



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Secretary
Select Committee on End of Life Choices in the ACT
Legislative Assembly for the ACT
GPO Box 1020
CANBERRA
ACT 2601

Dear Secretary

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Capital Health Network (CHN), ACT's primary health network (PHN), is pleased to make this submission in response to the inquiry into end of life choices in the ACT.

CHN plays a pivotal role in supporting general practice, primary, aged care and community care services to better meet the health needs of the community. We're building health system capability to achieve **better health outcomes** and **better care** for the community, a **better supported workforce** and **better value** from the health resources we have available.

Our comprehensive Needs Assessment reveals current issues and emerging trends in the health and wellbeing of the ACT population. We collected information about health inequalities in the ACT population and focused on disadvantaged or vulnerable groups. The Needs Assessment can be found here:

<https://www.chnact.org.au/activity-work-plans-and-needs-assessments>.

Capital Health Network, the ACT PHN, recommends the following actions for enhancing the end of life choices for ACT residents:

- Rapid access to GPs for homebound patients both in hours and after hours.
- Improving the integrity and uptake of advanced care planning through the adoption of multi-faceted interventions including increasing community and consumer awareness and encouraging and promoting health professional involvement
- Supporting the introduction of specialist palliative care practitioners
- Supporting the expansion of the Geriatric Rapid Acute Care Evaluation model in both the Canberra Hospital and Calvary Emergency Departments to better address the needs of RACF residents and avoid unnecessary hospital presentations
- Proactively and rapidly implementing the new Palliative Care Model of Care
- Introducing a Compassionate Communities approach that increases community resilience and capacity
- Providing access to palliative care and opioid registered prescribers both in hours and after hours
- Providing access to pain management and palliative care medications both in hours and after hours
- Recognising and addressing the psychological needs of those with chronic conditions and their carers, particularly at end of life stage
- Supporting and strengthening carer capacity and resilience.

Terms of Reference 1(a): Managing end of life, including palliative care

Dying with Dignity and Respect – Advanced Care Planning (ACP) and Supported Decision Making

Each individual has the right to make decisions about their own health care, and it should be recognised that medical treatment should only be given following informed consent and that individuals have the right to refuse treatments. An Advanced Care Plan (ACP) provides the opportunity for individuals to document their personal choices regarding treatments and end of life care only coming into effect when individuals lose capacity to make such decisions.

A key issue remains the need for early attention and focus on supported decision making and advance care planning. While there has been an increased uptake of advanced care plans in hospital patients, this is often too near the end of life.

The ACT has an active Respecting Patient Choices Program operating from the Canberra Hospital to support ACPs. CHN (previously ACT Medicare Local) facilitated training for RACFs and GPs in ACPs, and in May 2014 launched a communication campaign involving a TV advertisement and an advance care planning support website branded Be My Voice.

The Health Care Consumer Association (HCCA) has been funded through the Respecting Patient Choices program (from January 2015 to November 2016), to deliver consumer education workshops focused on initiating and having difficult conversations associated with advanced care planning. Targeting general multicultural and vulnerable consumer groups, these workshops are aimed at ensuring that choice and control is maintained in all aspects of an individual's health care. HCCA also tailor and deliver this education to health care professionals.

To enable end of life choices, emphasis should be placed on routine and systematic advanced care planning and supported decision making at multiple stages across chronic disease trajectories and ideally facilitated within the community setting prior to end stage decline and/or hospitalisation.

Emphasis should subsequently be placed on the effective communication and accessibility of an ACP to ensure that this proactively guides any further clinical interventions. It is critically important that an ACP is flagged and linked to the patients My Health Record and inpatient record.

Increasing the capacity and capability of the whole health and care system, encompassing primary health care and community services to deliver coordinated care to patients with complex chronic conditions and support timely advanced care planning (encompassing acknowledgement of health literacy levels and decision making capacity) continues to be identified as a priority need.

Guidance and assistance with advance care planning requires a fundamental understanding that it is a 'process' not a one off occurrence. Advanced care planning should be a part of routine health care and GPs can play a guiding role.

A recent program entitled 'Enabling a Quality End of Life Journey' conducted by Calvary Public Hospital (Bruce), and sponsored by Capital Health Network through the ACT PHN Programme, has developed resources to equip and support general practice and RACF staff with advance care planning particularly to identify individuals, provide tools and support clinicians.

If we are to truly promote end of life choices, investment in all the above needs to be reintroduced and sustained and the above training, services, tools and supports systematised within the health and care system. The above should be mainstream and routine not adhoc and unsustainable.

Access to GP Services and Appropriate Home/Community Based Responses to Rapid Decline in Condition

Ready access to GP services for homebound patients and people in residential aged care, including quality end of life care, was identified as a priority area for action by the GP Taskforce in 2009 and still remains a significant issue. When the health or independence of an individual deteriorates rapidly they should have access to rapid urgent care, including effective alternatives to hospital.

