Palliative Care Australia
Submission to the Royal Commission into Aged Care Quality and Safety on the impact of COVID-19 on Aged Care Services

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care. 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. We believe quality palliative care occurs when strong networks exist between specialist palliative care providers, primary care providers and support care providers and the community.

PCA has previously engaged with the Royal Commission into Aged Care Quality and Safety (the Commission) via a range of submissions and a witness appearance (see Appendix A). Through these submissions, PCA has made numerous recommendations in relation to palliative care in aged care, in particular:

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 include both health and aged care.
5. Funding is needed to fully implement the National Palliative Care Strategy 2018 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. Ensure a 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 and the Health Council, supported by the appointment of a National Palliative Care Commissioner (PCA has previously called for palliative care to be a COAG priority).

PCA believes that these recommendations are even more relevant in light of the COVID-19 pandemic. A summary of the palliative care experience during COVID-19 and the learnings from this period are further outlined below.
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 the 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, the Australian Department of Health and individual experts as identified by the ACPCWG. The ACPCWG first met on 3 March 2020 and has continued to meet at least fortnightly. More details can be found at: [https://palliativecare.org.au/covid-19-updates](https://palliativecare.org.au/covid-19-updates)

PCA has drawn on the work of the ACPCWG, its Member Organisations (representing all State and Territory 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.

**Summary of key recommendations presented in this submission**

PCA recommends:

1. Funding infrastructure for aged care providers that currently do not have adequate telehealth capability.

2. Continued commitment by the aged care sector to adopt compassionate and balanced approaches to aged care visitors, especially for residents receiving palliative care. This includes an understanding that palliative care is not only limited to the last days/hours of a resident’s life.

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

4. Continued investment by the Australian Government to increase Australia’s supply of Personal Protective Equipment (PPE) and essential medications held in the National Medical Stockpile.

5. Establishing systems to ensure that residential aged care and community care providers have guaranteed supplies and access to approved PPE, as well as appropriate training in its use and disposal.

6. National consistency in the granting of exemptions from influenza vaccination requirements (including on compassionate grounds) – as well as to the proof of vaccination ordinarily required.

7. A proactive and coordinated approach to allow the delivery of best practice infection control and individualised clinical care in facilities that have COVID-19 outbreaks with national guidance on integration of health services and residential aged care, communication and shared decision-making with residents and their families. This needs to include approaches to manage scenarios where clinical care requires the resident to move between and across settings.

8. Provision of timely and appropriate mental health, grief and bereavement and employee assistance programs, and support for aged care workers, families and residents.

9. Increased measures to ensure that aged care professionals support a best practice approach to advance care planning and planning for future clinical problems with their residents, ensuring residents and their families are provided with information from professionals who are equipped to explain their specific condition and treatment options, as part of regular ongoing conversations and care planning. This provides a basis for further conversation and shared decision-making in relation to preferences for end-of-life care in the context of a pandemic.
10. In line with the *National Palliative Care Strategy 2018* 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 will grow and increased investment in palliative care in aged care will be needed to ensure that residents are provided with the high-quality palliative care where and when it is needed.

11. The development of pandemic triage guidelines and a ‘crisis palliative care’ guidance strategy to bring together learnings and strategies from the current COVID-19 pandemic to be applied in other pandemic and crisis situations where increased numbers of people dying is possible.

**MBS telehealth items**

In the COVID-19 environment, providing as many MBS consultations as possible by telehealth balances optimising clinical care and minimising risk for vulnerable patients. Video/telehealth consultations can allow for projected increases in patient numbers and acuity of the clinical issues when deterioration or COVID-19 infection occurs, including in regional and remote areas, or where workforce shortage occurs due to illness.

PCA welcomed the amendments made by the Australian Government to increase access to MBS telehealth items, specifically the 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. A concern remains, however, for Palliative Care Nurse Practitioners where there is an inequity in remuneration, and additional conditions requiring a participating physician to be involved in the consult, further limiting patient access to specialist consultations.

