



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

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PalliativeCare
AUSTRALIAN CAPITAL TERRITORY

Select Committee on
End of Life Choices in the ACT

Submission

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Glenda Stevens

CEO

Introduction

Legislation of euthanasia and physician assisted suicide are two frequently debated issues that are seen as important matters for society to consider. They are highly complex and raise significant and ethical issues. There is a broad spectrum of opinion and support for reform in the ACT community. This reflects our diverse cultures and belief systems.

Regardless of the legality of euthanasia, palliative care and aged care services will continue to care for the vast majority of Australians at the end of life. We know that palliative care services make a real difference to peoples' quality of life and provide support to their families after their death.¹

Understanding the need for palliative care is essential in planning services, and giving patients holistic person-centred care and the choices that satisfy their preferences. In high income countries, such as Australia, 69- 82% of those who die need palliative care.² The earlier palliative care is initiated, the greater the benefit. The World Health Organization states that palliative care should be considered from diagnosis onwards, and integrated into care.³

This submission will focus on the important contribution that palliative care makes to the end of life journey in reference to Terms 1, 3 and 6 of the Terms of Reference. This submission gives an overview of palliative care, and palliative care in the ACT. It also explains the difference between 'choice' and 'preference'. In response to criteria 1, the submission outlines current palliative care practices in the ACT, and in response to criteria 6, it speaks on gaps in our palliative care services, and how addressing these gaps will influence end of life decisions. In response to criteria 3, this submission discusses the risks to our palliative care system that need to be considered that are associated with a debate on end of life choices.

About Palliative Care

Palliative Care

The following statements explain the nature and importance of palliative care:

- The goal of palliative care is to improve quality of life for both the patient and the family, regardless of diagnosis.⁴
- Palliative care relieves the suffering of patients and their families by the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms experienced by patients. As comfort measures intensify, so should the support provided to the dying

¹ Dr Jane Fisher, President Palliative Care Australia.(Nov 2017). Media Release - Palliative care must be prioritized after historic euthanasia vote. Palliative Care Australia Canberra ACT.

² Murtagh F, Bauseweun C et al. 2014. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine 2014.Vol 28(1) 49-58

³ Murray,S. Kendall, M et al (2017). Palliative Care from diagnosis to death. BMJ 2017; 356:j878 (Feb). Cross Mark. UK.

⁴ Rome, R.B, Luminair. H. et al (2011). The Role of Palliative Care at end of life. The Ochsner Journal - Winter, 11 (4) 348-352. New Orleans USA

patient's family. After the patient's death, palliative care focuses primarily on bereavement and supporting the family.⁵

- There is clear evidence of the benefits of timely access to palliative care and end of life care for persons, family and carers and the health care system.^{6,7,8,9}
- End-of-life care and palliative care are often viewed as one in the same. Both are person-centred and focus on the needs of a person approaching end-of-life, and their family. However, palliative care has an added layer - it is more than end-of-life care. A definition of both terms is at the end of this paper.
- Palliative care does not include euthanasia or physician assisted suicide, nor does palliative care intend to hasten or postpone death.¹⁰
- Late palliative care is a missed opportunity to do better for patients, families and health services. Controlled trials have shown they improved quality of life and, for some people longevity, while further studies of older people in Australia have shown significant reduction in hospital admissions.¹¹

Choice v Preference

The ACT Select Committee is examining End of Life Choices in the ACT. It needs to be stated that 'choices' does not necessarily equate to 'preferences'. 'Choice' implies selecting between one of an available set of option. Whereas 'preference' is a mental state of desire. A preference may include possibilities that are not available, and therefore not considered when making a choice.

With this premise in mind, people in the ACT may choose end of life options that are not their preference, but the best option from the choices available.

