary care level.⁶³ Dutch Government policy is based on the principle that palliative care is generalist care and should therefore be provided by any health professional, whenever necessary.⁶⁵ As such, palliative care is not a distinct medical specialty.⁶⁵ In the Netherlands, the GP is the central figure in the provision of palliative care; however, district nurses, home care providers, volunteers, nursing home staff, and consultants also play key roles.⁶³ Reforms were introduced in 2015 aimed at containing growing costs for long-term care; greater priority is now given to care at home provided by informal caregivers.⁶²

6.1 Definition of palliative care

The Dutch Government has adapted the WHO's definition of palliative care as follows:⁶⁶

Palliative care is care that improves the quality of life of patients and their families who are affected by a life-threatening condition or vulnerability, by preventing and alleviating suffering, through early identification and careful assessment and treatment in order to ensure physical, psychological, social, and spiritual well-being. During the course of the disease or vulnerability, palliative care focuses on the preservation of autonomy, access to information, and options.

The Government has noted that the inclusion of the concept of vulnerability aims to capture the diversity of the patient groups who need palliative care.⁶⁶

6.2 Vision and objectives

National policy in the Netherlands envisions a society in which those facing a life-threatening condition are surrounded by respect and loving attention, both from those who are closest to them and from health professionals.⁶⁷ Health care ought to lead to dignity for all people enduring life-threatening illnesses and for those nearing the end of life.⁶⁷

The key goals of national palliative care policy in the Netherlands are that:⁶⁷

- Palliative care is integrated into curative care and is available as soon as a patient is diagnosed with a life-threatening condition.
- Palliative care is available as close to the patient as possible and is chiefly provided by primary care providers, including GPs, community nurses, and nursing home doctors.
- Patients and their loved ones can rely on a network of health professionals who collaborate to identify palliative care needs in a timely manner and provide coordinated care.
- Primary care providers are supported by health professionals with specialist knowledge of palliative care and can consult them as needed.
- Patients and their loved ones are in charge, supported by professionals. Care is tailored to the needs and preferences of patients and their loved ones, with attention to physical, psychological, social, and spiritual care, as well as cultural diversity.
- Care is evidence based and scientific research has been incorporated into practice as much as possible, through evidence-based guidelines and care standards and through ongoing training for providers.
- People can choose where the last phase of their life is spent, and can die at home if possible and if they so choose. If this cannot be achieved, a patient must be able to rely on high-quality palliative care being available in a hospice, nursing home, or hospital.

Ensuring equitable access to high-quality palliative care throughout the Netherlands has been a challenge.⁶⁷ The National Palliative Care Programme 2014–2020 aims to address this by implementing five key actions:⁶⁸

1. Publishing a national quality framework for palliative care
2. Investing €51 million in projects aiming to improve palliative care
3. Establishing seven regional networks to improve local and national coordination of palliative care
4. Establishing a national Palliative Care Practice Team to support health professionals
5. Launching a public awareness campaign to promote conversations about palliative care and the end of life

The *Quality Framework for Palliative Care*, which was published in 2017, lays out the principles of palliative care in the Netherlands and provides detailed guidelines for providers. Its development was led by Palliatief (the Dutch national association of palliative care professionals) and the Netherlands Integrated Cancer Center, in collaboration with a wide variety of stakeholders, including patient representatives and health insurers.⁶⁹ An adapted version of the *Quality Framework* was published for the public, and was developed in collaboration with the Netherlands Patients Federation. In addition, a set of quality indicators for palliative care based on the *Quality Framework* are to be developed by the end of 2021. The *Quality Framework* is described in detail in section 6.4.

The Dutch Government's €51 million investment in palliative care is being implemented by ZonMw (the Netherlands Organisation for Health Research and Development), a public body that funds health research and promotes knowledge uptake.⁶⁸ The funding programme runs from 2014–2020 and focuses on projects that fall under four key areas of palliative care: healthcare innovation; coordination and continuity of care; patient and family participation in care choices; and public awareness of palliative care and of advance care planning.⁶⁸ All projects must include research, practice and training components.⁶⁸

The seven regional networks for palliative care incorporate key stakeholders, including GPs, hospices, nursing homes, home care, hospitals, volunteers, and patient organisations in each region.⁶⁸ Each regional network is tasked with: translating national guidelines for its local context; identifying local challenges in the quality and availability of palliative care; promoting expertise among health professionals and volunteers who provide palliative care; and facilitating support for health

professionals and volunteers through phone consultations with palliative care experts.⁷⁰ The regional networks also link providers by phone to the national palliative care help desk, which was established to improve support for palliative care providers.⁷⁰ The seven networks work collaboratively and coordinate with the National Consultation Network for Palliative Care. Two representatives from each of the seven networks meet four times a year during meetings organised by the National Consultation Network for Palliative Care.⁶⁸ Additionally, a free app for providers was developed. It includes a variety of resources including care guidelines and it links providers to palliative care support teams.⁷¹

The Palliative Care Practice Team aims to support palliative care providers by addressing challenges that they identify in the organisation and funding of palliative care.⁶⁸ It includes experts from the national government, health insurers, and palliative care professionals. Every 2 months, the Palliative Care Practice Team visits various locations in rotation to hear from health professionals about the problems they face in providing palliative care and about areas that they think can be improved.⁶⁸

The public awareness campaign to promote conversations about palliative care and the end of life is being implemented by a coalition of non-governmental organisations and is funded by the Ministry of Health, Welfare and Sport.⁶⁸ All projects that are part of the campaign are coordinated, and the key output of the campaign is a public-facing website aimed at promoting awareness of the importance of talking openly about and planning for palliative care and the end of life.⁷² The website focuses specifically on encouraging individuals to have open conversations with their loved ones and their GP to explore their options and to discuss their wishes, needs, and concerns. It includes practical tips for the public about how, where, and when to start the conversation, and acknowledges the unique challenges around discussing care plans and the end of life. Additionally, as part of the public awareness campaign, the Dutch College of General Practitioners and the Royal Dutch Medical Association have collaborated to develop a digital refresher course for members of the public on the end of life.⁶⁸

A steering group has been established by the Ministry of Health, Welfare and Sport to coordinate the implementation of the five key activities described above, as part of the National Palliative Care Programme 2014–2020.⁷³ All relevant professional groups, health insurers, and organisations are represented on the steering group.⁷³

6.3 Governance

In the Netherlands, the Ministry of Health, Welfare and Sport is ultimately responsible for governing palliative care policy. However, the Ministry coordinates closely with professional associations and key stakeholders to develop and implement national policy for palliative care.⁶⁹ Health professionals are represented in policy-making groups, as are representatives of organisations involved in palliative care provision.⁶⁷ The key organisations that the Ministry engages with to collaboratively govern the implementation of palliative care policy are:⁷¹

