

2020

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

**UPDATE ON THE GOVERNMENT RESPONSE TO SELECT COMMITTEE ON END
OF LIFE CHOICES IN THE ACT RECOMMENDATION 12: 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**

**Presented by
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Minister for Health
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Update on implementation of the end of life care recommendations made in the Productivity Commission's report, *Inquiry into Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*.

On 30 November 2017, the ACT Legislative Assembly established a Select Committee to review and report on end of life choices in the ACT. The Committee's report, which contained 24 recommendations, was tabled in the Legislative Assembly on 21 March 2019 and the Government's response was tabled on 30 July 2019.

In response to Recommendation 11, it was agreed that the ACT Government would work cooperatively with Governments from all Australian jurisdictions to implement the recommendations on end-of-life care made by the Productivity Commission in its October 2017 report: *Inquiry into Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services* (PC Report).

In addition, Minister for Health, Rachel Stephen-Smith MLA, wrote to the Commonwealth Minister for Health, the Hon Greg Hunt MP, to advise of the ACT Government's commitment to cooperating on delivering the PC Report's recommendations. Minister Hunt was also updated on the outcomes of the ACT Legislative Assembly's Select Committee review and report on end of life choices in the ACT.

For Recommendation 12 of the Select Committee's report, it was agreed that in August 2020, the Minister for Health would provide the Legislative Assembly with an update on the timetable and progress of actions to achieve the implementation of five relevant end of life care recommendations (4.1–4.5) from the PC Report.

Canberra Health Services (CHS) and the ACT Health Directorate (ACTHD) have collaborated on the ACT End of Life and Palliative Care Project (ELPCP) towards providing seamless, integrated and high-quality care to people who are at the end of their life, and to support their families and carers in line with the *National Palliative Care Strategy 2018* and the Palliative Care Australia (PCA) *National Palliative Care Standards*. The project was established in July 2018 and runs for four years, covering care across the health service continuum.

The work of the ELPCP is supporting implementation of the PC Report recommendations in the ACT. The ACT has also been participating in work to progress actions at the cross-jurisdictional and national level through the COAG Health Council and associated sub-committees.

Progress to date at the Territory and national level is provided under each recommendation below.

RECOMMENDATION 4.1

State and Territory Governments should increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so. To achieve this, State and Territory Governments should:

- a. assess the need for additional community-based palliative care services*
- b. design services to address identified gaps in service provision*
- c. establish standards for community-based palliative care services and fund the provision of those services for people who wish to and are able to die at home. The standards should include integrated and coordinated nursing, medical and personal care*
- d. use competitive processes to select providers (or a single provider) to deliver additional community-based palliative care services*
- e. monitor and evaluate the performance of community-based palliative care services against the specified standards*
- f. ensure that consumer safeguards are in place so that quality care is provided, and oversight is maintained, as the volume of services provided increases.*

The ACT Government is working to ensure that there is sufficient community based palliative care.

To assess the need for additional community-based palliative care services, a mapping of end of life and palliative care services was completed for the ACT under the ELPCP.

To assist in addressing identified gaps, the following activities are being undertaken:

- A service function review and development of a model that includes specialist and non-specialist in-home palliative care delivery options required to address the needs of people in the ACT community.
- Development of care pathways for under-served populations to address existing barriers for those with disability accessing the health care system, including direct and indirect discrimination.
- Development of a reporting framework with ACT palliative care providers to address palliative care programs, demand, funding and delivery.

In addition, a number of initiatives are being undertaken to support those in the ACT requiring palliative care at end of life and who wish to die at home:

- Provision of home-based palliative care services by Clare Holland House (CHH), providing for example, support with syringe drivers and regular home visits.
- The Community Options Palliative Care Program provides community-based (non-clinical) palliative care services for people who are diagnosed with terminal, end-stage illnesses who wish to die at home or remain at home for as long as possible, such as case management and assistance with access to practical in home and community-based support services to eligible ACT residents.
- Palliative Care ACT is funded by ACTHD to train and coordinate volunteers and provide volunteer support services to people with palliative care needs, as well as respite care to enable patient's carers to stay connected with community and to sustain their caring role.

