

Seniors Rights Service Submission to the Royal Commission into Aged Care Quality and Safety

Submission into the impact of Covid-19

Seniors Rights Service is the leading rights-based community organisation representing the interests of seniors in NSW. Since January 2020, the community has seen the devastating impact that Covid-19 has had on older Australians, particularly those who reside in aged care facilities, who often are particularly vulnerable, frail or have chronic illness. It has been reported that the median age of fatalities due to the pandemic in Australia is 80 years old, and that 69% of deaths in Australia have occurred at residential aged-care facilities (*Dept of Health, sourced on 3/0/20 <https://www.health.gov.au/resources/covid-19-cases-in-aged-care-services-residential-care>*).

Seniors Rights Service has been at the forefront of the community's response to this pandemic in NSW. By the end of August, the organisation had dealt with 1700+ enquiries related specifically to Covid-19, representing an unprecedented increase in demand for our legal and aged care advocacy services.

The observations and recommendations made in this submission are drawn from this daily experience. They are also informed by specific learnings gained from our response to the outbreak of Covid-19 at Anglicare's Newmarch House in Western Syd where Seniors Rights Service provided on the ground advocacy support to over 97 residents and their families during what was then the largest cluster of Covid-19 cases in the country. They are also based on our current experience assisting the Victorian aged care advocates as they respond to the Covid-19 pandemic in that state. This hands-on experience along with that gained by handling so many Covid-19 enquiries has given us an in-depth understanding of the many complex economic, social and psychological impacts the pandemic has had on senior Australians and in particular those in aged care.

Seniors Rights Service has made four recommendations in this submission for consideration by the Royal Commission in improving the management and response to any further outbreaks of Covid-19 in aged care facilities around the country.

SRS Response to the Terms of Reference

The Royal Commission has asked for responses to a range of issues concerning the handling of the Covid-19 pandemic in the aged care sector. Seniors Rights Service will reserve its comments to the specific areas where we have had direct experience as a community service provider responding to the pandemic.

Question 1: The role and responsibilities of State, Territory and Federal governments in responding to such crises in aged care services

Early in our engagement with Newmarch House it became clear to Seniors Rights Service that there was a significant communications issue, and that residents and their families did not understand the roles and responsibilities of the different levels of government, and therefore who was responsible for making the decisions that were directly effecting them and their loved ones.

At the beginning of the outbreak, this lack of clarity was manifested in several incidences of families being unclear about the standing or authority of various decisions and whether they were being made by the facility itself, were due to NSW Department of Health public health orders, or had been made by other government agencies. As an example, Seniors Rights Service heard on several occasions of residents in Newmarch House losing their dignity and individuality, such as residents losing their own clothes when they went to the laundry, or soiled clothing left in their room for weeks in a plastic bag, and , hold ups in clean clothes being returned and residents being dressed in other peoples' clothes. This caused much stress to families and to the residents themselves. In this circumstance, laundry practices were guided by NSW public health orders and not the facility itself, but residents and families were not aware of this and thought the problem was with facility management and systems. Raising the issue with facility management appeared to "go nowhere" because laundry processes were being managed by the requirements of NSW Health and facility management were not in control of the process. This was a confusing and frustrating time for families and something that Seniors Rights Service advocates focussed on clarifying as a matter of priority once we became involved.

Seniors Rights Service became aware of several other circumstances where residents had been confused about what was happening because so many different players were responsible for different decisions. This was particularly the case with issues such as whether visits by allied health workers were allowed and whether families could visit or not. Decisions and rules appeared to keep changing almost on a daily basis and this situation led to families becoming doubly distressed and to a feeling that people didn't know what was going on. In this situation, Seniors Rights service believes that right from the beginning of any outbreak it is critical that there is a structured approach for rapid and clear information flow between the various people in charge of different aspects of the pandemic and the people on the ground.

