



ACT
Government

ACT Health

FOI18-104

Dear [REDACTED]

Freedom of information request: FOI18/104

I refer to your application under section 30 of the *Freedom of Information Act 2016* (the Act), received by ACT Health on 25 October 2018.

In your application you requested:

“Ministerial briefs prepared for the Minister for Health and Wellbeing on issues related to palliative care and end of life issues from 1 January 2018 to date. These briefs may include, but are not limited to, General Briefs, Question Time Briefs, Estimates Briefs and Annual Report Briefs.”

I am an Information Officer appointed by the Director-General of ACT Health under section 18 of the Act to deal with access applications made under Part 5 of the Act.

ACT Health was required to provide a decision on your access application by 13 December 2018.

Decision on access

Searches were completed for relevant documents and 20 documents were identified that fall within the scope of your request.

I have included as [Attachment A](#) to this decision the schedule of relevant documents. This provides a description of each document that falls within the scope of your request and the access decision for each of those documents.

I have decided to grant full access to 15 documents and partial access to 3 documents as documents identified as relevant to your request contain information that I consider to be information that would, on balance, be contrary to the public interest to disclose under the test set out in section 17 of the Act.

I have decided to refuse access to 2 documents as these documents identified as relevant to your request contain information that I consider to be as the contrary to the public interest information under Schedule 1 of the Act.

My access decisions are detailed further in the following statement of reasons and the documents released to you are provided as [Attachment B](#) to this letter.

In reaching my access decision, I have taken the following into account:

- the FOI Act, Schedule 1 and Schedule 2;
- the content of the documents that fall within the scope of your request;
- the views of relevant third parties; and
- the *Human Rights Act 2004*.

My reasons for deciding not to grant access to the identified documents and components of these documents are as follows:

Contrary to the public interest information under Schedule 1

Folios 19 and 20 of the identified documents contain information that is considered to be contrary to the public interest under Schedule 1 of the Act;

- Schedule 1 1.6 (1) (c) Cabinet Information – that is a copy of, or part of, or contains an extract from, information mentioned in paragraph (a) or (b).
- Schedule 1 1.6 (1) (d) Cabinet Information - the disclosure of which would reveal any deliberation of cabinet (other than through the official publication of Cabinet decision).

Information contained in folios 19 and 20, is an official cabinet record, or has been brought into existence for that purpose, and if disclosed, would reveal deliberations of Cabinet.

Contrary to the public interest under Schedule 2

Folios 7, 17 and 18 of the identified documents are composed of, or contain information that I consider, on balance, to be contrary to the public interest to disclose under the test set out in section 17 of the Act.

I have decided to grant access, under section 50 of the Act, to copies of documents identified below, with deletions applied to information that I consider would be contrary to the public interest to disclose.

Folios 17 and 18 contain personal information about identifiable individuals who are non-government employees.

I have identified that there are no factors favouring disclosure of this information under Schedule 2, section 2.1. I have identified that the following factor favours non-disclosure:

- Schedule 2 2.2 (a) (ii) - prejudice the protection of an individual's right to privacy or any other right under the Human Rights Act 2004.

On balance, the release of information identified is contrary to the public interest and I have decided not to disclose this information.

Folio 7 and 17 contains information provided by Daryl Jackson Alastair Swayn Pty Ltd and South Western Sydney Local Health District. I determined that there are no relevant factors in favour

of the disclosure of the identified information and the following factors were considered relevant in favour of the non-disclosure:

- Schedule 2.2 (a) (xi) prejudice trade secrets, business affairs or research of an agency or person.

If the redacted information concerning South Western Sydney Local Health District was released, it would be expected to unduly impact on the business affairs and research of the organisation or may impact on the organisations current partnerships.

If the redacted information concerning Daryl Jackson Alastair Swayn Pty Ltd was release, it could reasonably be expected to have an adverse effect on the trade secrets and business affairs of the company, as their intellectual property could be used by a competitive firm.

The public interest would not be advanced by the release of this information. As such, I have decided that on balance, disclosure of the information would be contrary to the public interest

Charges

Processing charges are not applicable for this request under Section 107 (2) (e) of the Act.

Online publishing – disclosure log

Under section 28 of the Act, ACT Health maintains an online record of access applications called a disclosure log. Your original access application, my decision and documents released to you in response to your access application will be published in the ACT Health disclosure log not less than three days but not more than 10 days after the date of this decision. Your personal contact details will not be published.

You may view ACT Health's disclosure log at <https://www.health.act.gov.au/about-our-health-system/freedom-information/disclosure-log>.

Ombudsman review

My decision on your access request is a reviewable decision as identified in Schedule 3 of the Act. You have the right to seek Ombudsman review of this outcome under section 73 of the Act within 20 working days from the day that my decision is published on ACT Health's disclosure log, or a longer period allowed by the Ombudsman.

If you wish to request a review of my decision you may write to the Ombudsman at:

The ACT Ombudsman
GPO Box 442
CANBERRA ACT 2601

Via email: ACTFOI@ombudsman.gov.au

ACT Civil and Administrative Tribunal (ACAT) review

Under section 84 of the Act, if a decision is made under section 82(1) on an Ombudsman review, you may apply to the ACAT for review of the Ombudsman decision.

Further information may be obtained from the ACAT at:

ACT Civil and Administrative Tribunal
Level 4, 1 Moore St
GPO Box 370
Canberra City ACT 2601
Telephone: (02) 6207 1740
<http://www.acat.act.gov.au/>

If you have any queries concerning the ACT Health's processing of your request, or would like further information, please contact the FOI Coordinator on 6205 1340 or e-mail HealthFOI@act.gov.au.

Yours sincerely



Patrick Henry
Executive Director
Policy, Partnerships and Programs

13 December 2018

FREEDOM OF INFORMATION REQUEST SCHEDULE

Please be aware that under the *Freedom of Information Act 2016*, some of the information provided to you will be released to the public through the ACT Government's Open Access Scheme. The Open Access release status column of the table below indicates what documents are intended for release online through open access.

Personal information or business affairs information will not be made available under this policy. If you think the content of your request would contain such information, please inform the contact officer immediately.

Information about what is published on open access is available online at: <https://www.health.act.gov.au/about-our-health-system/freedom-information/disclosure-log>

NAME	WHAT ARE THE PARAMETERS OF THE REQUEST	File No
[REDACTED]	"Ministerial briefs prepared for the Minister for Health and Wellbeing on issues related to palliative care and end of life issues from 1 January 2018 to date. These briefs may include, but are not limited to, General Briefs, Question Time Briefs, Estimates Briefs and Annual Report Briefs."	FOI18/104

Ref No	No of Folios	Description	Date	Status	Reason for non-release or deferral	Open Access release status
1	1 - 4	Annual Report Hearing Brief – Palliative Care and Clare Holland House Capacity	24/10/2018	Full Release		Yes
2	5 - 7	Annual Report Hearing Brief – End of Life	24/10/2018	Full Release		Yes
3	8 - 10	Question Time Brief – End of Life	17/10/2018	Full Release		Yes
4	11 - 14	Question Time Brief – Palliative Care and Clare Holland House Capacity	17/10/2018	Full Release		Yes



5	15 - 18	Media Implications Summary – AIHW Embargoed Report – Palliative Care Services in Australia – Web Report Update	17/10/2018	Full Release		Yes
6	19 - 61	Ministerial Brief – COAG Health Council Out of Session Item 353 – National Palliative Care Strategy 2018 with attachments	5/10/2018	Full Release		Yes
7	62 - 91	Ministerial Brief – Meeting with Snow Foundation on 17 September 2018 – 9am to 9.45am – Concept Design Options for a Potential Expansion of Clare Holland House with attachment	17/09/2018	Partial	Schedule 2, 2.2 (a) (xi)	Yes
8	92 - 94	Question Time Brief - End of Life	07/09/2018	Full Release		Yes
9	95 - 97	Question Time Brief – Palliative Care and Clare Holland House Capacity	07/09/2018	Full Release		Yes
10	98 - 100	Question Time Brief – End of Life	20/07/2018	Full Release		Yes
11	101 - 104	Question Time Brief – Palliative Care and Clare Holland House Capacity	19/07/2018	Full Release		Yes