- The seven regional palliative care networks
- National Center for Palliative Care
- Netherlands Integrated Cancer Center
- Palliatief (the Dutch national association of palliative care professionals)
- Foundation for Palliative Care at Home
- Centre of Expertise in Children's Palliative Care
- Dutch Centre of Expertise on Health Disparities
- Volunteers for Palliative and Terminal Care
- Dutch Association of Hospice Care
- Dutch College of General Practitioners
- Seven academic centres for palliative care based in Dutch university hospitals

The National Center for Palliative Care and the Netherlands Integrated Cancer Center play particularly important roles in the governance of palliative care.⁶⁷ The National Center for Palliative Care supports the Ministry of Health, Welfare and Sport by focusing on the following core tasks: vision development; quality improvement and research; facilitating and supporting networks of care providers and patient organisations; and informing networks of care providers and patient organisations about regional initiatives.⁶⁷

The Netherlands Integrated Cancer Center supports the Ministry by organising regional consultation teams to support health professionals and by ensuring quality of care through registering and monitoring health professionals.⁶⁷

6.4 Model of care

The *Quality Framework for Palliative Care* was developed in 2016 as part of the National Palliative Care Programme 2014–2020.⁶⁶ It is akin to Ireland’s *Adult Palliative Care Services – Model of Care for Ireland*. The *Quality Framework* is a model of care that lays out in detail the principles of palliative care in the Netherlands and provides guidelines for providers. The document was informed by two evidence reviews: one focused on national literature and the second focused on international literature. It is a living document – it is available as a website rather than as a PDF, and it is regularly updated. In this section, we summarise key aspects of the *Quality Framework*.

6.4.1 Four phases of palliative care

There are four phases of palliative care identified in the *Quality Framework*, with guidance for providers in each phase:

- Disease-oriented palliation – Health professionals who are actively providing palliative care to a patient who is undergoing curative treatment for a disease are encouraged to communicate openly with their patient regarding their mutual hopes and expectations regarding the treatment, and regarding the pros and cons of treatment and of refraining from or discontinuing treatment.
- Symptom-oriented palliation – Providers should focus on communicating the implications of treatment of symptoms (or refraining from treatment of symptoms) on physical, psychological, social, and spiritual well-being.
- Palliation in the dying phase – When providing palliative care in the dying phase, providers should focus on identifying symptoms that are causing stress, providing comfort and relief from suffering, and improving the quality of death.
- Aftercare – After the patient’s death, providers should provide support to the patient’s loved ones.

The *Quality Framework* notes that, in practice, for patients undergoing curative treatment, disease- and symptom-oriented palliation often take place simultaneously. However, the key difference between the two is that symptom-oriented palliation is aimed solely at maintaining or improving quality of life by alleviating symptoms while preserving cognitive functions as much as possible. Above all, it should be guided by the patient’s priorities.

In the dying phase, the focus of symptom-oriented palliation shifts to striving for the best possible quality of death. There are no strict criteria for marking the start of the dying phase; it begins when it is clear that death is unavoidably close and typically spans the last 1–2 weeks before death.

6.4.2 Domains of the *Quality Framework for Palliative Care*

The *Quality Framework* is organised into 10 domains:

1. Core principles and values
2. Structure and process

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3. Physical health
 4. Mental health
 5. Social well-being
 6. Spiritual well-being
 7. Dying
 8. Loss and grief
 9. Culture
 10. Ethics and justice

Within each domain, the *Quality Framework* outlines standards of practice and, where relevant, recommends specific tools and measures for assessing well-being.

6.4.2.1 Core principles and values

The *Quality Framework* outlines the core principles of palliative care in the Netherlands. It acknowledges that quality of life is highly dependent on the patient's personal characteristics, the quality of their relationships, their psychological balance, the fulfilment of their life goals, the degree of adaptation to their circumstances, and their reaction to their environment. It therefore highlights the importance of addressing psychological, social, and spiritual well-being in addition to focusing on pain relief and improving symptoms.

There is a strong emphasis on patient choice. Because cognitive functions (hearing, seeing, understanding, and thinking) are required to be able to experience many aspects of well-being, there is an acknowledgement that some patients may prefer to forgo pain and symptom management in order to preserve cognitive functioning. In these cases, the patient's wishes must be respected.

The *Quality Framework* specifies a number of key principles that should guide providers of palliative care:

- Start palliative care early (e.g. upon diagnosis of a life-threatening illness) and simultaneously with disease-oriented treatment.
- Draw up an individual care and treatment plan together with the patient based on their goals, needs, limitations, and wishes.
- During the course of the disease trajectory, regularly consult with the patient to see whether their needs or wishes have changed.
- Be mindful of the patient's ability to cope with their illness and adapt care and support accordingly.
- Involve all relevant care providers (in the home, nursing home, hospital, and other institutions) actively and as early as possible in the treatment process.
- Communicate and collaborate with each other, know your own limits, and respect each other's opinions and expertise.
- Coordinate care for continuity and to ensure smooth transfers between care providers.
- Ensure that it is clear to the patient at all stages of care who their lead practitioner is and who their lead practitioner's supervisor is.
- Consult experts if you are unsure of how to support a patient in any aspect of palliative care – physical, psychological, social, or spiritual
- Maintain awareness of the emotional impact that the provision of palliative care has on you, reflect on your own attitudes and actions, and strive to take care of yourself and your colleagues

Additionally, the *Quality Framework* states that palliative care must:

- Provide a sense of safety and security to patients without judgement, coercion, discrimination, or intimidation.
- Prevent unnecessary risks or burdens.
- Prevent unnecessary repetition of medical tests and examinations.
- Guarantee privacy and confidentiality.
- Be provided according to national laws and regulations.

6.4.2.2 Structure and process

The standards regarding the structure and process of palliative care in the Netherlands focus on early recognition of care needs; joint decision-making between providers, patients, and their loved ones; proactive care planning; individualised care plans; coordination between providers; and continuity of care.

There is a strong emphasis on communication with patients and fellow providers in this domain. For example, regarding the early recognition of palliative care needs, there is specific guidance on assessment of needs and communication with patients. Palliative care is integrated into general care in the Netherlands and is primarily provided by GPs, community nurses, and doctors working in nursing homes. As a result, in addition to recommending that palliative care begin upon diagnosis of a life-threatening illness, the *Quality Framework* recommends that primary care providers be guided by asking themselves a key question when assessing a patient's need for palliative care: Would I be surprised if this patient died within a year? The *Quality Framework* also specifically notes that this question should be kept in mind for older frail patients and for patients with a chronic condition who have deteriorated. If, upon reflection, providers feel that they would not be surprised if their patient died within a year, they should consider beginning a conversation with the patient about their wishes for their care and the end of their life. This process should be guided by proactive care planning, which is a continuous and dynamic process in which the life goals and choices of the patient are central. The *Quality Framework* suggests that providers pay careful attention to:

- Gauging the patient's openness to discussing the end of life
- Introducing the sensitive subject of the end of life
- Making an inventory of the topics to be discussed, covering physical, psychological, social, and spiritual well-being
- Establishing mutual expectations about the course of the disease prognosis
- Identifying the goals and choices for now and in the future – for example, around the desired care in the last phase of life
- The role of loved ones and caregivers, and
- The instructions of the patient, loved ones, caregivers, or volunteers.

