



Victorian Government

COVID-19 IMPACTS ON PALLIATIVE CARE

Palliative Care Victoria
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Executive Summary

Palliative Care Victoria in partnership with 12 other key organisations and members of the Victorian community welcomes the opportunity to submit to the Public Accounts and Estimates Committee (PAEC) on the Victorian Government's Management of the COVID-19 pandemic.

The COVID-19 pandemic has been a challenging time for people receiving palliative care, their carers and families, healthcare professionals across all work environments, those from a culturally and linguistically diverse background, and those who are grieving the loss of a loved one.

During a pandemic, life does not stop; other illnesses continue, and people continue to be born and to die. People continue to be diagnosed with life-limiting conditions and those who were undergoing active treatment for medical conditions find themselves in positions where the treatment is no longer of benefit.

This submission provides an opportunity to highlight the importance of person-centred palliative care and to provide opportunities based on this experience for government to better support palliative care for all Victorians, now, in the future and particularly in the event of future pandemics. A further wave of COVID-19 could re-emerge at any time and it is imperative that we learn from what has gone before in order to be better prepared in the future.

People living with disability and dying in the community had been hit the hardest in the pandemic

Community Palliative Care Consultant

The intention of this submission is to inform PAEC on 6 Key Matters

1. The Impacts of the Pandemic on Palliative Care in Victoria.
2. Impacts on Palliative Care Services and Health Professionals.
3. Impacts on Grief and Bereavement across the Victorian Community.
4. Looking to the Future.
5. Actions Taken by the Victorian Government in Relation to Palliative Care.
6. Recommendations.

To the many individuals who have shared the stories of their experiences as carers of loved ones with palliative care needs during the pandemic; Palliative Care Victoria thanks you wholeheartedly. Individual names have not been included to respect family privacy.

Services who have contributed to the submission:



About Palliative Care Victoria.

Palliative Care Victoria is the peak body for palliative care and end-of-life care. Established in 1981, we are an incorporated association and charity supported by the Victorian Government, individual and organisation members, other groups and funders. A founding and current member of Palliative Care Australia, we also contribute to national policies and initiatives in collaboration with the other state and territory palliative care peak bodies.

Our Vision

All people with a life-limiting illness and their families are supported to live, die and grieve well.

Our Mission

To achieve our vision through empowering leadership, capacity building and advocacy.

What is Palliative Care?

The World Health Organization defines it as follows:

- Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
- Palliative care:
 - provides relief from pain and other distressing symptoms
 - affirms life and regards dying as a normal process
 - intends neither to hasten nor postpone death
 - integrates the psychological and spiritual aspects of patient care
 - offers a support system to help patients live as actively as possible until death
 - offers a support system to help the family cope during the patients illness and in their own bereavement
 - uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
 - will enhance quality of life, and may also positively influence the course of illness
 - is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(World Health Organization. 2020)

Specialist palliative care services can support people with a life-threatening illness in these ways:

- direct care for people requiring specialist palliative care interventions
- shared care arrangements with other healthcare providers
- consultation and advice to other services and healthcare teams providing end-of-life care
- education and training on palliative care and end of life issues
- undertaking and disseminating research about caring for the dying and their families/carers

Palliative Care in Victoria.

The estimated population need for palliative care at the end of life is 75% of all deaths in Victoria, this estimate is based on ten conditions that are recognised as benefiting from palliative care including cancer, heart failure and Alzheimer’s disease. A conservative estimate indicates that 10,000 Victorians who die miss out on needed palliative care. Data suggests up to 80% of those who died in residential aged care and 63% of those who died in acute care may have missed out on palliative care.

These alarming figures demonstrate a deficit of access to care for Victorians which Palliative Care Victoria and the Government of Victoria have been striving to improve over recent years. Government estimates indicate an annual 4% growth in the need for palliative care.

The myriad of issues in the Aged Care Sector are well documented and the subject of a Royal Commission at present and whilst measures have begun to remedy shortfalls in care, to date no specific measures have addressed the palliative care requirements for this sector.

This report highlights how a sector under enormous strain has responded to a pandemic and worked tirelessly to meet the needs of dying Victorians.

1 The Impacts of the Pandemic on Palliative Care in Victoria.

1.1 Impacts on those receiving palliative care and their carers/families

Case Study – Jenny

Jenny was 48, married to Darren. They had a 15-year-old daughter and 12-year-old son. Jenny had been living well with metastatic breast cancer but over the last four months her body stopped responding to treatments and she developed significant symptoms. Her mobility was affected: she needed to walk with a wheelie frame, required an over-toilet chair and had to have support to shower, or to function. Her brain metastases caused seizures and she could not be left alone.

Darren was still working. While the community palliative care service was free, he had to keep working due to the high cost of treatments, medicines and supportive care requirements.

The kids also needed him. The effort of coping with home schooling and Jenny's care seemed overwhelming. The phone also kept ringing; as his work commitments increased, he barely slept.

Darren began to realise the care Jenny required was too much for him. He discussed options to have Jenny transferred to an in-patient palliative care unit. A direct admission was not possible due to the pandemic. She would stay in a COVID screening ward for at least 24 hours until she was screened as clear. Her shortness of breath and symptoms due to her cancer were similar to those of the virus; a COVID infection had to be ruled out. The family could not be with her. But Jenny's time was short; every minute was sacred. The in-patient unit was not an option.

Darren battled on. A community palliative care nurse came daily. They wished to come twice but they had many extra clients in similar situations. Community palliative care isn't funded for respite or general nursing. Darren was worried about access to respite care as an option – and the cost.

Jenny died peacefully in August with her children and husband by her side but the ongoing bereavement trauma of caring for her through this time remain with the family.

The impact that COVID-19 has had on patients and families with palliative care needs has been devastating. Options for care have been driven by people's desire to remain together and not have loved ones dying alone in institutions such as hospitals, residential aged care facilities and specialist palliative care units.

More patients and families have chosen home as the place for end-of-life care, leading to a cultural shock for much of society. Whilst some culturally diverse communities may be familiar with a person dying at home, many Victorians have not had experience of supporting normal home dying. Relatives

with no experience or knowledge of what a person needs at the end of their life were being challenged to witness and to be responsible for providing care for their dying loved ones; this had added to already heightened anxieties during care of the dying.

The reliance on carers to report distress for dying clients, and pain being used as the common language for any distress, has contributed to proportionally more reports of pain when there is no increase in the proportion of people dying with painful diseases (i.e. cancer) than before.

Caring for a person who is unwell is an incredibly difficult undertaking – it is much harder than anyone generally anticipates. There are several components of the challenges for carers irrespective of cultural or language background, ranging from watching a person that you care about deteriorate and ultimately die to the physical demands as that person deteriorates – not only in needing to care for them and assist them in their daily activities, but also picking up their role, and chores and all of the other responsibilities that may have been shared in the past. Add a global pandemic with lockdowns, job losses, home schooling and restricted visiting in hospital settings, and the stress on carers has increased exponentially.

Community Palliative Care Provider

Communities where languages other than English are spoken report even higher levels of stress in the absence of extended family support, unfamiliarity with health systems, distrust of impersonal hospital systems and poor in-language communication from health professionals.

Increased stress on the person who has the life-limiting condition has also been seen during the pandemic. Many ill people are very concerned about becoming a burden to their families and this increased emotional distress has increased the need for counselling support. For Aboriginal and Torres Strait Islander peoples and, cultural and gender diverse people, the lack of options for counselling support results in unmet care needs at end of life.

People who are ill and dying are also scared of catching the corona virus. Dying at home is a choice some people have made to avoid the risk of infection. The terror of COVID-19 has seen patients and families further isolated as they are wary about visiting local doctors, clinic appointments and hospitals and welcoming health professionals into their homes. Even family members who could offer support are deterred due to the fear of fines if they breach lockdown laws or if unaware of how they might be able to seek exemptions on compassionate grounds.

Joyce described herself as being trapped inside her home, not wanting to leave her sick husband in case he dies (she sleeps on a chair beside him) – their [adult] children live outside of the 5 km radius and are working from home and home schooling. She doesn't want to be a burden on them, when they have enough going on.

1.2 Hospital avoidance actions.

Ordinarily, a number of the people who are linked in with a community palliative care service will, at some stage, be admitted as an in-patient, to a specialised palliative care unit to relieve the emotional or physical demands on carers; to hospital for symptom management; or to a palliative care unit for end-of-life care. The number of clients accessing these options has been much lower throughout the pandemic with more and more people remaining at home for end-of-life care or at least staying at home for as long as possible. This has meant that some services have reported a higher number of clients remaining at home with much higher needs than usual: very ill people whose physical needs are more than their carers can cope with. In turn, this significantly increases the stress for carers.

While people with a life-limiting illness were often reluctant to go to hospital before the pandemic, they are now even more fearful. They fear contracting COVID-19. They fear being alone and dying alone, surrounded by people almost unrecognisable in gowns, gloves, face shields and masks. This avoidance of hospitals equates to many Victorians remaining at home, trying to self-manage complex needs and leading to a less-than-optimal quality of life. Lack of a support person to advocate for the patient adds to hospital avoidance by Aboriginal and Torres Islander peoples and, cultural and gender diverse people faced with a serious illness during the pandemic.

There are health consequences for ill people trying to remain in their homes for longer. One palliative care service reported that clients who are physically deteriorating had a direct impact on the number

I knew she was in pain. She wouldn't let me say anything because she was concerned then she wouldn't be allowed to come home. We got through that night, I tried to call Palliative Care who I'd previously been in touch with, so I'd already done that, but the waiting list had blown out to four weeks. But clearly, I needed help prior to then. Mum had been discharged home and I couldn't manage what was going on by myself. I tried to call Pall Care to escalate it on that Monday but didn't have any luck in getting through.

