



THE AUSTRALIAN CANCER PLAN 2023 - 2033

*Submission to Consultation Exercise
Palliative Care Australia (PCA)*

MARCH 2022



PalliativeCare
AUSTRALIA



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Introduction to PCA

Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it.

PCA Purpose:

PCA leads a united voice to strengthen our collective impact towards excellence in palliative care.

Vision:

We see a world where quality palliative care is available for all, when and where it is needed.

Introduction to Submission

PCA welcomes the opportunity to make a submission on the Australian Cancer Plan 2023 – 2033. PCA includes membership of all eight State and Territory palliative care peak organisations and affiliate membership with the following professional bodies:

- The Australian and New Zealand Society of Palliative Medicine (ANZSPM)
- Palliative Care Nurses Australia (PCNA)
- Paediatric Palliative Care Australia and New Zealand (PaPCANZ).

In this submission, PCA references input from these bodies together with input from allied health professionals working in palliative care.

Definition of Palliative Care

PCA uses the definition of palliative care outlined in the National Palliative Care Strategy 2018 (signed by the Australian Government and all State and Territory governments). It is based on a definition first outlined by the World Health Organization.

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

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or 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 the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance 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 those investigations needed to better understand and manage distressing clinical complications.”¹

The Structure of this Submission

The PCA submission is in three parts:

Part A will address a range of policy issues which related to cancer and palliative care.

Part B are responses to the specific Australian Cancer Plan 2023 – 2033 Consultation Questions

Part C are the PCA responses to the Opportunities Identified in the Communique from the Australian Cancer Plan Roundtable 22 April 2021

PART A: Policy issues related to cancer and palliative care

Palliative Care and Cancer

Palliative care is for all people with a life-limiting illness. However, the evidence indicates that cancer still remains the diagnosis with the largest access to palliative care. Latest data from the Australian Institute of Health and Welfare (AIHW) states:

- **53.6%** of palliative care and **33.9%** of other end-of-life care hospitalisations involved cancer as the principal diagnosis in 2018–19.²
- **Almost 3 in 4 (72%)** palliative care episodes were for people with cancer.³

Access to appropriate palliative care is an essential component of the spectrum of care needed by many people with a cancer diagnosis. Fortunately, a diagnosis of cancer does not necessarily equate to a life-limiting prognosis. Prevention measures, early diagnosis and treatment options mean that cancer can be prevented, detected early and often treated, so that it is cured. This is a credit to medicine, science and the care of treating clinicians. There will be cases, however, where the cancer or a combination of co-morbidities will mean a cancer diagnosis is life-limiting and will be the contributing factor in a person’s death. For this reason, palliative care must be available to support people during their illness trajectory.

The Australian Government and all state and territory governments have signed up to the *National Palliative Care Strategy (2018)*. The Strategy notes what palliative care offers people including those with cancer:

¹ Definition of Palliative Care in [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) Based on World Health Organization, 2017.

² [Palliative care services in Australia, Admitted patient palliative care - Australian Institute of Health and Welfare \(aihw.gov.au\)](#)

³ [Palliative care services in Australia, Palliative care outcomes - Australian Institute of Health and Welfare \(aihw.gov.au\)](#)

For many people, accessing effective palliative care will mean the ability to live longer and to experience each moment of their lives more fully as a result of effective pain and symptom management, and holistic assessment of physical, psychological, social, emotional and spiritual needs.⁴

A very common misconception is that palliative care is care that is provided at the very end of a person's life (last days or weeks). In fact, palliative care and the support structures embedded in palliative care can be offered throughout a person's life-limiting illness journey. This is also noted in the National Palliative Care Strategy:

People who require palliative care may be at different stages of an illness trajectory; they may be young or old, with different cultural, social, emotional, relational and spiritual needs; they may need palliative care for a short period of time, intermittently, or consistently over a period of months or years. Regardless of their circumstances, people affected by a life-limiting illnesses, including carers and families, may benefit from the varied support available through palliative care. Helping people to live as well as possible for as long as possible is ultimately what palliative care is seeking to achieve⁵.

The improvements to quality of life provided by palliative care are clear in the definition of palliative care outlined above. PCA emphasises that palliative care must be a core foundation within Australia's first *Australian Cancer Plan (2023 – 2033)*. PCA was pleased to see the reference in the Communique from the Roundtable held on 22 April 2021 which noted as one of the opportunities:

- Consider sustainability of specialist palliative care community services to ensure they are available to all who want or need them.

PCA supports this reference but considers there is greater scope to reference the role of palliative care within the Australian Cancer Plan and supporting evidence for this will be provided throughout this submission. With evidence to support this claim, PCA would like to see that palliative care is offered to people living with a life-limiting cancer much earlier in their illness trajectory.