Providers should also specifically focus on identifying the patient's wishes in the following areas:

- Treatment of the disease and symptoms
- Resuscitation and ventilation
- Administration of fluid and food
- Drawing up a written living will
- Appointing a legal representative
- Desired place of death

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- Stopping eating and drinking to accelerate the end of life
 - Palliative sedation
 - Euthanasia

The patient's wishes should then be recorded and shared with other care providers. Their wishes should be implemented through an individual care plan that is adapted as the patient's needs and wishes change. The *Quality Framework* recommends that the individual care plan should be revisited and updated at the following times:

- On the instructions of the patient, loved ones, caregivers, or volunteers
- At disease or frailty progression
- At transition from disease-oriented to symptom-oriented treatment
- With multiple hospital admissions in a relatively short period
- If the benefits of disease- or symptom-oriented treatment no longer outweigh the disadvantages
- With expected functional or cognitive decline due to illness or frailty
- On diagnosis of diseases associated with cognitive impairment, such as dementia
- On admission to a nursing home or hospice
- With severe physical, psychological, or spiritual suffering

6.4.2.3 Physical health

The management of physical symptoms starts with a structured and methodical inventory of each symptom, but symptoms are also assessed and discussed with patients on an ongoing basis. Symptom management ought to focus on:

- The nature and severity of the symptom
- The cognitive, social, and spiritual dimensions of the symptom
- The burden to the patient
- The consequences of the symptom for the patient's loved ones

The *Quality Framework* recommends the use of a symptom diary to track the severity of symptoms. It specifically recommends the Edmonton Symptom Assessment System; this is a standardised questionnaire in which common symptoms are graded.

Specific guidelines and validated measures of assessment are provided for the following physical symptoms:

- Ascites
- Cancer pain
- Complaints of the mouth
- Constipation
- Cough
- Dehydration and fluid administration
- Diarrhoea
- Dyspnoea
- Fatigue
- Fever

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- Hiccups
 - Itching
 - Lymphoedema
 - Nausea and vomiting
 - Pain
 - Pressure sores
 - Ulcers
 - Urogenital problems, fistulas, and tenesmus

Additionally, specific palliative care guidelines are provided for the following conditions:

- Amyotrophic lateral sclerosis
- Cancer
- Chronic obstructive pulmonary disease
- Dementia
- Heart failure
- Multiple sclerosis

There are also guidelines on palliative care for people with intellectual disabilities.

6.4.2.4 Mental health

A fundamental aspect of palliative care is that providers address the psychological consequences of a life-threatening condition or vulnerability. Mental health support aims to increase the psychological well-being of the patient and their loved ones. The *Quality Framework* recommends that providers focus on the following key areas regarding their patients' mental health:

- Supporting patients as they work towards processing and accepting the illness or condition
- Identifying patients' values and choices
- Helping patients maintain a sense of identity
- Helping patients maintain or regain a sense of meaning in life
- Identifying risks and obstacles to mental well-being
- Managing the burden of the illness or condition on the family

In the Netherlands, primary care providers receive targeted training in recognising and treating common psychological and psychiatric symptoms (including anxiety, depression, delirium, complex grief, loneliness, hopelessness, hallucinations, suicidal thoughts, and withdrawal symptoms from addiction). Specific guidelines and validated measures of assessment are provided for supporting patients receiving palliative care who are experiencing:

- Anxiety
- Fear
- Delirium
- Dementia
- Depression
- Sleeping problems

Providers are encouraged to seek support from specialists if they feel that their skill set does not meet the patient's mental health needs, particularly in cases of anxiety, delirium, depression, and suicidal thoughts.

6.4.2.5 Social well-being

A life-threatening condition or vulnerability affects a patient's social functioning because it changes their roles and responsibilities. Moreover, it affects the well-being of their children, partner, parents, extended family, colleagues, friends, neighbours, and employer. Providers need to support the social well-being of their patients so that their goals, wishes, and needs can be met and so that the well-being of their loved ones can be increased.

Palliative care providers can support the social well-being of both the patient and their loved ones by:

- Understanding a variety of ways to support those experiencing illness, loss, and grief so that care can be tailored to individuals
- Providing emotional and social support
- Discussing the goals, wishes, and needs of all involved
- Having a transparent decision-making process where the patient and their loved ones are central
- Communicating closely with other care providers and volunteers

Together with the patient and their loved ones, providers should assess a patient's priorities for their social well-being by discussing:

- Family structure and function – changing roles and responsibilities, patterns of communication, coping, processing, and decision-making
- Strengths and vulnerabilities – ability to cope with challenges, resilience, presence of supportive social and cultural networks, effect of illness or vulnerability on intimacy, previous experience with illness, disability, and loss
- Making choices and setting priorities – participation in social networks, school, and work, and wishes for daytime activities and recreational activities
- Living situation – changes in financial situation, geographical location, and suitability of residential environment; use of aids and transport; and adaptations in the home where required
- Estimation of care needs and availability of care – professional care options in the area, peer support from others experiencing the same illness, financial support for care, commitment of volunteers, and respite care
- End of life – restoring lost contacts, making last wishes, drawing up a will and an advance directive, and arranging the funeral

Providers should discuss the feasibility of the patient's goals, wishes, and needs with the patient and their loved ones. Providers should document areas that have been identified in which the patient needs support in the individual care plan. Experts should be consulted if required, and the patient should be referred to appropriate authorities for support with identified social needs.

6.4.2.6 Spiritual well-being

Supporting spiritual well-being is central to palliative care, and the *Quality Framework* stipulates that all providers of palliative care should be able to support a patient's spiritual well-being. The following principles should guide support in this area:

- The provider is aware of their own values and beliefs, recognises that their own spirituality is part of their professional functioning, and does not impose their personal values, spiritual beliefs, or existential beliefs on patients, loved ones, or colleagues.

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- The provider has received targeted training, is able to identify spiritual needs, and has basic skills for providing support.
 - In communicating with the patient and their loved ones, the provider shows respect for spiritual beliefs and rituals.
 - The provider pays attention to the patient's life story and is able to recognise what the patient derives meaning from and areas in which they have lost a sense of meaning.
 - The provider pays attention to the values, wishes, and needs of the patient and their loved ones in terms of spiritual well-being and identifies how the patient feels their care could be adapted to meet their spiritual needs.
 - The provider pays attention to what touches and moves the patient and their loved ones in their confrontation of illness and loss, and is able to recognise spiritual distress or existential crisis

Providers should maintain awareness of the following factors that can influence a patient's spiritual well-being:

- Fear, sadness, resignation, anger, and resistance in relation to experiencing meaning in life
- The search for meaning in the past, present, and future
- Questions about existence, identity, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, and love and joy, and the need for rituals
- Relationship to oneself, neighbours, culture, ethics, morality, and life itself
- Philosophical beliefs, faith, conviction, relationship with the divine, and relationship with nature, and
- Barriers and risks to spiritual well-being.

