

**2019**

**THE LEGISLATIVE ASSEMBLY FOR THE  
AUSTRALIAN CAPITAL TERRITORY**

**ACT GOVERNMENT RESPONSE TO THE REPORT OF THE SELECT COMMITTEE  
ON END OF LIFE CHOICES IN THE ACT, MARCH 2019**

**Presented by:**  
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**Minister for Health**  
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The Government notes the report of the Select Committee on End of Life Choices and thanks the Committee for its considered approach. The Government welcomes this opportunity to respond to the Committee's recommendations.

The ACT Government is committed to continued advocacy for individuals to have the right to make their own choices at the end of their lives and for the ACT community to determine its own position on voluntary assisted dying. It is an important commitment of this Government that the ACT has a visionary end of life and palliative care service that provides freedom of informed choice to meet the needs of the whole ACT community through access to appropriate care and support at the end of people's lives.

In light of this commitment, Canberra Health Services (CHS) and the ACT Health Directorate (ACTHD) commenced a project in July 2018, to be implemented over four years, to improve the coordination of end of life and palliative care services that are delivered to the ACT community through a network of providers. This Territory-wide End of Life and Palliative Care Project (ELPCP) aims to provide seamless, integrated and high-quality care to people who are at the end of their life and support their families and carers. It covers care across the health service continuum, including general practitioners (GPs), residential aged care facilities (RACFs), non-government organisations, inpatient settings, community providers and specialist palliative care providers.

The ELPCP has planning already in place in relation to many of the recommendations made by the Select Committee for End of Life Choices. The Government welcomes the opportunity to further strengthen the model, building on the momentum from the Select Committee's inquiry.

## **Response to recommendations**

### **Recommendation 1—Agreed**

*The ACT Government develop a community education campaign on Advance Care Planning, or update existing community education resources, including:*

- *Information about what an Advance Care Plan entails and why it is important.*
- *Information about the benefits of discussing end of life choices and developing a plan early.*
- *Information about the importance of ensuring the terms of an Advance Care Plan are clear.*
- *Information about the benefits of reviewing Advance Care Plans over time.*

The Government recognises the importance of communicating clearly with consumers, their families and stakeholders about Advance Care Planning.

Information on Advance Care Plans is available online through: the ACT Government Advance Care Planning Program at CHS; Advance Care Planning Australia; Be my Voice; and the Palliative Care ACT *Directory of Assistance and Information Services for You (DAISY) at End of Life*. As some Advance Care Plans documents are not legal documents, discussions are underway with key stakeholders to help ensure Advance Care Plans include suitable, clear information for paramedic and medical staff to inform care decisions.

The Advance Care Planning Program at CHS provides education for health workers and the community, as well as promotional material, community forums (for example at the Council of the Ageing Seniors' Week, the Elder Abuse Forum, Carers ACT, and Dementia Australia), Advance Care Planning Week, and participation in Dying to Know Day.

In addition, the Advance Care Planning Program ensures documents provided to CHS are available for clinicians to access; provides information sessions at RACFs; and ensures consumer documents are available when a consumer is admitted to hospital or accesses community health services.

### **Recommendation 2—Agreed**

*The ACT Government work with members of the ACT's Culturally and Linguistically Diverse (CALD) communities in order to devise culturally-appropriate strategies to increase the uptake of Advance Care Planning among this sector of the population.*

The ELPCP's development of care pathways for the CALD community will address increased access to end of life care and palliative care, and include strategies to increase the uptake of Advance Care Planning.

In addition, CHS is funding the Health Care Consumers' Association (HCCA) to work with CALD communities to increase the uptake of Advance Care Planning.

### **Recommendation 3—Noted**

*The ACT Government fund the training of volunteer representatives from specific cultural communities to promote Advance Care Planning in their community.*

The ACT Government funds HCCA to work with CALD communities to increase the uptake of Advance Care Planning. The ELPCP's development of care pathways for the CALD community will address increased access to end of life care and palliative care, and include strategies to increase the uptake of Advance Care Planning by CALD communities.