There are benefits to the continuation and expansion of telehealth consultations in RACFs to enable 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 including Palliative Care Nursing and Allied Health Practitioners.

While telehealth supports good clinical care and serves an important purpose, especially in a pandemic, it is not always an appropriate substitute for in-person face-to-face consultations. Telehealth can only replicate some clinical activities and, when provided alone, diminishes the availability of bedside procedures and investigations. There need to be safeguards to ensure that providers continue to facilitate access by aged care residents to face-to-face appointments. PCA is aware of feedback from families that during the COVID-19 pandemic aged care residents are not accessing bedside procedures such as essential blood tests, other investigative tests or regular appointments with GPs, allied health practitioners, specialists and physicians. This can lead to delays in diagnosis of new conditions, in receiving necessary and critical treatment and preventable deteriorations in chronic conditions.

Telehealth infrastructure needs to be supported and funded across health and aged care. Not all 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, appropriate privacy systems in place or the required network bandwidth. Capability for clinical assessments within the aged care facility, and presence of health professionals to support the resident during the consultation, will also be required to fully realise the potential of telehealth in the residential aged care sector. There is also a need to consider equity in access to and use of telehealth opportunities by all patient and family groups within our diverse population and in diverse settings. Training and information resources for different population groups should be developed to help support aged care providers and consumers e.g. Aboriginal and Torres Strait Islander people.
Visitors in Residential Aged Care

PCA recognises the importance of RACFs needing to take active measures to protect residents, their families and staff by minimising the risk of COVID-19 entering their facility. However, this must also be balanced with ensuring that residents maintain social contact with loved ones. In particular, PCA supports compassionate responses to visiting arrangements for dying patients and those receiving or needing palliative care. PCA also recognises that allowing providers to make individual decisions regarding visitation has created a varied and inconsistent approach across facilities and has placed pressure on providers to make decisions with limited direction from the Department of Health or Aged Care Quality and Safety Commission.

PCA welcomed the release of the Industry Code for Visiting Residential Aged Care Homes during COVID-19. The Code recognises the need for providers to make compassionate exceptions in the case of residents receiving palliative care. Compassionate visits should commence as early as possible and visitors should be able to visit the resident while they are still able to converse and interact. The current structure of the Aged Care Funding Instrument (ACFI) which provides palliative care funding for the final week/days of life, and lack of adequate palliative care training and experience hinders the best practice approach to recognising residents receiving palliative care which is not limited to only the last hours to days of life.

Imprest Stock

RACFs are required to follow the relevant state/territory legislation and regulations when it comes to storing of medications (impress stock). The COVID-19 pandemic is demonstrating that further reforms are needed to ensure aged care providers are operating effective medication impress systems. Further efforts are needed to ensure legislation and aged care regulations together with appropriate training for aged care staff are in place to ensure that the impress stock system in residential aged care facilities allows for adequate and appropriate palliative care medications to 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 impress stock at RACFs. It is critical that there is more uniformity in relation to impress stock and the ability to change the amount stored in response to emergency events.

In addition to impress 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. Similarly, timely access to clinical assessment, proactive planning for symptom medication needs and an appropriately skilled prescriber is needed to ensure tailored medication management for the resident. It is not just availability of palliative care medications that is critical but also the dispensing time and rapid mechanisms for distribution, and timely clinical assessment and prescription for an individual resident.

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. This would support residents to have access to appropriate medications, including pain relief, whenever they require it.
Personal Protective Equipment

Residential aged care and community care providers need guaranteed supplies of, and access to, Personal Protective Equipment (PPE). The source of funding for PPE has remained ambiguous to date during the pandemic. PCA’s understanding is that aged care providers were told to access PPE through the National Medical Stockpile (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 will assist in clearing up this ambiguity. PCA acknowledges that the Department of Health has provided clearer guidance on which providers can access the National Stockpile during the recent Victorian outbreak.