While clarifying the different roles to residents and families would have been something that Seniors Rights Service was well able to communicate, it was also clear from the outset that the aged care facility was not aware of the role of community aged care advocacy and how it could be utilised to assist in communications between residents, families and the facility. Despite providing information to many aged care facilities, this information is often not distributed to residents and their families, nor to staff.

Once Seniors Rights Service was involved at Newmarch House, it immediately set up a dedicated six-person advocacy team to specifically communicate with and support residents and their appointed representatives by telephone. This team facilitated clearer and faster communication and response between the families and facility management. Seniors Rights Service also organised weekly family meetings by zoom at which families were able to speak openly and to express their concerns and frustrations in a supportive environment. These meetings were attended by most of the resident's representatives. Seniors Rights Service also provided an advocate who attended the facility on four days to specifically talk with residents. The ability to speak directly to an independent advocate gave residents a greater sense of their own agency and their rights in the situation. It did take several weeks for permission to be granted to Seniors Rights Service to enter the facility. It should be noted that the advocate attending was the Manager of Advocacy at Seniors Rights Service who is a former nurse who has been trained in and utilised professional PPE protocols.

Seniors Rights Service acknowledges that a protocol has now been developed to support the joint management of a COVID-19 outbreak in a residential aged care facility in NSW by the Commonwealth Government Department of Health, the Aged Care Quality and Safety Commission and the NSW Ministry of Health. This protocol will make the roles and responsibilities of government agencies and the aged care provider clearer amongst other things and support better communications. Seniors Rights Service welcomes the inclusion in this protocol of a responsibility for Commonwealth government to

assist providers with access to aged care advocacy services for residents and their representatives and to notify national and state-based advocacy services of outbreaks.
(Protocol to support joint management of a COVID-19 outbreak in a residential aged care facility in NSW, July 2020)

The protocols also provide for a responsibility of aged care service providers to

enable access and respond to aged care advocates, and provide to residents and their representatives communications, collateral and materials provided by advocacy services.

The independent review into the COVID-19 outbreak at Newmarch House has also made a number of recommendations based on the key learnings from the response to this outbreak including that

access to advocacy services should be a priority during an outbreak. Advocates can assist providers and residents (or their legally appointed representatives) to resolve issues expeditiously *(Prof L Gilbert Final Report, Newmarch House Covid-19 Outbreak, 2020: 15)*

Aged care advocacy services must be contacted as soon as an outbreak of COVID-19 is indicated so that appropriate, accessible and responsive support can be provided to the people involved on the ground. Seniors Rights Service makes the following recommendation

recognising the important role that aged care advocacy services provide in supporting families and residents of aged care to understand the different roles and responsibilities of government, management and industry during any health emergency.

RECOMMENDATION 1: *State-based aged care advocacy services will be notified by the relevant aged care facility as soon as there is a Covid-19 case identified. That facility must communicate directly with the advocacy service and also provide information to residents (and their representatives) about the advocacy service and how it can assist them during the crisis.*

Question 2 What should be done and by whom in the future to support the aged care sector to respond to pandemics, infectious disease outbreaks or other emergencies

The crucial role of independent aged care advocacy organisations in supporting residents and their families of aged care facilities during infectious disease outbreaks or other emergencies cannot be

underestimated. The ability to support families, to supply information and to advocate on their behalf during a crisis not only provides emotional support but also a much needed conduit between various authorities and families for clearer communication and transparency.

Seniors Rights Service has observed that many aged care facilities know little about the role of aged care advocacy organisations and the benefits of advocacy acting as a vehicle to assist in communication to families. Seniors Rights Service made contact with Newmarch House on three separate occasions at the

beginning of the outbreak attempting to offer advocacy support but the facility declined to engage. Seniors Rights Service then sent brochures to Newmarch about our services for distribution to staff and residents so they would have an independent advocate to assist them to raise any concerns. It took several weeks before the facility engaged with Seniors Rights Service and we were able to act for families.