For example:

In Australia, 70% of people preferred a home death, but only 14% had this wish fulfilled.¹²

In the ACT, 75% of people preferred to die at home, yet just 18.7% did; while 0% preferred to die in hospital but 31% actually did. Factors such as carer fatigue, absence of community support such as

⁵ Ibid

⁶ Higginson IJ, Bausewein C et al. An integrated palliative care and reparative care service for patients with advanced disease and refractory breathlessness: a randomized controlled trial. *Lancet Respir Med.* 2014 Dec; 2 (102): 979 -87

⁷ Bakitas MA, Tosteson et al. Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE 111 Randomised Controlled Trial. *J Clin Oncol.* 2015 May;33 (13): 1438-45

⁸ Dionne-Odom JN, Azuero A, et al Benefits of Early Versus Delayed Palliative Care in Informal Family Caregivers of Patients with Advanced Cancer: Outcomes for ENABLE 111 Randomized Controlled trial. *J Clin Oncol.* 2015 May;33(10):1446-52

⁹ May P, Garrido MM et al. Prospective Cohort Study of Hospital Palliative Care Teams for Inpatients with Advanced Cancer: Earlier Consultation is Associated with Larger Cost-Saving Effect. *J Clin Oncol.* 2015 Sep;33 (25): 2745-52

¹⁰ World Health Organization. WHO Definition of Palliative Care. 2004

¹¹ Ibid

¹² Bartel, X. 2016. Australian Institute for Health Research.

respite, and lack of intensive care support at home meant that people chose to die in a place that was not their preference.¹³

About Palliative Care ACT

Palliative Care ACT (PACT) is the representative voice for palliative care in the ACT. Formed in 1985 PC ACT is a not for profit organisation, a registered charity, and founding member of the national peak body Palliative Care Australia.

Our Mission is to influence, foster and promote the delivery of quality care at end of life for all, and to offer compassion and support to the terminally ill, their carers and families.

PC ACT Promotes palliative care in the community; provides community education, delivers volunteer palliative services to support clients and their families with care, compassion, respect and dignity; advocates for, and promotes, provision of best quality palliative care services and supports other like-minded organisations through partnerships and collaboration.

PC ACT staff manage palliative programs that engage 170 trained volunteers in providing palliative support services across a range of settings, including:

- In clients' homes
- The Canberra Hospital
- Residential Aged Care facilities, and in
- Clare Holland House (ACT Hospice, operated by Calvary Health Care).

Palliative Care ACT believes:

In consensus with Palliative Care Australia, Palliative Care ACT believes:

- Every Australian living with a life-limiting illness should have timely and equitable access to quality, evidence-based palliative care and end of life care based on needs.¹⁴
- Compassion, dignity, respect and participation in decision-making are important to all and integral to delivery of high quality palliative and end of life care. A request for euthanasia or physician assisted suicide requires a respectful and compassionate response.
- When aligned with a person's wishes, withdrawing or refusing life sustaining treatment, (including withholding artificial hydration) or providing medication to relieve suffering, do not constitute euthanasia.

¹³ Communio 2017. Supporting people for their end of life choices. Palliative Care ACT Canberra ACT

¹⁴ Zimmerman C, Swami N, et al. Early Palliative Care for patients with advanced cancer: a cluster-randomized controlled trial. *Lancet*. 2014 May; 383 (9930): 1721-30

Term 1 – Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care.

Current Palliative Care Practices in ACT

Primary (or General) palliative care are services in all health sectors that provide the day to day care for patients and are designed to alleviate symptoms and concerns. Whereas, specialist palliative care is provided by specialist services for patients with complex problems that are not adequately covered by other treatment options, and is delivered by multi-professional teams with recognized specialist training.

Both primary and specialist palliative care are delivered in different ways across settings, from home-based palliative care delivered by GPs and community care teams to specialist teams supporting highly complex needs. Attachment A – Palliative Services in the ACT, shows the structure of the Palliative Care Services in the ACT.

2017 Health Care Consumers ACT research showed that people in the ACT value our publicly funded specialist services very highly. The research also showed areas of unmet need which could be addressed by:

- An expansion of home-based palliative care services, to meet current and future demand
- Dedicated palliative care areas in all ACT hospitals
- More overnight respite opportunities, to better support people caring for a loved one receiving palliative care at home
- Training for relevant clinical staff in ACT hospitals in the palliative approach and shared decision-making, and
- An expansion of hospice care, including exploring the establishment of a second hospice, and identifying hospice models that would meet the needs of people who cannot receive care at home, but who require palliative in-patient care over an extended period of time.¹⁵

These changes will allow more people in the ACT to receive end of life care in the place of their preference; and to receive high quality, safe and person-centred palliative care.