There is also an increasing and proactive approach to early integration for improving quality of life. This follows a robust body of evidence demonstrating the benefits of early access to palliative care for patients, their family caregivers and the health care budget. Despite this, palliative care is too often considered, in the minds of both health care providers and the public, as exclusively about death and dying, and associated with a loss of control or abandoning of hope. This has significant negative consequences, including that many people are missing out on the benefits that palliative care can offer.⁶

⁴ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 2

⁵ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 6

⁶ See statement and supporting references in Hudson, P., Collins, A., Boughey, M. and Philip, J. *Reframing Palliative Care to Improve the Quality of Life of People Diagnosed with a Serious Illness*, Med J Aust 2021; 215 (10): 443-446. || doi: 10.5694/mja2.51307, Published online: 1 November 2021 ([Reframing palliative care to improve the quality of life of people diagnosed with a serious illness | The Medical Journal of Australia \(mja.com.au\)](#))

Generalist and Specialist Palliative Care

While specialist palliative care offers a multi-disciplinary approach to care and support for people living with life-limiting illness, it is important to note that palliative care is provided by a range of health professionals. People living with cancer and who could benefit from palliative care will have their quality of life improved if both specialist and generalist palliative care is supported in Australia's Cancer Plan.

Palliative Care Australia's (PCA's) Service Development Guidelines⁷ differentiate between generalist palliative care and specialist palliative care as follows:

- **Generalist palliative care:** All healthcare providers who provide care to people living with a life-limiting condition, their families and carers should have minimum core competencies in the provision of palliative care and understand the palliative approach to care.
- **Specialist palliative care:** People will have different levels of need for palliative care. People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience, and training in palliative care. Palliative Care Australia refers to this type of care that is provided by specialist palliative care services as 'specialist palliative care'. PCA has specified service delivery standards for specialist palliative care.⁸

Further, the Service Development Guidelines define the following workforce envisaged as relevant to generalist palliative care:

- The management and coordination of care for people living with a life-limiting condition may be undertaken by a wide range of care providers including General Practitioners (GPs) and other medical specialists such as oncologists, nurses, allied health professionals and pharmacists. These healthcare providers are 'generalists' with respect to palliative care, notwithstanding that many of them might be specialists in their own discipline.

The role of healthcare providers is summarised as follows:

- To treat people living with a life-limiting condition, healthcare providers should have minimum core competencies to manage physical symptoms, support medication management, to provide or refer to psychosocial spiritual support services, and to discuss the goals of treatment and the person's prognosis.

PCA will soon be releasing *National Palliative Care Standards for All Health Professionals and Aged Care Services* (separate standards exist for those working in specialist palliative care). These Standards have been developed following extensive consultation with health professionals from across a range of disciplines and professional backgrounds. These Standards will provide extensive guidance for all health professionals who will be required to provide some level of palliative care as part of their scope of practice. PCA considers that these Standards will provide very useful guidance in the development of the *Australian Cancer Plan (2023 – 2033)* and PCA will make them available on publication.

The release of *National Palliative Care Standards for All Health Professionals and Aged Care Services* will also form the basis of education and training for health professionals across Australia. Cancer patients will benefit significantly from the increase in knowledge and expertise in the principles and practice of palliative care gained by health professionals across health disciplines.

7. Palliative Care Australia, 2018, National Service Development Guidelines. [Palliative Care Service Development Guidelines - Palliative Care Australia](#)

8. Palliative Care Australia, 2018, National Palliative Care Standards, 5th edition. [National Palliative Care Standards - Palliative Care Australia](#)

Seamless transitions in care provision

An important aspect of palliative care that is often misunderstood is that it 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 those investigations needed to better understand and manage distressing clinical complications [see definition of palliative care on page 1-2].

One of the biggest barriers to high quality care experienced by people with a life-limiting illness (and their families and carers) is that there can be barriers to patients moving between places of care. This can include transitioning between primary care and specialist care and between other medical specialists (such as oncology, haematology) and palliative care.

Ideally patients will experience a seamless transition between curative treatment and palliative care with appropriate and timely referrals. Referrals can also be an introduction between the treating and palliative care team which may involve the patient/family so that palliative care can be seen as an extension to the treating team. In some cases, people will continue to pursue curative treatment while accessing palliative care. As and when the person's illness progresses, they may stop any curative treatment and will be fully under the care of a palliative care team.

Seamless transitions for patients would involve:

- Continuous person-centred care where palliative care patients can move seamlessly between medical specialists and services depending on what they need at the time.
- Greater comfort provided by medical teams including GPs, discussing death and dying earlier with their patients and discussing the range of options available to their patients which might include curative treatments and referral to palliative care.
- Specialist palliative care teams working more closely with other medical teams to provide a person-centred approach to the care of a palliative care patient.
- Carers empowered and free of the burden of navigating a fragmented service delivery system.

Some barriers to be explored include:

- A misconception about palliative care – that it is the last resort and cannot be provided at the same time as curative or other intervention treatments – i.e., there can be a view that there is treatment for a disease, this stops when it can't be cured, and then palliative care begins.
- A misconception by some medical teams that palliative care is a sign of “giving up.”
- A perception or in some cases a regulatory barrier that a person cannot be seen by more than one medical specialist for the same medical condition.
- Where a patient changes their setting of care, such as a move to a residential aged care facility, a reduction in the services offered or available to that person.