(Tracey, Daughter)

and types of referrals to the Occupational Therapist. The majority of referrals have been due to clients falling, carers lifting clients, clients no longer able to weight-bear and not having suitable equipment, and the development of pressure injuries. These are all issues that normally lead to hospital admissions. The complexity of the referrals to community palliative care services is consequently much higher.

1.3 Hospital restrictions on visitors

Case Study- Siblings aged 9 and 13.

Dad has been having chemotherapy for his Hodgkin's Lymphoma with the view to having his second stem cell transplant. Dad's cancer has been present for 10 years. Dad is required to be an inpatient for 3 weeks during his chemotherapy then he goes home for 10 days and returns to the hospital.

He has had very adverse side effects with his treatment and has had to go into ICU at times and has not looked like surviving.

During this time the children have not been able to visit him in hospital as there were restrictions on number of visitors and the number of hours they could be there for. Only two people (no children) were allowed for no more than 2 hours until last week, when the hospital went into lockdown.

The children's mum is not allowed to visit either at present; the whole family is distraught. During the hospitalisation of their dad, both young people have had birthdays and there has been no face-to-face contact. If the stem cell transplant goes ahead, the young people will not see their dad for months.

When a dying person does seek admission to hospital, there are further problems. They must have one, even two, negative COVID-19 tests before they can be accepted for admission, and must be isolated while they are waiting for the mandatory test results. If they are admitted through the emergency department, they are placed in isolation. During this time, whether they are at home or in hospital, they cannot have visitors. After admission, the number of visitors is severely restricted. Some families have to make very difficult decisions about which family members and friends will be able to see their loved ones at the end of life. Some hospitals have more relaxed rules for visiting if the person is known to be very close to death, but even in these hospitals, visits from children and the total number of visitors are still highly restricted. There has also been ambiguity around the definition of "end of life", which has resulted in inconsistent interpretation by some hospitals of the Chief Health Officer's visitor guidelines.

While we understand the need to limit visitors to help protect the health and safety of patients and staff, we are seeing strong evidence that the policies adopted by individual healthcare services over the stage 3 and stage 4 restrictions are more limiting than the guidelines recommended.

We are hearing many accounts from community members that visitor policies are not being implemented consistently, and, alarmingly, that some healthcare services have suspended visiting altogether.

Carers, families and friends are confused about where and how to find the guidelines that apply in individual healthcare services, because there is no single place where this information is made available, and guidelines can vary significantly even within the one institution. Information about the circumstances where visiting is allowed, the process for applying to visit, and how to escalate a request on compassionate grounds is not always clear. Additionally they do not adequately support people with poor health literacy or those who face additional communications challenges related to age, disability, language or cultural barriers.

Through the support helplines of Cancer Council 13 11 20, Breast Cancer Network Australia, Canteen, Palliative Care Victoria and many other patient advocacy groups, we are hearing numerous stories of severe distress caused by current visitor restrictions. From the beginning of the second lockdown until 12 September, an average of 24% of calls to 13 11 20 each week have been related to the impact of COVID-19, and a constant theme of the calls has been the anxiety and distress caused by visiting restrictions.

Canteen counsellors have been supporting young people who are scared, anxious and deeply upset that they cannot visit a dying parent or sibling. We believe immediate action is required to overturn blanket bans on young people visiting family members who are unwell.

People who are dying in hospital have been having fewer social interactions with the outside world as a result of the social distancing rules and lockdown restrictions. Their mental health is exacerbated by additional fear, anxiety and panic about the virus and concerns about their family members' wellbeing. People wish to die at home.

Families of loved ones nearing the end of life in hospitals and residential aged care facilities are angry and frustrated with the lack of consistent rules around visiting and not being able to be with their deteriorating family members. Not being able to have face-to-face and personal contact with family members is causing an enormous amount of distress and anguish.

1.4 Border and travel restrictions

John and Mary live in rural Victoria. They both have a life-limiting cancer diagnosis. John is currently in the terminal stages of his illness with Mary as his main carer. Whilst they have community palliative care support, Mary is very distressed that their two sons, one in South Australia and one in Western Australia, cannot visit and say goodbye to their father without significant risks that they may not get permission to go home again. This would impact on their family and work lives for an indefinite amount of time. In the case of the son living in Western Australia there would also be a significant hotel bill for quarantine. John and Mary don't want to be a burden on their sons but are grieving their ability to say goodbye as a family.

International travel restrictions have prevented people with life-limiting illness from returning to their home country to die and this has caused emotional distress for them and for their families. This distress is compounded by the increased sense of isolation as family members cannot travel from overseas to support the family and say their final goodbyes.

Travel restrictions within Australia have had a huge impact on people who are dying and their carers, where they have had to limit visitors and supports to their home. Families cannot visit whenever necessary. Some family members have sought permission to travel to support a client and carer if they lived in regional Victoria. Some have obtained a letter from their doctor so that they can visit. Other family members have risked fines and ignored the travel restriction to provide necessary care and support. Some severely ill people and carers have remained very isolated with their only visitors being specialist palliative care staff. This again highlights the inconsistent approach to the application of lockdown and visiting rules.

Bill and Hilda live in metropolitan Melbourne; their three children live 50 km away in rural Victoria. Current restrictions mean that they are unable to provide care for Mum and Dad. Bill has end-stage dementia and is often awake and agitated for long periods of time. Hilda is exhausted but unwilling to admit Bill for respite care for fear he will catch the virus and she won't be able to visit him. They have been married for 57 years. Their three children are extremely distressed that they cannot offer support or relocate Mum and Dad closer to them.

1.5 Culturally and linguistically diverse community experiences

Brian had been in hospital for 8 weeks. During this time, Alice had been unable to visit due to COVID-19 visiting restrictions. Alice decided to bring Brian home (she would not normally have done this). Brian and Alice's preference had been for Brian to die in hospital but the lack of ability to visit forced this decision. Brian had complex care needs, physical and psychological, during the 5 weeks that he lived at home. Alice found Brian's care confronting and she struggled on a daily basis. Culturally in their country of origin people die in hospital and medical staff look after the body for a number of days before moving it. Alice could not keep Brian's body at home over night, and he was removed. Alice is now experiencing a distressing bereavement period as her cultural expectations were not met.

Our feedback shows that those with low health literacy or English as a second language have many issues that are unresolved. We are also concerned by community feedback that current restrictions do not adequately address cultural needs around caring for the dying, including for Aboriginal and Torres Strait Islander peoples. We hope that the new directive in Hospital Visiting Directions (no. 12) to extend the number of visitors for those dying beyond immediate family members to include people with kinship ties who may not be blood relatives, meets some of the concerns raised by our Indigenous communities and community support agencies.

Carers in diverse communities have an increased burden. Support services, such as in-home carer respite, social support and others that are mainly provided by volunteers, for carers who are not fluent in English have been limited. Carers are concerned about the infection risk from home and personal care support services provided to their dying loved one, with some carers deciding to undertake the care by themselves. Support from friends and communities has also been reduced due to the lockdown restrictions, and connecting remotely to health professionals has been challenging. Consequently, the level of carer' distress has increased, along with increased workload due to the pandemic.

The situation has been extremely challenging for older carers with limited digital knowledge and skills. We have also had reports from carers and family members about the challenges of receiving remote support from a health professional via a telephone. Many members of the older population have limited or no English language skills and the visiting restrictions further add to the isolation of the dying person or their carer, without family members on hand to translate.

Achieving cultural expectations in the rituals of death and dying have been increasingly challenged during the pandemic-forced lockdown changes.

A family's grief in the last days of a loved one has been often been compounded by communication difficulties especially when family members are dealing with institutions like hospitals and aged care facilities. In addition to the inability to be with the dying person, the general media interest and adverse publicity, sometimes revealing traumatic experiences, around the hundreds of COVID-19 deaths in aged care facilities, has made it nearly impossible for families to do what is culturally appropriate for their loved one.

2 Impacts on Palliative Care Services and Health Professionals

Case study: Tracy, daughter of pancreatic cancer patient

72-year-old wife, mother and grandmother, Harma, was diagnosed with stage 4 pancreatic cancer in January this year. Harma's cancer diagnosis, treatment and end of life was endured during the COVID-19 pandemic, which impacted many treatment and care decisions Harma and her family made.

"Even as in immunocompromised patient, she was regularly held in wards with other patients awaiting COVID results," said Tracy. "So, you've got an immunocompromised patient sitting on a ward with three other people in the room waiting for COVID swabs. They're all being swabbed because they're showing signs of having coronavirus."

Due to this experience, towards the end, she avoided going to emergency wherever possible.

"She knew if she went to ED it would mean that she would have no support system," Tracy said. "Again, it meant that she would end up with more COVID swabs. It meant that she would end up on a ward awaiting results, where she was potentially at risk of coronavirus again. And she wouldn't go there."

The family's access to hospital was severely limited with restrictions and communication with hospital staff was inconsistent and at times non-existent.

Despite, never expecting to palliate at home, in the end the family chose to keep Harma at home. But Palliative care services were stretched and there was a four-week waiting period.

"She was discharged home on a Sunday night," Tracy said. "She was discharged home with no support services in place. Having had a lot of pain issues within the hospital environment, she was discharged to me with nothing in place. Nothing. No directive as to how to manage her pain, no directive as to the impact on basic things like her blood sugars. At that point in time she was hardly eating anything.

"Mum had been discharged home and I couldn't manage what was going on by myself. I tried to call Pall Care to escalate it on that Monday but didn't have any luck in getting through.

They came out on the Thursday to assist Harma, but sadly Tracy lost her mum on the Friday after that.