¹⁵ Spiller S, Cox D. 2017. Consumer and Carer experiences and expectations of home-based palliative care in the ACT. Health Care Consumers ACT. Canberra ACT

Term 6 - Other relevant matters

Other relevant material – Gaps in Palliative Care in ACT

Australia has one of the best palliative care systems in the world. However, there are still many people who are unable to access services, or who do not receive the end of life journey of their preference due to location, diagnosis, ethnicity or socio-economic status. More needs to be done to address the gaps in services.¹⁶

Palliative care practices are evolving rapidly due to the inclusion of non-cancer conditions.¹⁷ Demand for palliative care is also increasing due to population increase, an aging population, and people living longer with chronic and/or palliative conditions. The majority of ACT palliative care services are operating at capacity, with further unmet demand. It is when services do not meet demand that people have sub optimal experiences. Carers or family of a person who has had a 'bad death' or poor end of life experience often quote that negative experience as the impetus for wanting to manage the place and time of their own death.

To enable patient to make fully informed decisions regarding their end of life journey, including the consideration of voluntary assisted dying, it is strongly recommended that the following palliative care related matters be considered:

Supporting non-palliative practitioners

The advisory panel, set up by the Victorian government to set out the framework for the state's assisted dying regime, said "A person has the right to be supported in making informed decisions about their medical treatment and should be given, in a manner that they understand, information about medical treatment options, including comfort and palliative care."¹⁸

Failure to talk about and plan for death is one of the most significant obstacles to improve the quality of dying. This is partially because health professionals are uneasy about discussion death and dying with patients. Often, they do not feel they have the required skills to have these conversations.¹⁹

Doctors can delay referral with "Palliative care? You're not ready for that yet". The decision to move from actively treating a serious disease to focusing on making a patient comfortable can represent abandonment for the patient and failure for the doctor. But without timely access to palliative care, the patient risks exposure to futile treatments and additional discomfort.²⁰

¹⁶ Dr Jane Fisher, President Palliative Care Australia.(Nov 2017). Media Release - Palliative care must be prioritized after historic euthanasia vote. Palliative Care Australia Canberra ACT.

¹⁷ Murtagh F, Bauseweun C et al. 2014. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine 2014.Vol 28(1) 49-58

¹⁸ Duckett S 2017. Assisted dying is one thing but the government must ensure palliative care is available to all who need it. The Conversation <http://theconversation.com/assisted-dying-is-one-thing-but-governments-must-ensure-palliative-care-is-available-to-all-who-need-it-86131>. Accessed 20 March 2018

¹⁹ Swerissen H, Duckett S. 2014 Dying Well. Grattan institute

²⁰ Maddocks I. 2016. Palliative Care, you are not ready for that yet. The conversation May 2016 <https://theconversation.com/palliative-care-should-be-embraced-not-feared-59162> accessed 20 March 2018

More needs to be done to up-skill health professionals outside of the palliative care sector, such as GP's nurses, aged care staff, allied health professionals and other health professionals to ensure they are equipped with the knowledge and skills to best support people with life limiting illnesses and their carers.²¹

Champion, advocate and representative voice

Each week PC ACT receives numerous requests from members of the ACT public for information on palliative care, the services available, and how to navigate the system. These communications show that patients and their families, despite being under the care of a GP or specialist team, are still confused and lacking knowledge of their options and services. These situations can lead patient to make choices that are often not their preference, but a result of other factors.

Community awareness and normalise discussion about death and dying

We need the courage to promote mature discussions about a topic that many dislike, but that we cannot avoid. People who plan ahead for their preferred care and talk about those wishes with their family and health team, are more likely to receive it.²²

Advanced Care Planning (ACP)

Awareness of Advanced Care Planning remains low.²³ When people's preferences are not clear, it is hard to shift from a focus on cure, to a focus on palliative care. ACP is a way that a person can communicate their wishes regarding health care and medical treatment. It is also a place that a person can articulate the circumstances in which they would wish to actively managing the time and circumstances of their death. Including such information in an ACP needs to be a substantial process. The submission to the Committee by Health Care Consumers ACT well covers these details.