12	105 - 122	Select Committee on End of Life Choices on the ACT Public Hearing 1 June 2018	1/06/2018	Full Release		Yes
13	123 - 125	Media Implications Summary – Palliative Care Services in Australia (Web Report)	23/05/2018	Full Release		Yes
14	126 - 128	Question Time Brief – End of Life	22/05/2018	Full Release		Yes
15	129 - 130	Question Time Brief – End of Life Choices	11/05/2018	Full Release		Yes
16	131	Advisory Note – Request for Advice – E-mail Minister for Health and Wellbeing (Adviser) Home Palliative Care Program (PEACH Guidelines)	30/04/2018	Full Release		Yes
17	132 - 189	Ministerial Brief – NSW Health Palliative Care Home Support Packages (PEACH) Program Guidelines with attachment	31/03/2018	Partial	Schedule 2, 2.2 (a) (ii) and (xi)	Yes
18	190 - 193	Ministerial Brief – Status Update – Palliative Care Services in Canberra – The Snow Foundation	21/03/2018	Partial	Schedule 2, 2.2 (a) (ii)	Yes
19	194 - 225	Ministerial Brief – Cabinet submission – ACT Government Submission to the Select Committee Inquiry	14/02/2018	Refused	Schedule 1, 1.6 (c) (d)	Yes



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		into End of Life Choices in the ACT with attachments				
20	226 - 251	Ministerial Brief - Cabinet submission – ACT Government Submission to the Select Committee Inquiry into End of Life Choices with attachments	04/02/2018	Refused	Schedule 1, 1.6 (c) (d)	Yes
Total No of Docs						
20						

Item 50

Portfolio/s: Health and Wellbeing

ISSUE: PALLIATIVE CARE AND CLARE HOLLAND HOUSE CAPACITY

Talking points:

- Treating people with respect and in a manner that protects their dignity is an important role for our health service at all stages of life.
- Palliative care is not just care provided in the final stages of life, but helps people to live well with a terminal illness. Sometimes palliative care can be of benefit for a person at their initial diagnosis of a life-limiting condition, or be useful on and off through various stages of an illness. Many people have long-term interactions with their palliative care team, seeing them during the course of their illness.
- There are many elements to palliative care, including pain and symptom management and advice and support to carers. Palliative care ensures people are kept comfortable and maintain a good quality of life.
- In the ACT, there are a number of palliative care services offered. These primary and specialist palliative care services are of high quality and deliver excellent care to the community.
- The Government spends over \$10 million each year to provide palliative care services in the ACT.
- In recent years, the Government has provided additional investment in palliative care services, with increased support of home based palliative care packages, a new paediatric palliative care service to specifically address the palliative needs of children and adolescents, as well as investment in more staff and education.
- Calvary is funded to provide the majority of specialist palliative care services in the ACT, with Clare Holland House being the largest palliative care inpatient unit in the ACT.

Cleared as complete and accurate:	24/10/2018	
Cleared by:	Executive Director	Ext: 79143
Information Officer name:	Patrick Henry	
Contact Officer name:	Peter Matwijiw	Ext: 78445
Lead Directorate:	Health	

ANNUAL REPORT HEARING BRIEF

- The Clare Holland House inpatient unit currently has a capacity of 19 beds.
- Other palliative care service models provided from Clare Holland House include:
 - Home based palliative care;
 - specialist outpatient clinics;
 - outreach programs to residential aged care facilities; and
 - a specialist care and support clinic at Winnunga Nimmityjah Aboriginal and Community Health Service.
- Demand for palliative care will continue to increase as our population ages, and people live longer lives. We need to respond to this so that people receive the care and dignity they deserve at the end of their life.
- As part of the Territory-wide Health Services Framework, ACT Health is developing a specialty services plan for palliative care.
- On 25 September 2018, a major expansion of Clare Holland House was announced with a \$6 million commitment from the Australian Government in partnership with The Snow Foundation, which will see an increase in the number of specialist in-patient palliative care beds.

Key Information

Clare Holland House

- Clare Holland House consists of a specialist inpatient unit, home based palliative care services and community specialist palliative care services.
- The average length of stay in 2017-18 was 11.7 days, but it can vary widely from hours to months.
- Clare Holland House staffing is 61.53 Full Time Equivalent positions or a headcount of 90 staff across all categories of employees. Staffing levels at Clare Holland House are adjusted to meet patient/staff ratios and to ensure consistently high quality, safe and compassionate care is provided to all admitted patients and their families.

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ANNUAL REPORT HEARING BRIEF

- All staff at Clare Holland House receive education in all clinical aspects of palliative care, from primary care to specialist care, to enable support of other health practitioners, carers and patients.
- Clare Holland House staff also provide extensive palliative care education and training programs for primary care providers, other health facilities and residential aged care facilities staff. This extends to programs such as the Program of Experience in the Palliative Approach which provides education to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.
- Medical specialists are on duty from Monday to Friday from 8:00am to 5:30pm, and on call after hours.

Referrals

- Palliative care services are available to patients with a life limiting illness whose complexity of symptoms (physical, psychosocial/emotional, and spiritual/existential symptoms) cannot be managed by their primary care provider. Care is provided to patients who need end of life care and who choose to die at the inpatient unit at Clare Holland House.
- Care to patients requiring palliative support is provided by their primary treating team such as a general practitioner, community nurse or the team on an inpatient ward. These treating clinicians are able to access advice and support from the specialist palliative care service without needing to refer their patient for direct services.
- Patients who have more complex needs and require specialist palliative care are referred to the service by their treating specialty team or general practitioner. Patients can be referred for either inpatient or outpatient treatment at Canberra Hospital. The focus of care is on advanced symptom management and psychosocial support.

Calls for palliative care ward at Canberra Hospital

- Consideration may be given to a specialist palliative care ward at Canberra Hospital as part of future health services planning.

Palliative Care in Residential Aged Care Facilities

- The 2018-19 Federal Budget included a measure on Comprehensive palliative care in aged care, which forms part of the Australian Government's *More Choices for a Longer Life – healthy ageing and high quality care package*.

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ANNUAL REPORT HEARING BRIEF

- The Measure will provide \$32.8 million over four years from 2018-19 to support state and territory governments to improve palliative and end-of-life care coordination for older Australians living in residential aged care homes. Funding for individual jurisdictions will be negotiated over coming months.
- The Measure is premised on a cost-shared model with states and territories matching Commonwealth funding. The Commonwealth recently sought the nomination of the appropriate ACT Health representative to receive a draft National Project Agreement and accompanying schedule.

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ANNUAL REPORT HEARING BRIEF

Item 41

Portfolio/s: Health and Wellbeing

ISSUE: END OF LIFE**Talking points:**

- The Commonwealth *Euthanasia Laws Act 1997* discriminates against ACT citizens by restricting the ability to introduce, through elected representatives, legislation to recognise the right to choose the manner and timing of one's death in certain circumstances.
- This is an issue not only for people who support euthanasia – it is a critical debate for all people who value the right of residents of the ACT to engage and participate in democratic processes to determine the laws that apply to them.
- The ACT Government Submission to the Select Committee Inquiry into End of Life Choices argued that the ACT Government should not be prevented from legislating for an assisted dying scheme, should it choose to do so, and that the states and territories should be treated equally in terms of their power to legislate.
- The ACT Government submission did not hypothesise on possible end of life schemes that could be appropriate for the ACT at this point. This would have been a matter for extensive consultation with the ACT community, had the prohibitive Commonwealth laws been repealed.
- There is much sensitivity in the ACT community around voluntary assisted dying, with strong sentiments on both sides of the argument.
- The ACT Government believes all Canberrans are entitled to quality end of life care, which relieves pain and suffering, and provides empowering support to family, friends and carers.
- For most patients at the end of their life, pain and suffering can be alleviated through the provision of good quality end of life care, including palliative care that focuses on symptom relief, the prevention of suffering and improvement of quality of life.