"I'm sorry that mum had to go through it," said Tracy. "It was really traumatic. Even though she didn't have the virus, she was a victim of it. She won't be counted in those statistics because obviously she didn't have the virus, but she was a victim of the impact that this virus has had on treatment for people that have got things like terminal illnesses.

"I can't get back now that time with Mum."

Specialist community palliative care is provided to people who are diagnosed with a life-limiting illness with symptoms best managed by a specialist service.

As noted in the previous section, many more people are choosing to die at home. There have been consistent reports across the community specialist palliative care services in Victoria of exponential increases in service referrals since March 2020. The impact of the virus has been broad, far reaching and overall very concerning for any death (not only for those dying with COVID-19).

One community palliative care service reported:

- a 59% increase in calls to triage services, 367 in March 2020 compared to 220 in the same period in 2018/19
- in July and August calls reached between 300 and 350 per month
- the number of overnight nursing visits doubled from an average of 27 to 52 in March
- nurses visits overnight increased to 37(July) and 44 (August)
- the length of visits to clients also extended with nurses reporting that visits were taking 1–1½ hours (normal visit times are 45 minutes to 1 hour)
- nursing visits decreased to 4 per day where staffing allowed (pre-COVID-19 it was 5 nursing visits per day).

The service's duties were not restricted to clinical care alone: in the initial months of the pandemic they were also receiving calls from clients asking if the service could supply foods and groceries as clients and carers did not want to expose themselves to the risk of getting COVID-19 in a public place. With the increase in home deliveries this is no longer being reported as an issue but at the time this added to the stress of those being cared for and those caring for someone at home.

It now takes at least several sets of personal protective equipment – masks and gloves, even gowns and face shields – and often more staff (and cars) to deliver the same care safely. Some services reinvented everything to protect care delivery.

Community palliative care teams have been greatly affected by the pandemic: the type of work they are doing has needed to change; the way they are doing their work has changed; the practices and procedures have altered; training and education has had to respond; and hours have been extended. It will be important to evaluate how this has affected health care workers, including both emotional and moral distress.

2.1 Increasing complex community patients

The growing number of complex patients who are choosing to die at home are significantly increasing the need for services. Because people are so unwell, even though the nurse's preference is to limit the time in the houses, due to infection risk, this was not possible as more work needed to be done during each visit.

Across community support organisations, there are concerns that dying peacefully is not the case for many people now. Resources are limited and case numbers high. Data provided by Palliative Care South East, a service in the south-east metropolitan region of Melbourne, shows that, since the pandemic began, demand has increased by 61%, which has been met without additional funding.

In our experience, Covid-19 has seen a significant increase in people staying in their home, and an increase in the stress they experience as a result of this. The restrictions around hospital admissions has seen fewer people opting for hospital care and has removed the option for respite. To a large degree, the pandemic has removed people's choices. Carers fear losing their loved one in hospital and not being there. They also have guilt – many have spoken about feeling guilty about seeking respite or hospitalisation. Patients have been much sicker at home, significantly increasing the need for our services, and increasing the demands on carers – during lockdown the pressure increased as family members who would in normal times, help out, have often been unable to assist in the same way, due to the restrictions on visitors in homes, travel zones and curfews. With intensive and extensive support and guidance though it is difficult, people are doing things they would not have thought they could for people they love.

Community Palliative Care Provider

We are hearing from community palliative care providers that teams are worried about their inability to do more for families, to remove some of the challenges that 24/7 care brings and meet the gaps that are created by providing only specialist palliative care, not general and supportive care.

Jenny's condition deteriorated, and her needs increased. At night, she required at least two-hourly re-positioning. She became incontinent. Her wounds needed regular attention: fluid seeped through her skin, a complication of her condition. The sheets needed changing four times a day; just washing and drying them was so hard. Darren [her husband] provided all Jenny's care with help from their teenagers and some close friends.

It is distressing to hear stories from families who are being denied the opportunity to focus on the moments that matter, while they cope with direct care, or families separated from their loved ones who feel a sense of helplessness and despair that they cannot support them or say their goodbyes in the way they had planned.

2.2 Changes in models of care delivery

Different services have adopted different models of care throughout the pandemic, so the support that people have received has varied, literally based on their postcode. Some services have continued face-to-face care, while others have transitioned mostly to telephone support with visits restricted to people in their final days or with severe symptoms.

In the face of adversity, specialist palliative care teams have continued to deliver above and beyond expectations to ensure that those dying at home, and their carers, are as supported as well as possible within COVID-19 limitations. It is a testament to their professionalism and dedication to their community. But this level of effort has now been sustained for more than six months and staff fatigue is beginning to become evident. Service leaders become increasingly challenged to balance service delivery and staff well-being. A further surge of COVID-19 would severely test clinicians and palliative care services.

We list some of the exemplary care examples below but acknowledge many providers have worked tirelessly to support the increase in service demand during the COVID19 pandemic

Banksia Palliative Care Service have continued to carefully deliver face-to-face care and support in people's homes and adapt to the greater-than-20% increase in client numbers – a feat achieved without any additional funding or resources. Implementation required reviewing every process connected with service delivery and general operations, with the executive officer supporting appropriate changes to keep the team, their families, the clients and their families, safe and well.

Eastern Palliative Care Association Incorporated (EPC) has achieved a 76% death in place of choice over the past 4 years. This is despite the fact that, EPC has achieved an average of 63% of people on their program dying at home. Over the previous two pre-COVID years, this figure was 48%. Since COVID, in some weeks they achieved up to 83% of people dying at home.

Staff have been inspiring – though they have all been touched in some way personally by the pandemic (whether through partners losing jobs, home schooling, separation from parents and loved ones, inability to attend normal activities such as gym, dinner, etc.), they have not let one person go without care – they have been incredibly brave (and done so under the radar as far as any recognition for the work they do).

There has been huge change in daily processes, requiring a great deal of adaption and flexibility. Using PPE for every interaction has been mandated; extensive training in relation to donning and doffing has been needed; strict systems in place for COVID positive clients and every general daily routine and action has been scrutinised and changed – unsettling. Staff emotional and physical health, wellbeing and safety has been primary priority. Daily management meetings to review EVERY aspect of work and processes have been imperative in ensuring management are fully informed and following DHHS guidelines and recommendations. The staff are the heroes – they have been patient, adhered to all processes and been incredibly diligent in protecting themselves and others.

Specialist Community Palliative Care Executive Officer

2.3 Financial impacts for community palliative care services

A range of financial impacts for community palliative care services has been evident during the pandemic.

Palliative care staff are spending more time visiting people who need greater care due to the pandemic. This has obvious financial consequences. More staff are needed, not just due to the increase in demand for services but to an increase in personal leave. Some staff or their family members who have had symptoms needed to be absent while waiting for test results, a wait of up to 4 days. More calls at night have not only resulted in the payment of call-out entitlements but also staff absence due to the “10 hours break” required after a call-out. Any increase in wages is a major impost for service providers.

General operational costs, such as petrol and utilities, have increased, due to more visits, and longer hours in the office. Then there is the cost of personal protective equipment, with organisations having to buy additional supplies. There have been increased equipment costs, as clients have needed more dressings, more syringes, and even more massage oil.

There have also been dying people and their families who are in financial stress, requiring financial support from community organisations to help pay for necessary equipment to ease their final days.

Finally, for those services that rely on donations, there is a noticeable decrease in donations. Job losses and general insecurities indicate that people feel insecure about their financial situation.

2.4 Reduced stays in acute specialist palliative care services

As patients and their families strive to remain at home, if the care becomes too complex and the symptoms too challenging to manage at home, admission to a specialist palliative care unit is still an option in Victoria. While it is not unusual for the place of care to change as the end-of-life care realities begin to hit those caring for someone at home, services are reporting that it is taking much longer for the decision to be made. There has been a marked reduction in the length of stay in specialist palliative care units for end-of-life care: decreasing from 10 days before the pandemic to the current average of 4 days. This change puts increased pressure on the in-patient specialist palliative care team who have a limited time to facilitate a peaceful and dignified end-of-life experience for the patient and their family.

For some people who have been admitted to hospital, and then discharged home linked in with a community palliative care organisation, their discharges have been rushed as the patient, their family and hospital staff push for discharge as soon as possible. This has meant that comprehensive assessments to enable effective discharge planning have not always been completed during the lockdown period, resulting in the patient returning home without being properly set up. The community organisation has been required to “pick up the pieces” – to arrange increased services or the necessary equipment, and complete carer education that would normally be completed while the dying person was in hospital.

2.5 Moral distress of clinicians

The inconsistency of approach by organisations in applying visiting restrictions has also caused considerable concern for palliative care health professionals who are striving to deliver care within the palliative care philosophy, while adhering to organisational rules, working long hours with depleted resources and an increasingly complex case load of patients. The emotional distress has been felt across community and hospital palliative care teams, and moral distress has also been experienced when clinicians feel their care is ‘not good enough’.

2.6 Palliative care – bridging the residential aged care facility (RACF) gap

Specialist palliative care teams are specialists in alleviating suffering at the end of life, including symptoms such as dyspnoea, cough, fever and shortness of breath that affect COVID-19 patients. They are trained to manage complications that may affect COVID-19 patients at the end of life. They are trained to provide holistic support to the dying person and their family. They are trained to break bad news compassionately. They are trained to support general healthcare teams to provide generalist palliative care. In Victoria, they have been instrumental in the support and management of COVID outbreaks in residential aged care facilities. But it should be recognised that this was not a systematic approach. Funding and resources did not flow to support this additional activity. Practitioners driven by their duty of care advocated for the opening of acute beds and the transfer of patients, in addition to triaging and coordinating movement of residents until Commonwealth Government support arrived.