PA ACT commends and supports the Commonwealth Government for its initiative, Advance Care Planning week, which focus attention to ACP. More could be done at an ACT level to promote ACP.

Bereavement

Standard 6, of the National Palliative Care Standards²⁴ states that all families and carers should have access to bereavement support services and are provided with information about loss and grief. It optimal for services to have mechanisms in place to identify people who are at risk of, or who are

²¹ Dr Jane Fisher, President Palliative Care Australia.(Nov 2017). Media Release - Palliative care must be prioritized after historic euthanasia vote. Palliative Care Australia Canberra ACT.

²² Dr Jane Fisher, President Palliative Care Australia.(Nov 2017). Media Release - Palliative care must be prioritized after historic euthanasia vote. Palliative Care Australia Canberra ACT.

²³ Swerissen H, Duckett S. 2014 Dying Well. Grattan institute

²⁴ Palliative Care Australia. 2018. National Palliative Care Standards 5th Edn. Palliative Care Australia. Canberra ACT.

experiencing a complex response to bereavement, and facilitate access to experts in grief, loss and bereavement management, in a timely manner. The ACT Health services do have some services, but they are not universal.

National Standards

The nine Standards of Care articulated in the National Palliative Care Standards (5th Edn), describe the system and enablers necessary to deliver high quality clinical care, and governance standards in regards to quality management, quality improvement and benchmarking.²⁵

The Palliative Care Service Development Guidelines, 2018, outline the minimum core competencies in the provision of palliative care and the care that providers will give, plus the rights and responsibilities of people living with life limiting illnesses. A strong network of support, regional planning and workforce support are important system capabilities noted in the Guidelines.²⁶

It is recommended that the palliative care services provided in the ACT be developed and benchmarked against these publications. As stated previously, the quality of palliative care a person receives will influence their end of life journey, choices and decisions.

Term 3 – Risks to individuals and the community associated with voluntary assisted dying and how these can be managed

The issues noted below do not compile an exhaustive list, but are considered to be major palliative care related issues, that should be considered when deliberating the question of voluntary assisted dying.

The ‘social slippery slope’

There is a belief that voluntary assisted dying, initially intended to be a regulated last-resort option activated in only very select situations, could, over time, become less of a last resort and be sought more quickly, even becoming a first choice in some cases.²⁷

Investing in and maintaining a comprehensive palliative care system, available to all, would contribute to negating the possibility of this slippery slope.

The “social slippery slope” and palliative care

In Switzerland in 2006, the university hospital in Geneva reduced its palliative care staff (to 1.5 from 2 full-time physicians) after a hospital decision to allow assisted suicide and the community-based palliative care service was also closed.²⁸

²⁵ Palliative Care Australia 2018. National Palliative Care Standards. Palliative Care Australia. Canberra ACT.

²⁶ Palliative Care Australia 2018. Palliative Care Services Development Guidelines. Palliative Care Australia. Canberra ACT.

²⁷ Pereira, J. 2011. Legalizing euthanasia or assisted suicide: The illusion of safeguards and controls. Current Oncology. Ottawa.

²⁸ Ibid.

There is an argument that attracting doctors to train in and provide palliative care may be more difficult because of access to voluntary assisted dying, perceived by some to present easier solutions, because providing palliative care requires competencies and emotional and time commitments on the part of the clinician.²⁹

Ongoing resourcing and financial support of palliative care and government and community recognition of the value that palliative care brings to the majority of Australian at the end of life is needed to ensure continued delivery of quality and effective palliative care. Palliative care services make a real difference to the vast majority of peoples' quality of life.

Medical professionals

In 2006, 15% of physicians in the Netherlands expressed concern that economic pressures may prompt them to consider euthanasia for some of their patients.³⁰

This one is too sad to think about, perhaps these physicians should retrain as economists.