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ANNUAL REPORT HEARING BRIEF

- However, there are some instances where palliative care is not enough to achieve satisfactory relief of suffering. Even with the best palliative care, patients sometimes ask for alternative approaches to relieve extreme suffering.
- The potential for difficult situations to arise towards the end of life was reinforced by evidence via submissions to the Select Committee.
- End of life choice is an issue that is close to the heart of many in our community. As our city continues to grow and our community continues to age, there is need for a robust discussion on approaches for dealing with situations where palliative care is not enough to relieve extreme suffering.
- The establishment of the Select Committee on End of Life Choices in the ACT provides the ACT community with a valuable opportunity to discuss the important social policy and legal considerations relating to end of life choices in the ACT.
- End of Life choices is an important issue to many in the community. This was made evident by the number of submissions received by the Inquiry, with nearly 500 received. The Select Committee held eight public hearing sessions involving evidence from 80 witnesses.
- A report from the Select Committee to the Legislative Assembly is due by the last sitting day in 2018 (29 November 2018).

Key Information

- On 30 November 2017, the ACT Legislative Assembly established a Select Committee to conduct an inquiry into End of Life Choices in the ACT (the Inquiry).
- The Inquiry was established following the Victorian Parliament passing the *Voluntary Assisted Dying Act 2017* (Victorian Act) on 29 November 2017, which introduced a voluntary assisted dying scheme for Victorian residents. Victoria is the first Australian state to legalise voluntary assisted dying.
- Currently, the ACT cannot legislate for voluntary assisted dying due to law making restrictions placed on the ACT Legislative Assembly by the Commonwealth Parliament.
- The Commonwealth laws discriminate against Territory citizens by restricting the ability to introduce, through elected representatives, legislation to recognise the right to choose the manner and timing of an individual's death in certain circumstances.

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ANNUAL REPORT HEARING BRIEF

- Section 122 of the Australian Constitution enables the Commonwealth Parliament to override any Territory law, which it did by enacting the *Commonwealth Euthanasia Laws Act 1997* (also known as the Andrews Bill). This legislation precludes the Legislative Assembly from passing a voluntary assisted dying scheme similar to the Victorian Act.
- For the ACT to be able to legislate in relation to an assisted dying scheme similar to Victoria's, the Commonwealth Parliament must first repeal s23(1A) of the *Australian Capital Territory (Self-Government) Act 1988* and Schedule 2 to the *Euthanasia Laws Act 1997*.
- On 9 February 2018, the ACT and the Northern Territory Chief Ministers signed a Strategic Cooperation Agreement. One area of collaborative interest involved the removal of the *Euthanasia Laws Act 1997*.
- On 27 June 2018 Liberal Democrats Senator David Leyonhjelm moved to force debate in the Australian Parliament on his private bill (Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015) to restore the rights of the ACT and the NT parliaments to legislate on the issue of euthanasia; and repeal the *Euthanasia Laws Act 1997*. The motion was passed 36-27.
- In July 2018, the Chief Minister wrote to federal MPs and senators calling for their support to repeal the *Euthanasia Laws Act 1997*.
- On 15 August the Australian Senate voted on Senaor Leyonjhelm's Bill to restore Territory Rights. The Bill was defeated by two votes.
- On 23 August 2017, the Western Australian Parliament established a Joint Select Committee of the Legislative Assembly and Legislative Council to inquire and report on the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices. The Joint Select Committee tabled its report, 'My Life, My Choices', in the Legislative Assembly and Legislative Council on 23 August 2018. The report included 53 Findings and 24 Recommendations, Recommendation 24 being:

'The Western Australian Government develop and introduce legislation for voluntary assisted dying having regard to the recommended framework and following consultation with the Panel established under Recommendation 21.'

The Premier, Minister for Health and the Attorney General are required to report to the Assembly as to the action, if any, proposed to be taken by the Government with respect to the recommendations. Cabinet ministers are considering the report recommendations.

- On 2 September 2018, the Queensland Premier, Anastacia Pallaszczuk, announced Queensland will undertake an inquiry into end-of-life care, including the use of voluntary euthanasia.

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QUESTION TIME BRIEF

GBC18/580

Portfolio/s: Health & Wellbeing**ISSUE: END OF LIFE****Talking points:**

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- The ACT Government submission did not hypothesise on possible end of life schemes that could be appropriate for the ACT at this point. This would have been a matter for extensive consultation with the ACT community, had the prohibitive Commonwealth laws been repealed.
- There is much sensitivity in the ACT community around voluntary assisted dying, with strong sentiments on both sides of the argument.
- The ACT Government believes all Canberrans are entitled to quality end of life care, which relieves pain and suffering, and provides empowering support to family, friends and carers.
- For most patients at the end of their life, pain and suffering can be alleviated through the provision of good quality end of life care, including palliative care that focuses on symptom relief, the prevention of suffering and improvement of quality of life.

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QUESTION TIME BRIEF

- However, there are some instances where palliative care is not enough to achieve satisfactory relief of suffering. Even with the best palliative care, patients sometimes ask for alternative approaches to relieve extreme suffering.
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- End of life choice is an issue that is close to the heart of many in our community. As our city continues to grow and our community continues to age, there is need for a robust discussion on approaches for dealing with situations where palliative care is not enough to relieve extreme suffering.
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Portfolio/s: Health & Wellbeing**ISSUE: PALLIATIVE CARE AND CLARE HOLLAND HOUSE CAPACITY****Talking points:**

- Treating people with respect and in a manner that protects their dignity is an important role for our health service at all stages of life.
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- There are many elements to palliative care, including pain and symptom management and advice and support to carers. Palliative care ensures people are kept comfortable and maintain a good quality of life.
- In the ACT, there are a number of palliative care services offered. These primary and specialist palliative care services are of high quality and deliver excellent care to the community. The services are embraced within the ACT Palliative Care Clinical Network.
- The Government spends over \$10 million each year to provide palliative care services in the ACT.
- In recent years, the Government has provided additional investment in palliative care services, with increased support of home based palliative care packages, a new paediatric palliative care service to specifically address the palliative needs of children and adolescents, as well as investment in more staff and education.
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Lead Directorate:	Health	

QUESTION TIME BRIEF

- Clare Holland House staff also provide extensive palliative care education and training programs for primary care providers, other health facilities and Residential Aged Care Facilities staff. This extends to programs such as the Program of Experience in the Palliative Approach which provides education to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.
- Medical specialists are on duty from Monday to Friday from 8:00am to 5:30pm, and on call after hours.

Referrals

- Palliative care services are available to patients with a life limiting illness whose complexity of symptoms (physical, psychosocial/emotional, and spiritual/existential symptoms) cannot be managed by their primary care provider. Care is provided to patients who need End of Life Care and who chose to die at the inpatient unit at Clare Holland House.
- Care to patients requiring palliative support is provided by their primary treating team such as a General Practitioner, community nurse or the team on an inpatient ward. These treating clinicians are able to access advice and support from the Specialist Palliative Care service without needing to refer their patient for direct services.
- Patients who have more complex needs and require specialist palliative care are referred to the service by their treating specialty team or General Practitioner. Patients can be referred for either inpatient or outpatient treatment at Canberra Hospital. The focus of care is on advanced symptom management and psychosocial support.

Calls for palliative care ward at Canberra Hospital

- Consideration will be given to a specialist palliative care ward at Canberra Hospital as part of future health services planning.

Palliative Care in Residential Aged Care Facilities

- The 2018-19 Federal Budget included a Measure on Comprehensive Palliative Care in Aged Care, which forms part of the Australian Government's *More Choices for a Longer Life – healthy ageing and high quality care* package.
- The Measure will provide \$32.8 million over four years from 2018-19 to support state and territory governments to improve palliative and end-of-life care coordination for older Australians living in residential aged care homes. Funding for individual jurisdictions will be negotiated over coming months.

