His Excellency General the Honourable David John Hurley AC DSC (Retd), Governor-General of the Commonwealth of Australia, and Her Excellency Mrs Linda Hurley, Patrons

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Senator Katy Gallagher
Chair, Senate Select Committee on COVID-19
C/O the Committee Secretary
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600

10 June 2020

Dear Senator Gallagher,

Senate Select Committee on COVID-19

Thank you for the opportunity to provide a submission to the Senate Select Committee Inquiry into the Australian Government's response to the COVID-19 pandemic.
Palliative Care Australia (PCA) represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care.

Palliative Care and COVID-19

By early March 2020, overseas reports of people dying from COVID-19 indicated a need to educate and support healthcare services in Australia. The palliative care sector in Australia was already taking measures to prepare for a potential surge in the number of people dying from COVID-19; deal with any disruption to the ongoing palliative care of patients not dying from COVID-19; and support health professionals faced with the prospect of caring for a significant number of dying patients.

Additionally, the palliative care sector began to think strategically about the needs of existing palliative care patients and the palliative care workforce; what resources would be needed to ensure palliative care patients and their families continued to receive the care

and support they needed in the face of any disruption caused by COVID-19 or the national response to COVID-19; and how to ensure that the health workforce had access to relevant and emerging evidence during this pandemic period. The palliative care sector was also looking at how to share its expertise in advance care planning, caring for the seriously ill, management of the dying person, and bereavement with the broader health and social workforce.

Specifically, the palliative care workforce was clear about the role palliative care has during this pandemic. *Palliative care* can help manage the physical symptoms of COVID-19, particularly severe shortness of breath, pain and delirium, as well as emotional and spiritual distress, and provide personal support for people who are seriously ill or, dying and their families. Effective palliative care can assist in *the assessment and management* of clinical problems in the community, including residential aged care, and help vulnerable people to avoid unnecessary emergency department presentations and hospitalisation. The palliative care sector has provided innovative and compassionate solutions to overcome the challenges to i*nterpersonal connection* caused by the necessities of infection control.

The President of the European Association for Palliative Care (EAPC), Professor Christoph Ostgathe, has pointed out that during the disordered emergence of this pandemic, many people may not have considered why palliative care is an essential service. **However, he warned, palliative care is key**.

In an EAPC statement on 20 March 2020, he wrote:

> *"During this crisis, in palliative care we need to step up and ensure that we are proactive; that we fully utilise our well-honed skills and competencies and prove that we are an important part of our hospitals and our services crisis plans. It is important that we are able to speak out loud where there is treatable suffering in this crisis. We need to make it clear that in a pandemic like this palliative care is not a luxury, it is a human right!"*[1]

Australian Coronavirus Disease 2019 Palliative Care Working Group

PCA formed the Australian Coronavirus Disease 2019 (COVID-19) Palliative Care Working Group (ACPCWG) in partnership with experts from around the country. The Working Group's first meeting was 3 March 2020 and it has continued to meet weekly (and more recently fortnightly) since then.

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[1] Ostgathe, C. (20 March 2020). Start thinking about palliative care in times of a pandemic: The case of Corona. *EAPC Blog.*

Membership of the Australian COVID-19 Palliative Care Working Group (ACPCWG):

- Palliative Care Australia
- Australian and New Zealand Society of Palliative Medicine (ANZSPM)
- Palliative Care Nurses Australia (PCNA)
- Australasian Chapter of Palliative Medicine of the RACP (AChPM)
- End of Life Directions for Aged Care (ELDAC)
- Paediatric Palliative Care Australia and New Zealand (PaPCANZ)
- CareSearch, Flinders University
- Caring@Home
- Australian Department of Health
- Individual experts as identified by the Working Group

PCA has drawn on the work of the ACPCWG, PCA Member Organisations (representing all State and Territories peak bodies for palliative care) and professional Affiliate Members to develop key learnings from the COVID-19 crisis, including lessons for palliative care in the future. PCA would like to share these learnings with the Committee as they relate to the terms of reference of your Inquiry.

A summary of the key recommendations from this submission:

PCA recommends:

1. Continuation of MBS telehealth items for palliative care consultations and an extension of these telehealth provisions for palliative care nurse practitioners and allied health professionals.

2. Funding infrastructure for health and aged care providers that currently do not have adequate telehealth capability.

3. In relation to compulsory flu vaccination requirements for visitors to residential aged care facilities, build national consistency for grounds for exemptions (including compassionate grounds), and nature of the evidence of vaccination required.