### **Recommendation 4—Noted**

*The Minister for Health and Wellbeing publishes the number (without personal details) of Advance Care Plans and Advance Care Directives held by hospitals and care institutions in the ACT.*

It is important that Advance Care Planning focus on ensuring that appropriate time is taken with each patient to develop a tailored and clear plan that reflects the consumer's wishes. A focus on the number of plans in place may detract from this and could result in planning becoming a 'box ticking' activity. The ACTHD will give consideration to whether there is an appropriate data set in which this information could be included as part of routine reporting.

### **Recommendation 5—Agreed**

*The ACT Government develop an education campaign for health care professionals using and assessing Advance Care Plans in a hospital setting.*

As noted under recommendation 1, the Advance Care Planning Program provides education for health workers and undertakes promotional activities. It also ensures documents provided to CHS are available for clinicians to access; provides information sessions at

RACFs; and ensures consumer documents are available when a consumer is admitted to hospital or accesses community health services.

### **Recommendation 6—Agreed**

*The ACT Government, in consultation with appropriate community, legal professionals, and public guardian bodies, undertake an ongoing program to educate ACT health care professionals about:*

- *the nature, purpose and effect of Advance Care Directives and Enduring Powers of Attorney in the ACT;*
- *how to determine and recognise a valid Advance Care Directive; and*
- *identifying a lawfully appointed substitute decision maker.*

The Public Trustee and Guardian engages in education and community presentations on guardianship, Enduring Power of Attorney, and other topics relating to supported and substitute decision making.

CHS also provides education on Enduring Power of Attorneys for Advance Care Planning.

In addition, a national palliative care project has recently been rolled out by the Commonwealth Department of Health for online and face-to-face training of medical staff and GPs. As part of this national project, a workshop will be conducted in the ACT.

### **Recommendation 7—Agreed**

*The ACT Government liaise with other Australian jurisdictions, particularly the Commonwealth, through the COAG process, to encourage the implementation of the Productivity Commission’s recommendation on establishing a Medicare item number to encourage doctors and practice nurses to have more in-depth discussions about Advance Care Planning.*

GPs and general practices are recognised as important in the delivery of high quality and sustainable end of life and palliative care in the community. Currently GPs are not funded to spend time having conversations with patients about these matters. Early conversations conducted by a GP could avert last minute decisions being made by people in crisis on arrival at a hospital.

The ACT Government supports the Productivity Commission recommendations, and recognises that the Commonwealth Department of Health would lead this work. As a member of the Council of Australian Governments (COAG) Health Council, the ACT Minister for Health will write to the Commonwealth Minister for Health supporting the recommendations.

### **Recommendation 8—Agreed**

*The ACT Government continue to work with other Australian jurisdictions to investigate the feasibility of reforming Power of Attorney legislation or introducing a single, Enduring Power of Attorney across Australia and that report on progress be included in the appropriate agency annual reports.*

As a member of the Working Group on Enduring Power of Attorney, the ACT Government is working with other jurisdictions to investigate the feasibility of reforming Power of Attorney legislation or introducing a single, Enduring Power of Attorney across Australia.

The public release of information on the progress of this work is subject to the agreement of the Council of Attorneys-General.

### **Recommendation 9—Agreed**

*The ACT Government works with key stakeholders to:*

- a) develop a strategy to make Advance Care Plans and Advance Care Directives more widely accessible for people living with dementia and their families and carers.*
- b) develop a community education campaign for people with dementia, particularly early onset dementia, which emphasises the importance of developing or revisiting their Advance Care Plan soon after their diagnosis.*

The ELPCP education strategy will include the development of community education on Advance Care Planning relevant to high priority groups, including those diagnosed with dementia.

In addition, education under recommendations 1, 5 and 6 could also include this population group.