Cleared as complete and accurate: 17/10/2018
Cleared by: Executive Director Ext: 79143
Information Officer name: Patrick Henry
Contact Officer name: Peter Matwijnw Ext: 78445
Lead Directorate: Health

QUESTION TIME BRIEF

- The Measure is premised on a cost-shared model with states and territories matching Commonwealth funding. The Commonwealth recently sought the nomination of the appropriate ACT Health representative to receive a draft National Project Agreement and accompanying schedule.

Cleared as complete and accurate: 17/10/2018
Cleared by: Executive Director Ext: 79143
Information Officer name: Patrick Henry
Contact Officer name: Peter Matwijiw Ext: 78445
Lead Directorate: Health



Australian Institute of Health and Welfare Reports

MEDIA IMPLICATIONS SUMMARY

For: Minister for Health and Wellbeing

Subject	AIHW Embargoed Report Palliative Care Services in Australia – Web Report Update
Date for Release:	17 October 2018, 1 am
What is the Report about?	<p><i>Palliative care services in Australia</i> is an online report on the activity and characteristics of palliative care services across Australia. Data is presented under specific topic areas with detailed data available for current and previous years. The AIHW update the data twice a year.</p> <p>The AIHW has updated the following sections of the web report:</p> <ul style="list-style-type: none"> • Palliative care-related medications 2016-17 • Palliative care outcomes 2017 • Palliative care in residential aged care 2016-17 <p>Highlights of the report are:</p> <ul style="list-style-type: none"> • 1 in 50 (2%) of aged care residents had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for palliative care. • Nationally, there were about 914,000 palliative care-related prescriptions provided to almost 495,000 patients in 2016-17. • 95% of patients had their episode of palliative care commence the day after they were ready for care. <p><u>Palliative care-related medications 2016-17</u></p> <p>In 2004, the Australian Government introduced the Pharmaceutical Benefits for Palliative Care Schedule as a subsection of the PBS Schedule to improve access to essential and affordable medications for patients receiving palliative care.</p> <p>Due to significant changes to the items listed on the palliative care schedule from June 2016, data for 2016-17 is not comparable with previous years.</p> <p>Key points:</p> <ul style="list-style-type: none"> • Nationally, there were about 914,000 palliative care-related prescriptions provided to almost 495,000 patients in 2016-17. • About 1 in 17 (5.9%) patients, who were supplied palliative care-related prescriptions in 2016-17, were aged 85 or older, with one-third (33.0%) aged 65 or older. • Anti-inflammatory and anti-rheumatic medications were the most commonly prescribed medication type (subsidised) in 2016-17 (61.8%), followed by analgesics (26.7%) and laxatives (7.2%). <p><u>Palliative care outcomes 2017</u></p> <p>The Australian Palliative Care Outcomes Collaboration (PCOC), established in 2005, is a national palliative care outcomes and benchmarking program. PCOCs primary objective is to systematically improve patient outcomes (including pain and symptom control).</p>

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	<p>As participation in PCOC is voluntary, the data presented in this section describe a subset of all specialist palliative care services delivered in Australia in 2017. An estimated 85% of palliative care services participate in PCOC.</p> <p>Key points:</p> <ul style="list-style-type: none"> • 39,800 patients accessed specialist palliative care services from 130 PCOC participating palliative care providers in 2017. • 53,200 episodes of palliative care were provided, of which just over half were inpatient episodes. • 77.6% of episodes were characterised by a cancer diagnosis. • 74 was the median age for all patients reported to PCOC during 2017. • 94.8% of patients had their care commence on the day of, or the day after, the date they were ready for palliative care. • 86.9% of patients had urgent needs managed in 3 days or less. <p><u>Palliative care in residential aged care 2016-17</u></p> <p>The Australian Government subsidises residential aged care services for older Australians whose care needs are such that they can no longer remain in their own homes. Residential aged care services provide accommodation and services to people who require ongoing health and nursing care due to chronic impairments and a reduced degree of independence in activities of daily living. They provide nursing, supervision or other types of personal care required by the residents.</p> <p>Key points:</p> <ul style="list-style-type: none"> • Of the 239,600 permanent aged care residents in Australia in 2016–17 with completed ACFI appraisals, about 2% (4,500 residents) indicated a need for palliative care. • Around 30% of permanent residents with an appraised need for palliative care had been diagnosed with cancer.
<p>Is there any ACT funding (or Programs) in this area/subject?</p>	<p>YES: <input checked="" type="checkbox"/> NO <input type="checkbox"/></p> <p>The ACT Government provides a range of services for people in need of palliative care, their families and carers, including:</p> <ul style="list-style-type: none"> • Approximately \$6 million per annum provided to Calvary Health Care ACT to deliver palliative care services, including specialist palliative inpatient hospice services from Clare Holland House. On 25 September 2018, an expansion of Clare Holland House was announced, with \$6 million from the Australian Government and The Snow Foundation. • Over \$2 million over four years was allocated in the 2016–17 ACT Budget, for the expansion of paediatric palliative care (both inpatient and outpatient). • Almost \$2.5 million over four years was allocated in the 2015–16 ACT Budget to support the End of Life Care at Home program and education programs for health care professionals. • Palliative Care ACT receives approximately \$650,000 per annum to provide volunteer support services in the community for people with life limiting illness; and a weekly activity day for homebound patients.



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	<ul style="list-style-type: none"> • \$100,000 per annum grant funding is provided to Community Options for 2017–19 to coordinate in-home (non-clinical) support services for people with end-stage illnesses and their families, and to continue to improve pathways between home-based palliative care, the acute care and the community care system. • In 2017–18, one-off funding of \$262,000 was provided to the Centre for Palliative Care Research (through Australian Catholic University) to investigate integration of palliative care into residential aged care. • Demand for palliative care will continue to increase as our population ages. • As part of the Territory-wide Health Services Framework, ACT Health is developing a specialty services plan for palliative care.
<p>Is there any ACT specific data in the Report?</p>	<p>YES: <input checked="" type="checkbox"/> NO <input type="checkbox"/></p> <p><u>Palliative care-related medications 2016-17</u> During 2016–17, about \$14.3 million was paid nationally in benefits for medications on the palliative care schedule (\$54 per patient). The average cost per patient ranged from \$35 for the NT to \$120 per patient in the ACT. Nationally, analgesics made up about two-thirds of this expenditure (62.2%), followed by anti-inflammatory and anti-rheumatic products (24.3%). The proportion of benefits paid for analgesics ranged from 44.4% for the NT to 86.5% for the ACT.</p>
<p>Is Media Interest likely?</p>	<p>YES <input type="checkbox"/> NO <input checked="" type="checkbox"/></p> <p>Note: This report will not be accompanied by a media release.</p>
<p>What are the key positive elements contained in the Report?</p>	<p>The web update to national data shows the following:</p> <ul style="list-style-type: none"> • In 2016-17, nationally, there were about 914,000 palliative care-related prescriptions provided to almost 495,000 patients in 2016-17. • 95% of patients had their episode of palliative care commence the day after they were ready for care. • In 2017, 39,800 patients accessed specialist palliative care services from 130 PCOC participating palliative care providers in 2017. • 53,200 episodes of palliative care were provided, of which just over half were inpatient episodes.
<p>What are the negative elements contained in the Report?</p>	<p>The web update to national data shows that</p> <ul style="list-style-type: none"> • Around 30% of permanent aged care residents with an appraised need for palliative care, had been diagnosed with cancer. The types of cancer most often recorded were Lung cancer (19.1%) and Colorectal (bowel) cancer (14.2%).

can I get an update on this work please

MEDIA TALKING POINTS:

- Australia's growing and ageing population, combined with increasing consumer expectations presents a major challenge to health care systems across all states and territories.
- Expenditure on health care is increasing at an even faster rate, including for palliative care, creating significant sustainability challenges.
- We know that our public health services need to continue to evolve to meet current and future demands for palliative care.