4. In line with the ***National Palliative Care Strategy*** and in recognition that if Australia experiences further waves of the current COVID-19 pandemic or other pandemics of

a similar nature, the demand for palliative care grow will grow. An increased investment in palliative care is needed to ensure that the systems and people are available to provide quality palliative care where and when it is needed.

5. Any national strategy for pandemic planning includes palliative care as part of the formal planning and national response.

6. Investing in a national system to ensure residential aged care facilities have imprest stock of essential palliative care medications and the ability to change levels in response to emergency events.

7. Continued investment by the Australian government to increase Australia's supply of PPE and pharmaceuticals held in the National Medical Stockpile.

8. Establish systems to ensure that residential aged care and community care providers have guaranteed supplies and access to Personal Protective Equipment (PPE) and appropriate training in its use.

9. Planning for future pandemics needs to augment mental health, grief and bereavement services with palliative care to ensure that the people have the support and care they need through these exceptional circumstances.

10. Increase measures to support health and aged care professionals undertake advance care planning with their patients and residents which recognises decisions and preferences for end of life care in a pandemic.

11. Supporting the Australian Department of Health to provide trusted sources of advice and information during all stages of a pandemic.

In relation to the Terms of Reference for this Inquiry:

a): The Australian Government's Response to the COVID-19 pandemic

PCA would like to make particular note of the following Australian Government and National Cabinet measures and actions which contributed positively during this time:

1. The Australian Government acted quickly to enable the Medicare Benefits Schedule (MBS) telehealth items for health professionals including palliative care physicians and specialists, nurse practitioners and other health professionals to continue to

consult with their patients, ensuring continuity in care and enabling health professionals, patients and family members to remain safe.

2. The Therapeutic Goods Administration (TGA) and the Department of Health acted quickly to ensure that sufficient palliative care medications were available for actual and potential needs, while key palliative care medicines and devices were included on the TGA Shortages Watchlist.
3. The Australian Government acknowledged that many existing programs and services needed additional resourcing to meet increased demand, including funds to purchase personal protective equipment (PPE), and to support people to continue to receive the care they needed and to stay safe. This included additional resources and funding allocated to a range of programs and support services including the Caring@home initiative, Home Care Packages, Residential Aged Care, the Commonwealth Home Support Program (CHSP), My Aged Care and the Older Persons Advocacy Network (OPAN).
4. PCA supported the Australian Government's measures to increase Australia's supply of PPE and pharmaceuticals held in the National Medical Stockpile.
5. The Department of Health's daily email updates, newsletters, training materials, factsheets and other resources quickly became a trusted source of advice and information during all stages of the pandemic. The webinars provided by the Department of Health for aged care providers and staff, General Practitioners (GPs), mental health care practitioners, primary care and allied health practitioners and rural and remote practitioners supported these healthcare professionals to provide appropriate care to Australian's vulnerable populations during a period of uncertainty.
6. The Australian Government supported the development of the *Industry Code for Visiting Residential Aged Care Homes during COVID-19*: https://www.cota.org.au/wp-content/uploads/2020/05/Industry-Code-RACH-Visits-during-COVID-10-FINAL-as-at-11-May-2020.pdf. The Code was developed in a short timeframe and received agreement from aged care provider peak bodies, consumer advocacy organisations, the Australian Government and the National Cabinet.
7. The Australian Government establishment of the National COVID-19 Clinical Evidence Taskforce is also an important initiative. PCA welcomes the creation of a palliative and aged care panel which acknowledges the important of rapid appraisal of emerging evidence and subsequent national guidance in these clinical areas as part of a COVID-19 response.

Which of these changes need to be sustained into the future?

MBS telehealth items:

As PCA outlined in a submission to the Department of Health Primary Care Implementation Response (COVID-19 response) in early April 2020, in the COVID-19 environment, providing as many consultations as possible by telehealth balances optimising clinical care and minimising risk for vulnerable patients. Video/telehealth consultations can allow increased coverage especially given a projected increase in patient numbers and acuity of the clinical issues when deterioration or COVID-19 infection occurs, in regional and remote areas, or where workforce shortage occurs due to illness.

As outlined above, PCA welcomed the amendments to increase MBS telehealth items and specifically welcomed the Australian Government's amendments which ensured Palliative Medicine Physicians and Palliative Medicine Specialists had equitable MBS rebates for telehealth items, as this inequity in the general MBS has been a broader concern for some time.