Palliative care service provision in the ACT is required to meet standards of care and is monitored and evaluated to ensure this is the case:

- Palliative Care ACT is required to use and participate in assessment against the *National Palliative Care Standards* (2018) and the *National Standards for Volunteer Involvement* (2015).
- The ACTHD monitors the performance of Calvary Public Hospital Bruce (CPHB) through the negotiation of the annual Performance Agreement, which specifies funding and activity targets and Key Performance Indicators (KPIs) for the

financial year. While there is no specific KPI to monitor the performance of CHH, monthly monitoring and analysis of financial sustainability, and monitoring and analysis of KPIs occurs.

- CPHB and CHH were assessed for re-accreditation against the National Safety and Quality Health Service (NSQHS) Standards in March 2020. Both Calvary campuses, 'met' all 148 actions specified for each service in the NSQHS Standards. Only one of these actions had a 'recommendation for further improvement' and this related to governance.

RECOMMENDATION 4.2

End-of-life care should be core business for aged care facilities, and the quality of end-of-life care in residential aged care should align with the quality of that available to other Australians. To achieve this the Australian Government should:

- a. remove current restrictions on the duration and availability of palliative care funding in residential aged care*
- b. provide sufficient funding for this additional clinical care.*

While this recommendation is addressed to the Australian Government, the ACT Government has been working with the Commonwealth to improve the provision of palliative care services within RACFs.

In 2019–20, the ACT Government invested \$1.66 million over three years for the Palliative Care Needs Rounds (PCNR) model of care, a nationally recognised program developed in the ACT. The PCNR model is led by nurse practitioners, who provide palliative care consultancy services to RACFs through CHH. The PCNR model involves monthly triage meetings to discuss the situation of residents who are at risk of dying and who may not have an adequate plan in place. The PCNR model is based on risk stratification and specialist need.

To support this new approach, the ACT Government and Commonwealth have signed the five-year *Comprehensive Palliative Care in Aged Care Project Agreement* (PA), which commenced on 1 July 2019.

The PA provides matched Commonwealth funding to states and territories to support the delivery of projects that expand existing models of care, or support new

approaches, to improve the way palliative and end of life care is delivered for older Australians living in RACFs.

The PA for the ACT provides a total of \$1.850 million, \$0.925 million each from the Commonwealth and the ACT Government.

The PA will enable the recruitment of two more Palliative Care Nurse Practitioners to:

- support the delivery of specialist palliative care services, both in-reach and out-reach, to all RACFs across the ACT through the PCNR model of care;
- develop and establish a data collection framework; educate and train RACF staff to build capacity and capability to support the delivery of specialist palliative care in all RACFs to ensure best health outcomes for residents;
- engage with hospitals to facilitate early assessment of palliative care needs of patients transitioning to RACFs; and participate in the national evaluation of the Comprehensive Palliative Care in Aged Care measure.

RECOMMENDATION 4.3

The Australian Government should promote advance care planning in primary care by:

- a. including the initiation of an advance care planning conversation as one of the actions that must be undertaken to claim the '75 plus' health check Medicare item numbers. At a minimum, this would require a general practitioner to introduce the concept of advance care planning and provide written information on the purpose and content of an advance care plan*
- b. introducing a new Medicare item number to enable practice nurses to facilitate advance care planning.*

At the COAG Health Council (CHC) meeting of 1 November 2019, health ministers endorsed a request to the Medicare Benefits Schedule (MBS) Review Taskforce for advice in relation to the efficacy of introducing a specific MBS item number for undertaking Advance Care Planning (ACP) and preparation of Advance Care Directives (ACDs) with GPs. A letter has been sent to the Chair of the MBS Review Taskforce by the Chair of the CHC.

Following consideration and advice from the MBS Review Taskforce, the Commonwealth will prepare a paper for consideration by health ministers on the introduction of a specific MBS item number for undertaking ACP discussions and preparation of ACDs with GPs.

RECOMMENDATION 4.4

The Australian Government should amend the aged care Quality of Care Principles to require that residential aged care facilities ensure that clinically trained staff hold conversations with residents about their future care needs. This should include helping each resident (or their family or carers) to develop or update an advance care plan (or to document that the resident would prefer not to complete an advance care plan) within two months of admission to the facility.