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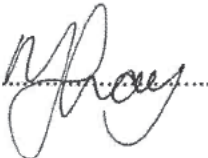
- ACT Health is also focussed on supporting people to live independently in their own home for as long as possible through a range of strategies, such as:
 - home based palliative care packages
 - outreach programs to Residential Aged Care Facilities
 - a specialist care and support clinic at Winnunga Nimmityjah Aboriginal and Community Health Service

- A Territory-wide Palliative Care Service Project is currently underway to provide direction for the delivery of care in line with recently revised national standards developed by Palliative Care Australia.
- ACT Health palliative care services provide high quality care and support to all people in the ACT, regardless of their diagnosis. All care is based on ACT Health's person-centred care.
- Our services follow the palliative approach that links primary care services with health professionals to improve quality of life for those with a life limiting illness, as well as their caregivers and family.
- The ACT has endorsed the *National Palliative Care Strategy 2018* which includes seven goals relating to improving understanding, capability, access and choice, collaboration, investment, data and evidence, and accountability.

Recommendation

That you note the information contained in this summary.

Noted / Please Discuss

Meegan Fitzharris MLA.....  17.10.18

Signatory Name:	Nicole Kefford	Phone:	59371
Title:	Senior Manager, Health Policy Unit		
Date:	8 October 2018		
Action Officer:	Kaye Sperling	Phone:	76819



MINISTERIAL BRIEF

Health Directorate

UNCLASSIFIED

To: Minister for Health and Wellbeing Tracking No.: AHM18/62
- 3 OCT 2018

From: Michael De'Ath, Director-General, ACT Health

Subject: COAG Health Council Out of Session Item 353 -
National Palliative Care Strategy 2018

Critical Date: 5 October 2018

Critical Reason: A response is due to the COAG Health Council (CHC) Secretariat by this date.

• DG 3/10/18

Recommendations

That you:

1. Note the information contained in this brief;
Noted / Please Discuss

2. Agree to endorse the *National Palliative Care Strategy 2018* (Attachment A);
Agreed / Not Agreed / Please Discuss

3. Agree to approve the publication of the *National Palliative Care Strategy 2018* on the Commonwealth Department of Health's website; and
Agreed / Not Agreed / Please Discuss

4. Sign the response letter to the COAG Health Council Secretariat supporting the recommendations (Attachment B).
Signed / Not Signed / Please Discuss

5/10/18

Meegan Fitzharris MLA

Minister's Office Feedback

UNCLASSIFIED

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Background

1. Following national consultation, the *National Palliative Care Strategy 2010* has been updated to include seven goals relating to improving understanding, capability, access and choice, collaboration, investment, data and evidence, and accountability.
2. The development of the updated *National Palliative Care Strategy 2018* took place in 2017, based on the findings of the evaluation of the *National Palliative Care Strategy 2010* and extensive consultation with Commonwealth, state and territory health departments, carers, peak bodies for consumers and service providers, clinicians, service managers, and a range of public, private and not-for-profit organisations involved in palliative care.
3. The updated Strategy is a commitment by all Australian governments to ensure that evidence-based, quality palliative care is available to everyone who requires it.
4. A formal national governance structure for the updated Strategy, with links to Australian Health Ministers' Advisory Council (AHMAC), will be put in place to improve accountability and collaboration across jurisdictions.
5. A monitoring and evaluation plan will be developed to identify how progress on the priorities in the updated Strategy will be monitored and reported.

Issues

6. AHMAC endorsed the updated Strategy on 31 July 2018.
7. Following CHC endorsement and subject to CHC approval, the updated Strategy will be published on the Commonwealth Department of Health's website.

Financial Implications

8. There are no financial implications for the ACT Government relating to the endorsement of the updated Strategy.

ConsultationInternal

9. Not applicable.

Cross Directorate

10. Not applicable.

External

11. Not applicable.

Work Health and Safety

12. Not applicable.

Benefits/Sensitivities

13. The updated Strategy will facilitate cross-jurisdictional collaboration through strengthened national governance, an implementation plan, and a monitoring and evaluation plan.

UNCLASSIFIED

UNCLASSIFIED

Communications, media and engagement implications

14. Media interest is unlikely, however, possible local interest may arise due to the current Legislative Assembly *Select Committee Inquiry on End of Life Care in the ACT* which has a focus on palliative care.

Signatory Name: Paul Wyles Phone: 79262
Action Officer: Geraldine Carling Phone: 54395

Attachments

Attachment	Title
Attachment A	Updated <i>National Palliative Care Strategy 2018</i>
Attachment B	Response letter for the COAG Health Council Secretariat

UNCLASSIFIED



E-MAILED
- 8 OCT 2018

Meegan Fitzharris MLA

Minister for Health and Wellbeing
Minister for Higher Education
Minister for Medical and Health Research
Minister for Transport
Minister for Vocational Education and Skills
Member for Yerrabi

Ms Barbara Levings
Secretariat
COAG Health Council
CHCSecretariat@health.sa.gov.au

Dear Ms Levings *Barbara*

Thank you for providing me with COAG Health Council Out of Session Item 353 on the updated *National Palliative Care Strategy 2018*.

I note that the Australian Health Ministers' Advisory Council endorsed the updated *National Palliative Care Strategy 2018* on 31 July 2018.

I endorse the updated *National Palliative Care Strategy 2018*, and I approve the publication of the endorsed *National Palliative Care Strategy 2018* on the Commonwealth Department of Health's website.

Thank you again for providing me with this out of session item.

Yours sincerely

Meegan Fitzharris MLA
Minister for Health and Wellbeing

5/10/2018

ACT Legislative Assembly

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COAG Health Council

Date of issue: 5 September 2018
Due date: 5 October 2018

Out-of-Session item no.: 353
Originator: NSW for HSPC

National Palliative Care Strategy 2018

Recommendations

That Health Ministers:

1. **Note that the Australian Health Ministers' Advisory Council (AHMAC) has endorsed the National Palliative Care Strategy 2018.**
2. **Endorse the National Palliative Care Strategy 2018.**
3. **Approve the publication of the National Palliative Care Strategy 2018 on the Commonwealth Department of Health's website.**

Purpose of the paper

To seek members' endorsement of the National Palliative Care Strategy 2018 and publication on the Commonwealth Department of Health's website.

Summary of issues for discussion

Following extensive national consultation, the National Palliative Care Strategy 2010 has been updated to include seven goals relating to improving understanding, capability, access and choice, collaboration, investment, data and evidence, and accountability.

AHMAC endorsed the National Palliative Care Strategy 2018 on 31 July 2018.

Subject to COAG Health Council (CHC) endorsement, the updated Strategy will facilitate cross-jurisdictional collaboration through strengthened national governance, an Implementation Plan and a Monitoring and Evaluation Plan.

Background

The National Palliative Care Strategy 2010 was evaluated in 2016 to determine relevance and useability. Overall, the National Palliative Care Strategy 2010 was considered to be a valuable document that highlighted palliative care as a priority at the national level and provided an authorising environment in which to implement state level activities.

The updated Strategy document was developed through extensive national consultation including targeted consultations with jurisdictional health officials through workshops, and an online submission portal in August and September 2017.

On 24 April 2018, the updated Strategy was endorsed by the National Aboriginal and Torres Strait Islander Health Standing Committee (NATSIHSC).

On 4 June 2018, the updated Strategy was endorsed by the Health Services Principal Committee (HSPC).

On 31 July 2018, the updated Strategy was endorsed by AHMAC.

The Strategy demonstrates its alignment with international, national and state and territory policy frameworks, and addresses deficiencies of the 2010 Strategy, as identified through the

2016 national evaluation. Specifically, deficiencies were identified around governance and accountability.

Results of consultations with jurisdictions / implications for other ministerial councils

All jurisdictions have endorsed the National Palliative Care Strategy 2018, through HSPC and AHMAC.

Regulation impact assessment

Not applicable.