There are also concerns that larger providers/corporations have more power to negotiate with companies and order PPE, leaving smaller providers struggling to access it. Smaller providers and those that cannot access the National 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 if they are not able to access the National Stockpile. In addition, further support will be needed for all aged care services to ensure that their workforce has access 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 whose preference is to receive their care and also potentially to die at home, where possible.

Compulsory flu vaccinations in residential aged care

PCA understands the rationale for the compulsory flu vaccination for all visitors to residential aged care facilities and health premises. However, there have been certain examples during the pandemic where the ambiguity about the requirement in different jurisdictions has 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 or nearing the end of life.

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

If flu vaccinations continue to be an ongoing requirement in aged care, then more consideration and clarity needs to be given to consistency across state/territories. This includes grounds for exemptions, and nature of the evidence of vaccination required, and what to do in the event that someone cannot obtain a vaccination or requires an exemption (especially in an emergency and needing to visit a dying person).

Following the decisions by the National Cabinet to introduce visitor restrictions and compulsory flu vaccination in residential aged care, each state and territory passed a health directive to implement these restrictions. There was some inconsistency in the wording of these directives, creating confusion especially for those providers operating services in more than one state or territory. As each state and territory has taken a different approach to the lifting of COVID-19 restrictions, this continues to impact the content of health directives and this has not been acknowledged by the Australian Department of Health when sending advice to providers.
Facilities with COVID-19 cases

RACFs that have suspected or confirmed COVID-19 infections need to establish clear communication protocols to engage with families, GPs, allied health and other people closely connected to the facility. Families should be provided with regular updates on the health status of their family member and the results of any COVID-19 testing and supported to have regular contact with their family member via video/phone calls, emails and window visits. A supported decision-making approach to treatment decisions should be used, whereby residents are able to involve family members who can support them in understanding and making decisions about treatment options. For residents who do not have decision-making capacity, the appropriate proxy (as per state or territory legislation) should be involved in such decisions. It is important that information is provided by professional(s) equipped to explain their specific condition and treatment options. Communications should include the steps being taken by the provider, local health authorities and government departments to manage the suspected and/or confirmed cases.

Residents in facilities with COVID-19 cases should still be provided with the daily personal care, nutritional needs, services and medication they need to meet their needs. They should have regular communication and engagement with staff to support their mental wellbeing and reduce isolation and loneliness during a very challenging and distressing time.

Experience during the pandemic has shown that RACFs are not sufficiently funded or resourced to meet the extreme rise in health demands during an outbreak. Also, staff are not trained or equipped sufficiently to cope with these increased demands. This can lead to significant resident and staff infections and preventable deaths. In some instances, state/territory and local health authorities are able to supply additional resources, however, to date the experience has been that in some instances this support was provided too late and was not appropriately coordinated.

There needs to be a more effective long-term strategy for dealing with facilities with COVID-19 cases and managing the increased health demands. This strategy needs to ensure comprehensive clinical assessment and diagnosis of the clinical impact of COVID and the potential for other intercurrent problems/differential diagnoses; and cover a range of clinical needs from supportive care where recovery is possible, and end of life care where death is imminent. Additionally, there needs to be palliative care involvement through in-reach crisis teams during outbreaks in RACFs, particularly if patients remain at the facility rather than being transferred out.

Grief and Bereavement

There are likely to be a number of long-term impacts relating to grief, bereavement and distress for residents, patients, family and staff in aged care as a result of their experiences during COVID-19. Families may be unable to see their family member before they die, to view the body after the person has died and have restrictions placed on funeral attendance, potentially compounding their grief due to infection control requirements. Poor communication and engagement with families during the pandemic may also cause distress and compound grief.

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.
Complex responses to these challenges are not limited to family members. Aged care providers need to acknowledge that some staff may have an increased burden of fear and anxiety during a pandemic. Staff must be supported when overwhelmed and stressed and given access to appropriate and timely employee assistance programs.