### **Recommendation 10—Agreed in Principle**

*The ACT Government consider trialling the funding of ‘death cafés’, including exploring funding existing non-governmental organisations which undertake this work, to establish the initiative in the ACT, with an aim to encourage broader conversations about death and dying and improve death literacy.*

Palliative Care ACT has run five ‘death cafes’ in the ACT. There is anecdotal feedback that, in an aged care setting, the term ‘death café’ was not well received. The first of Palliative Care ACT’s events was held in 2014 at a public café in Lyneham, North Canberra and was marketed as ‘What are you Dying to Know’. The Government notes the work of organisations such as Palliative Care ACT in trialling initiatives to break down the barriers to support people to start thinking and talking about death in a timely way.

Given this, the Government will explore the implementation of a broader education and engagement campaign to encourage discussion on death and dying in safe and accessible environments. Further work will include engagement through forums that already exist as well as considering variations on the ‘death café’ model and other potential opportunities in partnership with community stakeholders.

Resources on conversations about death and dying are already available online through Palliative Care Australia’s ‘Dying to Talk’ initiative. The ELPCP has also commenced the initial stages of a communication strategy on death and dying which will be informed by research and consultation.

In addition, during National Palliative Care Week in 2019, Engagement Stalls were held at the Canberra Hospital, providing information, discussions on death and dying, and Advance Care Planning kits. An easy to read document was also developed in conjunction with Palliative Care Australia to give to people to take home and discuss with their families.

#### **Recommendation 11—Agreed**

*The ACT Government will work cooperatively with Governments from all Australian jurisdictions to implement the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia.*

As noted under recommendation 7, the ACT Government supports the Productivity Commission recommendations, and recognises that the Commonwealth Department of Health would lead this work. As a member of the COAG Health Council, the ACT Minister for Health will write to the Commonwealth Minister for Health supporting the recommendations.

#### **Recommendation 12—Noted**

*The ACT Government report to the Legislative Assembly on the timetable and progress of actions to achieve the implementation of the proposed reforms advocated by the Productivity Commission report on End-of-life Care in Australia as part of its response to this report as well as including that information in relevant annual reports.*

See recommendation 11. The Minister for Health will provide an update to the Legislative Assembly on the national work by the end of August 2020.

#### **Recommendation 13—Agreed**

*The ACT Government assess the demand for higher palliative care options in the ACT and investigate the feasibility of funding the extension of in-home palliative care options.*

A mapping of end of life and palliative care services has been completed for the ACT. The ELPCP has planned to utilise this mapping and undertake a service function review. This could be used to inform service capacity and delivery required to address the needs of people in the ACT community. Based on consumer feedback, this review will include specialist and non-specialist in-home palliative care options.

#### **Recommendation 14—Agreed**

*The ACT Government investigate the respite options available to families providing in-home palliative care and whether these options meet the increasing demand for such services.*

See recommendation 13.

### **Recommendation 15—Noted**

*The Legislative Assembly refer the provision of palliative care to paediatric and adolescent patients in Canberra to the Legislative Assembly Standing Committee on Health, Ageing and Community Services for inquiry and report.*

The ACT has a specialist paediatric palliative care service, provided by a specialist paediatric palliative care nurse and on-call specialist palliative care medical specialists. The ACT specialists are supported by paediatric palliative care medical specialists in NSW. The ACT Health Paediatric Palliative Care Model of Care was developed and endorsed in 2017, following extensive consultations with families, paediatric and neonatal services, adult palliative care services, other clinicians and key stakeholders. CHS is currently working with Palliative Care ACT and Westmead Hospital to better train specialist palliative care volunteers to provide paediatric volunteer support in the home.

### **Recommendation 16—Agreed**

*The ACT Government evaluate what level of funding is required for the provision of palliative care within residential aged care facilities and work with the Commonwealth Government to provide this funding.*

The 2019-20 ACT Budget allocated new funding of \$1.66 million over three years for the INSPIRED model of care. This is a nationally recognised program developed in the ACT, where nurse practitioners provide palliative care consultancy services to RACFs through Clare Holland House. A population needs based funding model is planned to be developed as part of the ELPCP to inform future funding decisions.