Collaboration between health providers is critical to ensure seamless transitions for patients with cancer who may benefit from palliative care. This is recognised in the *National Palliative Care Strategy (2018)*:

...collaboration is essential to ensure that people involved in palliative care are communicating and sharing information, and that those affected by life-limiting illnesses have a seamless experience of palliative care wherever and however they are being supported.⁹

⁹ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 16.

PCA supports the views of the Australian and New Zealand Society of Palliative Medicine (ANZSPM) that Palliative Medicine specialists are currently delivering palliative services across all healthcare settings and the specialist workforce is not able to meet demand alone. It is therefore important that the generalist palliative care workforce is urgently upskilled in a coordinated manner to meet future demands. These primary care providers should be enabled, trained and reimbursed to provide generalist palliative care with the support of specialist services as required. This will require a flexible model which is responsive to changes in the current and future demands for palliative care services, including in-home service provision by primary care providers.

PCA also supports the view of ANZSPM that timely engagement with palliative care is an essential part of comprehensive cancer planning. Effective collaborations between palliative care and cancer care services requires oncologists to fully understand the scope of palliative care, and the benefits of early engagement with palliative care services. In this respect, PCA supports ANZSPM call for mandated palliative care training and clinical experience for Medical Oncology Trainees. This would support the priorities listed in the *National Palliative Care Strategy (2018)*:

2.1 Medical, nursing and allied health graduates can identify and address people's palliative care needs.

2.4 Health professionals provide early referrals for palliative care for those affected by life-limiting illnesses based on need with specialist palliative care services playing an important role in meeting complex needs and supporting others to provide this care.¹⁰

Advance Care Planning

A critical area that needs to be covered in Australia's first Cancer Plan is support for advance care planning by people with a cancer diagnosis.

As noted in the *National Palliative Care Strategy (2018)*:

Evidence also demonstrates the benefits of individuals, their carers and families discussing their care preferences early in their illness¹¹. Advance care plans or other similar documents are becoming more widely used and provide an important mechanism to communicate an individual's preferences regarding their care.¹²

PCA has a joint Position Statement with Advance Care Planning Australia (ACPA), [Advance Care Planning and Advance Care Directives](#), that outlines the importance of advance care planning processes, particularly for people with life-limiting illness and those receiving palliative care.

Advance care planning enables the coordination of access to resources and services, to match anticipated care needs, and offers individuals the opportunity to take control of decisions which

¹⁰ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 21.

¹¹ Senate Community Affairs References Committee, 2012 cited in [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 17.

¹² [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 17.

affect their care. PCA and ACPA emphasise that advance care planning is not the exclusive domain of any particular health sector or setting and should involve all members of the care team.

Written Advance Care Plans or Advance Care Directives are an important part of the advance care planning process, serving as a vehicle for documentation regarding preferences and values as well as decisions about the type and level of medical intervention people wish to receive during significant illness and at the end of life.

PCA recommends that the Australian Cancer Plan 2023 – 2033 emphasise the importance of advance care planning for any person with cancer so that their care preferences during treatment can be documented and understood and further, should palliative care and end-of-life care be needed by the person, their wishes and preferences are clear to their families and the health professionals and others providing care and support to them at that time.

This would support the priority listed in the *National Palliative Care Strategy (2018)*:

2.2 Clinical and non-clinical service providers can assist individuals, their families and carers to have discussions on palliative care including the development of advance care plans¹³

Access to Medications including Opioids for Pain and Symptom Relief

Pain and symptom management is a key component of palliative care and in cancer care, the need for opioids to relieve pain and symptoms which hinder quality of life is core to the work of palliative care teams. Opioids are an essential part of the pharmacological options needed to help relieve the pain and/or breathlessness that may be experienced by someone living with a life-limiting illness. Evidence shows that up to 25% of palliative care patients report severe pain¹⁴ in advanced disease states with up to 60% experiencing pain that causes them distress in the last 4 months of life.¹⁵ Chronic breathlessness is also a recognised distressing symptom in advanced disease, with reports of prevalence up to 70% in advanced cancer and 60-100% in non-malignant life-limiting illness.^{16 17}

Australia, as a member state of the World Health Assembly, is part of the resolution of 2014 committing to improving access to palliative care as a human right and concurrently “ensure adequate availability of pain relief. This includes removing unnecessary regulations that restrict availability and access to essential medications like oral morphine”.¹⁸

¹³ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) page 21.

¹⁴ Pidgeon, T., Johnson, C.E., Currow, D., et al 2016 A survey of patients’ experience of pain and other symptoms while receiving care from palliative care services. *British Medical Journal Supportive and Palliative Care*. Vol. 6, Issue 3.

¹⁵ Wilkie, D.J., and Ezenwa, M., 2018 Pain and Symptom Management in Palliative Care and at End of Life. *Nursing Outlook*. 60(6)

¹⁶ Simon, S.T., Bausewein, C., Schildmann, E., et al 2013 Episodic Breathlessness in Patients With Advanced Disease: A Systematic Review. *Journal of Pain and Symptom Management*. Vol 5, No 3.