Additionally, the guideline *Meaning and spirituality in palliative care* is available so that providers can distinguish between situations in which:

- A patient's spiritual well-being can be adequately supported by primary providers of palliative care
- A patient would benefit from counselling to support their spiritual well-being and to help them address existential questions, and
- A patient is experiencing an existential crisis that requires crisis intervention by a spiritual counsellor, medical social worker, or psychologist.

The guideline provides information on how to address a patient's questions and concerns about meaning and spirituality and how to enter into a conversation about spirituality and existential questions with a patient, as well as outlining the training that is available to providers.

Once providers have identified the patient's needs in terms of spiritual well-being, they should document them in the individual care plan and should consult experts and refer the patient to a spiritual caregiver as needed. Visits by spiritual caregivers should take place at home if the patient wishes.

6.4.2.7 Dying

In the dying phase, the focus shifts from striving to maintain quality of life to striving for the best possible quality of dying. The dying phase begins when it is clear that death is unavoidably close; it typically spans the last 1–2 weeks before death. A specific guide entitled *Care Path in the Dying Phase* provides details on how to care for patients who are approaching death. Three aspects of palliative care become paramount during the dying phase: relief of symptoms, attention to psychosocial and spiritual problems, and care coordination.

Specifically, the *Quality Framework* recommends that as a patient enters the dying phase, providers address the following:

- Communicate to all providers involved in the patient's care that the patient's death is imminent.
- Provide adequate relief of pain and other symptoms.
- Avoid an unnecessarily long dying period.
- Maintain awareness of the values, wishes, and needs of the dying patient.
- Identify the patient's desired place of death.
- Maintain the patient's sense of control over their own life.
- Maintain clear and collaborative decision-making, with the patient and their loved ones ultimately being in charge (with agreements documented in the individual care plan).
- Establish agreements regarding the accessibility and availability of care providers in the event of changes in a patient's physical, psychological, social, and spiritual well-being.
- Discuss sensitive issues such as autopsy, organ and tissue donation, or the provision of the body to science.
- Prepare the patient for dying.
- Give the patient the opportunity to complete life and to strengthen their bonds with their loved ones.
- Support the patient's loved ones and caregivers and prepare them for grieving.
- Give loved ones space to say goodbye and ask if they want to provide the last care to their loved one.
- Ensure that post-death care is respectful and honours the dignity, culture, and philosophical beliefs of the patient and their loved ones.
- Upon death, inform all of the patient's care providers that the patient has died, preferably by phone rather than in writing.

Timely recognition of the dying phase is crucial. The *Quality Framework* highlights the risks of missing the dying phase for the patient in terms of preparing for the best possible quality of death, and for their loved ones in terms of preparing for grieving.

Several indicators of the dying phase are identified:

- The patient no longer gets out of bed.
- The patient is semi-comatose.
- The patient is only able to drink small sips.
- The patient is no longer able to take tablets.

However, because the above indicators can be present for long periods of time, ultimately the identification of the dying phase should be based on the collaborative judgement of multidisciplinary care providers.

In the dying phase, the management of symptoms takes priority for many patients, and thus the maintenance of cognitive functions is sometimes no longer feasible or desirable. There is specific guidance for providers regarding palliative sedation, the intention of which is to reduce discomfort and not to shorten the patient's life. Palliative sedation is defined as the deliberate lowering of a patient's consciousness in the final stage of life. Typically, palliative sedation takes the form of continuous sedation until death; however, it can also be used for short or intermittent periods. Palliative sedation is widely used in the Netherlands. The *Quality Framework* notes that approximately 18% of all deaths in the Netherlands involve continuous and deep sedation prior to

death. Among these, it is estimated that 47% of patients have cancer, 17% have cardiovascular disease, and 36% have other diseases. Additionally, it is estimated that approximately 75% of patients who choose to undergo continuous and deep sedation until death are aged 65 years or older.

The *Quality Framework* also discusses euthanasia; it refers to and summarises a separate guideline for physicians regarding euthanasia. The intention of euthanasia is to end life according to the patient's wishes. Euthanasia has been legal in the Netherlands for nearly 20 years. In order to proceed with euthanasia, the physician must establish in advance that all due care criteria have been met, including the requirement to consult with at least one other independent physician regarding the patient's request for euthanasia. The *Quality Framework* notes that national and international literature was consulted when developing the guidelines for euthanasia; however, there was very limited literature available. Therefore, the guidelines were primarily based on Dutch law, judgments from Dutch medical disciplinary boards, and judgments and annual reports from regional review committees on euthanasia. The guidelines were also reviewed by key medical and scientific associations as well as by individual experts.

6.4.2.8 Loss and grief

Supporting loved ones as they grieve is considered a key part of palliative care in the Netherlands. Providers should guide patients' loved ones through the grieving process while being mindful of their social, cultural, and spiritual preferences. Providers should pay particular attention to the way in which next of kin respond to the loss of their loved one, including their physical, emotional, cognitive, spiritual, existential, and behavioural responses. A few weeks after the death of their loved one, next of kin should be contacted by the central care provider to see how they are coping, and how they look back on the period of the patient's illness and death and on the care provided. In the event of signs of complex grief, next of kin should be advised to contact their GP, and the care provider may also contact the GP directly in consultation with the next of kin. Experts, including grief therapists, spiritual counsellors, social workers, psychologists, and psychiatrists, are available in cases of complex grief. The *Quality Framework* also emphasises the importance of providers maintaining awareness of their own grief from the loss of patients, and encourages providers to seek support from specialists when they feel they need help coping.

6.4.2.9 Culture

The cultural background of the patient, their family, and their community should be recognised and respected throughout the care process. Each provider should also be aware of their own cultural background and should reflect on how their cultural values, professional culture, and potential prejudices may influence their perception of patients and their loved ones, and of colleagues.

The patient and their loved ones should receive support from providers that is appropriate to their cultural background. When assessing care needs, the provider should discuss culture with their patient, focusing on customs and rituals, cultural forms of support, and the meaning of life, illness, vulnerability, and death. The preferences of the patient and their loved ones should be recorded in the individual care plan. If necessary, experts or organisations with knowledge of the relevant cultural background should be involved in care. In cases of patients who do not speak Dutch, interpreters should be contacted as needed (if loved ones are unavailable).

The *Quality Framework* also links to a separate document with detailed guidance on providing palliative care to patients with a non-Western background.

6.4.2.10 Ethics and justice

Palliative care is provided within the framework of applicable laws and regulations, existing professional ethical codes, and available guidelines and care standards for all disciplines involved. Providers must be able to recognise, acknowledge, and address complex ethical and legal issues that may arise in the care of patients with a life-threatening condition or vulnerability. In order to do so, they should have access to ethical and legal expertise. In particular, in the event of disagreement among providers and/or patients and loved ones regarding ethical or legal dilemmas, an ethicist or

ethics committee should be involved, or legal support should be sought. Ethical dilemmas may include establishing wishes regarding refraining from or stopping treatment; resuscitation; palliative sedation; and euthanasia. All ethical decisions must be noted in the patient's medical file and individual care plan.