Planning for future pandemics needs to augment mental health, grief and bereavement services within aged 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 has changed during the pandemic (e.g. telephone consults, online consults, time 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 a previous submission to the Royal Commission:

> 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.’

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 their wishes known when they have the opportunity to do so and not in a crisis or pandemic situation. The best practice approach to advance care planning and planning for future clinical problems is iterative and requires residents and their families to be provided with information by a professional(s) equipped to explain their specific condition and treatment options, as part of regular ongoing conversations and care planning. This then provides a solid foundation for further conversation and shared decision-making in relation to preferences for end of life care in the context of pandemic, with further information about the clinical scenario COVID-19 infection may pose for that resident. There are a broad range of clinical decisions which may need to be made in the context of a pandemic, including the role of hospitalisation, antibiotics, and other supportive treatments (oxygen and hydration). Similar to other clinical scenarios, shared decision-making in this new scenario can be assisted with the knowledge of a person’s prior expressed preferences and wishes through an advance care planning process, supported by ongoing conversations and information about the clinical situation to hand.

During the COVID-19 pandemic, it has become very clear in the US and UK that early advance care planning has been a vital component in the management of patients with complex co-morbidities who have contracted COVID-19. Advance care planning has allowed patients to refuse unwanted treatment that would be of little or low benefit, while continuing to receive all care and treatment up to their agreed ceiling of care with many even surviving a severe COVID-19 infection. However, advance care planning should not be conflated with discussions about lack of resources required to treat all those people who it is believed would benefit from, and who would desire, treatment. Additionally, advance care planning should never be used to disguise a decision based on lack of resources not to provide treatment to a patient, as a decision by the patient to not accept that treatment.

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2. Cairns, W. & Coghlan, R. (2020). *Palliative care during the COVID-19 pandemic: understanding the necessity for honest conversations and difficult decisions*. Prepared on behalf of the Australian Coronavirus Disease 2019 (COVID-
triage approaches if resources become critical, a pandemic plan also needs to include a transparent framework for pandemic triage decision-making which is founded on and justified by clear ethical and clinical standards, and then supported by unambiguous frameworks for making difficult decisions; and it also needs to be clearly signalled when the framework is being enacted in practice.³

Palliative Care Funding

Currently in Australia, around 160,000 people die each year. This will reach 200,000 by 2030⁴. The 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 will surge and specialist palliative care may be needed by more people for longer periods of time. Should Australia experience further waves of the current COVID-19 pandemic or indeed other healthcare crises of a similar nature, the demand for palliative care grow will grow even further.

To meet current and future demand for palliative care in aged care, further investment is needed. This is consistent with the National Palliative Care Strategy 2018 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”.⁵

There are significant beneficial outcomes to investing in palliative care. Access to quality care in residential aged care can help reduce avoidable hospital admissions. 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 if 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 (see Appendix A). KPMG reported that palliative care services in RACFs are currently underfunded and underserviced with only one in 50 permanent residents receiving ACFI-funded palliative care. The report recommends an increase in funding of $75 million per annum for palliative care within residential aged care. This investment should include both direct specialist palliative care services and integrated support that includes the residential aged care workforce and other health professionals such as GPs. This investment could deliver between $135 million and $310 million in reduced hospitalisation and emergency transport costs and free up to between 100,000 and 220,000 hospital bed days. The report also finds that a $1 investment in palliative care nurses in residential aged care can return up to $4.14 in savings elsewhere

in the health and aged care system.

Further recommendations are included in the KPMG report about enabling reforms that would improve coordination, data and stewardship for palliative care across the Australian Government and states and territories. PCA will provide more comprehensive detail on the KPMG report findings and recommendations about aged care in a further submission to the Royal Commission.

**Future Pandemic Planning**

Whilst Australia has not suffered the COVID-19 impacts experienced in other countries, it is important to undertake proactive planning to meet the challenges posed by another COVID-19 wave or other pandemics and health crises. Planning should encompass worst-case scenarios while acknowledging that they may not eventuate in every pandemic.