Seniors Rights Service has over 30 years experience supporting older Australians to articulate their rights. Aged care advocacy services similar to Seniors Rights Service in NSW exist in all states and are dedicated to protecting and advancing the rights of older people, particularly those who are vulnerable and disadvantaged. In providing free and confidential advocacy support, they assist older people who receive Commonwealth-funded aged care services at home or in residential care, as well as their carers or family members. In 2017, these organisations set up the Older People's Advocacy Network (OPAN) of which they are now members. OPAN is the peak body representing advocacy services for the purpose of having a centralised secretariat and a conduit at the national level.

Even outside of an emergency such as the Covid-19 pandemic, outcomes for older people in aged care are improved when advocacy services are present and it should be made mandatory for all aged care providers, including home care services, to undertake education sessions delivered by these advocacy organisations about the rights of older people. It is

essential that all aged care providers receive this education annually and that it is compulsory rather than discretionary.

Aged care providers who are aware of aged care advocacy services generally can have matters dealt with early rather than let them fester. While all the state delivery organisations in the OPAN network deliver independent advocacy education to aged care providers, it is not mandatory and Seniors Rights Service has found that, despite being offered free education, some providers still decline this service and do not welcome aged care advocates to conduct education or one-on-one advocacy to the aged care recipient.

Many older people who contact Seniors Rights Service for assistance are in their late 80s and 90s and are frail. Often they do not have family or friends to support them to raise issues of concern, or to speak up for them if they need assistance to raise their concerns. Many older people do not know about the role or the availability of independent advocates who could support them to raise and resolve issues early. Our experience shows that where they can access advocates, their issues can often be resolved easily once they are identified, and the quality of services for all consumers, improves as a result. This is even more so the case during a health emergency such as the Covid-19 pandemic.

This general lack of knowledge of the importance of advocacy and how to utilise aged care advocacy services became more acute in the crisis situation of the pandemic. Seniors Rights Service is therefore recommending that education sessions about the role of advocacy services should be compulsory for residential aged care facilities, for home care services and for the Community Visitor Scheme and that it should be conducted annually. Also, Seniors Rights Service recommends that managers as well as front line staff, be required to attend these sessions. We applaud the aged care providers who ensure all staff, including kitchen, garden and maintenance staff, attend sessions run by aged care advocates as it may well be these people who observe something in the older person or situation that requires addressing. Aged care facilities who are aware of advocacy services and prepared to contact them at the first sign of any outbreak of COVID-19 will be better equipped to deal with issues compared to those facilities that do not engage with aged care advocacy services.

RECOMMENDATION 2: *The Commonwealth Government support the state-based community Aged Care Advocacy Organisations, through OPAN, to deliver a communication and training program for all aged care services, including home care, on the role of community advocacy services and community visitor schemes and how these services can provide support to older people and aged care facilities in responding to pandemics and other national emergencies. This training should be made compulsory for all aged care facilities and services receiving government support.*

Clearly communicating the various changes to public health messages that are being made, often on a daily basis is another issue that arose during the Newmarch House outbreak that must be responded to in order to support the aged care sector to respond to pandemics, infectious disease outbreaks or other emergencies in the future.

During the Newmarch House outbreak, families expressed the perception that decisions concerning their loved ones were being made in an ad hoc fashion and changed frequently and that it was difficult to know what was happening from one day to the next. Seniors Rights Service noted that one reason for this perception was that, indeed, public health orders were

being changed frequently, often on a daily basis, but that these changes were not being consistently and expeditiously communicated. This resulted in a lack of trust within the family group about what they were being told from day to day. By way of example, some families were provided with the possessions of their loved ones immediately after that person had passed away. However, only a few days later, a family was not given the possessions and had to ask repeatedly for them, being told that they were not being returned due to infection control measures. This caused great distress and frustration and a feeling that the rules were being arbitrarily applied. Clearly the public health orders regarding items being removed from the facility had changed but this was not clearly articulated and was difficult to succinctly explain to distressed family members. Another example concerned who was responsible for making the decision to restrict visits to residents and therefore, who families could appeal to for an exemption to this rule in a particular circumstance (for example, where a resident was in a critical condition).