Attachments

Attachment1: National Palliative Care Strategy 2018

Jurisdiction:	Commonwealth
Contact Person:	Louise Riley
Phone:	02 6289 8526
Email:	louise.riley@health.gov.au

NATIONAL PALLIATIVE CARE STRATEGY 2018

Foreword

Every day across Australia, people will die from life-limiting illness. Palliative care is holistic care that helps people nearing the end of their life to live as well as possible for as long as possible. 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.

Australia has been identified as a world leader in the provision of palliative care and in the quality of our palliative care research programs. All people require evidence-based and person-centred care at the end of their lives, and it is recognised that appropriate care should be based on appropriate need. At the same time, palliative care is not equally available to all people across Australia, for reasons of geography, awareness, economics, workforce, and accessibility. Aboriginal and Torres Strait Islander people, in particular, are impacted by unique factors such as intergenerational trauma, cultural dislocation, oppression, and systemic racism that influence their decision making around end of life considerations. In addition other groups of people are historically under-served including people from culturally and linguistically diverse backgrounds, people in rural and remote locations, and people with disability. People do not always have a choice in deciding where and how they wish to be supported, including where they wish to spend their last days and where they wish to die.

The National Palliative Care Strategy represents the commitment of the Commonwealth, state and territory governments to ensuring the highest possible level of palliative care is available to all people. It builds on previous strategies and on a legacy of investment into research, education and training, workforce and service development, and community awareness and engagement. This version of the Strategy has been produced following the 2016 evaluation of the National Palliative Care Strategy 2010 and has been developed through extensive consultation with Commonwealth, state and territory health departments, carers, peak bodies for consumers and service providers, clinicians, service managers, and a range of public, private and not-for-profit organisations involved in palliative care. We would like to acknowledge the contribution of all those who took part in the consultation or who provided feedback on earlier drafts of the Strategy, as well as the contribution of state and territory representatives through the former Community Care and Population Health Principal Committee (CCPHPC) of the Australian Health Ministers' Advisory Council and the End of Life Care Working Group under the Council of Australian Governments.

There is more to be done to maintain Australia's high standards of palliative care and to ensure that care is available to those who need it as well as their families and carers, including bereavement support following the death of a loved one. This Strategy is intended to provide direction and accountability so that people affected by life-limiting illnesses are able to receive the care they need and can live their lives as fully as possible.

(signed by Ministers)

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Appendix A

Consultation to develop the National Palliative Care Strategy 2018

Summary

Palliative care plays a vital role at the end of life for many Australians, improving quality of life for individuals and the carers¹, family and friends supporting them as well as reducing the physical and emotional distress of dying. As noted by the World Health Assembly (of which Australia is a Member State),

“palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.”²

It is estimated that 40 million people worldwide would benefit from palliative care but only about 14% receive the care they need.³ Palliative care is a fundamental component of universal health coverage.⁴ While Australia is among a relatively small number of countries currently providing a level of integrated, comprehensive palliative care there is still much work to be done to ensure that people affected by life-limiting illnesses get the care they need to live well.

This National Palliative Care Strategy (National Strategy) is a commitment by all Australian governments to ensure that evidence-based, quality palliative care is available to everyone who requires it.

Purpose

The National Strategy is intended to be used by all Australian governments, as well as organisations and individuals, in guiding the improvement of palliative care across Australia so that people affected by life-limiting illnesses get the care they need to live well. The National Strategy provides a shared direction and an authorising environment for the continual improvement of palliative care services throughout Australia.

While the key audience for the National Strategy is governments and providers of care, this Strategy also articulates the care that people affected by life-limiting illnesses should expect.

Within each of the goals in the National Strategy there are statements identifying the outcomes of achieving each goal's priorities for people affected by life-limiting illnesses, providers of care, and governments.

The Implementation Plan (refer to page 23) articulates, within a five-year timeframe, the activities critical to realising the priorities identified in the National Strategy. The Monitoring and Evaluation Plan (refer to page 24) provides the mechanism for ongoing assessment of the progress made towards achieving the goals.

¹ For the purposes of this Strategy the term 'carers' refers to unpaid carers such as family members, friends or neighbours who provide personal care, support and assistance to people with life-limiting illness (see Glossary)

² Based on World Health Assembly, 2014, Page 1

³ World Health Organization, 2017a

⁴ World Health Organization, 2013

Overview of the National Palliative Care Strategy

Vision

This National Palliative Care Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well. 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 achieve.

“People affected by life-limiting illnesses get the care they need to live well”

Guiding Principles

Palliative care is person-centred care
 Death is a part of life
 Carers are valued and receive the care they need
 Care is accessible
 Everyone has a role to play in palliative care
 Care is high quality and evidence-based

Six guiding principles (see pages 7-8) are identified as fundamental to ensure that all people experience the palliative care they need. These are aspirational principles expressed in current and future tenses to emphasise the need for each of these principles to be visible in all palliative care.

Goals

To make the vision for this Strategy a reality, seven goals are outlined (from page 9 onwards). Priority statements are defined for each goal. These statements are framed as descriptions of the achievement of the goal. For example, if Goal 2: Capability is achieved, then “the needs of people from underserved population groups are identified and respected”. It should be noted that the goals and priorities are numbered to provide ease of reference, and are not attempting to provide a hierarchy of importance.

There are a series of statements, expressed in the first-person, identifying the outcomes of achieving each goal for people affected by life-limiting illnesses, providers of care and governments.

Understanding
 Capability
 Access and choice
 Collaboration
 Investment
 Data and evidence
 Accountability

Implementation Plan and Monitoring and Evaluation Plan

Activities to achieve the priorities are defined within the Implementation Plan. This includes identified responsibilities and timing for these activities.

Likewise, the statements identifying the outcomes under each goal form the basis of the Monitoring and Evaluation Plan, which sets out indicators for measuring progress towards the goals, data sources and timeframes for monitoring and evaluation.

A person-centred approach

The availability of palliative care is not limited to one type of illness but can assist all people with life-limiting illness, their families and carers. The World Health Assembly recognised that

“...palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients’ need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received.”⁵

The National Strategy affirms that palliative care is a person-centred approach with those affected by life-limiting illnesses at the heart of their care, surrounded by their community and supported by services. The types of palliative care and support that may be needed by an individual, their families and carers will vary and may include one or more of a range of formal and informal supports (see Figure 1 following).

Figure 1 – Placing the person at the centre of their care



Palliative care may be required at any age. The needs of children and young people, and their parents and families, are often quite different from those of people facing the end of life at a much older age. Cultural factors, such as kinship and community, and end-of-life practices and rituals of Aboriginal and Torres Strait Islander people need to be considered to enable cultural capability of palliative care services for Aboriginal and Torres Strait Islander people. People with differing illnesses (such as cardiovascular disease, dementia or cancer) will have differing physical, psychosocial and spiritual needs over various timeframes.

Because people’s palliative care requirements will differ and will also change over time, it is important that their needs and preferences are assessed regularly and that services are able to adapt accordingly. This includes the needs of families and carers as well as the person with a life-limiting illness.

⁵ World Health Assembly, 2014

Palliative care in Australia

Palliative care, while originally associated primarily with the diagnosis of cancer, is appropriate for anyone with life-limiting illnesses including other chronic conditions, dementia, and non-malignant degenerative diseases.

In the last few decades, palliative care has become available within almost every healthcare setting, including neonatal units, paediatric services, general practices, residential aged care facilities, acute hospitals, and generalist community services. Palliative care is also provided through specialist palliative care services which operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services.⁶ Care is also provided in the home, often by carers supported by home-based outreach services from public, private or not-for-profit agencies.