The difficulty in accessing a GP limits peoples' choices and often results in a presentation to ED as an alternative - for those people in the end of life stage with an active ACP this is often inappropriate. It is a common view amongst ACT health professionals and aged care advocates, and indeed in other national and international jurisdictions, that EDs are not geared to fully address the complex underlying physical, social, cognitive, and situational needs of older people, nor adequately care for the dying. Medicare Benefits Schedule data indicates that older persons in the ACT have consistently lower rates of Medicare services per capita than the national average.

A key point highlighted by the ACT palliative care service is the value of having specialist palliative care practitioners (who are knowledgeable of ACT legal requirements set out in the Medical Treatments Act;

have established relationships with the ACT Office of the Public Trustee and Guardian, and appropriate prescribing capability under the *Medicines, Poisons and Therapeutic Goods Regulation 2008*) integrated within RACF and community based GP services. The benefits of this enhanced community capability include: reduced hospitalisations; increased access to palliative care medicines; increased access to prescriptions and medication reviews; timely assessment of palliative care needs (e.g. having injectable medicines in place such as morphine has reduced hospital transfer at end of life); and increased dying in preferred place of death – which is usually the home or RACF and not hospital.

It is recognised that the current service model needs to be transformed to meet the needs of people with co-morbidities and complex needs including those in end stage decline when they deteriorate rapidly. Transitions in and out of acute hospital settings are particularly critical as patients in their last year of life are admitted to hospital an average of 3.5 times. This indicates the need to strengthen cross boundary coordination and discharge planning.

CHN supports the development of models which encourage care provision in the right place at the right time. For instance, the Geriatric Rapid Acute Care Evaluation (GRACE) Model, based on collaborative arrangements between hospital staff, GPs and RACFs, has been in existence in other States for a number of years and is currently being trialled by Calvary Public Hospital (Bruce) sponsored by Capital Health Network through the ACT PHN Programme. Introduced mid-2017 it is already demonstrating positive outcomes for consumers and the health system alike – respecting patient choices and providing the right care in the right place at the right time; reducing ED presentations by coordinating primary and community based interventions and providing outreach services; where ED presentations are warranted increasing discharges and reducing the length of stay; and if admitted, reducing the average length of stay for eligible patients. The service works collaboratively with RACFs, GPs, ACT Ambulance Service, RADAR and Palliative Care Services.

Model of Care – Palliative Care

The draft Productivity Commission report, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services* published in 2017 notes the following:

‘Australia’s health system is doing a poor job of managing people in their final years of life’.

‘Hospitals remain the last preferred place of death but still remain the most common places to die: about 70% of Australians would prefer to die at home yet it is estimated that less than 10% do so’.

‘It is safe to assume that the vast majority of people do not die in a way, or in a place that reflects their values, preferences or their choices’.

‘Advances in medical care mean that we can do more to treat illnesses and the majority of people now die in acute care settings with many being actively treated right up to the moment of their death, in some cases involving expensive and futile treatment’.

According to Palliative Care Australia (2010) limited community and professional awareness of end of life issues, a societal reluctance to talk about and normalise death, combined with the inability of health professionals to recognise and appropriately treat those who are dying, are significant barriers to achieving quality care and a quality death.

Many of the problems associated with the effective provision of end of life care, and indeed the management of complex and chronic cases in general, relate to barriers that occur at the interfaces between settings, between services and between health care professionals. These are further exacerbated in the ACT “as different services interfacing with palliative care [are] set up in silos and there are difficulties associated with incompatible software and information systems” (National Clinicians Network, 2013).

End of life dementia patients are particularly at risk due to the complex medical, cognitive, emotional, ethical and social considerations that accompany dementia. Often people with dementia are subjected to interventions such as tube feeding or hospitalisation for pneumonia that may be of limited benefit and not consistent with quality end of life care.

Some of the strongest anecdotal evidence about system failure to care appropriately for people with dementia, as they approach the end of life, is found at the transitions between care sectors. Inappropriate transfers into unfamiliar environments such as busy EDs, coupled with invasive procedures often leave patients disoriented, confused and anxious resulting in further complications and behavioural changes that these settings are generally ill-equipped to deal with.

The ACT is serviced by a specialist palliative care service offering Palliative Aged Care Consultancy supported by the Calvary Palliative and End-of-Life Care Team. This service operates out of Clare Holland House and provides both hospice and community based in-home support.

Feedback from consumers suggests that while the quality of palliative care programs is high in the ACT, there is greater demand for services than can currently be met. With an ageing population, the increase in future demands on palliative care services, including those in the community and RACFs, should be considered a high priority (Health Care Consumers Association, 2016).

The new *Palliative Care - Model of Care* (2016) provides a framework and commitment to enhance palliative care services and we are pleased to note ACT Health is now looking at implementation of this model. However, the number of people wishing to die at home with the support of community and community-based palliative care services far exceeds the availability of that care, particularly for those with life-limiting conditions other than cancer. More community-based palliative care services are needed to enable more people who wish to die at home to do so. End of life care in RACFs needs to be better resourced and delivered by skilled staff.

Alternative approaches that promote and enable personal choice and control by driving cultural change and building community capacity need to be developed – doing things differently. We need to invest in a *Compassionate Communities* approach which integrates community based capacity, networks and supports into the system of care – extending formal and informal networks and supports.