Vulnerable people from RACF have also been referred to community palliative care services where a family member has decided to remove a loved one from the aged care facility due to fears around their family member contracting COVID-19. These families are looking for support to care for very frail and disabled people.

Community and hospital specialist palliative care services have highlighted a range of increased service demands from residential aged care facilities. In some parts of Victoria there have been pre-existing relationships between residential aged care facilities and palliative care teams; in others this relationship is non-existent.

During June, July, August and September, many of these RACFs [aged care facilities] have had multiple cases of COVID-19 infections, resulting in many untimely and COVID-19 related deaths – including in our region 3 ACFs which are in the top 10 numbers of cases in Melbourne (St Basil’s, in Fawkner with 44 deaths, Twin Parks in Reservoir with 20 deaths and Japara Goonawarra in Sunbury with 17 deaths). (Service 1)

Over the last 6 weeks, due to our close relationships with many of these RACFs, and also with partnerships with many of the hospital inpatient, in reach and rapid response teams, we have been called to respond to this influx of aged care COVID-19 related deaths and the bereaved families. (Service 2)

[Our service] has received 45 aged care referrals in the past 6 weeks for patients who have COVID-19. This is a clear increase in referral numbers and this is expected for weeks into the future – as management of ACFs develop relationship with Melbourne City Mission Palliative Care and are informed about subsequent deaths, and backtrack deaths that have already occurred. Twelve of these referrals were referred for support in the terminal or deteriorating phase of individuals in ACFs who are COVID positive, and 33 were referred due to the complex circumstances associated with the COVID-19 death and concerns about the grieving family. The majority of these referrals have come from staff at three main ACF s who have over time, established very close relationships with our team. It is likely that other ACFs that work closely with MCMPC will also request follow up bereavement support. We have 5 allied care staff sharing the workload at present, to make condolence calls and send out information and cards. (Service 3)

2.7 Impacts on aged care

The experience of Covid-19 in the residential care sector in Victoria has highlighted the pre-existing fault lines that exist between the state and federally funded health programs. The bridge over that divide has always been the community-based palliative care providers and the residential in-reach teams. Due to the catastrophic size of the outbreaks in residential aged care facilities in Victoria, that divide appeared to be an ever-widening chasm.

Lessons need to be learned to assist us in moving forward and developing an aged care sector that is “fit for purpose”. Significant federal reform and funding will need to occur to establish the baseline for minimum standards of care, diversity needs, staffing, and improved transparency. Confidence in the sector’s ability to do what it is funded for will be necessary to ensure there is a robust and highly functioning sector that provides the best care to our frail elders, including support as the person approaches the end of their life and dies. State-based health systems also need to look at engaging with and developing a better understanding of the aged population, the variety, language and culturally appropriate care needs of people living within aged care services, and the sector capacity to provide this care. Appropriate services can then be rationalised and developed to provide better access for this population. Removal of duplicated services, appropriate funding and resourcing of the support services

should see an improvement in avoided hospital admissions, care provided in the most appropriate place and significantly better outcomes for our elders and their support systems.

In the short term, there also needs to be a significant investment in supporting the mental health needs of staff, residents and families to recover from the tragic effects of this virus. At present in Victoria there are very few grief counselling services in language for CALD communities. Families have been unable to grieve or have had their bereavement seized by the associated anger. Their inability to care for or be present at the time of illness or death of their beloved family member will have significant ongoing impacts for people personally, and for the sector. Residents who survived this pandemic may have lost entire friendship groups or be traumatised by the lockdown experience resulting in significant functional, psychological or cognitive decline that is unrecoverable. Staff who worked throughout this pandemic may reconsider their employment in residential aged care, particularly when the sector is so heavily reliant on a poorly paid, ethnically diverse, casual workforce. Retaining and attracting appropriate numbers of skilled staff will be an ongoing challenge.

Long-standing challenges for the sector have been highlighted including access to:

- an appropriately trained and skilled medical response outside usual business hours
- medication “imprest” systems onsite to avoid the delay of appropriate medication
- timely and relevant response of support services
- aged care-specific guidance and advice including care and treatment protocols and prescribing guides.

While it is easy to focus on the limitations of the sector’s response, it is also critical to acknowledge that a significant number of facilities were able to control facility outbreaks and limit the spread of this virus. In addition some creative and welcomed innovation saw staff going to incredible lengths to keep residents socially connected with their friendship groups, families and the wider community (Appendix C)

We need, as a palliative care sector, to objectively critique our performance and identify areas for improvement and celebrate the successes and innovation from this experience.

2.7.1 Impact of COVID-19 deaths and bereavement issues for the aged care sector

The referring staff at residential aged care facilities have expressed their deep concerns about these lonely deaths during the pandemic, which they felt have been difficult, traumatic, and complex for the families involved. The majority of aged care facilities that we have contacted have been unable to offer follow-up bereavement support to those families. They are aware that in such circumstances these families are at risk of complex grief symptoms. The families are dealing with high amounts of anger, guilt, regret and isolation over their loved ones who have been dying of COVID 19 in aged care facilities or inpatient units. Staff at residential aged care facilities are not skilled or trained in managing some of these complex bereavement issues and have been keen for the community specialist palliative care team to offer this bereavement support.

Many staff at the facilities have been furloughed, are on sick leave or are temporarily employed to cover shortages, and management and organisation at these premises have been disrupted and outsourced at various times. Instability in staffing and management means familiarity and routine family support and communication have been further affected and reduced.

Families are angry, distrustful and frustrated by the situation – intense reactions that are directed at many sectors, including the residential aged care facilities themselves, the Department of Health and Human Services, the government and the media. Staff at the residential aged care facilities are unable to adequately respond to the needs of these bereaved families.

3 Impacts on Grief and Bereavement across the Victorian community

Case study Jess aged 12 (real name not used)

Jess is being supported by a Canteen counsellor and has a very unwell mum in her palliative care stages. Jess's mother is the sole carer for Jess and her two brothers but is in and out of hospital due to her cancer spreading rapidly around her body.

Recently the family received news the cancer had spread to her brain. Jess is no longer able to attend appointments with her mother due to COVID restrictions. Jess explained to Canteen that she has not been able to sleep recently and has been having panic attacks, worrying that her mum will soon die in hospital where she cannot be with her.

Jess is very aware that her mother doesn't have long left and that it's likely she won't be here in a few months. The family has done a lot of anticipatory grief work and preparation for her death. Much of the current therapy sessions Canteen are supporting Jess with, are focused around anxiety at not being able to spend the final moment with her mum. This is taking away from the vital work in spending quality time together as a family in these final moments.

There is a need for enhanced bereavement support for families whose end-of-life experience has been less than ideal because of the pandemic. Not all Victorian health services offer bereavement support. Those that do, are generic and not always tailored to meet specific needs of faith, culture, language and gender diverse groups. Visiting restrictions and changes to the way palliative care services are being delivered currently mean that many families have not had usual access to the available support.

Our last meeting was in February and since then we have some recently bereaved carers/ family members who have been struggling to cope without strong local connections. I have kept in contact via phone and sent out a letter during this time, but I am concerned about the well-being of many in our group. The majority don't have the capacity or skill to engage via online platforms so are left without any support.

Regional bereavement walking group leader

Additionally, restrictions on numbers at gatherings and funerals, combined with travel limitations, have seen many families unable to grieve and support each other in a ways that are socially and culturally meaningful. In usual circumstances, many families find out about and are referred to bereavement services by incidental contact with clinical staff while they are visiting their loved one. As visiting cannot now happen in the usual way, there is a need for bereavement services to be offered in alternative modes, across usual service borders and considered in the broader mental health response.

Funerals, support and the rituals associated with farewelling, mourning and bereavement have all been negatively affected – from visiting the deceased and viewings, the number of people attending services and the numbers of relatives, friends and community services supporting the bereaved.

The carers and bereaved are disenfranchised from normal caring roles, normal health support, farewelling the dying, cultural and religious practices and rituals, funerals and memorials, and bereavement support. Bereaved people are at heightened risk of complex grief symptoms due to the presence and impact of COVID-19.

Lack of access to effective and timely bereavement support needs to be addressed without delay. There is a need for an effective system solution to manage the complicated grief from COVID-19 deaths that is already out there and prevent further complicated grief into the future. This should include staff able to provide culturally appropriate bereavement support.

Some family members with limited English skills are finding it hard to prepare and arrange a funeral because of the restrictions of the pandemic. Several family members are feeling distress for not being with their love one at the time of their death and not being able to hold a desirable funeral. Some have been experiencing overwhelming grief because of being unable to visit the cemetery. The bereaved have also been having comparatively less emotional and social support from their friends and the community because of the pandemic.

4 Looking to the future

4.1 Impact on potential increased palliative care service requirements

The Victorian Cancer Registry reported a 13% decline in cancer pathology notifications from March to the end of July compared to last year, which heralds the real possibility of a significant increase in late presentation of cancer diagnosis, and a potential increase in demand on palliative care services. It is vital that post-pandemic planning deals with gaps in workforce and service delivery to address additional demands that could leave to inequities across health services and regions in accessing palliative care.

4.2 Potential Impact on future palliative care volunteer programs

Community Palliative Care Services, hospitals and hospices usually have trained palliative care volunteers. The main role of volunteers is face-to-face patient and family/carer support. They visit patients in hospital, hospices and at home and provide respite for carer.

The majority of palliative care volunteers are in the age group of 65plus and therefore in a higher risk category for COVID-19.

The past death of a loved one is for many people the main reason to volunteer in palliative care. They live by themselves and are often feeling lonely. Volunteering gives them a purpose and provides them with social interaction.

All programs which offered face-to-face interaction/visits between volunteers and patients were ceased based on risk assessments to protect patients, their families and the volunteers.