Providers must have knowledge of, and act on, a variety of ethical and legal aspects of palliative care, including:

- Access to the patient's medical file or provision of personal medical information
- Informed consent
- Advance directive
- Consciously stopping eating and drinking
- The role and responsibilities of legal representatives
- Organ donation
- Palliative sedation
- Euthanasia

The patient and their loved ones should be advised by the provider to seek professional advice when drawing up or updating legal or financial documents, including wills and custody documents. For patients who are no longer able to communicate and who have not previously made their wishes known, the provider should identify whether a legal representative has been appointed, and whether there is a living will or whether the patient's wishes have been put down in writing.

6.4.3 Future recommendations

As part of the development of the *Quality Framework*, a review of palliative care in the Netherlands was undertaken and several key policy recommendations were made:⁶⁶

- The quality indicators that are under development (and will be released by the end of 2020) should be used to ensure high-quality care.
- Implementation of the *Quality Framework* should be carried out in consultation with patients, care providers, and health insurers.
- A coordination group should be set up to facilitate implementation.
- Supplements to the *Quality Framework* should be developed for specific target groups.
- Awareness of palliative care among citizens should be increased by expanding the public awareness campaign to include information on the importance of joint decision-making, of proactive care planning, and of the individual care plan.
- A digital individual care plan for palliative care that is available to all providers and to the patient is an essential tool to overcome the challenges in coordinating care that have been identified.
- The palliative care component of training for health providers should be updated based on the guidelines in the *Quality Framework*.
- Support for providers (GPs and district nurses in particular) should be expanded, with a specific focus on addressing the high levels of burnout that have been identified among palliative care providers.
- A national register of data on palliative care should be developed to facilitate research and evidence-based practice.

6.4.4 Care settings and providers

The *Quality Framework* sits within the specific context of palliative care in the Netherlands, where there has been a longstanding focus on palliative care as generalist care. Dutch national policy states that palliative care should primarily be provided in the primary care setting, where GPs and district nurses play a leading role.⁶⁶ In care homes, geriatricians who have specialised in palliative care play a key role.⁷¹ Palliative care is also provided by voluntary workers and, in rare cases, by medical specialists.⁷⁴ The Ministry of Health, Welfare and Sport has stated that a key goal in palliative care is to further improve integration across settings and providers, as demonstrated by the establishment of regional networks that aim to promote collaboration and coordination of care (as described in Section 6.2).⁶²

6.4.4.1 Care in the community

GPs in the Netherlands perceive palliative and end-of-life care as an integral part of their role, and all GPs in the Netherlands have formal palliative care training.⁶⁴ It is estimated that 61–80% of palliative care needs are identified at the primary care level.⁷¹ On average, GPs support around five or six patients annually in their practice.⁷⁵ In their last year of life, it is estimated that people in the Netherlands have, on average, 27 contacts with a GP.⁶²

There is a strong emphasis on providing care at home and dying at home when possible.⁷⁴ Among GP contacts, the number of home visits is twice as high as office visits in a patient's last year of life.⁶² In the last week of life, patients have, on average, five home visits from their GP.⁶⁴ Among home-dwelling patients who do not die suddenly, it is estimated that 51% die at home.⁷⁶ This aligns with the preferences of the population; a national survey found that among those with advanced cancer, 84% of people in the Netherlands preferred to die at home.⁷⁷

GPs lead palliative care in the Netherlands and refer patients to specialists when complex problems arise, which reflects the country's gatekeeper model of access to specialists.⁷⁸ A qualitative study in the Netherlands evaluated the opinions of GPs and oncologists regarding who should provide care for patients receiving palliative chemotherapy.⁷⁹ The authors found that both the GPs and oncologists agreed that GPs should provide end-of-life care and that they should be involved in decisions about palliative chemotherapy. However, the authors also concluded that the specific delineation of care responsibilities between GPs and oncologists during palliative chemotherapy has not been clearly defined. Notably, a majority of participants highlighted communication between the GP and the oncologist as essential to further improving the coordination and quality of care.⁷⁹

A study of GPs and district nurses in the Netherlands assessed the extent to which they engaged other service providers in palliative care, and found that most GPs reported that they sometimes or often involved palliative home care teams (99%), hospices (94%), and palliative care consultation services (93%).⁷⁸ Most district nurses reported sometimes or often involving volunteers (90%), hospices (88%), and spiritual caregivers (80%). Notably, the least involved service providers were psychologists and psychiatrists; 51% of GPs and 50% of district nurses reported that they sometimes or often involved psychologists and psychiatrists and 44% of GPs and 57% of district nurses reported that they sometimes or often involved social welfare workers. Additionally, the participating GPs and district nurses suggested improvements in three key areas to promote engagement with a wider variety of service providers: establishment of local centres providing information on available services and facilities; presentation of services and facilities in local multidisciplinary meetings; and supporting organisations to proactively offer their facilities and services.⁷⁸

6.4.4.2 Palliative care consultation teams

Palliative care consultation teams were established in 1997 to inform, support, and advise GPs, nursing home physicians, home care nurses, and district nurses in providing palliative care without taking over responsibility for direct patient care.⁸⁰ They support primary care providers with complex problems, such as managing challenging symptoms or negotiating a difficult family meeting.⁶⁵ However, it is ultimately up to the patient's lead palliative care provider (typically their GP) to decide whether or not to take on the palliative care consultation team's suggestions.⁶⁵

A nationwide study found that the problems that providers sought advice from palliative care consultation teams about covered the entire field of palliative care, although physical problems were most commonly discussed.⁸⁰ The study also found that the physician from the palliative care consultation team was often able to identify more problems than initially discussed by the requesting provider, even though the physician from the palliative care consultation team rarely saw the patient in person. According to GPs and district nurses who participated in the study, support from palliative care consultation teams was helpful and contributed to improving the quality of palliative care that they provided.⁸⁰

6.4.4.3 Hospital-based care

National policy in the Netherlands stipulates that every hospital must have a palliative care team – a group of hospital-based physicians and nurses with extensive experience of providing palliative care, and from whom other hospital-based providers can seek support.⁶⁵ Notably, hospital-based palliative care teams are separate from palliative care consultation teams which support primary care providers (see section 6.4.4.2 above). A study of hospital-based palliative care teams found that the most common providers represented on the teams were nurses (72%) and nurse practitioners (54%), physicians specialising in internal medicine (90%) or anaesthesiology (75%), and spiritual caregivers (65%).⁶⁵ Most teams (77%) were only available during office hours. Twenty-six per cent of the teams could be consulted by both health professionals and patients or loved ones. The annual number of consultations ranged from 2 to 680 (median: 77). On average, teams were consulted for 0.6% of all patients admitted to the hospitals, which the authors noted is low compared with other countries. The authors also found that hospital staff highlighted the lack of adequate financing for palliative care teams as a challenge, particularly in terms of training and skills development.⁶⁵ Despite these challenges, a recent study assessing the impact of palliative care consultation teams on the quality of life of patients with advanced cancer in Dutch hospitals found that consultations decreased patients' symptom burden and had a positive effect on quality of life, even when the team was consulted late in the patient's disease trajectory.⁸¹