This approach:

- recognises that formal services are not enough on their own and cannot provide all the support patients and carers need
- seeks to:
 - normalise attitudes to death through acknowledging that death, dying, loss and care is everyone's responsibility
 - builds community capacity to better care for and support individuals at the end of life and their carers through social and emotional support
 - promotes consumer choice and control
 - normalises seeking help and the acceptance of help from family, friends, neighbours and communities
 - draws on the strengths, resources and resilience of communities to work together to provide best possible home-based end of life care
- has the ability to reduce some of the burden on health and care systems.

CHN is keen to explore how this approach could be adopted for the benefit of the community and the health system alike.

Prescribing and Access to Medications

Access to palliative care and opioid registered prescribers both in hours and after hours is a key issue – not all GPs are registered and able to do this.

Access to palliative care and pain related medications in the after-hours period is a significant issue that undermines quality of care. CHN, through the ACT PHN Programme, has recently funded Capital Chemists Wanniasa and Charnwood to address this system gap through a pilot project which enables a 24/7 palliative care approach to improve access to medications and most significantly providing home based deliveries during the after-hours period for palliative care patients.

Carer support

Carer capacity is critical to effective end of life care. Carers are an integral part of our health system and are the foundation of our aged, disability and community care system. Feedback suggests that the lack of access to carer supports is likely to increase as the population ages, as the complexity of chronic and comorbid conditions increases and a preference for care in the home and community settings also rises. Carers require support in the end of life phase to better care for their own physiological, psychological and social needs, so in turn they care better care for their loved one. The current service system for carers is complex, fragmented and difficult to navigate. In addition to financial support, carers need to access support for aged care, disability and mental health services, and find referral pathways and information for the person they care for.

Terms of Reference 2(b-f): Voluntary assisted dying

Consideration of voluntary assisted dying presents moral and ethical dilemmas for both society and health professionals.

Whilst the RACGP welcomed the passing of the Voluntary Assisted Dying Bill in the Lower House of the Victorian Parliament in October 2017, saying that it was satisfied that the Bill had been appraised appropriately and appropriate safeguards put in place for patients, relatives, medical and health professionals, it should be recognised that there is a wide range of views amongst CHN members. Given this is a highly emotive and personal issue it is difficult to find consensus opinion.

When considering this matter the following issues are raised:

- Is this to be universally available or limited to certain conditions or clinical scenarios; and if the latter, to certain stages of illnesses?
- If such legislation is to go ahead what safeguards are required to ensure that beneficence and non-maleficence is balanced.
- How would legislation ensure the individual has legal capacity to make an informed choice and instruct the medical practitioner?
- Who would carry out the assisted dying – the individual themselves (as in Switzerland) or a medical practitioner (as in Victoria)?
- If a medical practitioner, what skillset would they require? Is this similar or different to those of Specialist and/or GPs? If different should special interests/skills and referral pathways be developed?
- Under the *Medicines, Poisons and Therapeutic Goods Regulation 2008 (ACT)* can a medical practitioner prescribe a deadly pharmaceutical product?

If such legislation is introduced primarily on the basis of patient autonomy and choice, it may well be assumed that all GPs are willing, professionally skilled and competent to manage these issues. The rights and autonomy of medical practitioners (Specialists and GPs alike) should be safeguarded and respected in a similar way to that of clinician participation in the management of patients seeking abortion. These rights should not be eroded nor abused – no medical practitioner should be forced to be involved in any such procedure, whether arranging it or taking part.

‘Assisted suicide’ has been available in the state of Oregon, USA since 1997. This is a rare event – accounting for approximately 1% of deaths, a similar rate to that of the ‘medically assisted deaths’ introduced in Canada in June 2016. Under the [Swiss Criminal Code 1937](#) assisted suicide is legal in Switzerland where lethal medication may be prescribed as long as the recipient takes an active role in its administration. Switzerland is the only country which accepts foreign nationals for a legal medically assisted suicide. The introduction of non-profit organisations in the 1980s has led to the development of ‘suicide tourism’. One person per fortnight goes to Dignitas alone from the UK for assisted dying, however the highest proportion of suicide tourists are from Germany. If legislation were enacted safeguards would be required to mitigate the risks of suicide tourism in the ACT.

Whilst illegal in the UK, consumer advocacy on the right to control one’s own death is increasing. Consumer perspectives are expressed through the [Campaign for Dignity in Dying](#). Similarly consumer views are expressed via the [Dying with Dignity campaign in Canada](#).

CHN strongly supports the implementation of changes to the ACT health system that will enhance end of life care, including better advanced care planning, strengthening the availability of, and access to, palliative care and an informed discussion on the merits of assisted dying both from a patient and clinician perspective.

We look forward to learning the outcome of the Inquiry. If in the meantime you require any further information please feel free to contact me directly.

Yours faithfully

A handwritten signature in black ink, which appears to be "Gaylene Coulton", is written over a solid black rectangular redaction box.

Gaylene Coulton
Chief Executive