Patients are also vulnerable to the level of training and experience that their physicians have in palliative care and to the personal views of their physicians about voluntary assisted dying. A USA study showed that the more physicians know about palliative care, the less they favour voluntary assisted dying.³¹

Affording palliative care respect as a mainstream career option for medical students through options such as palliative care being a defined area of study or at the least, medial student rotations with palliative care services.

As mentioned previously, supporting medical practitioners with knowledge and information for an understanding of palliative care, and available care in the ACT will assist with their decision making.

Long term effect on palliative care

The current discussion and focus on voluntary assisted dying, is drawing attention to end of life and palliative care. This is increasing community and therefore political interest in improving current practices, and introducing new models of care to increase peoples' quality of life and to provide family support. There is a concern, that if a Bill was introduced and passed, that an 'our work is done' attitude may develop, and that palliative and end of life care be a casualty of voluntary assisted dying.

Reduced support, will lead to reduced end of life choices, which will result in fewer people achieving their end of life preference, and a shorter, more stressful end of life journey, resulting in the vast majority of Australians experiencing a sub-optimal end of life journey.

²⁹ Ibid

³⁰ Ibid

³¹ Portenoy RK, Coyle N, Kash et al. Determinants of the willingness to endorse assisted suicide. A survey of physicians, nurses, and social workers. *Psychosomatics*. 1997 May-Jun; 38(3):277-87.

Going forward it palliative care needs to be supported and recognised as the most effective method of supporting a person and family during their end of life journey, and it is for the majority of citizens. Voluntary assisted dying and palliative care are separate, not entwined.

Individual Risks

Uncontrolled pain and symptoms remain among the reasons for requesting euthanasia or voluntary assisted dying. Physician knowledge of palliative sedation and pain management, to achieve comfort at the lowest doses of sedative possible is a major factor in patients achieving comfort and allowing them to continue interacting with family, if possible.³²

Studies have shown that losing a sense of dignity and hope and taking on a sense of burden prompt some people to seek voluntary assisted dying.³³ Strategies to improve the sense of dignity, based on empirical studies that have explored the concept of dignity within palliative care, have been shown to work³⁴ Similar strategies should be developed in the areas of hope and burden.

External influences could affect decision-making by vulnerable people. People who have been diagnosed with a life limiting illness and have "decision-making capacity" but whose judgment is impaired by depression, mood disorders or on-going extreme pain due to their illness; people who are frightened by their disease, failing mental powers or of "being a burden" on their family or society; people whose voluntary request for assisted suicide is manipulated, influenced or misrepresented, or unconscionable conduct of others including family and carers; or people who do not have the capacity to make sound decisions, will need protection through the mechanisms of the law.

³² Cherny NI, Radbruch L, Board of the European Association for Palliative Care European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Med.* 2009;23:581–93. doi: 10.1177/0269216309107024

³³ Emanuel EJ. Depression, euthanasia, and improving end-of-life care. *J Clin Oncol.* 2005;23:6456–8. doi: 10.1200/JCO.2005.06.001.

Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry.* 1995;152:1185–91.

Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA.* 2000;284:2907–11. doi: 10.1001/jama.284.22.2907.

³⁴ Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol.* 2005;23:5520–5. doi: 10.1200/JCO.2005.08.391.

Conclusion

PC ACT sincerely thanks the ACT Government's Select Committee for the opportunity to provide a submission on End of Life Choices in the ACT.

While assisted dying is an avenue for someone with intolerable suffering to be able to relieve that suffering, the government must still ensure everyone has good end-of-life care. In recognition of the enormous positive contribution that palliative care makes to end of life, the Victorian Andrews government, in line with the assisted dying bill, also pledged to spend \$62 million over five years to improve palliative care across the state.

Palliative Care ACT would welcome further opportunity to consult or expand on our discussion or recommendations in this submission.

Definitions

End of life care³⁵

End-of-life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death.