Unfortunately, volunteers are not covered by insurance. VMIA Insurance has released a fact sheet confirming that their Medical Indemnity Policy Does not cover the transmission of a contagious disease by an insured person or virus carried by the insured person, who at the time knew or ought reasonably to have known that the disease or virus was being carried. <https://www.volunteeringvictoria.org.au/wp-content/uploads/2020/04/VMIA-Insurance-Responses-to-COVID-19-Community-Services-Organisations.pdf>

With no protection through insurance and without a vaccine it's highly unlikely that face-to-face volunteer programs can resume in the near future. This has a huge impact on the volunteers and their mental wellbeing, and on the patients and their families.

Some services could adapt parts of their programs. Volunteer Coordinators were creative and adjusted programs and policies and procedures. Volunteers received training in how to connect with patients through phone calls, emails, or video calls.

Some biography programs could continue when the patient felt comfortable to tell the volunteer their life story over the phone or video call.

Some Volunteer Coordinators implemented "pen pal" programs. Volunteers are writing handwritten letters to patients and receiving a response back.

Due to the strict physical distancing regulations to slow down disease transmission with Palliative Care patients it has meant Palliative Care Volunteers have not been volunteering face to face.

The programs that volunteers assist in have been placed on hold, these are Day Respite, Bereavement Walking Group, Hospice, In-home Volunteer Support, Administration support, Biography program and Bereavement phone calls. The programs on hold has meant that the volunteers are unable to provide the usual volunteer face to face support to patients and their families/carers.

The Palliative Care Volunteers ceased volunteering in March 2020 until further notice. Since this time Volunteer Services have reviewed the Palliative Care Volunteering program and potential plans during the pandemic looking at the possibility of a remote service such as Volunteer Telephone Support Service and zoom chats.

The pandemic has many challenges with providing volunteer support at this stage. By facilitating volunteers remotely to volunteer from home could be one way for volunteers to continue to support some of the palliative care programs.

5 Actions taken by the Victorian Government in relation to palliative care

In May 2020, the Victorian Palliative Care Advice Service (Advice Service) commenced a staged implementation throughout Victoria. The nurses and doctors of the Advice Service offer specialist guidance and advice to people living with a life-limiting illness and those who support them. It is for family, friends and neighbours as well as all healthcare workers.

The Advice Service provides information about serious illness and symptoms, being a carer and the palliative care service system. For healthcare workers such as general practitioners and community nurses, it offers guidance about prescribing, symptom management and decision-making.

Parkville Integrated Palliative Care Service at Melbourne Health run this phone-based service 7am – 10pm, seven days a week. The Advice Service is free, safe and available for everyone.

COVID-19 has made Victorians change not only the way they live but also the way they access health care. There has been a greater demand on community healthcare providers, who themselves have had limited access to their usual supports. In its first months of operation the Advice Service has guided general practitioners and paramedics in making decisions around end-of-life care, helped members of the general public to access their local palliative care providers and supported staff in residential aged care.

During and after COVID-19 the Advice Service will help ensure that everyone in Victoria can access specialist advice and support about life-limiting illness.

Esther McMillan-Drendel, Nurse Unit Manager, Palliative Care Advice Service

In May 2020 the Victorian Government provided a \$2.4 million COVID-19 grant to community palliative care providers (hospitals, community health services and non-government organisations). This funding was to support services to provide additional care and supports clients/families to meet the costs of equipment, medications and other support services throughout the pandemic.

To help support services to provide access to palliative care services and enhance continuity of care the Victorian Government has also provided financial support to the sector to either establish telehealth infrastructure or build on telehealth capacity to support and enhance continuity of care. This enabled hospitals to provide support to community providers and aged care facilities to support people at home through provision of clinical consults, assessments and advice. In some cases this has enabled clients to remain at home and not forgo clinic appointments or access medical consults to address new symptoms,

6 Recommendations.

1. A compassionate response to visiting arrangements for dying people and those receiving palliative care.

While Palliative Care Victoria and its member organisations understand and support that measures need to be taken to protect individuals from COVID-19 infection, there needs to be a balance between the needs of patients and protection of the community. We require a compassionate and ethically proportionate response to the visiting arrangements for dying patients and those receiving palliative care. Such a response needs to be tailored to diverse language, culture and gender needs of CALD and First Nations Peoples. Guidance for visiting has been developed by the Australian and New Zealand Society of Palliative Medicine, and ethics guidance has been developed by a collaboration of Melbourne Ethicists.

2. Coordinated communication of information and support available at each healthcare.

A central, well-promoted information and support contact number at each healthcare service should be available in English and multi-lingual formats to suit diverse needs of CALD and First Nations Peoples. Where families can raise concerns with a supportive care health professional around the impact of visitor restrictions for people with serious or progressing illness, including end-of-life care.

3. Increased funding for community palliative care services.

Increased funding is needed to ensure people can access timely and adequate community palliative care services, together with a comprehensive set of practical and supportive care services and case management support. This is needed to enable people to be safely cared for at home and for families to receive the bereavement support they may need.

4. Increased investment in bereavement support across Victoria.

Increased investment is required to ensure that all bereaved individuals regardless of spiritual and cultural backgrounds are able to access the support needed to manage after the death of a loved one. Nominated centralised bereavement triage, advice and referral service to ensure access and consistent approach for COVID-19-specific bereavement support which is diversity focussed and locally available.

5. Investment in new models of care.

Explore opportunities such as targeted incentives for GP engagement that have been demonstrated to be of benefit in some community specialist palliative care services. Explore new models in partnership with community members.

6. System agreed decision-making for residential aged care facilities in the event of a new pandemic wave.

It is essential that future outbreaks of COVID-19 or any other infectious disease is managed quickly and effectively to minimise the harms to palliative and dying people, and their families. Shared decision making is needed between State and Commonwealth Governments, and those engaged on the front line of care. The system needs to be transparent and able to activate and escalate the system response in a timely manner to: effectively manage an outbreak; reassure residents and families; secure community trust; and achieve optimal care for those affected.

7. Residential aged care facilities to be provided with substantial support to recover from the impact of COVID-19

A system approach to implementing the Palliative Care Australia 8 key recommendations in the Pallia8 program (Appendix F), to ensure that palliative care is core business for aged care. This will require collaboration and co-ordination between State and Commonwealth Governments.

8. Ensure Palliative Care is included in the whole-of-government planning, preparedness and response to a pandemic health emergency.

Include palliative care specialist teams in future planning across portfolios, to map the patient journey. This includes: considering the cultural/language diversity of the dying person; the changing needs of the dying person and their loved ones at each stage of the illness; and the training required for generalist health professional to 'break bad news compassionately', discuss ceilings of care, understand the palliative supports they can provide, and practise self-care.

Appendices

A. Complex bereavement arising out of COVID-19 ACF deaths – Stories from families

Overall families who receive a condolence and assessment call by Melbourne City Mission Palliative Care staff, after a COVID-19 death at an aged care facility, express relief and gratitude at being contacted and cared about. They are glad that the call was made, not concerned as to who our service was (we explain the aged care facility has asked us to ring), and readily taking the opportunity to debrief and review their caring experience, their distress about the illness and death of their loved ones, and their coping with the initial phases of bereavement that have been restricted and impacted by COVID issues. Many families have been very concerned about individual staff at the aged care facility, who may also be sick from COVID, or are unable to be contacted – they show empathy and concern for the situation at the facilities and often say /“everyone was trying their best” when speaking about the staff caring for their loved ones, who have often been involved for years with these families. These relationships have been cut off, and families feel isolated from the aged care facilities due to restrictions that have been in place for so long.

The complexities of dying from COVID-19 mean that families are experiencing what should be a natural part of life as chaotic, undignified and out of control. Families are expressing “it shouldn’t have been this way”. The whole process has been disturbing for them. One family simply said “it’s all been very ugly”. From the start of restrictions on visiting to the spread of virus in aged care facilities, to further restrictions on contact, to their aged care facilities being implicated, their loved ones being at risk then subsequently exposed and testing positive, to facing staff changes and communication difficulties, media exposure, and added community outrage, to uncertain illness trajectories, concern over adequate health care, movement of loved ones to inpatient hospitals, to decline and then the death of their loved ones who are often alone without loved ones present for comfort, then not having follow-up condolence support and guidance about ongoing bereavement assistance – many families have had months of anxiety and strain, and their bereavement is equally complex, isolated and not well supported.

Deep sadness for the impact on our aged population is prominent. One daughter who had known many residents who had died said “they passed away from broken hearts” because they weren’t able to see their relatives and had declined as a result from the isolation and disruption. Her grief extends beyond the death of her own mother, to holding broader grief for the other residents. She lamented the apparent lack of value of our ageing citizens, saying “we’re living in terrible times” when our aged care facilities are so poorly supported and so heavily bearing the brunt of the COVID impact.

Families have often expressed anger, frustration, confusion and a feeling of being let down by the whole system. Blame is placed on broad factors – from the aged care facilities, Department of Health and Human Services, and the government policies, to community members who have spread the virus and a lack of communication and information. Frustration has been directed at the inability for them to visit and support their loved ones or be involved in the dying phase and get information when they needed it.

Some bereaved people have had traumatic incidents and are experiencing complicated grief reactions as a result. Not being present as mothers, fathers, wives and husbands take final breaths, imagining the isolation and anxiety of their loved ones, particularly when suffering and dying in unfamiliar environments and away from known staff, having gaps in communication at critical and extended times, having been separated for months, with many of the elderly suffering dementia and confusion – these circumstances can add to already heightened anxiety, stress and grief.