For many, the greatest concern in the COVID-19 pandemic is that a surge in demand will overwhelm the capacity of acute medical services, disrupt the care of people with other conditions, and infect numerous healthcare workers, further decreasing supply of a critical workforce. All of these experiences have been seen in countries with high rates of COVID-19 infections. The Australian COVID-19 Palliative Care Working Group (ACPWG) has prepared a paper that considers the practical and ethical considerations in the event of overwhelming demand for medical services. A summary of the main themes and recommendations are outlined below:

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**Palliative care during the COVID-19 pandemic: understanding the necessity for honest conversations and difficult decisions**

High quality palliative care must continue to be provided to those who had been referred prior to the outbreak of the pandemic and for patients who are diagnosed with new or progressing fatal illnesses other than COVID-19 during the course of the pandemic and will require palliative care. Most importantly, palliative care and palliative care services have a new role in caring for those who are dying from COVID-19. This last challenge will be made more difficult if some patients are referred for palliative care because, due to limits to supply, they cannot be offered intensive life-prolonging treatments, even though they may have benefited.

Faced with the potential for our healthcare systems to be overwhelmed by large numbers of seriously and critically ill people, Australia must commence preparation for pandemic or disaster triage. Current triage systems in Australia already take into consideration patients who are not fit for intensive treatment, patients who choose not to consent to intensive treatment and patients for whom treatment has not been successful: These groups of patients are already managed with little controversy by conventional clinical and ethical decision-making processes and do not need to be subjected to the processes of pandemic triage. However, when ICU bed supply (or any other treatment modality or venue) is not sufficient to meet demand, it becomes necessary to activate a pandemic triage protocol and engage in the potentially very difficult clinical decision-making that requires exclusionary choices of resource allocation.

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Pandemic guidelines could be further supported by the development of a crisis palliative care guidance strategy to bring together learning and future strategies from the current COVID-19 pandemic to be applied in other pandemic and crisis situations where increased numbers of people dying is possible.

**Conclusion**

Australia is taking a proactive approach to managing the COVID-19 pandemic. However, there is still a lot to learn from Australia’s experience during the pandemic. The value of preparing for death, advance care planning, maintaining and accessing adequate medication stocks, accessing PPE and access to telehealth are all paramount considerations. The pandemic has highlighted the importance and role of palliative care particularly in aged care and the need for the health and aged care sectors to work collaboratively and effectively.

PCA would welcome the opportunity to provide any further details about the role of palliative care during this pandemic and the role palliative care should play in any future pandemics or health crises where planning for an increase in the numbers of people dying is expected. Palliative care should be core business in aged care and this has been emphasised by the COVID-19 pandemic.
Submissions to the Royal Commission into Aged Care Quality and Safety

PCA has previously engaged with the Commission via a range of submissions available at: https://palliativecare.org.au/submissions-and-reports

These include the following:

- **Issues Overview: Palliative care within aged care** – prepared for the Royal Commission into Aged Care Safety and Quality (May 2019);
- **PCA Submission to the Royal Commission into Aged Care Quality and Safety** (October 2019);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Consultation Paper - Aged Care Program Redesign: Services for the Future** (January 2020);
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting’s Submission on Workforce** (March 2020); and
- **PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting’s Submission on Program Redesign** (March 2020)

Evidence to the Royal Commission into Aged Care Quality and Safety

The former chair of PCA gave evidence before the Commission on 27 June 2019:

- **PCA Board Chair Witness Statement** (May 2019);
- **Appearance at the Perth hearings by the PCA Board Chair** (June 2019);

KPMG Report

*Investing to Save – The economics of increased investment in palliative care in Australia,* was commissioned with the assistance of The Snow Foundation by Palliative Care Australia and prepared by KPMG. It is available at: https://palliativecare.org.au/kpmg-palliativecare-economic-report