6.4.4.4 Hospices

As of 2019, there were 46 standalone inpatient hospices for adults in the Netherlands.⁷¹ Approximately 10% of all non-sudden deaths in the Netherlands occur in inpatient hospice facilities.⁸² Most of these facilities are concentrated in large cities and in the western part of the country.⁸² A national study of inpatient hospices found that 84% of patients applying for inpatient hospice care had cancer, and 52% of applicants resided in hospital at the time of admission. The most frequent reasons for application were the wish to die in an inpatient hospice facility (71%), needing intensive care or support (52%), relieving caregivers (41%), and needing pain/symptom control (40%). Several factors were associated with being admitted to an inpatient hospice: living alone, having cancer, wanting to relieve caregivers, needing pain/symptom control, wanting to be admitted as soon as possible, and being referred by a primary care professional. The authors noted that non-cancer patients seem to be an under-represented population, especially because they are less often referred to hospice care, and they suggest that staff should consider applications based on need for palliation, irrespective of diagnosis.⁸²

6.4.5 Training

Palliative care policy is based on the principle that the majority of palliative care should be provided at the primary care level, with input from experienced providers when required.⁸³ This requires a high level of expertise among generalist providers of palliative care.⁸³ Variation in the skills required to recognise and address palliative care needs has been identified as a barrier to high quality care.⁸³ An educational framework for palliative care was developed in 2016 to clarify the required competencies of generalist providers of palliative care.⁶⁶ Core aspects of palliative care, including symptom management and aligning treatment with patients' goals, are integrated into professional training.⁶⁵ The Dutch College of General Practitioners has developed a directory of all GPs who have completed the palliative care accreditation process.⁷¹

For care providers with expertise in palliative care (most of whom work as part of palliative care teams supporting generalists), there is as yet no description of the required qualifications. The Dutch Government has acknowledged the need to develop an educational framework for expert-level providers supporting generalists in palliative care.⁶⁶

For volunteers involved in palliative care, there are a variety of training programmes available, and many hospices run their own courses for volunteers.⁷¹

6.5 Key performance indicators

A set of national quality indicators for palliative care based on the *Quality Framework* are to be developed by the end of 2021.⁶⁶

6.6 Trends in demand

In 2017, approximately 105,766 people died in the Netherlands.⁸⁴ An estimated 70% of these deaths may have required palliative care support. More deaths occurred in densely populated areas, suggesting the need for additional resources in these areas to meet demand. The leading cause of death was cancer (44%); however, there were no notable differences in cause of death across regions.⁸⁴

In the Netherlands, approximately 19% of the population is over 65. By 2030, this is projected to increase to 24% of the population.⁸⁵ Due to increased life expectancy, over-65s will outnumber young people by 2030. Increased life expectancy means the proportion of people living with chronic conditions will also rise, but the disability burden is expected to remain stable during this period. Dementia is also predicted to surpass lung cancer to become the leading cause of death by 2030.⁸⁵

6.7 Interface between adult and children's palliative care

Palliative care policy documents from the Netherlands do not clarify how the interface between adult and children's palliative care is addressed. However, extensive details are provided regarding how children's palliative care is provided. The *Quality Framework* notes that children's palliative care differs fundamentally from palliative care for adults,⁶⁶ and these differences are largely due to the types of disorders that are prevalent, the longer duration of palliative care in children, and differences in the organisation of care. Due to the medical complexity of the care of children with life-threatening illnesses, children's palliative care primarily takes place in university medical centres, top clinical centres, and centres that provide high-level neonatology. However, children who can be cared for at home are provided with a nurse at home. GPs rarely provide palliative care for children, and palliative care teams in hospitals are only involved in paediatric palliative care in exceptional cases.⁶⁶

Paediatric palliative care is primarily provided by multidisciplinary children's teams with paediatricians and subspecialists, including neonatologists, as lead providers.⁶⁶ All university medical centres in the Netherlands have *Kinder Comfort Teams* which provide palliative care to inpatient children. These are multidisciplinary teams with paediatricians, nurses, psychologists, social workers, spiritual counsellors, and pedagogical specialists. There are also 45 palliative day care programmes for children across the country, which are primarily staffed by nurses. Additionally, there are several respite centres for families with terminally ill children. There is a move towards increasing the provision of palliative care at home for children, and the intention is that the paediatrician in charge of a child's care in a university medical centre would coordinate closely with the patient's GP and district nurses to facilitate home care.⁶⁶

While the *Quality Framework* (see section 6.4) is specifically for adult palliative care, each domain has a subsection explaining differences between palliative care for children and adults.⁶⁶ We have summarised these subsections below.

6.7.1 Core principles and values

Palliative care for children aims to improve quality of life, preserve dignity, and reduce suffering for seriously ill or dying children in a way that suits their education, environment, and culture. It is essential to continue to see the child behind the illness and to pursue an approach based on their developmental potential. Palliative care begins at diagnosis and continues regardless of whether the child is receiving disease-specific treatment. Care for siblings and parents, including aftercare following death, is also integral to paediatric palliative care.

6.7.2 Structure and process

Healthcare providers should carefully assess and support a child's physical, psychological, and social well-being. The *Paediatric Palliative Care Guideline* provides extensive detail on the structure, process, and standards of care for children's palliative care. Because the care of children with life-threatening illnesses is often complex, many different disciplines are often involved.

The following areas are particularly important in providing palliative care to children:

- The lead provider must have completed training in the field of paediatric palliative care.
- A case manager (typically a coordinating nurse) and a lead practitioner are appointed to ensure coordination and continuity of care.
- Joint decision-making is crucial due to the multidisciplinary nature of care.
- Proactive care planning and communication of expectations with parents and siblings is especially important.
- The hospital's Kinder Comfort Team provides direct support to providers and to families.
- Providers can also access support from others with extensive experience of paediatric palliative care through the national Centre of Expertise in Children's Palliative Care.

6.7.3 Physical health

There is specific guidance provided for treating the following symptoms because they have been identified as particularly common among children:

- Dyspnoea
- Haematological symptoms
- Cough
- Rattle
- Skin symptoms (itching, wounds/pressure sores, mucositis)
- Nausea and vomiting
- Pain
- Neurological symptoms
- Seizures
- Spasticity
- Symptoms of failure
- Fatigue

6.7.4 Mental health

There is an emphasis on treating anxiety and depression in children receiving palliative care and on the importance of supporting the psychological well-being of parents and siblings throughout care and after death.

6.7.5 Social well-being

Key aspects of a child's social well-being are highlighted in the *Paediatric Palliative Care Guideline*:

- Daily schedule and prioritising activities
- Contacts with the school
- Creating an inventory of family needs (including respite care)
- Maintaining an ordinary life as much as possible

6.7.6 Spiritual well-being

A spiritual caregiver is a key member of Kinder Comfort Teams. Key aspects of spiritual well-being for children that are emphasised are:

- Family wishes surrounding religious traditions
- The role of philosophical factors in anxiety and depression
- Involving a spiritual counsellor to review philosophical factors

In addition, there is recognition that religious beliefs often determine how parents care for their children, how they process illness, and how they make end-of-life decisions.