For many palliative care patients (regardless of where they live), the option to have video/telehealth consultations should continue into the future as it can broaden access by complementing to face to face consultations. Patients will benefit from broader access, improved continuity of care and more rapid support in the event of clinical deterioration, particularly noting that, for many palliative care patients, travel to appointments will remain difficult after the pandemic has finished.

Telehealth options have enormous potential to bring together the patient, their carers and more than one person from their treating and care team – for example, members of a specialist palliative care team and the patient's GP.

The use of telehealth in aged care facilities can improve outcomes by enabling access to GPs and palliative medicine specialists, especially in, but not limited to, rural and remote locations.

Further, consideration should also be given to expanding MBS telehealth capacity for other health professionals working in palliative care including Nursing and Allied Health Practitioners.

Telehealth infrastructure needs to be supported and funded across health and aged care. Not all health and aged care providers are currently set up to undertake telehealth consults. They may not have the necessary equipment and support systems to be able to administer telehealth consults or have the necessary privacy systems in place. There is also a need to consider equity in access and use of telehealth opportunities by all patient and family groups within our diverse population. Training and information resources for different population groups should be developed to support health consumers.

While telehealth options are good and serve an important purpose in a pandemic, they are not a substitute for in-person face-to-face consultations. There need to be safeguards to make sure people who require face-to-face appointments continue to be able to see health professionals when they need to. There has been evidence throughout the pandemic of patients not accessing essential blood tests, other investigative tests and regular appointments with GPs, allied health practitioners, specialists and physicians. This may lead to delays in the diagnosis of underlying conditions and in receiving necessary and critical treatment.

Compulsory flu vaccinations in residential aged care

While PCA understands the rationale for the compulsory flu vaccination for all visitors to residential aged care facilities and health premises, there were certain examples during the pandemic where the ambiguity about the requirement in different jurisdictions adversely affected family members and their loved ones. Some flexibility is needed in making suitable arrangements for loved ones to see a palliative care patient who is dying.

Community awareness and education before the next flu season is essential to ensure health and aged care providers together with the general public are prepared and planning for vaccinations and also understand the requirements and obligations for visiting people in residential aged care and hospitals.

If flu vaccinations continue to be an ongoing requirement in aged care then more consideration needs to be given to consistency across state/territories including grounds for exemptions, and nature of the evidence of vaccination required, and what to do in the event that someone cannot obtain a vaccination (especially in an emergency such as a need to visit a dying person). In particular, more clarity is required about grounds for a flu vaccination exemption, particularly on compassionate grounds in an emergency.

What does Australia need to do to prepare in the event that the pandemic continues and to plan for future pandemics?

Adequate funding for palliative care and palliative care as part of the national response

Palliative care health professionals have stated that one positive outcome of the COVID-19 pandemic has been better relationships between palliative care and the state and territory health departments and the Australian Health Department in planning for a potential increase in palliative care demand across various sectors. Further, the threat of a surge in deaths from COVID-19 brought the value of palliative care sharply into focus. This led to better relationships between the palliative care sector and other parts of the health system as the particular skills of palliative care health care professionals were needed – for example, planning for goals of care, caring for a dying patient, pain and symptom relief and grief and bereavement support.

The palliative care sector was proactive, working with governments and health and aged care professionals to be ready to care for and support people who were dying, and those who love them.

Currently in Australia, around 160,000 people die each year. This will reach 200,000 by 2030[2]. The great majority of these deaths are what is described as 'expected' or 'predictable' deaths, that includes many people who have had terminal conditions, or have been elderly and frail.

As Australia's population rapidly ages and grows, and more people live longer but with more complex chronic conditions, including dementia, the need for palliative care and Advance Care Planning is going to surge and specialist palliative care may be needed for people for longer periods of time. Should Australia experience further waves of the current COVID-19 pandemic or indeed other pandemics of a similar nature, the demand for palliative care grow will grow even further.

To meet current and future demand for palliative care, further investment is needed. This is recognised in the ***National Palliative Care Strategy*** which states, "investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care where and when it is needed".[3]

There are significant beneficial outcomes to investing in palliative care. Access to quality care in the community, including in residential aged care settings and at home, can help reduce avoidable hospital admissions. We know that when people with life-limiting conditions receive good palliative care they have fewer hospital admissions, shorter lengths of stay and fewer admissions to intensive care when they do need to go to hospital.