Most of the families have experienced heightened anxiety and stress – beyond that with any other death and bereavement. Organising visits, care, funerals, picking up possessions, finalising associated paperwork have been extremely strained and restricted. They have also expressed heightened worries about virus exposure (one family had an elderly grandfather die of COVID and the husband currently COVID positive – very anxious about the disease and the risk of a similar death); feeling judged by media and the community (the insincerity of politicians who seemed to imply aged COVID deaths were of lesser value); and have come up against uninformed opinions and difficult communications where they have to repeat and explain complex emotional situations to multiple parties. Many have been financially impacted and extremely isolated by general COVID restrictions which have added to the bereavement issues.

Overall the experiences of staff at MCMPC have highlighted a deep concern regarding this crisis that exists in our community at present. The result of the high numbers of our ageing population from aged care facilities dying of COVID-19 is that there are multiple family members and friends for each of these individuals who are experiencing complicated bereavement and are at risk of ongoing serious mental health concerns in the future.

B. Example of a real situation from a community service provider

A client was admitted to our program with metastatic advanced ovarian cancer. This client was well supported at home by her loving family, three daughters, two son-in-laws and her elderly husband of 52 years with early stage Alzheimer's disease. Our client was the main carer for her husband.

One of the client's daughters contracted COVID-19 at her workplace (a healthcare facility). While unaware of her infectious status, the daughter visited her parents to render care and assistance. This daughter inadvertently passed on the virus to all family members. Initially the family were unwell and unable to continue to provide the care required, so EPC facilitated admission of the client to a private hospital. Unknowingly, EPC staff were exposed to the family members during their infectious period.

This resulted in two staff having to self-isolate at home for two weeks. It was fortunate that EPC staff were wearing masks and practised excellent hand hygiene and social distancing in the home environs. Neither of the furloughed staff contracted COVID-19, their absence however impacted on our ability to manage the roster and care of other clients and casual staff had to be organised to cover the gaps.

After two weeks in hospital, the client was discharged home to the care of EPC and was COVID-19 positive at this time. The client was stable and was therefore managed initially via telehealth. This family required intensive psychosocial support during this time and also required EPC to liaise on their behalf with the public health team of the Department of Health and Human Services. There were communication difficulties and trying to ascertain ongoing COVID-19 status of the household was challenging. The client then deteriorated and became unstable, so EPC staff attended the home in full PPE to provide the care required. This limited our ability to provide after-hours visits from nurses as our safety process is to send two nurses when PPE is required in the case that the client receiving care at home is COVID-19 positive. One nurse dons PPE and the other nurse acts as a 'spotter' (to ensure that PPE is donned and doffed correctly) and a 'runner' (to access medical equipment as required from the car). This results in two staff having to be scheduled to attend to all COVID-19 positive or suspected clients in the community environment. This proved to be very challenging at an extremely busy time.

The client refused to go back to hospital or to an inpatient palliative care unit as her family would not be able to visit until she was in the “terminal” phase (last couple of days of life). This was unacceptable to the client, so it was agreed that care would continue in the home. This client required daily visits with two nursing staff and 2 syringe drivers to manage complicated symptoms at the end of life caused by a bowel obstruction. Despite all of these challenges, EPC was able to, with the family (some of whom continued to be COVID-19 positive through this episode of care) care for this client at home until she died peacefully 4 weeks after discharge from the hospital.

C. Example of good practices in aged care

<https://www.bendigoadvertiser.com.au/story/6921493/watch-how-boort-brought-joy-to-aged-care-residents/>

D. How SMRPCC supported the Aged Care sector during the pandemic.

There are approximately 160 facilities providing residential care to nearly 13,000 residents in the southern metropolitan region of Melbourne.

The Southern Metropolitan Region Palliative Care Consortium (SMRPCC) Aged Care Worker had been engaging in face-to-face contact with the aged care sector including the provision of deceased resident file audits, education and change implementation support. Obviously with the inability to continue with “work as usual”, alternative methods of support were required.

Throughout the last 6 months SMRPCC has provided the following support to the sector:

- update of the database for the sector to ensure we had access to every aged care facility in our region. In addition, the database contains the contact details of participants from recent aged care forums, meetings and networking groups.
- linking state services with residential aged care facilities in the region
- weekly newsletter or updates. Facilities were inundated with emails and information from both the state and federal government. Rather than expecting facilities with limited resources to find relevant information in this deluge, we highlighted particularly relevant information to ensure this was seen and prioritised by the facility.
- pointing facilities in the direction of important information including PalliAged, ELDAC or other relevant information
- supporting and advising facilities to apply for a “Health Service Permit” and implement a medication imprest system including recommended medications list
- the development and distribution of a simple clinical practice guide for the management of COVID-19 symptoms for the aged care sector, which is since available nationwide on CareSearch

- support and advice on negotiating the significantly larger support networks. Who and how to contact when in need of resources, PPE, equipment and staffing.
- online meetings with other “Aged Care Project” workers throughout the state. Sharing of developed resources and networking.
- online meetings with facilities currently participating in ELDAC projects improving end-of-life care for elders to ensure ongoing implementation
- online education including
 - symptom management of COVID-19
 - medication usage for COVID-19 and symptom management in end-of-life care
 - syringe driver education
 - Advance Care Planning and Goals of Care during a pandemic
 - communication skills and having difficult conversations
 - self-care during a pandemic, online debriefing and psychological support of staff
 - psychological support for residents during a pandemic, including Finding Hope
 - distribution of the DHHS COVID-19 assessment tool and education in its use
 - presenter participation in DHHS webinars on Palliative Care and Pandemic Preparation
 - participation in the Care of Older People Clinical Network meetings for Safer Care Victoria
 - developing and distributing “so what have we learnt this week” updates and information where facilities have shared their experiences that can then be distributed to our network.

This engagement with the sector was significantly enhanced during the period of lockdown due to the voracious information requirements of the residential aged care facilities and their willingness to engage. It is anticipated that, as we emerge from lockdown, this level of engagement will continue due to the overwhelming success and mutually beneficial relationships that have been developed.



25 September 2020

Ms Violet Pratt
Palliative Care Victoria
Level 2/182 Victoria Parade
East Melbourne Victoria 3002

Dear Violet,

Cancer patient experience of palliative care during the COVID-19 pandemic

“Mum was a victim, a victim of COVID. Even though she didn't have the virus, she was a victim of it. She won't be counted in those statistics because obviously she didn't have the virus, but she was a victim of the impact that this virus has had on treatment for people that have got things like terminal illnesses.”

- Tracy, daughter.

Thank you for developing a submission in relation to palliative care for the Inquiry into the Victorian Government's Response to the COVID-19 pandemic. We have been in contact with several leading cancer NGOs, including Breast Cancer Network Australia, Canteen, Lung Foundation Australia, Prostate Cancer Foundation Australia and Pancare, and collated this summary that reflects the concerns arising from the patient and carer experience of palliative care during the COVID-19 pandemic in Victoria.

Prior to the pandemic it was apparent that access to quality palliative care for people with cancer is challenging and variable across the state due to a lack of resources and investment. The onset of the pandemic has further exposed the flaws in the system and new issues have also arisen. These issues relate primarily to the difficulties of visiting palliative patients in healthcare services, the complexities of providing palliative care in the community during a pandemic and the lack of bereavement support, including for children.

We are pleased to note that the recently released Victorian Cancer Plan (VCP) acknowledges that all Victorians are entitled to quality palliative care and that compassionate support should be provided to family, friends and carers. The VCP also announces activities aimed to improve delivery of palliative care.

We hope that the experiences outlined below will support future reform initiatives for the delivery of high quality, highly accessible palliative care for all Victorians who need it in the future.

Preventing Cancer • Empowering Patients • Saving Lives

Cancer Council Victoria
ABN: 61 426 486 715
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E: enquiries@cancervic.org.au
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 Cancer Information
and support
131120

Key concerns raised by consumers during the Victorian restrictions

1. Health service visiting restrictions adding to the distress of end-of-life care for patients and families

While we understand the need to limit visitors to help protect the health and safety of patients and staff, we are seeing strong evidence that the policies adopted by individual healthcare services over the stage 3 and stage 4 restrictions are more limiting than the guidelines recommended by Victoria's Chief Health Officer and that some groups, including children, are being excluded from visiting entirely.

We are hearing many accounts from community members that visitor policies are not being implemented consistently, and, alarmingly, that some healthcare services have suspended visiting altogether.

We understand that there is a lack of direction on how people can navigate the visitor guidelines that apply in individual healthcare services. Information about the circumstances where visiting is allowed, the process for applying to visit and how to escalate a request on compassionate grounds is not always clear and do not adequately support people with poor health literacy or those who face additional communications challenges related to age, disability, language or cultural barriers.

"I couldn't handle it anymore. I called up and I just said, "My mum's in your care, and she's in an incredible amount of pain. I can't come and help her. She's begging for us to come and pick her up. You and I both know that that's not in her best interest to come home. She needs to have this procedure done. Who can I escalate this to? Because this is awful. This is inhumane." Tracy, daughter.

We are concerned for people who need to support loved ones facing end-of-life care during this pandemic. We understand that the Minister for Health has received a high number of complaints about the current visitor guidelines from families with loved ones in palliative care since restrictions began. Many of these stories are highly emotive and sensitive. We know that people usually only complain through formal processes as a last resort.

Our feedback illustrates that those with low health literacy or English as a second language are having many issues that have been unresolved. We are also concerned by community feedback that current restrictions do not adequately address cultural needs around caring for the dying, including for Aboriginal and/or Torres Strait Islander Peoples.

Through the support helplines of Cancer Council 13 11 20, Breast Cancer Network Australia, Canteen and many other patient advocacy groups, we are hearing numerous stories of severe distress caused by current visitor restrictions. Since the beginning of the second lockdown until 12 September, an average of 24% of calls to 13 11 20 each week have been related to the impact of COVID-19, and a constant theme of the calls has been visiting restrictions causing anxiety and distress.