6.7.7 Dying

There is specific guidance in the *Paediatric Palliative Care Guideline* regarding symptoms that mark the beginning of the dying phase in children, options for alleviating suffering, and how to support the family to say goodbye in a meaningful way and in an appropriate environment.

6.7.8 Loss and grief

There is a strong emphasis on supporting parents and siblings in mourning, particularly because complex grief is very common following the loss of a child. Anticipated grief should also be addressed and supported throughout the progression of the disease.

6.7.9 Culture

The *Paediatric Palliative Care Guideline* states that the cultural background of the child should play an important role in how care is provided throughout the progression of the disease and at the end of life. The *Quality Framework* notes that more details are required in the next update of the *Paediatric Palliative Care Guideline* to support providers in being sensitive to cultural issues with children receiving palliative care.

6.7.10 Ethics and justice

Ethical and legal considerations regarding palliative care differ considerably for children. The *Paediatric Palliative Care Guideline* discusses these issues in detail. It highlights the complex ethical issues in palliative care for children and their families, including how to address moral dilemmas and what to do when disagreements arise. It also clarifies the legal aspects of the decision-making process regarding the provision of information, consent, and care of children in the palliative phase.

6.8 Telemedicine

We did not identify information in the English literature regarding the prevalence of or nature of telemedicine for direct patient care in the Netherlands. However, the focus on generalist provision of palliative care in the Netherlands necessitates a strong emphasis on specialist support through phone and email consultations between generalists and palliative care consultation teams (see section 6.4.4.2 for a description of palliative care consultation teams).⁶⁵ In 2018, more than 6,000 phone consultations for palliative care providers were registered.⁸⁶ The questions were mainly asked by GPs (68%), but medical specialists, nurses, and carers also use the service. The most frequently discussed problems were pharmacological in nature (70%) focusing on dosage, administration, or contraindications. Providers also access support through an app called Palliarts.⁸⁶ In 2018, the app was most frequently used to access care guidelines (28%), availability of beds in hospices (22%), and medication information (17%).⁸⁶

6.9 Funding and costs

Most palliative care services in the Netherlands are covered by the Government-subsidised basic health insurance package⁷¹ – the costs of GPs, hospital visits, and medicines are reimbursed under the Healthcare Insurance Act.⁶⁷ A dedicated palliative care budget was introduced in 2012 for hospital consultation and advisory services, and it has improved both the profile and stability of hospital-based services.⁶⁵ Notably, hospitals and hospices both function as privately owned non-profit organisations in the Netherlands.

Home care and care in nursing homes is financed under the General Exceptional Medical Expenses Act.⁶⁷ Support for informal caregivers is regulated by the Social Support Act and differs across regions. Additionally, the national support organisation Volunteers for Palliative Terminal Care receives a subsidy from the Ministry of Health, Welfare and Sport for the promotion of expertise among volunteers. There is also strong reliance on charitable funds to support services, which can contribute to regional inequities or instability in funding during economic downturns.²⁵

Funding for hospital- and community-based palliative care services is based on a mixture of activity-based and non-activity-based funding. Hospital-based palliative advisory services care are funded based on service characteristics or intensity of provision (e.g. hours of care provided, number of contacts provided), while hospices are paid per bed day used.²⁵ GPs are funded through a combination of capitation, fee-for-service, and pay-for-performance.⁸⁷

A study of mean per capita hospital expenditures in the last 180 days of life among people aged 65 years and older who died of cancer found that expenditures were lower in the Netherlands than in Belgium, Canada, England, Germany, Norway, and the United States.⁸⁷ This may be a reflection of the shift away from long term care towards ageing-in-place, which has led to increased utilisation of district nursing support at an overall lower cost for over 65s.⁸⁸

6.10 Response to COVID-19

A wide variety of resources have been developed to support providers of palliative care in the context of COVID-19 in the Netherlands. A six-part series of training videos focusing on palliative care for COVID-19 patients has been developed for doctors and nurses.⁸⁹ Additionally, a two-page 'pocket guide' to providing palliative care for COVID-19 patients was published.⁹⁰ It begins by outlining three core principles of palliative care for COVID-19 patients:

1. It focuses on allowing patients to die with dignity, primarily by alleviating suffering.
2. It concerns attention to physical, psychological, social, and spiritual well-being.
3. The preservation of autonomy, access to information, and options is paramount.

The document lays out three key aspects of palliative care for COVID-19 patients that providers should focus on: attention, presence, and anticipation. The concept of attention emphasises getting

to know the patient by keeping the following question in mind: Who is the person behind the patient? It then suggests key questions to ask patients:

- What is your background (partner, children, profession, living situation, religion)?
- What is important to you?
- What hopes, fears, or expectations do you have for the near future?
- Do you have any concerns?
- Who do you want to have with you and/or who would you like to speak with?
- What are your expectations of my care and how can we work together to achieve this?

The second concept – presence – focuses on being as supportive as possible of the patient and their loved ones. Providers are advised to display their name and professional role on a sticker on their protective clothing or to use a large photo ID card with their name and wear this on a lanyard. Providers are also encouraged to help patients maintain contact with their loved ones to the extent that is feasible. Because protective measures limit opportunities for meaningful contact and saying goodbye, the guide notes that it is very important to be honest and open with patients and their loved ones about what is feasible in terms of contact. Providers should also emphasise to patients that they are there to support them.

The third concept – anticipation – encourages providers to communicate honestly with patients and their loved ones about their expectations, and not to avoid conversations about the future. Because COVID-19 patients can deteriorate very quickly and unexpectedly, patients and families should be prepared for this potential outcome. Patients and their families may not realise how quickly deterioration can take place, and it is therefore important not create unrealistic expectations while keeping in mind that many will find it very difficult to cope with facing sudden deterioration. Providers are advised to:

- Initiate a conversation with the patient and their loved ones about what may come and about the end of life, and create space for them to discuss feelings of guilt, fear, uncertainty, and grief about impending loss.
- Discuss the patient's wishes and needs and implement these as much as possible.
- Refer the patient to appropriate authorities for support with social needs during their care (e.g. childcare).
- Identify who may speak on behalf of the patient if they are no longer able to make decisions regarding their care.
- Consider linking the patient to a spiritual counsellor if the patient feels they would benefit from this.
- In the case of death, support loved ones as they mourn and link them to support services, for instance grief therapists and spiritual counsellors, if they are experiencing complex grief.

The guide also notes that providers should not hesitate to reach out to their hospital's palliative care team if they feel unsure of how to support a patient. Additionally, providers are encouraged to be mindful of their own well-being, to reach out for support if they are having difficulty coping, and to ask their colleagues how they are doing and encourage their colleagues to reach out for support.