Furthermore, ongoing recognition of the need for sustainable access to medications (such as opioids) that relieve suffering in life limiting illness, and their inclusion as essential medications on the TGA Shortages Watchlist are needed. Such outcomes are even more necessary in an impacted health environment such as the lived experience of a pandemic.

PCA recently commissioned KPMG to undertake an economic study about the value of palliative care: https://palliativecare.org.au/kpmg-palliativecare-economic-report. The KPMG report finds that with an additional annual investment of $365m on national palliative care reform, Australia could save up to $464m in other health system costs while making the system work best for those experiencing it[4]. The report recommends an

[2] Australian Bureau of Statistics (2012). *3222.0 Population Projections, Australia, 2012 (base) to 2101*. (Accessed at: www.abs.gov.au/ausstats/abs@.nsf/mf/3222.0)

[3] Australia Government (2018). *National Palliative Care Strategy*. (Accessed at: https://www.health.gov.au/sites/default/files/national-palliative-care-strategy-2018.pdf

[4] Palliative Care Australia & KPMG (2020). *Investing to Save – The economics of increased investment in palliative care in Australia.* (Accessed at: https://palliativecare.org.au/kpmg-palliativecare-economic-report)

increase in funding of $240 million per annum for integrated home and community-based services, $75 million for the provision of palliative care within residential aged care and $50 million per year for palliative care services in hospitals.

Further recommendations are included in the Report about enabling reforms that would improve coordination, data and stewardship for palliative care across the Australian Government and states and territories. PCA argues that there needs to be a change agent appointed, a National Palliative Care Commissioner, who can work with agility across federal, state and territory governments to ensure the National Strategy is put into effect and key performance targets are met.

The UK Government has recognised the importance of palliative care services, especially during the COVID-19 crisis, and has recently announced additional funding of £200 million per quarter to UK hospices. This is a clear acknowledgement that investing in palliative care during the pandemic will benefit the whole health system. The intention of the additional funding is to allow hospices to continue to deliver palliative care services and take pressure off the National Health Service (NHS).

As part of planning for pandemic in Australia, any national strategy for pandemic planning, palliative needs to be part of the formal planning and national response.

Aged care 'imprest' systems for medication

Residential Aged Care Facilities (RACFs) are required to follow the relevant state/territory legislation regulations when it comes to storing of medications (imprest stock). Aged care needs more support in operating effective medication imprest systems to ensure that adequate and appropriate palliative care medications can be stored safely and securely and in suitable quantities during a pandemic.

There is currently no system of national coordination to amend the levels of imprest stock at RACFs. It is critical that there is more uniformity in relation to imprest stock and the ability to change levels in response to emergency events.

In addition to imprest systems, further work may be required to build links between residential aged care and community pharmacies to ensure a supply chain and rapid delivery of essential medications. Included in the list of essential medicines is oxygen which should be available according to relevant palliative care guidelines. In addition to having availability of palliative care medications, it is critical to have rapid mechanisms for

Consideration should also be given to expanding the RACF imprest system to include community pharmacies holding palliative care medicines for patients in their own homes. There can be significant delays between scripting medicines and having them arrive at the patient's house which can cause unnecessary suffering.

Access to medications for aged care residents has also highlighted ongoing staff needs in aged care – appropriate resourcing is required for training care staff and supporting 24-hour access to a registered nurse onsite.

Guaranteed access to PPE in health and aged care and appropriate training

Residential aged care and community care providers need guaranteed supplies and access to Personal Protective Equipment (PPE). During the pandemic there seemed to be some ambiguity about who was responsible for paying for PPE. PCA's understanding is that aged care providers were told to access PPE through the national stockpile, however, this was mostly made available to services with confirmed cases of COVID-19. Clearer messaging around the use of and access to the national stockpile may have cleared up this ambiguity.

There are also concerns that larger providers/corporations had more power to negotiate with companies and order PPE, leaving smaller providers struggling to access it. Smaller providers and those that cannot access the government stockpile may not have established access to a quality supplier who can provide high quality PPE.

Further measures should clarify funding for PPE in RACFs. In addition, further support will be needed for all health and aged care services to ensure access for their workforce to training and information about using and disposing of PPE for all staff and visitors entering the premises.

Similarly, access to PPE and training in its use by informal carers is important when considering care for COVID-19 patients who preference is to receive their care and potentially also die at home, where possible.