People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

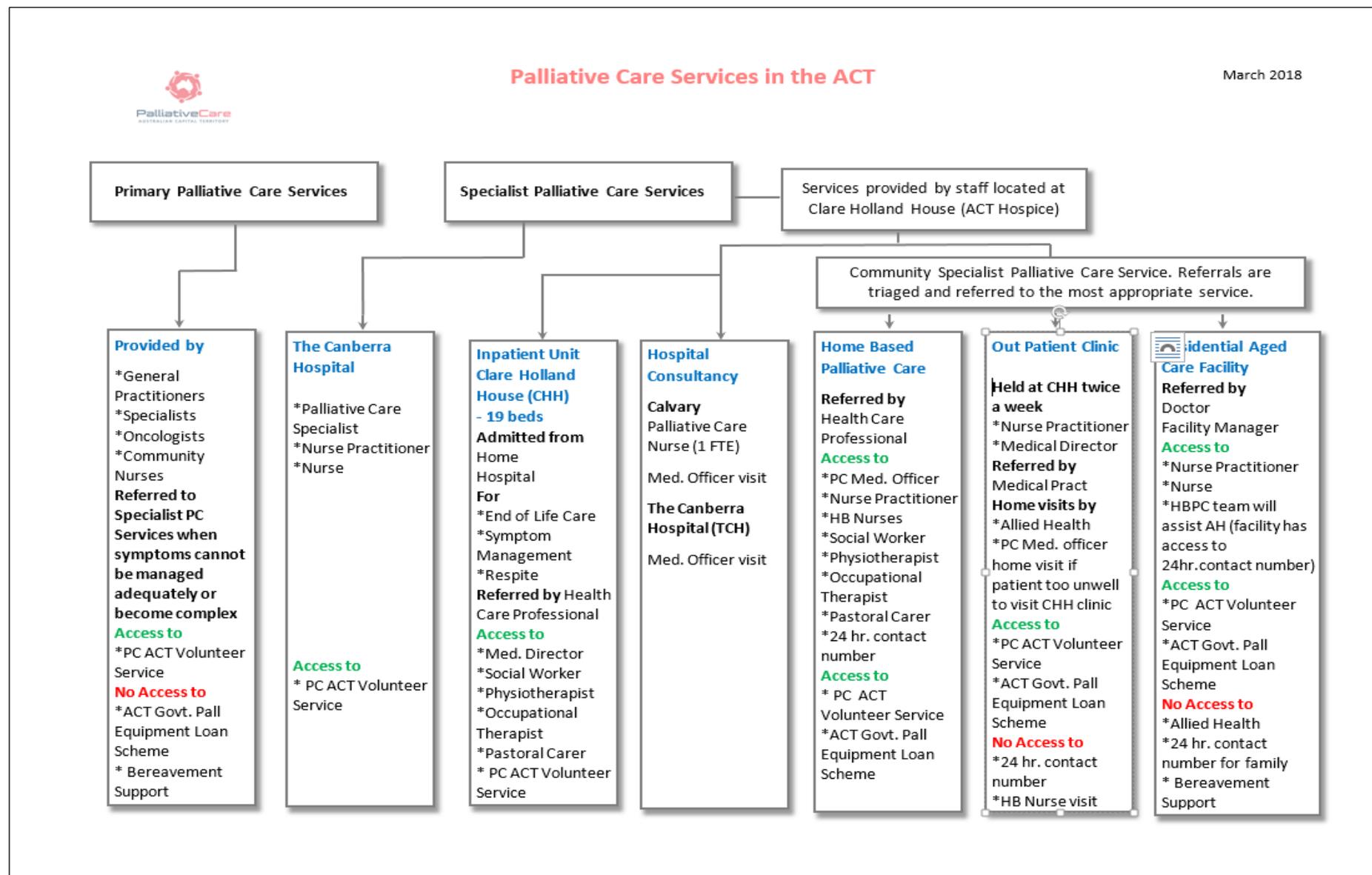
Palliative Care³⁶

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening 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 patients 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.

³⁵ Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential Elements for safe high quality end of life care. 2015

³⁶ World Health Organization. WHO definition of Palliative Care. 2004



Contacts

Glenda Stevens
CEO

Palliative Care ACT
5 Flemington Rd Lyneham 2602
PO Box 31 Campbell, 2612
P: 02 6255 5771
E: office@pallcareact.org.au
www.pallcareact.org.au