¹⁷ Bausewein, C., and Simon, S.T., 2013 Shortness of Breath and Cough in Patients in Palliative Care. *Deutsches Arzteblatt International*. 110(33-34).

¹⁸ World Health Assembly, Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course, 67th session, 9th plen mtg, Agenda Item 15.5, A67/VR/9 (24 May 2014) Accessed at https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_31-en.pdf

Furthermore, there is international consensus around classifying opioids as an essential medication class that should be available for palliative patients throughout the world.^{19 20} Opioids are widely used to treat strong pain particularly in malignant disease, supported at Step III of the World Health Organisation (WHO) analgesic ladder.^{21 22}

In recent years, the Australian governments and other governments around the world have supported measures to reduce inappropriate prescribing that can lead to harm from misuse and abuse of opioids in the general population. These measures are warranted and stewardship measures particularly in acute settings is needed to respond appropriately. However, these measures can have a detrimental consequence if exceptions to these measures are not given to palliative care patients including those with cancer. Palliative care patients including those with cancer can be at risk of unintended harm through reduced or ceased opioid prescribing. Existing literature suggests that risks of opioid abuse are low in palliative care populations.²³ In palliative care, opioid use is usually limited to the final months of life and is therefore unlikely to lead to the same problems. Tolerance and dose escalation are of little consequence when the intent is time-limited symptom control.²⁴

There have been instances where there has only been one licensed supplier in Australia for certain palliative care medications. This has caused significant problems when the only supplier withdraws from the market. This occurred in Australia in 2020 and in particular this affected cancer patients. Patients suffer as it can be difficult to source alternatives or they can be prohibitively expensive.

Many of the above references are included in the May 2019 PCA Position Statement endorsed by 12 other peak health bodies, [Sustainable Access to Prescription Opioids for use in Palliative Care](#). This Position Paper outlines PCA's views about access to opioids for people living with a life-limiting illness and receiving palliative care including in acute settings. The recommendations (abbreviated) from the Position Statement are:

1. All prescribers are enabled to access appropriate opioids (oral and parenteral) consistently for pain and breathlessness management for people living with life-limiting illnesses, without the burden of unnecessary regulatory barriers.
2. Compulsory palliative care and opioid management education for all medical, nursing, allied health and pharmacists to be built into undergraduate curriculum.
3. Ensure an adequate supply and stock (imprest) of minimum levels of opioids commonly used in palliative care.
4. Nationally consistent and streamlined prescribing approval policies for opioids that promotes pain and addiction specialists working closely with palliative care.

¹⁹ Morin, L., Laroche, M-L., Vetrano, D.L., et al 2018 Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: a European expert consensus. *European Journal of Clinical Pharmacology*. Vol 74, No 10.

²⁰ 7. Knaul, F.M., Farmer, P.E, Krakauer, E.L., et al 2018 Alleviating the Access Abyss in Palliative Care and Pain Reliefan Imperative of Universal Health Coverage: The Lancet Commission Report. *Lancet* 391, 10128.

²¹ World Health Organisation, 2018. WHO guidelines for the pharmacological and radiotherapeutic management of cancer pain in adults and adolescents. Accessed at [https:// apps.who.int/iris/bitstream/handle/10665/279700/9789241550390-eng .pdf?ua=1](https://apps.who.int/iris/bitstream/handle/10665/279700/9789241550390-eng.pdf?ua=1)

²² Hanks, G.W., de Conno, F., Cherny, N., et al 2001 Morphine and alternative opioids in cancer pain: the EAPC recommendations. *British Journal of Cancer* 84, 5

²³ Pinkerton, R., Mitchell, G., and Hardy, J. (2020), Stringent Control of Opioids: Sound Public Health Measures but a Step Too Far for Palliative Care? *Current Oncology Reports* 22(4), 1-9.

²⁴ Mitchell, G., Willmott, L., White, B., Piper, D., Currow, D., and Yates, P. (2019), A Perfect Storm: Fear of Litigation for End of Life care. *Medical Journal of Australia* 210 (10) 441.

5. The introduction of national real time monitoring for all opioid prescriptions with software that is enabled to identify palliative care prescriptions at point of care across acute, sub-acute, aged care and primary care sectors.
6. Palliative care teams to work with acute services to develop opioid stewardship policies informing clinical plans to ensure appropriate prescribing, de-prescribing, and dispensing of opioids with rapid communication to the primary care team and community pharmacy to reduce risk of forced tapering of appropriate opioid management.
7. The Australian Government to review (on a regular basis) the Palliative Care Schedule of the Pharmaceutical Benefit Scheme (PBS).
8. Review of the Medicare Benefits Schedule (MBS) specific to palliative care by way of item numbers and explanatory notes to facilitate consultation in primary and specialist practice.