COVID-19 and Palliative Care Volunteers

Many palliative care services around Australian are supported by a network of palliative care volunteers who provide direct help and support to patients and their families. The volunteers are also a support to palliative care health professionals.

During COVID-19, physical distancing restrictions meant that many palliative care volunteers were unable to undertake their normal roles and support functions.

Some jurisdictions were able to use the "compassionate communities" model to rally community members to be available to provide care and support to palliative care patents and other vulnerable members of the community including providing bereavement support. Further, consideration should be given to funding these initiatives in future pandemics. The QLD Carers Army is an example.

Mental Health, Grief and Bereavement Support

There are likely to be a number of long-term impacts relating to grief, bereavement and distress for residents, patients, family and staff in health and aged care as a result of the experiences during COVID-19. Due to infection control requirements, families may experience compounded grief resulting from being unable to see their family member before they die, to view the body after the person has died and/or restrictions on attending a funeral.

Family members and friends accessing aged care facilities during this time may have had differing experiences, especially if the service implemented robust restrictions early on. These may lead to immediate or delayed anger, frustration, loneliness and despair, as well as disrupted and prolonged grieving.

Health care staff may experience an increased burden of fear and anxiety if their colleagues become infected with COVID-19 or are required to enter isolation. Health and aged care providers need to manage staffing capacity and ensure staff are supported when overwhelmed and stressed.

Planning for future pandemics needs to augment mental health, grief and bereavement services with palliative care to ensure that the people have the support and care they need through these exceptional circumstances. Australia needs to have integrated mental health, grief and bereavement care across systems and providers, recognising that the way that this support can be provided as changed during the pandemic (eg telephone consults, online consults, limited visits, physical distancing requirements).

Advance Care Planning

The COVID-19 pandemic has highlighted the importance of advance care planning and encouraging people of all ages to have discussions about their preferences for care at the end of life. As PCA noted in its submission to Royal Commission into Aged Care Quality and Safety:

> Advance care planning conversations should be undertaken early, not left to be done in a 'crisis' situation or at the end of 'end of life.' [5]

[5] PCA, 2019, ***Submission to the Royal Commission into Agee Care Quality and Safety***, page 20 (https://palliativecare.org.au/wp-content/uploads/2019/11/PCA-Submission-to-the-Royal-Commission-into-Aged-Care-Quality-and-Safety-October-2019.pdf)

The pandemic has demonstrated that conversations about a person's life choices and preferences should be the norm in everyday medical practice, core business for all clinicians, not just palliative care health professionals, so that patients can make wise decisions when they have the opportunity to do so and not in a crisis pandemic situation.

This is particularly relevant for residents in residential aged care facilities where decisions about transferring residents to hospital would be assisted with the knowledge of a person's preferences and wishes through an advance care planning process.

Aged Care Royal Commission

The Aged Care Royal Commission into Aged Care Quality and Safety provides a unique opportunity to explore the quality of aged care services in Australia and their response to the COVID-19 crisis. PCA has been engaging with the Commission via a series of submissions and has provided a range of recommendations in relation to palliative care in aged care including:

1. Aged care policy should align with the World Health Organisation definition of palliative care and not be restricted to 'end of life' or last days/weeks.
2. Palliative care must be included and clearly articulated in the Aged Care Quality Standards, which all Commonwealth funded aged care services are required to meet.
3. All undergraduate nursing, allied health, medical courses and Certificate courses for care workers must include mandatory units on palliative care.
4. Establish National Minimum Data Sets for palliative care which includes both health and aged care.
5. Funding is needed to fully implement the National Palliative Care Strategy ensuring aged care is included.
6. Investment and the development of innovative models of care are required to ensure older people have equitable access to specialist palliative care.
7. Greater focus on community awareness on death and dying, palliative care and advance care planning.
8. Palliative care should be a priority of the National Federal Reform Council, National Cabinet supported by the appointment of a National Palliative Care Commissioner (PCA has previously called for palliative care to be a COAG priority).

b): Any related matters

For the information of the Senate Committee, PCA is attaching the terms of reference of the Australian COVID-19 Palliative Care Working Group (ACPCWG). Should the committee wish

to discuss any of the issues raised in this submission, a member of the Working Group will be available to respond to any questions or issues raised by Committee members.

If you have any queries relation to the issues outlined above please feel free to contact Margaret Deerain, National Policy Manager at [redacted] or phone [redacted].

Yours sincerely,

Rohan Greenland
Chief Executive Officer
Palliative Care Australia