In addition to the pocket guide, a wide variety of documents have been published to support health professionals in providing palliative care to COVID-19 patients, as outlined under the six categories below.⁸⁹

Patient care:

- *Principles of palliative care in the time of COVID-19*
- *Guide for GPs providing palliative care for COVID-19 patients*

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- *Symptom control in patients with COVID-19*
 - *Symptom control in patients with COVID-19 in the nursing home setting*
 - *Guidelines for palliative sedation in case of shortages of medications and/or medical equipment*
 - *Information for healthcare and funeral home staff in the time of COVID-19*
 - *Guidelines for engaging spiritual caregivers to support COVID-19 patients*
 - *Practical tools for palliative care for people with dementia in the time of COVID-19, and*
 - *Recommendations for hospice care in the time of COVID-19.*

Supporting carers and loved ones:

- *Practical information for informal carers of COVID-19 patients*
- *Care for carers and loved ones of COVID-19 patients*
- *Tips for family members of critically ill COVID-19 patients*
- *Guide for informal carers and volunteers providing palliative care for COVID-19 patients*
- *Guidelines for contact with family members of COVID-19 patients in hospitals or nursing homes*
- *Guidelines for contact with family members of COVID-19 patients in hospices.*

Supporting health professionals' mental well-being:

- *Guide for doctors and nurses on dealing with stress in the time of COVID-19*
- *Tips and advice for the mental health of health professionals*

Ethical issues:

- *Ethics support for care teams in the time of COVID-19*
- *Guide to ethical issues surrounding COVID-19*
- *Recommendations for identifying COVID-19 on cause of death certificates*

Communication skills:

- *Communication guide for health professionals – communicating with COVID-19 patients and their loved ones*
- *Communication in crisis situations with COVID-19 patients*
- *Decision aid: making joint decisions in the time of COVID-19*
- *Talking about illness and death in the time of COVID-19*
- *Guide for doctors and nurses on communicating with COVID-19 patients experiencing emotional distress*
- *Communicating with people with limited health information in the time of COVID-19*
- *Proactive care planning – guide for discussing treatment requirements with vulnerable patients*
- *Treatment wishes form for COVID-19 patients*

Loss and grief:

- *Saying goodbye in extraordinary times*
- *Mourning the death of a loved one in the time of COVID-19*
- *Informing children about the death of a loved one in the time of COVID-19*

A national expert group on palliative care in the time of COVID-19 has also been established, consisting of academic and medical experts in palliative care from across the Netherlands. The purpose of the group is to share experiences about palliative care for COVID-19 patients and to address urgent issues. All findings and conclusions of the expert group are shared online.⁸⁹

7 Comparison across countries

Australia, New Zealand, and Scotland have palliative care systems that are very similar to Ireland's, in that care is provided primarily by specialists. In all three countries, policy objectives aim to shift care to the community with the aim of providing more equitable access to palliative services. All three countries intend to achieve this by having palliative care specialists provide support and guidance to community-level providers.

The Netherlands has a very different model of care, in which palliative care is provided by GPs and district nurses, and there are no specialists in palliative care. Instead, GPs with extensive experience of palliative care provide support and guidance to GPs with less experience. Of the four countries, the Netherlands is the most advanced in terms of providing accessible community-level palliative care.

Despite this key difference in palliative care provision between the Netherlands and Australia, New Zealand, and Scotland, there are many common policy objectives across the countries. Below, we have synthesised the policy objectives and have clarified which countries identify each objective in their policy documents.

- Person-centred care – patients and loved ones are informed and empowered to make their own care choices (Australia, New Zealand, Scotland, the Netherlands)
- Support families, loved ones, and communities by addressing their psychological, social, and spiritual needs (Australia, New Zealand, Scotland, the Netherlands)
- Provide care in the community and home-based care (Australia, New Zealand, Scotland, the Netherlands)
- Enhance generalists' ability to identify those who might benefit from palliative and end-of-life care (Scotland)
- Support primary level providers by linking them to specialist palliative care teams through consultative or consortium arrangements (Australia, New Zealand, the Netherlands)
- Revise referral guidance for generalists referring to specialist palliative care services (New Zealand)
- Establish a national palliative care practice team to support palliative care providers by addressing challenges they identify in the organisation and funding of palliative care (the Netherlands)
- Increase public awareness of palliative care and advanced care planning (Australia, New Zealand, Scotland, the Netherlands)
- Support and grow capability of informal carers and volunteers (New Zealand, Scotland, the Netherlands)
- Embed palliative care training within undergraduate and postgraduate medical and nursing programmes (New Zealand, Scotland)
- Roll out palliative care training programmes for existing providers (New Zealand, Scotland)
- Provide centralised online training resources and medical information for providers (New Zealand)
- Improve coordination and collaboration among providers and among key stakeholders (Australia, New Zealand, Scotland, the Netherlands)
- Ensure robust national data and a strategic and well-funded palliative care research agenda (Australia, Scotland, the Netherlands)
- Create accountability through structured national governance of strategy implementation (Australia)

8 Conclusion

Our analysis of national palliative care policies in Australia, New Zealand, Scotland, and the Netherlands demonstrates that equitable access to palliative care on a national scale is dependent on community-based service delivery. Moreover, many people prefer to be cared for and die at home, and community-based palliative care makes this possible. It also allows the health workers who know patients most intimately – GPs and community nurses – to address their patients’ palliative care needs holistically. Yet, primary care providers, including out-of-hours GPs, must have the skills and confidence to support physical, psychological, social, and spiritual well-being. Therefore, GPs and community nurses ought to receive formal training in palliative care, both as part of their basic training and on an ongoing basis.

The provision of palliative care as primary care also necessitates a strong system of support. GPs and district nurses can be linked with teams of providers with extensive experience in palliative care, from whom they can seek advice and guidance. Additionally, support systems for informal caregivers are crucial, as they play a pivotal role in palliative care.

Clear guidelines and standards of care help health professionals identify patients who would benefit from palliative care. Such guidelines ought to encourage providers to seek support whenever they feel they need it and to refer patients to other services as needed, including medical specialists, psychologists, social workers, and spiritual caregivers, among others. Referral to a wide variety of providers is crucial in order to holistically address all aspects of well-being.

There is some evidence that telemedicine can increase equity in access to palliative care services, especially for those in rural areas. Telehealth systems can facilitate structured video calls with providers and can allow patients and their carers to directly enter their own data. This allows providers to consistently monitor symptoms, which can lead to more efficient use of resources.

In response to COVID-19, Australia and the Netherlands have established national expert groups focusing on palliative care in the context of COVID-19. Additionally, all four countries have published resources for providers with guidance on palliative care for COVID-19 patients and their loved ones. There is a particular emphasis across countries on guidance regarding communication skills in the context of COVID-19.

As a global society, we are collectively facing the reality of illness and death more acutely than we have in a century. Palliative care was established as a field of medicine 50 years ago, and it has never been more important. Death is a universal experience, and palliative care is integral to our individual and collective well-being. The health system is the avenue through which people access palliative care. Yet, by addressing physical, psychological, social, and spiritual needs, palliative care enables the health system to improve all aspects of well-being.

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