People receiving palliative care have been shown to have fewer hospitalisations, shorter lengths of stay when they are hospitalised, and reduced visits to emergency departments.⁷ Those receiving palliative care at home have been shown to have increased quality of life and reduced need for hospital-based care⁸, providing cost-savings for government.⁹

The need for palliative care

Almost 160,000 people died in Australia in 2015.¹⁰ Many of these deaths were expected, with the leading causes of death being chronic diseases.¹¹ As the Australian population ages, the number of people dying with chronic diseases, and in many cases complex needs, will increase.¹² Estimates of the proportion of people that may benefit from palliative care vary from 50 to 90 per cent but even conservative estimates identify that around 80,000 people may benefit from palliative care each year.¹³

It is estimated that around 65,000 hospitalisations were palliative care-related in 2014-15.¹⁴ It is more difficult to quantify the palliative care received at home and in community-based settings, given current limited data sources. Data submitted to the Palliative Care Outcomes Collaboration (PCOC)¹⁵ for the second half of 2016 show that almost 44 per cent of reported episodes of care were provided by community-based services.¹⁶ Palliative care received at home and in community-based settings can be provided in different ways including care and support from families and friends, social networks, faith communities, private or not-for-profit nursing and allied health agencies or services, residential aged care facilities, general practitioners, public, private or not-for-profit social services, and specialist outreach services.

Demand for palliative care is increasing

It is anticipated that by 2066 around 25% of the population will be over 65.¹⁷

As around 80% of Australians who die in any given year are over 65, the number of people dying each year will increase consistently.¹⁸

The number of people receiving a palliative medicine specialist service through the Medicare Benefits Scheme increased by almost 85% in the five years to 2015-16.¹⁹

⁶ Australian Institute of Health and Welfare, 2016a

⁷ Palliative Care Australia, 2017

⁸ McNamara et al, 2016

⁹ Palliative Care Australia, 2017

¹⁰ Australian Bureau of Statistics, 2016

¹¹ Australian Institute of Health and Welfare, 2017b

¹² Australian Institute of Health and Welfare, 2016a

¹³ Productivity Commission, 2017

¹⁴ Australian Institute of Health and Welfare, 2017a

¹⁵ Palliative care services are not required to submit data to PCOC so these figures may not be representative of all palliative care.

¹⁶ Connolly et al, 2017

¹⁷ Australian Bureau of Statistics, 2013

¹⁸ Australian Institute of Health and Welfare, 2016a

¹⁹ Australian Institute of Health and Welfare, 2012

Improving palliative care in Australia

State and territory governments have made significant investments in the development and expansion of palliative care services over the years. More recently there has been a growing focus on improving the ability of specialists to provide outreach services into the community, and assisting people to remain at home for longer through the use of technology and home-based services.

At the national level, the Commonwealth Government has funded the National Palliative Care Projects since the 1990s, as well as Palliative Care Australia, the national peak body for palliative care. The Projects include significant investments in research, clinical education, and ongoing clinical benchmarking. Through the Projects, the Commonwealth has also provided funding for training materials, assessment tools, and other resources to assist health, social service and residential aged care providers, including a focus on the uptake of advance care plans and other mechanisms for increasing awareness and choice about planning at the end of life.

Australia has been rated highly in international assessments of palliative care services, due to the quality of services provided to people at the end of life, affirming the significant progress that has been made in Australia over many years.²⁰ The evaluation of the National Palliative Care Strategy 2010 found that the National Strategy provided direction to states and territories, and to individual services, in strengthening palliative care service delivery.²¹

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.

History of the National Palliative Care Strategy

The first National Palliative Care Strategy was endorsed in October 2000 by the Australian Health Ministers' Advisory Council. This document was significant because it was the first time that all governments, providers and community-based organisations had come together to agree national priorities for palliative care.

In 2010 the second National Strategy, *Supporting Australians to Live Well at the End of Life*, was launched with the endorsement of health ministers, following significant consultation with the sector. The 2010 National Strategy was broad in scope, with an ambitious set of actions aimed at improving services across all sectors of the health system as well as increasing public and service provider awareness of palliative care.

In 2016, the Commonwealth Government commissioned an evaluation of the 2010 National Strategy. This evaluation included consultation with the public, peak bodies, community and advocacy organisations, clinicians, service providers and managers, policy makers and government representatives as well as a literature review. Overall, the evaluation found "that the Strategy's existence contributes to an authorising environment for the continued expansion and improvement of palliative care service delivery across the health system".²² One of the actions recommended by the evaluation was to update the 2010 National Strategy to reflect the current service environment and challenges, strengthened by governance and an implementation plan and a monitoring and evaluation framework.

The development of this current Strategy took place in 2017 based on the findings of the evaluation and extensive consultation with over 200 individuals and organisations. This included carers, peak bodies for consumers and service providers, clinicians, public, private and not-for-profit organisations involved in palliative care and Commonwealth, state and territory health departments. A summary of the consultation process is provided in Appendix A.

²⁰ The Economist Intelligence Unit, 2015

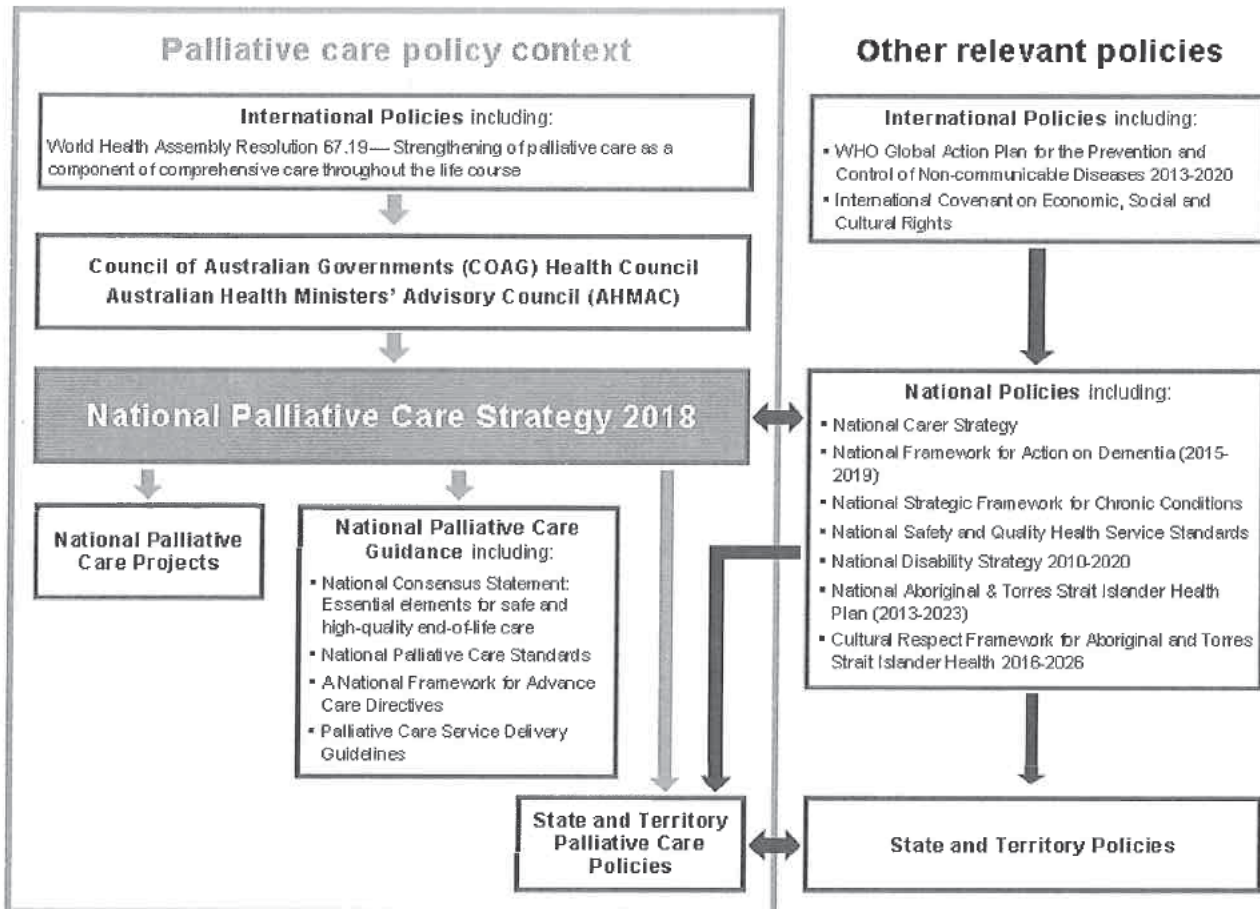
²¹ Urbis, 2016

²² Urbis, 2016, Page i

Alignment with other national strategic frameworks

Since the 2010 National Strategy, many state and territory governments have either updated or produced new policy frameworks for palliative and end-of-life care. At the international level, the 67th World Health Assembly produced resolution 67.19 in 2014, calling on nations to strengthen palliative care as a component of comprehensive care throughout the life course.²³ Also since 2010, a number of significant national strategic frameworks have been developed which will guide other services that might be required by people who also require palliative care. This update of the National Strategy has sought to align with these strategic frameworks as outlined in Figure 2 below.