Research suggests that under-prescribing of medications is an issue for people nearing the end of their lives. This includes cancer patients. As has been noted by Willmott *et al*, every day, thousands of health professionals provide medical treatment to Australians as they approach the end of their lives. An important component of that medical treatment is provision of medication to alleviate pain and other symptoms. So that patients can experience the best possible medical care at the end of life, it is critical that medical treatment can be provided by health professionals who are not constrained by ill-informed concerns about potential or even likely legal or disciplinary consequences of providing pain and symptom relief that may incidentally hasten a patients' death. The available anecdotal evidence in Australia suggests that under-medication of patients may be happening because of concern about potential regulatory repercussions of providing that treatment.²⁵

Therefore, more education is needed to alleviate such fears and help staff feel confident in their practice and supported by the law. This may point to the need for health practitioners to have better understanding about the true nature of the regulatory risk so health professionals can practise treating palliative care patients with confidence.

PCA recommends that the *Australian Cancer Plan 2023 – 2033* emphasise the importance of access to opioids for palliative care patients with cancer to ensure their pain and symptoms are managed well and their quality of life maximised.

Paediatric Palliative Care

Paediatric palliative care is about improving the quality of life of infants, children and young people diagnosed with a life-limiting condition and supporting those who care for them.

As noted by PCA Affiliate Member, Paediatric Palliative Care Australia and New Zealand (PaPCANZ):

Most commonly children with palliative care needs suffer from tumours of the central nervous system, other solid tumours and leukaemias. Whilst a relatively small population in terms of numbers, their needs are complex and significant and require the input of providers with specialist skills because:

- The paediatric population is diverse from a developmental point of view and ranges from newborns through to adolescents. Developmental level influences such things as symptom management, information needs and decision-making.

²⁵ Willmott, L., White, B., Piper, D., Yates, P., Mitchell, G. and Currow, D. (2018) Providing Palliative Care at the End of Life: Should Health Professionals Fear Regulation? 26 *Journal of Law Medicine*, 214.

- Prognosticating can be difficult given the uncertain trajectory of many cancers and the introduction of new therapies and trials.
- Complex ethical issues can arise given the involvement of parents as proxy decision-makers and the emerging autonomy of children and young people.
- Pharmacodynamics change with age and specialist knowledge of how medications behave in children is required to optimise symptom management.
- Children with tumours of the central nervous system can struggle with significant levels of disability for long periods and need specialist equipment and the involvement of occupational therapists, physiotherapists and other allied health professionals.
- Educational and play needs require consideration as a way of enhancing quality of life.
- Many parents wish to care for their child at home but this can be a daunting task and support is needed.
- Grief is especially intense for bereaved parents.

The Paediatric Palliative Care National Action Plan is due for release in the middle of 2022 and PAPCANZ would like to advocate for the incorporation of many of the recommendations into the National Cancer Action Plan. These include:

- The early integration of specialist palliative care into the overall care of children with cancers that are likely to be life-limiting,
- Training in advanced communication skills for clinicians working in paediatric oncology to facilitate the best possible conversations about difficult topics such as prognosis, dying and advance care planning,
- Ensuring all children across Australia who need palliative care have access to a specialist paediatric palliative care service,
- Ensuring palliative care coordinators are available to families,
- Developing and implementing national standards and guidelines for the provision of the best possible palliative care,
- The development of a peer support program for families,
- Transition pathways between paediatric and adult services,
- Increasing the capacity of communities to support families needing palliative care,
- Pathways for Aboriginal and Torres Strait Islander people and underrepresented groups,
- Improved data collection,
- Developing a dedicated and targeted research program for children's palliative care.

PCA recommends the *Australian Cancer Plan 2023 – 2033* refers to the specific paediatric palliative care needs of children with cancer and adopts recommendations that will be outlined in the Paediatric Palliative Care Action Plan released later in 2022.

New and Emerging Technologies & Medical Advances

New and emerging technologies are developing at a rapid rate. This is already leading to new frontiers in the diagnosis of illness and the options available for treatment together with helping individuals better maintain their own health and wellbeing. New and emerging technologies can change the concept of survivorship. Palliative care is not immune from these changes and clinicians working in palliative care will find themselves working with new technologies and data sources to inform their practice and care of palliative patients.

The emerging field of biotechnology and precision medicine will mean that life-limiting illness is easier to predict and biological markers will provide a clearer indication of life expectancy for many people with varying diagnoses.

This will mean that the treatment of life-limiting illnesses such as cancer or neurodegenerative diseases will be managed using knowledge about an individual's biological system to increase the efficacy of treatment outcomes. This will include immunotherapy, which enables a person to use their own immune system to fight off a disease. This could reduce the need for radiotherapy, chemotherapy or surgery. If a person does need chemotherapy, the emerging field of nanotechnology will increasingly be used to target cancer cells without the current side effects.

These are very positive advances for medicine. However, the fact remains that people will still have life-limiting illness and will need help living with the symptoms of their illness while also preparing for their death. It is also known that the dominant illnesses accounting for growth in palliative care need will be dementia and cancer.²⁶

Comorbidity will be a significant factor in palliative care. Many people will live with more than one comorbid condition. "This means that the complexity of palliative care need is likely to grow due to the high symptom burden, complex healthcare needs and high hospitalisation rates of patients with multimorbidity".²⁷

Specifically for palliative care, patients and their carers will depend on the skills, knowledge and experience of palliative care clinicians in interpreting the data and assessing the multitude of treatment options to determine the best care path available.