One of the most heartfelt complaints made to Seniors Rights Service advocates at the beginning of our involvement in Newmarch was the frustration felt by the families at the lack of clear communications to them about many issues. Lack of communication and confusion about changing rules, and who is making them, caused significant and unnecessary anxiety, frustration and in some cases anger and led to the appearance of a fragmented response, and the feeling for many that nothing was being done or that no one knew who was in control of the situation. The involvement of Seniors Rights Service ameliorated this situation, as did the eventual forming of a special dedicated communications unit at Newmarch House itself. Ensuring that any changes to public health orders are immediately communicated to all stakeholders, including the advocacy organisations involved, will go some way to removing this confusion and distress in future outbreaks. Seniors Rights Service believes that the importance of daily communications cannot be underestimated and a communications framework must be in place to facilitate information exchange between all stakeholders.

RECOMMENDATION 3: *The public health body in each state and territory must clearly communicate any changes that they are making to public health orders that will impact on aged care immediately they are made, and on a daily basis if necessary, to aged care facilities and to the state based advocacy organisations so that these can be clearly communicated and understood by aged care residents and their families.*

Question 3: The balance between managing risks posed by a future pandemic or infectious disease outbreak and maintaining the overall health and wellbeing of aged care recipients including their mental health and quality of life

Respect for the rights of older people is a fundamental tenet of a just and equitable society. Seniors Rights Service is a rights-based organisation with a vision of a society that respects and upholds the rights of older people. It provides support and resourcing to older people to know their rights, and to be empowered and supported to insist on the enactment of their rights. The rights of older people to live in a safe environment where their wellbeing and quality of life is maintained is fundamental to their rights as Australian citizens. Unfortunately, as the Covid-19 pandemic has progressed and lock down restrictions have come into place, many residents and their families have felt that their rights have been disregarded, subsumed under the priority of health directives.

During the Newmarch House outbreak, Seniors Rights Service advocates heard concerns from many families that their loved ones were not receiving the care that was crucial to their physical and mental wellbeing. There were stories of residents being left for hours unable to contact nurses who were on call but did not respond, of residents being left in nightclothes all day and not being changed regularly, of residents not being given meals, or having to eat frozen sandwiches for dinner, and even of essential medication being delayed or worse. This lack of respect for basic care needs was a frequent complaint of families but even more so was the fact that family members were not allowed into the facility to visit their loved ones and take stock of their situation. Frustration at not being able to assess for themselves what was happening inside the facility was palpable. And the emotional strain from not having contact with their loved ones during such a frightening time was overwhelming for many families. This situation was mirrored in other aged care homes, even in those that did not have a Covid-19 outbreak but were still subject to the public health orders that restricted any visitors entering aged care facilities.

Seniors Rights Service understands and accepts the basic need to protect the health of residents and workers, especially given the highly infectious nature of the Covid-19 virus. However, the decision to ban all visitors while still allowing casual staff into the facility, was difficult for many families to understand and accept. Questions were asked as to why workers could be allowed in, while they could not. If casual staff can be fitted with PPE then family visitors can also be required to wear PPE and be restricted in who they access and their visits managed to comply with infection controls. Families expressed frustration and distress at not being able to spend any time with their loved ones, many of whom were sick and dying, and others who were frightened and confused. Not being able to say final farewells to loved ones will be a sorrow that many will never get over.

There must be a more humane balance between protecting residents from infection and allowing human contact and care to be given by families or carers. In this way, family members could have been with their loved ones in their final hours. Instead several residents spent their last hours with total strangers. This represents a regrettable lack of respect for the rights of older people. Facilities must put in place procedures whereby residents, in particular those who are critically ill, can have contact with their families. While it is accepted that the priority must be to save lives this must be in the context of being humane and compassionate to residents and their families.