Canteen counsellors have also been supporting young people who are scared, anxious and deeply upset that they cannot visit a dying parent or sibling. We believe immediate action is required to overturn blanket bans on young people visiting family members who are unwell.

"Recently the family received news the cancer had spread to her brain. Jess is no longer able to attend appointments with her mother due to COVID restrictions. Jess explained to Canteen that she has not been able to sleep recently and has been having panic attacks, worrying that her mum will soon die in hospital where she cannot be with her."

Many patient advocacy groups are now stretched to capacity, supporting people to communicate with healthcare services at highly emotive and stressful times. On behalf of these groups and the consumers we represent, we call for healthcare services to provide accessible information to those in their care who need help communicating their individual situations. The more consistent this is across Victoria, the better it will be for people who require flexibility around visitor restrictions on compassionate grounds who are also very mindful of the need to keep staff and other patients safe.

RECOMMENDATION: During the pandemic we have called for a central, well-promoted information and support contact number at each healthcare service where families can raise concerns with a supportive care health professional around impact of visitor restrictions for people with serious or progressing illness, including end of life care.

2. The difficulties of providing palliative care in the community during a pandemic

There is evidence of growing distress with more Victorian families being forced to care for dying relatives at home due to fear of restrictive visitor policies and concern that COVID-19 screening requirements for palliative care patients could mean that loved ones may die alone in hospital, in SCOVID wards or the emergency department.

"I knew she was in pain. She wouldn't let me say anything because she was concerned then she wouldn't be allowed to come home. We got through that night, I tried to call Palliative Care who I'd previously been in touch with, so I'd already done that, but the waiting list had blown out to four weeks. But clearly, I needed help prior to then. Mum had been discharged home and I couldn't manage what was going on by myself. I tried to call Pall Care to escalate it on that Monday but didn't have any luck in getting through." Tracy, daughter

We have concerns that dying peacefully is not the case for many people now. Resources are limited and case numbers high. Data provided by Palliative Care South East, a service in the south-east metropolitan region of Melbourne, shows that since the pandemic began, demand has increased by 61%, which has been met without additional funding.

Although supporting those dying to live their remaining time as comfortably as possible is the focus of community palliative care, we are hearing from community palliative care providers that teams are worried about their inability to do more for families to remove some of the challenges that 24/7 care brings and address the gaps that providing only specialist palliative care (not general and supportive care) create.

"Jenny's condition deteriorated, and her needs increased. At night, she required at least two-hourly re-positioning. She became incontinent. Her wounds needed regular attention: fluid seeped through her skin, a complication of her condition. The sheets needed changing four times a day; just washing and drying them was so hard. Darren provided all Jenny's care with help from their teenagers and some close friends."

Darren, husband and carer.

It is distressing to hear stories from families who are being denied the opportunity to focus on the moments that matter, while they cope with direct care, or families separated from their loved ones who feel a sense of helplessness and despair that they cannot support them or say their goodbyes in the way they had planned, which severely disrupts the grieving process.

The Victorian Cancer Registry reported a 13% decline in cancer pathology notifications from March to the end of July compared to last year, which heralds the real possibility of a significant increase in late presentation of cancer diagnosis, and a potential increase in demand on palliative care services. It is vital that post-pandemic planning addresses gaps in workforce and service delivery to address additional demands that could leave to inequities across health services and regions in accessing palliative care.

RECOMMENDATION: Increased funding is needed to ensure people can access timely and adequate palliative care community services and a comprehensive set of practical and supportive care services and case management support to enable them to safely care at home and for families to receive the associated bereavement support they may need.

3. Access to bereavement support has been limited

Finally, we would like to raise the need for enhanced bereavement support for those whose end-of-life experience has been less than ideal because of the pandemic. All health systems offer bereavement support, however visiting restrictions and changes to the way palliative care services are being delivered currently, mean that many families have not had usual access to this support.

“Our last meeting was in February and since then we have some recently bereaved carers/ family members who have been struggling to cope without strong local connections. I have kept in contact via phone and sent out a letter during this time, but I am concerned about the well-being of many in our group. The majority don't have the capacity or skill to engage via Online platforms so are left without any support.”

Regional bereavement walking group leader

Additionally, restrictions on numbers at gatherings and funerals, combined with travel limitations have seen many families unable to grieve and support each other in a socially and culturally meaningful way. In usual circumstances, many families find out about and are referred to bereavement services by incidental contact with clinical staff while they are visiting their loved one. As visiting cannot happen in the usual way now, there is a need for bereavement services to be offered in alternative modes and across usual service borders and considered in the broader mental health response.

RECOMMENDATION: Increased investment is required to ensure that all bereaved individuals are able to access the support needed to manage following the death of a loved one.

4. Ensuring consumers' feedback informs post-pandemic planning for palliative care

Since March 2020, there has been a significant reduction in consumer engagement and consultation across cancer services, including palliative care. It is critical that consumers and consumer advocacy organisations are fully engaged with cancer services and post pandemic planning to integrate the lived experience and consumer perspective into new service model designs. This is considered vital for best practice care. Our organisations remain ready and willing to assist in the process of consumer engagement for palliative care service planning in Victoria.

We have provided case study examples for use in the submission in Appendix A to highlight some of the concerns we are hearing from the community. We would like to acknowledge the courage and strength of the patients and families who have shared their stories with us, and we thank them for their support in our advocacy efforts.

Yours sincerely



Todd Harper
CEO Cancer Council Victoria

Appendix A

Case study 1: Jenny

Jenny was 48, married to Darren. They had a 15-year-old daughter and 12-year-old son. Jenny had been living well with metastatic breast cancer but over the last four months her body stopped responding to treatments and she developed significant symptoms. Her mobility was affected: she needed to walk with a wheelie frame, required an over toilet chair and had to have support to shower, or to function. Her brain metastases caused seizures and she could not be left alone.

Darren was still working. While the community palliative care service was free, he had to keep working due to the high cost of treatments, medicines and supportive care requirements.

Jenny's condition deteriorated and her needs increased. At night, she required at least two-hourly re-positioning. She became incontinent. Her wounds needed regular attention: fluid seeped through her skin, a complication of her condition. The sheets needed changing four times a day; just washing and drying them was so hard. Darren provided all Jenny's care with help from their teenagers and some close friends.

The kids also needed him. The effort of coping with home schooling and Jenny's care seemed overwhelming. The phone also kept ringing; as his work commitments increased, he barely slept.

Darren began to realise the care Jenny required was too much for him. He discussed options to have Jenny transferred to an in-patient palliative care unit. A direct admission was not possible due to the pandemic. She would stay in a COVID screening ward for at least 24 hours until she was screened as clear. Her shortness of breath and symptoms due to her cancer were similar to those of the virus; a COVID infection had to be ruled out. The family could not be with her. But Jenny's time was short; every minute was sacred. The in-patient unit was not an option.

Darren battled on. A community palliative care nurse came daily. They wished to come twice but they had many extra clients in similar situations. Community palliative care isn't funded for respite or general nursing. Darren was worried about access to respite care as an option – and the cost.

Jenny died peacefully in August with her children and husband by her side but the ongoing bereavement trauma of caring for her through this time remain with the family.

Case Study 2: Siblings aged 9 and 13.

Dad has been having chemotherapy for his Hodgkin's Lymphoma with the view to have his second stem cell transplant. Dad's cancer has been present for 10 years. Dad is required to be an inpatient for 3 weeks during his chemotherapy then he goes home for 10 days and returns to the hospital.

He has had very adverse side effects with his treatment and has had to go into ICU at times and has not looked like surviving.

During this time the children have not been able to visit him in hospital as there were restrictions on number of visitors and the number of hours they could be there for. It was 2 people (no children) for no more than 2 hours until last week when the hospital has gone into lockdown.

The children's mum is not allowed to visit either at present and the whole family is very distraught. During the hospitalisation of their dad, both young people have had birthdays and there has been no face-to-face contact. If the stem cell transplant goes ahead, the young people will not see their dad for months.

Case study 3: Jess aged 12 (real name not used)

Jess is being supported by a Canteen counsellor and has a very unwell mum in her palliative care stages. Jess' mother is the sole carer of Jess and her two brothers but is in and out of hospital due to her cancer spreading rapidly around her body.

Recently the family received news the cancer had spread to her brain. Jess is no longer able to attend appointments with her mother due to COVID restrictions. Jess explained to Canteen that she has not been able to sleep recently and has been having panic attacks, worrying that her mum will soon die in hospital where she cannot be with her.

Jess is very aware that her mother doesn't have long left and that it's likely she won't be here in a few months. The family has done a lot of anticipatory grief work and preparation for her death. Much of the current therapy sessions Canteen are supporting Jess with, are focused around anxiety at not being able to spend the final moment with her mum. This is taking away from the vital work in spending quality time together as a family in these final moments.

Case study 4: Tracy, daughter of pancreatic cancer patient

72-year-old wife, mother and grandmother, Harma, was diagnosed with stage 4 pancreatic cancer in January this year. Harma's cancer diagnosis, treatment and end of life was endured during the COVID-19 pandemic, which impacted many treatment and care decisions Harma and her family made.

"Even as in immunocompromised patient, she was regularly held in wards with other patients awaiting COVID results," said Tracy. "So, you've got an immunocompromised patient sitting on a ward with three other people in the room waiting for COVID swabs. They're all being swabbed because they're showing signs of having coronavirus."

Due to this experience, towards the end, she avoided going to emergency wherever possible.