In addition to the changes that emerging medical advances and technologies will have for the care options available to people with life-limiting illness, palliative care clinicians will increasingly be called on to advise patients about when enough is enough for treatment proposed by other medical clinicians. The growing accessibility of biotechnology options will run the risk of more people being on a treatment treadmill and there will always be a point where further treatment will be too burdensome or non-beneficial. Palliative care expertise will be needed more than ever to advise patients about when to stop more active treatments and interventions and to ensure patients have quality of life and avoid unnecessary pain and distress.

PCA recommends that the *Australian Cancer Plan 2023 – 2033* refers to the unique roll that palliative care expertise will have in supporting cancer patients navigate treatment and intervention options to maintain quality of life and avoid unnecessary suffering.

PART B: RESPONSES TO SPECIFIC AUSTRALIAN CANCER PLAN 2023 – 2033 CONSULTATION QUESTIONS

The consultation documentation on the Australian Cancer Plan 2023 – 2033 referred to three questions for consideration. The following section of this submission will address responses to these specific questions. PCA has received input to these questions from our Member Organisations, Affiliate Members and from the PCA National Expert Advisory Panel (NEAP).

²⁶ Etkind, S.N., Bone, A.E., Gomes, B., Lovell, N., Evans, C.J. Higginson, I.J., and Murtagh, F.E.M., How Many People will Need Palliative Care in 2040? Past trends, future projections and implications for services in *BMC Medicine* (2017) 15:102.

²⁷ Etkind, *et al* (2017).

1. Think ahead to the next 10 years. What do you want the Australian Cancer Plan to achieve? Think big – what transformational change(s) should we be aiming to influence?

- Improved access for regional and rural patients – both for chemotherapy and radiation and also for optimal symptom management and control. For example, much of the interventional pain medicine work is only available in a few tertiary centres. Where it is not possible to have specialist expertise across the nation, it would be helpful to have an established pathway for access for those living in areas without such facilities / expertise available.
- Ensure GPs and oncologists know about the cancer and palliative care expertise available and how this can help patients. For example, a person living in a rural area with complex pain related to pancreatic cancer that may benefit from stenting and nerve block work – this pathway does not seem evident / obvious for use (resulting in inequity of access). It is important to maintain some sort of networked centre of updated data / quality information to support clinicians in their work.
- Clinicians need clear access to current evidence-based practice. The work done by Cancer Australia to review all the evidence for key cancers to inform development of roadmap work is a good example. Continuing this focus is beneficial together with considering where there is strong evidence or gaps needing to be investigated and researched and then translating how this relates to actual care delivery.
- Improved person-centred care. This means really enabling patients and families to be part of the ‘team.’ This is done well in many areas but could be improved and expanded.
- Earlier integration of palliative care (both generalist provision and access to specialist palliative care) across all care settings. Clinicians still see a ‘divide’ between active care and palliative care. PCA and stakeholders are working hard to break down this divide but it needs to be supported in other key frameworks including the *Australian Cancer Plan 2022 – 2023*.
- Investment in improved hospital environmental factors. Many of the centres for outpatient and inpatient care are just not environmentally pleasant and this has impacts on patients and loved ones. Working innovatively with designers to improve the environment of places of care would improve patient and family experience of care provision.
- To support Aboriginal and Torres Strait Islander peoples, there should be a greater emphasis on Aboriginal Health worker/s for Aboriginal populations and integration within cancer services.
- Integrate Adolescent and Young Adult (AYA) services /programs integrated into all cancer services, not just large centres.
- Increase integration of volunteer services into cancer care for inpatient/outpatient and those in the community.
- Given that Cachexia affects up to 50% of all patients with cancer, there needs to be further recognition and services designed specifically to prevent and treat Cancer cachexia especially in high-risk groups including upper Gastrointestinal and colorectal cancer. A

model to consider is the Cachexia clinic model from Barwon Health. The goals would be to see every major cancer hub having a dedicated multidisciplinary Cachexia clinic.

- Establishment of an Allied Health assessment service in every major cancer hub (eg Occupational Therapy, Physiotherapy, Social Work, dietetics). Patients who attend cancer centres often have limited time with an oncologist who is focused on their disease modifying treatment. Cancer care coordinators can fill the gap but in many cases they do not understand the full depth of what allied health clinicians can offer patients. Having an allied health team embedded in the team who are regularly screening patients and picking up potential issues early can help prevent issues down the track and support patient in having their planned disease modifying treatment.
 - E.g. malnutrition pick up before patients have had >5% weight loss, or strength/functional assessment picks up risk muscle loss, before falls, before ECOG (Eastern Cooperative Oncology Group) changes, potentially using new technology to assess muscle quality to determine treatment dose.
- Further recognition of the functional aspects of living with cancer and the way Allied Health plays a role as cancer progresses.

Consider a stocktake of all the cancer services, peak bodies and non-government organisations, consumer and support groups to help them all work together, avoid duplication and foster greater collaboration and the best value for money and other resources.