### **Recommendation 17—Agreed**

*The ACT Government review whether a dedicated palliative care ward should be established in the Canberra Hospital.*

The ACT Government has developed a model of care. In reviewing the proposed model of care, the HCCA agreed that an inpatient palliative care ward at Canberra Hospital would benefit the ACT community. Future planning to support greater palliative care services in the acute environment is currently underway.

### **Recommendation 18—Agreed**

*The ACT Government review and improve the counselling and support services available to all healthcare workers involved in palliative care to ensure it is adequate for demand and individual needs.*

Specialist Palliative Care staff receive recommended counselling and support that is adequate for demand and individual needs. A recent staff survey, of CHS and National Capital Private Hospital, determined that most staff felt they had support in their ward to meet their individual needs to deal with patients who were palliative. The government acknowledges the important work our staff do each and every day in supporting patients



and their families at the end of their life, and will continue to ensure staff receive the support they need.

#### **Recommendation 19—Agreed**

*The ACT Government conduct an independent investigation of Clare Holland House's capacity to meet future demand for palliative care services.*

In September 2018, the ACT Government along with the Commonwealth and the Snow Foundation, announced a \$6.0 million-project for twelve additional beds at Clare Holland House. The recently developed Joint Governance Committee overseeing specialist palliative care in the ACT will provide a Territory-wide perspective on potential expansion requirements for the ACT community. Advice provided by the Joint Governance Committee would inform any consideration of additional funding requirements.

#### **Recommendation 20—Noted**

*Clare Holland House receive adequate future funding to allow for additional operating costs associated with an expanded Clare Holland House.*

As per the response to recommendation 19, the Joint Governance Committee overseeing specialist palliative care will consider and advise on any additional funding requirements, including future funding requirements for additional operating costs associated with an expanded Clare Holland House.

#### **Recommendation 21—Agreed**

*The ACT Government consider and seek to reduce or remove the existing barriers to accessing good health care faced by people with a disability, including infrastructure at ACT health facilities, the quality of care provided and the risks of direct or indirect discrimination.*

The ELPCP's development of care pathways for under-served populations, including people with disability, will address existing barriers for those with disability accessing the health care system, including direct and indirect discrimination. ACTHD and CHS will also consider the findings of the recent ACT Council of Social Service (ACTCOSS) report, *Imagining Better: reflections on access, choice and control in ACT health services for people with disability*. Further work may, in the future, be informed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

#### **Recommendation 22—Agreed**

*The ACT Government invest in a community awareness campaign about what palliative care is and what it entails, including the choices available to ACT residents.*

Palliative Care ACT promotes community awareness about palliative care, including the choices available to ACT residents. In addition, the ELPCP has commenced work on the initial planning for development of a community awareness program for ACT residents, which will commence in the near future.

As noted under recommendation 6, a national palliative care project has recently been rolled out by the Commonwealth Department of Health for online and face-to-face training of medical staff and GPs. As part of this national project, a workshop will be conducted in the ACT.

### **Recommendation 23—Agreed**

*The ACT Government review and report on all aspects of palliative care delivery in the ACT, including programs, demand, funding and delivery and include specific reporting on palliative aged care and child and adolescent palliative care.*

See recommendation 13. The mapping exercise will be used to review all aspects of palliative care delivery in the ACT.

### **Recommendation 24 — Agreed**

*The ACT Government assess and review the network of healthcare specialists in the ACT involved in delivering palliative care across all settings, including for paediatrics and adolescents, to:*

- *compare the ACT to other jurisdictions; and*
- *make improvements to foster better networking and connectivity between patients and their families and carers, healthcare professionals and organisations; and, ensure timely referrals and access to hospice services.*

Since the Select Committee met, considerable work has been undertaken to implement a whole-of-Territory palliative care service delivered through a network of providers in the ACT. This has identified a better model for palliative care services to work together, including ensuring timely referrals and access to hospice services. Elements of this service are currently being rolled out as part of the ELPCP and will enhance access to palliative care supports and services.