On 30 July 2019, the *Quality of Care Principles 2014* were updated to include the Aged Care Quality Standards. The standards apply to all Australian Government-funded aged care services, and include measures to ensure that organisations undertake initial and ongoing assessment and planning for care and services in partnership with the consumer (and other stakeholders that are involved in the care of the consumer), with a focus on optimising health and well-being in accordance with the consumer's needs, goals and preferences.

ACP and end of life planning are to be undertaken if the consumer wishes, and the outcomes of assessment and planning are to be effectively communicated and documented in a care and services plan that is readily available to the consumer.

A national framework for ACP has been drafted (but is not yet released) that should improve the accessibility and consistency of patient level data. The framework aims to provide guidance for health and aged care providers, including hospitals, RACFs and general practitioners (GPs) to implement processes to ensure advanced care planning and end of life care documents are accessible to all appropriate parties, potentially linking ACPs and ACDs with patient records on My Health Record.

At the COAG Health Council (CHC) meeting of 1 November 2019, Health Ministers noted the need to adopt a national approach to support the uptake of existing palliative care education for all clinical staff who provide care to palliative care patients, and to include this issue within the Department of Health's palliative care

strategic workforce planning project Terms of Reference. Health Ministers agreed to refer the proposal to the Australian Health Ministers' Advisory Council (AHMAC), with AHMAC and Queensland to report back to the CHC by March 2020 on the proposal (note that the agreed reporting to CHC in March has been delayed due to COVID-19).

RECOMMENDATION 4.5

The Australian, State and Territory Governments should, through the Council of Australian Governments (COAG) Health Council, ensure that there is cross-jurisdiction co-operation to:

- a. plan, fund and deliver end-of-life care so that patients receive integrated services across different settings and jurisdictions*
- b. set standards for end-of-life care in each of the settings in which it is provided (such as those that will apply to end-of-life care in hospitals in all jurisdictions from 2019)*
- c. monitor and evaluate end-of-life care services.*

The COAG Health Council should oversee the development and implementation of a data strategy for end-of-life care that:

- a. establishes a national minimum data set for end-of-life care (including collecting and publishing linked information on place of death, primary and secondary diagnoses and details of service provision at time of death)*
- b. improves the accessibility of patient-level data (such as advance care plans or hospital discharge summaries) so that they are used to deliver high-quality care*
- c. uses system-level data to enable governments to plan, monitor and evaluate how well end-of-life care services are meeting users' needs across all settings and jurisdictions, and to drive improvements in end-of-life care.*

The COAG Health Council should, in 2025, commission an independent review of the effectiveness of end-of-life care across all settings in which it is, or should be, provided (note that this will not be actioned until 2025 so has not been addressed below).

In February 2019. The CHC endorsed *National Palliative Care Strategy 2018* (the National Strategy) was released following extensive consultation with Commonwealth, state and territory health departments and key stakeholders.

The Implementation Plan for the National Strategy was subsequently developed through consultation with states and territories and key stakeholders, and will be taken forward by the national Palliative and End of Life Care Project Reference Group under the Health Services Principal Committee. The inaugural meeting of the Reference Group was in March 2020.

The National Strategy and Implementation Plan outline the key goals, priorities and activities to be progressed by all Australian governments. Activity being undertaken in the ACT under the four initial action areas for the Implementation Plan includes:

- Improving access by developing end of life and palliative care pathways for each of the eight nationally identified underserved population groups; and a service model to improve access to care in identified service gaps in the ACT.
- Improving collaboration and coordination of palliative care by actively participating in the national governance structure for the National Strategy and the Health Round Table End of Life Care Working Group. At the Territory level, the ACT Palliative Care Governance Structure provides oversight of the end of life and palliative care work in the ACT, facilitates collaboration across services, and includes representatives from all organisations in the ACT and South East NSW that provide palliative care. Additionally, a review of education on end of life and palliative care has been undertaken and an End of Life and Palliative Care Education Framework is being developed.
- Promoting the preparation and use of ACPs in all community and acute service settings, providing information about ACPs online, and funding the Health Care Consumers' Association to work with culturally and linguistically diverse (CALD) communities to increase their uptake of ACPs. Information on ACPs is also provided to RACFs and training is provided for clinicians in the hospital sector.
- Expanding the collection of palliative care outcomes data to inform the ACT's contribution to the annual national reporting on implementation of the National Strategy and improve the monitoring and evaluation of end-of-life care services.