2. What are the opportunities with the greatest potential to realise your vision?

Think about what you would like the Australian Cancer Plan to achieve. What priorities need national action? In what areas could national action drive or accelerate progress?

- Improved focus on the integration of palliative care into cancer care. This is not only about referral to specialist palliative care but about living well with advanced disease whilst still receiving active care is as important as a complete focus on palliation closer to the end of life / terminal care. Leadership within other medical disciplines (medical oncology, radiation oncology, haematology) is needed in addition to the leadership provided by the palliative care sector.
- Collaborate and develop integrated models of care and increase co-ordination and pathways between Specialist Palliative Care for cancer patients and other specialist/primary health care and aged care services for people with cancer.
- Increase investment in workforce capacity and capability building for the specialist palliative care workforce, the aged care workforce, and other specialist/primary health care workforce. This could be improved by expanding the contribution of other specialist and primary health care services to palliative care provision.
- Increased focus on advanced practice nursing roles (Clinical Nurse Consultants/ Nurse Practitioners) to support complex care across care settings. Every patient with cancer should have a 'go to' person who can help them.
- National leadership and linkage of key datasets to inform optimal care. For example, bring the jurisdictions together and leverage off some of the effective work underway (such as from Cancer Institute NSW).

- National investment in research where identified gaps exist. The focus on priority-driven national research funding and equitable access to clinical cancer trials, as outlined in the Communique is supported. PCA supports the call from ANZSPM that palliative care be recognised as a specific priority area for cancer research. Where relevant and feasible, clinical research involving cancer patients should include verified quality of life indicators.
- Increase clinician confidence in Advance Care Planning and goal centred discussions and ability to discuss End of Life Care competently and confidently.
- Cachexia – making the word for commonly known, what to look for, how to treat within a multi-disciplinary team.
- Continued promotion of exercise in cancer and access to allied health to support body movement and functioning
- Breathlessness clinics for people with respiratory and other cancers to enable active participation in essential and valued everyday activities.
- Continued work on language in cancer care – palliative is not just the end...its more than you think.

3. What examples and learnings can we build on as we develop the Australian Cancer Plan? *Think about great examples of work within or outside the cancer sector in Australia and internationally. How can we learn from these examples and build on them to improve cancer outcomes and experience for all Australians?*

- Building on the work done by the Cancer Institute NSW to amplify patient and family experiences of care quality would be helpful.
- The Breast Care Nurse / Prostate Cancer Nurse etc are good models. Perhaps these models could be refined to be a 'cancer care nurse' who can assist across a region and is aligned with key teams / settings to expand this service to more cancer patients.
- Telehealth consultations and models for advice line to support more timely advice/education with appropriate infrastructure and resourcing.
- The care coordinator model could be enhanced by building a stronger relationship with GPs and point of contact.
- Barwon health cachexia and nutrition support service. This service has a truly multi-disciplinary team (physician, nurse, physiotherapist, dietitian). It has positive outcomes of quality of life and symptom management. It is currently a very small team in a regional health service. If similar service expanded in larger centres there would be more data to show about improved symptom management, quality of life, nutrition and muscle quality.
- Cambridge Breathlessness Intervention Service – multidisciplinary with Allied Health playing an integral role (see: <https://www.cuh.nhs.uk/our-services/breathlessness-intervention-service>).

- A resource that is helpful to many in the sector in relation to prescribing is the Australian cancer pain guidelines: https://wiki.cancer.org.au/australia/Guidelines:Cancer_pain_management). These guidelines provide a visible evidence base summary to inform practice and set the standard for appropriate prescribing and should be resourced to remain current, and be integrated into point of care systems, e.g GP software.
- Other health specialties including primary care, have skills and resources to provide palliative care to people with cancer within their scope. They also need to know when to refer people with complex needs. This capability needs more support from specialist sectors but also more resources to build capacity.
- Enabling patients and families to inform care providers of their experience of care quality across inpatient, community and outpatient settings is critical. National guidance in relation to appropriate tools and measures, developing key indicators and infrastructure to enable data capture and reporting is required. Patient reported experience measures are ideally placed to support service improvement work. Several have been developed for cancer care and for people living with serious illness and national guidance in relation to optimal tool choice for varied settings and populations would be helpful.

PART C: PCA RESPONSES TO THE OPPORTUNITIES IDENTIFIED IN THE COMMUNIQUE FROM THE AUSTRALIAN CANCER PLAN ROUNDTABLE 22 APRIL 2021

PCA offers the following observations on the opportunities outlined in the Communique of 22 April 2021:

- Provide national leadership in cancer prevention and align with and reinforce the National Preventive Health Strategy to reduce overall cancer incidence. **SUPPORT**
- Build the cancer literacy of all Australians, to improve understanding of personal cancer risk factors and to empower behaviour change that reduces risk of cancer. **SUPPORT**
- Continue to increase cancer screening rates nationally, particularly in populations and areas where cancer screening participation is low or where disparities exist. **SUPPORT**
- Support the role of primary care providers in investigating suspected cancer early and referring appropriately; adopt new and more accurate diagnostic tests and risk modified screening to pick up cancer earlier. **SUPPORT**
- Continue to promote value-based healthcare and embed optimal care pathways as the national standard for cancer care. **SUPPORT AND INCLUDE PALLIATIVE CARE AS PART OF THE OPTIMAL CARE PATHWAYS**
- Support patients to navigate the system and coordinate their care, across primary, secondary and tertiary settings and between the public and private systems; consider ways to optimise cancer care navigator roles. **SUPPORT AND INCLUDE NAVIGATION TO PALLIATIVE CARE SERVICES**
- Accelerate implementation of evidence-based, best practice care by setting care standards and establishing processes to translate evidence and clinical guidance into practice. **SUPPORT AND INCLUDE PALLIATIVE CARE EVIDENCE AND BEST PRACTICE IN CLINICAL GUIDANCE**

- Improve access to new cancer therapies and treatments while also reducing the financial burden of cancer on consumers and reduce out of pocket expenses. **SUPPORT**
- Accelerate the adoption of personalised medicine, better understanding the role of genomics and developing and embedding new models of care. **SUPPORT AND RECOGNISE THE ROLE THAT PALLIATIVE CARE HAS IN HELPING PATIENTS NAVIGATE CHOICES IN TREATMENT AND CARE**
- Analyse future population and cancer survivorship needs in the development of new community-based models of survivorship care. **SUPPORT**
- Consider sustainability of specialist palliative care community services to ensure they are available to all who want or need them. **SUPPORT INCLUDING SUPPORT FOR EQUITY OF ACCESS INCLUDING ACROSS RURAL AND REGIONAL AUSTRALIA AND FOR VULNERABLE/DIVERSE NEEDS GROUPS**
- Expand implementation of virtual care including tele-health, remote diagnosis and virtual consultation. **SUPPORT WITH PROVISIO THAT APPROPRIATE SYSTEMS ARE IN PLACE TO SUPPORT THE IT INFRASTRUCTURE AND THAT IN MOST SITUATIONS PATIENTS SHOULD HAVE A CHOICE FOR TELEHEALTH OR FACE TO FACE CONSULTATIONS**
- Plan future workforce capacity and capability requirements by identifying national trends, addressing current and future skills shortages and planning for future care needs; consider the need for a national cancer workforce strategy. **SUPPORT AND INCLUDE THE PALLIATIVE CARE WORKFORCE AS PART OF THE CAPABILITY REQUIREMENTS**
- Continue efforts to strengthen national data linkage, and reporting of data that relates to cancer stage, treatments and recurrence of cancer at the national level. **SUPPORT AND INCLUDE LINKAGES TO PALLIATIVE CARE WHERE APPROPRIATE**
- Continue to focus on priority-driven national research funding, targeted to meet the areas of greatest need nationally; increase equity of access to cancer clinical trials. **SUPPORT AND INCLUDE PALLIATIVE CARE WITHIN RESEARCH PARAMETERS**
- Guide development of standardised nationally agreed metrics to measure cancer outcomes and assist with prioritising equitable cancer care across the care continuum. **SUPPORT NOTING THAT OUTCOMES SHOULD INCLUDE PROMS AND PREMS NOT JUST ORGANISATIONAL BENCHMARKS AND KPIs.**

CONCLUSION

PCA is pleased to provide a submission to the Australian Cancer Plan 2023 – 2033. This Plan will be an important step in improving the lives of people with a cancer diagnosis, their loved ones and the workforce who treat, care and support them.

PCA has welcomed the opportunity to demonstrate the importance that palliative care has in supporting people living with cancer. Australia is a world leader in palliative care but there is more to be done. As noted in the National Palliative Care Strategy (2018) signed by the Australian government and all state and territory governments:

While there has been significant growth and improvement in the palliative care Australians receive over the past several decades, there is still much work to be done to ensure that all people affected by life-limiting illnesses get the care they need to live as well as possible for

as long as possible.²⁸

In addition to what has been included in this submission specific to cancer, PCA has a: [Palliative Care Australia Roadmap 2022-2027](#) which addresses actions that are required to meeting the growing need for palliative care into the future.

The Roadmap addresses key areas which need to be prioritised:

- Greater investment in dedicated palliative care services across Australia including rural and remote areas.
- Supporting and growing the palliative care workforce – this includes the specialist palliative care workforce and the workforce in primary care.
- Making palliative care core business in aged care – a key finding of the Royal Commission into Aged Care Quality and Safety.
- Augmenting palliative care data and research.
- Providing more support to carers so they can care for their loved ones in the place of choice.
- Fully funding the Paediatric Palliative Care Action Plan.
- Investing in palliative care awareness campaigns to raise community awareness about death, dying and palliative care.

Many of the measures outlined in the PCA Roadmap will also be of great benefit to people living with cancer.

For further information about the PCA Submission to the Australian Cancer Plan 2023 – 2033, please contact Margaret Deerain, National Policy and Strategy Manager (margaret.deerain@palliativecare.org.au).

²⁸ [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) pages 11-12