Figure 2 – Palliative care policy context



²³ World Health Assembly, 2014

Guiding principles

The following six principles are fundamental to good palliative care, and are expected to be demonstrated in all service delivery, quality improvement, policy and research development activities. These principles are aspirational statements that are reflected throughout the goal areas of the National Strategy and are written in the present and future tenses to highlight the expectation that each principle will be evident to those receiving and providing palliative care.



Palliative care is person-centred care

People affected by life-limiting illnesses receive care that is respectful of, and responsive to, their needs, preferences and values. Individuals and their families and carers will be included in decision-making about their care and will be provided with information to make informed choices. People affected by life-limiting illnesses will be represented in the planning and delivery of services at every level.

Palliative care is holistic care and will include attention to physical, emotional, psychological, social, and spiritual needs. It will be provided in a manner that is sensitive and culturally appropriate to the preferences and needs of the person, their family and carers.



Death is recognised as a part of life

Palliative care is an approach that values life and supports people to live as fully as possible for as long as possible, recognising that every life is meaningful. Maintaining quality of life is an important goal of palliative care, however the reality for many people is that impending death can hinder social interaction and leave people feeling isolated and alone. While maintaining social and emotional engagement and talking about the experience of dying can help, Australia has a very diverse society and people living with the expectation of an impending death may have different cultural preferences and varying levels of comfort in discussing, and planning for, the dying process and death itself.

Acknowledging the reality of dying and death can help people to prepare for the end of life in ways that are meaningful to them and their families and carers. This will look different for different people. Early and documented planning with formal care providers and carers can ensure that people facing an expected death are supported physically, emotionally, culturally, and spiritually, including bereavement support for families and carers.



Carers are valued and receive the support and information they need

Carers provide an essential component of palliative care and in many cases provide the majority of care for a person whose life is limited by illness. Uniquely, carers can be both providers and recipients of care and, historically, carers' needs have often not been considered in care planning. Their role will be acknowledged and respected and their health and wellbeing needs considered as a component of holistic palliative care, including bereavement support.²⁴

²⁴ Aoun et al, 2015



Care is accessible

All Australians will be able to access quality palliative care. There are population groups that are currently under-served, including people who are:

- Aboriginal and Torres Strait Islander
- culturally and linguistically diverse, particularly new migrants
- lesbian, gay, bisexual, transgender and intersex
- living with disability, including cognitive impairment such as dementia
- experiencing homelessness
- in long-term institutional care (including being incarcerated)
- ageing and frail
- living in rural and remote areas.

While many people across society will experience varying levels of access and quality of care, these population groups generally experience additional barriers in accessing services, which will be addressed in initiatives to improve access and equity of care.

Palliative care needs to be flexible and responsive to ensure that care is accessible respectful, culturally safe and appropriate according to need. Specialist palliative care services play an important role in meeting complex needs and supporting others to provide this care.



Everyone has a role to play in palliative care

Palliative care is provided by an active multi-disciplinary team which includes family and other carers, and considers people's relational, creative, spiritual, cultural and social needs as well as their physical and psychological needs. For that reason, 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.

While not everyone will need specialist palliative care, specialist palliative care providers have an important role to play across the health system in building the capacity of those providing palliative care, including people within the community, to ensure that people affected by life-limiting illnesses get the care they need.



Care is high-quality and evidence-based

Continued investment in research and knowledge sharing will improve the evidence base for the delivery and continuous improvement of quality palliative care. There is also a need for greater focus on the design and collection of meaningful data, including data on outcomes. It is vital that the experiences of people affected by life-limiting illnesses are included in regular monitoring and reporting. This evidence base needs to be accessible and integrated into education and training for care providers to improve the consistency and quality of care.

People affected by life-limiting illnesses will also have access to trustworthy resources to help them make informed decisions about their care.

Goal 1: Understanding

People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care

Why is this important?

We will all die. Before the advent of our modern hospitals, more people died at home and death was more visible in the daily life of families and neighbourhoods. Today, the experience of dying is largely hidden from view.²⁵ It is important that the end of life is recognised as an inevitable part of living so we can ensure that our health and social systems provide the support that individuals, carers and families need as life ends, and in bereavement.

The recent rise in public conversations about death and dying is an indication of the importance of end-of-life issues. Many new community-based initiatives have been created in recent years to raise awareness of death and dying. These encourage cultural change and provide opportunities for people to discuss death and its meaning, and to express what is of value to them.^{26,27}

The first goal of the National Strategy is about the public – all of us – because the experience of dying will affect all of us. Research has shown that raising awareness and helping people understand the importance of palliative care is necessary to ensure that they can talk about their wishes for the end of life. In turn, raising awareness of the services available should help individuals, their families and carers to seek and find the support they need to live well till the end of life,²⁸ and in bereavement.

Evidence also demonstrates the benefits of individuals, their carers and families discussing their care preferences early in their illness²⁹. 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.

The involvement of communities in discussing end-of-life issues and caring for those who are dying has also been shown to increase social capital and build the capacity of a community to care for one another during illness, dying and bereavement.³⁰

Families and carers undertake a large share of the responsibility of caring for their loved ones. Improving awareness and understanding of palliative care and its benefits will help communities to care for the carers who often find it difficult to maintain their own health and social well-being, including in bereavement.^{31,32}

²⁵ Zweig & Oliver, 2009

²⁶ Noonan et al, 2016

²⁷ McNamara & Hegney, 2016

²⁸ McIlpatrick et al, 2013

²⁹ Senate Community Affairs References Committee, 2012

³⁰ Horsfall, Noonan & Leonard, 2012

³¹ Stajdujar, 2013

³² Aoun et al, 2015

Priorities

- 1.1 More people are aware of the benefits and local availability of palliative care
- 1.2 Community-based networks and activities build local capacity to support people who are reaching the end of their life
- 1.3 More people are preparing, using and maintaining advance care plans, including within residential aged care facilities and for people with dementia
- 1.4 Carers have the information, training and support they need to help them undertake caring activities
- 1.5 More people consider and respect cultural beliefs practices and obligations when discussing palliative care needs

What does this mean for...

People affected by life-limiting illness	Providers of care	Governments
<p>1a I can access information on palliative care and end-of-life issues and make informed decisions about the care that I want to receive</p> <p>1b I can discuss my end-of-life wishes with my loved ones and develop and maintain an advance care plan</p> <p>1c My community enables me and others to talk about and plan for death</p> <p>1d My carers have the information and support they need</p> <p>My cultural health beliefs, health practices and culture are respected.</p>	<p>1e We support individuals and the wider community to have informed discussions on palliative care and end-of-life issues</p> <p>1f We build capacity of carers and the wider community to care for people at the end of life</p> <p>1g We provide care that is person-centred and is informed by an individual's choice</p> <p>1h We provide care that is culturally respectful and safe for Aboriginal and Torres Strait Islander people</p> <p>1i We are engaged in partnerships with local Aboriginal and Torres Strait Islander people and acknowledge cultural differences</p>	<p>1j We support the provision of information and education on palliative care and end-of-life care issues</p> <p>1k We facilitate the collection of relevant data and use that data to increase community capacity around end of life issues</p>