"She knew if she went to ED it would mean that she would have no support system," Tracy said. "Again, it meant that she would end up with more COVID swabs. It meant that she would end up on a ward awaiting results, where she was potentially at risk of coronavirus again. And she wouldn't go there."

The family's access to hospital was severely limited with restrictions and communication with hospital staff was inconsistent and at times non-existent.

Despite, never expecting to palliate at home, in the end the family chose to keep Harma at home. But Palliative care services were stretched and there was a four-week waiting period.

"She was discharged home on a Sunday night," Tracy said. "She was discharged home with no support services in place. Having had a lot of pain issues within the hospital environment, she was discharged to me with nothing in place. Nothing. No directive as to how to manage her pain, no directive as to the impact on basic things like her blood sugars. At that point in time she was hardly eating anything.

"Mum had been discharged home and I couldn't manage what was going on by myself. I tried to call Pall Care to escalate it on that Monday but didn't have any luck in getting through.

They came out on the Thursday to assist Harma, but sadly Tracy lost her mum on the Friday after that.

"I'm sorry that mum had to go through it," said Tracy. "It was really traumatic. Even though she didn't have the virus, she was a victim of it. She won't be counted in those statistics because obviously she didn't have the virus, but she was a victim of the impact that this virus has had on treatment for people that have got things like terminal illnesses.

"I can't get back now that time with mum."



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ENSURING PALLIATIVE CARE IS CORE BUSINESS FOR AGED CARE

As Australia's population ages and the number of people using aged care services increases, the demand for palliative care in aged care is also increasing. It is essential that palliative care is recognised as core business for all aged care providers. Aged care providers and their staff must be supported by appropriate systems, funding and training to provide quality palliative care.

Palliative Care Australia (PCA) has developed an eight-point plan for palliative care in aged care to highlight these issues and provide constructive solutions. By discussing and communicating these eight recommendations, PCA hopes to better support the aged care industry to deliver palliative care.

1. A PERSON-CENTRED APPROACH TO PALLIATIVE CARE IN AGED CARE

- » In the current aged care system, there is a narrow view of palliative care, influenced by Commonwealth aged care policy, standards and funding models.
- » For example, the Aged Care Funding Instrument (ACFI) only recognises and funds 'palliative care' at the 'end of life', where the definition of end of life is referenced as the 'last week or days' of life.
- » There needs to be a more person-centred and holistic approach to palliative care that is not only focused on dying and the last weeks of life. It should align with the World Health Organisation (WHO) definition:
 - 'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'
- » This approach will provide better care for older Australians diagnosed with a life-limiting illness, considering their needs beyond only end of life.

2. CLEARLY ARTICULATED, ROBUSTLY IMPLEMENTED - THE AGED CARE QUALITY STANDARDS MUST INCLUDE PALLIATIVE CARE

- » Commonwealth funded aged care services are required to comply with the Aged Care Quality Standards. The Standards focus on outcomes for consumers and reflect the level of care and services the community can expect from aged care providers, yet they do not include 'palliative care'.
- » The Standards include only two references to 'end of life', with Standard two focusing on end of life planning and Standard three on meeting the needs, goals and preferences of consumers nearing the end of life.
- » Palliative Care was a standalone outcome under the previous Accreditation standards (in use prior to 1 July 2019).
- » PCA commissioned KPMG to investigate the economic value of palliative care. The report, *Investing to Save – The economics of increased investment in palliative care in Australia*, recommended that the Aged Care Quality Standards be revised to include a specific palliative care standard, for the following reasons:
 - Palliative care in residential aged care is often confined to the last hours of life and not systematically integrated into core business in residential aged care services.
 - While the current Aged Care Quality Standards contain components of palliative care, the Standards do not effectively describe the expectations for palliative care in a holistic or systematic manner.
 - In light of the clear need for palliative care for this population cohort, and the high degree of complex needs within residential aged care, the Standards should be altered such that they define what 'good care should look like', and include specific minimum competencies for palliative care.

3. PALLIATIVE CARE TRAINING FOR EVERY HEALTH AND AGED CARE WORKER

- » Most staff working in aged care receive very little, if any, formal training in palliative care. Undergraduate and vocational education and training (VET) in aged care do not currently include palliative care as core units and there is no requirement for aged care providers to include palliative care on their training calendars.
- » 36% of all Australians who die do so in residential aged care. Staff working in aged care therefore need to be suitably trained and equipped to work with residents who have palliative care needs and their families.
- » As Australians continue to show a preference for staying in their homes as they age, it is also essential that staff working in home care are suitably trained in palliative care.
- » All health and aged care professionals must have minimum competencies to provide care for people with a life-limiting illness whose needs are relatively straightforward and know when to refer when needs are complex.
- » This could be supported through all undergraduate nursing, allied health, medical courses and Certificate courses for aged care workers including mandatory units on palliative care.

4. MIND THE DATA GAP: WE CAN'T IMPROVE WHAT WE DON'T MEASURE

- » Planning and identifying unmet and emerging needs for palliative care requires demographic and service data.
- » Without adequate data collection and linkages with other health data, it is not possible to accurately analyse how older Australians access and receive palliative care services.
- » There is currently inadequate data about palliative care particularly as it relates to those also accessing aged care services. In particular:
 - The current narrow view of palliative care in aged care means that the available data does not consider palliative care beyond definitions of 'end of life'.
 - Claims for palliative care funding made under the ACFI do not reflect the number of people who needed and/or received palliative care.
 - There is no data available in the Home Care Packages (HCP) Program or the Commonwealth Home Support Programme (CHSP) on the input of specialist palliative care or if providers used funds for services relating to palliative care needs.
- » The introduction of a palliative care National Minimum Data Set (NMDS) would allow for the collection of uniform data and reporting at a national level. Aged care should be included in planning for a palliative care NMDS.

5. FUND IN FULL – WE CAN'T IMPLEMENT IF WE DON'T INVEST

- » Funding is needed to fully implement the National Palliative Care Strategy 2018, ensuring aged care is included.
- » Currently, palliative care is not appropriately recognised and funded in aged care.
- » The ACFI is the instrument used to determine levels of funding in residential aged care. The ACFI only funds 'palliative care' at the 'end of life' where the definition of end of life is referenced as the 'last week or days of life', which only enables providers to claim for:
 - *'Palliative care program involving End of Life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting.'*
- » Home Care Packages funding does not provide any additional funding to support care recipients who are palliative, including purchasing equipment. Providers must find funds from within the home care package funds currently being received for the client.
- » PCA commissioned KPMG to investigate the economic value of palliative care. The report, *Investing to Save – The economics of increased investment in palliative care in Australia*, found that:
 - In 2017, 36% of deaths in Australia occurred in residential aged care
 - The prevalence of highly complex needs in permanent aged care residents has increased five-fold to 53% in the last decade
 - Only one in 50 permanent residents receive ACFI-funded palliative care.
 - Palliative care services in residential aged care are under-funded and underserved
 - Funding specialist palliative care in residential aged care can reduce presentations to hospital and lead to less time in hospital.
- » KPMG estimates that a \$1.00 investment in palliative care nurses in residential aged care can return between \$1.68 and \$4.14 in savings.
- » KPMG recommended an investment of \$75 million per annum to increase the provision of palliative care within residential aged care. The investment should include both direct specialist palliative care and integrated support provided by the aged care workforce and other health professionals.
- » Development of a new funding model is currently underway, the Australian National – Aged Care classification (AN-ACC). Its ability to ensure residents' palliative care needs are met is still being evaluated.

6. ENSURE EQUITABLE ACCESS - PALLIATIVE CARE IS A UNIVERSAL HUMAN RIGHT

- » The diversity of the Australian population and geography means that no single model of palliative care will work universally. Therefore, it is important that work is done to ensure the models are able to be adapted to provide equitable access across Australia.
- » Investment in, and development of, innovative models of care are required to ensure older people have equitable access to specialist and generalist palliative care services when and where they need them.

7. SUPPORT AUSTRALIANS WHO ARE DYING TO TALK

- » Dying should be seen as a normal part of life, with grief and bereavement supported in the community and within workplaces.
- » Death literacy across the community needs to be improved significantly so people are more comfortable talking openly about death and dying.
- » Older Australians also need to be supported to understand what good palliative care means for them regardless of their prognosis.
- » Work done across the community to normalise discussions of death and dying and grief and bereavement and building a better understanding of good palliative care will make care planning discussions more common and more accepted. This will in turn support the aged care workforce to better be able to facilitate advance care planning within aged care services.

8. PALLIATIVE CARE MUST BE A PRIORITY FOR ALL GOVERNMENTS

- » Palliative care should be a priority for all governments including the National Federal Reform Council, the newly formed National Cabinet and the Health Council.
- » Palliative care policy can be nationally supported by the appointment of a National Palliative Care Commissioner.
- » The role of the Commissioner would include:
 - Engaging with the palliative care sector and facilitating improved communication across jurisdictions by encouraging consistent approaches across all settings, including primary health, community health, tertiary health, aged care and disability.
 - Overseeing the Implementation Plan, and the Monitoring and Evaluation Plan which will underpin the National Palliative Care Strategy 2018.
 - Encouraging the development of a palliative care data collection framework that includes aged care.
 - Contributing to reforms and new initiatives across the palliative care sector, and
 - Providing advice and reporting to government.
- » It is not intended that the Palliative Care Commissioner would be a fund holding body or provide services; get involved in individual cases or advocate for individual people; or undertake dispute resolution, handle complaints or undertake investigations.
- » Currently, there are a number of National Commissioner roles that the Palliative Care Commissioner could be modelled on including National Rural Health Commissioner, National Data Commissioner, National Threatened Species Commissioner and National Skills Commissioner.

<https://palliativecare.org.au/palli8-core-business-in-aged-care>



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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.

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