The final step in recognising the rights of aged-care residents and their families as noted above is the facilitation of access to aged care advocates in every aged care facility so that they can support and represent the rights of residents and their families. This requires that aged care management accepts and provides access to advocates and their education services as a matter of priority.

RECOMMENDATION 4: *While controlling infection rates in aged care facilities during a health emergency is of primary importance, protocols must be developed to protect the human rights of older people to quality and consistent care, while still respecting their rights to have contact with their loved ones.*

In conclusion

The Royal Commission into Aged Care Quality and Safety has asked for comments on other questions including: the challenges faced by the aged care sector relating to management; workforce and access to personal protective equipment; and any other related matters. In this submission, Seniors Rights Service has determined to address the questions that directly relate to the services provided by our service and on which we have direct experience as a service delivery organisation. Seniors Rights Service has heard complaints and concerns voiced by families with loved ones in aged care facilities, and in particular the Newmarch families, about staffing numbers and ratios, inconsistent adoption of PPE, inability to get COVID-positive people separated from those who were still negative, difficulties in getting information about the care of their loved ones and access to care plans, and issues with the decisions around whether to hospitalise a resident or to keep them in the facility. However, Seniors Rights Service has determined that these issues are better addressed by the health professionals involved. We have kept our observations and recommendations to the areas that we believe most directly impacted on our ability to provide appropriate support to the residents and their families, and that must to be addressed before there are any more outbreaks in aged cared facilities in NSW.

Community-based aged care advocacy organisations are an essential part of any response to an emergency that might arise in an aged care facility. They can provide independent and informed advice and support that is immediately available to residents and their families and carers. Putting in place this advocacy support during the crisis at Newmarch House assisted residents, their families and their representatives to voice their concerns, and to navigate the complex and somewhat confusing lines of responsibilities. Assisting families to express their concerns to the facility management about many aspects of care during the crisis and to get these addressed as a matter of priority was important to ensuring procedural transparency and responsiveness, especially when families were not able to enter the facility themselves.

The immediate impact of the virus on the health of many older Australians living in residential aged care facilities is clear. The recent experience in Victoria has highlighted that aged care facilities are particularly vulnerable to outbreaks and that it is in these facilities that most deaths occur. People in these facilities must be protected both from any infection and from having their rights denied.

Covid-19 has had a significant impact on the mental health of older Australians, many of whom have become increasingly isolated from families, grandchildren, friends, and carers. This is especially true of those living in aged care facilities. The psychological impact of this sudden isolation will be long felt. SRS has identified that callers to our service are more anxious and fearful and many are highly emotional and require longer consultations, and social support. Seniors Rights Service strongly recommends that whatever additional resources are made available to the aged care sector and to the community to deal with the impacts of Covid-19 in aged care, will need to be put in place for the long term. The effects

on senior Australians of the Covid-19 pandemic will be felt for many months, if not years, to come.

About Seniors Rights Service: Advocacy, Legal Advice, Education & Social Support

Seniors Rights Service has been assisting older Australians across New South Wales since 1986, providing independent aged care advocacy services and legal advice as a community legal centre. Seniors Rights Service is the largest rights-based organisation for seniors in Australia. During 2018-19, Seniors Rights Service provided 3,422 legal services to older people, 4,451 aged care advocacy services to recipients of aged care in NSW and conducted 1,042 education and rights-based awareness raising events across NSW that were attended by 34,366 people.

Our advocates assist recipients of all Commonwealth funded aged care services, their carers, family members and representatives to understand their rights under the *Aged Care Act 1997*. We help them to advocate for themselves to resolve issues and complaints with aged care providers to ensure optimal care is achieved. We provide independent advocacy to support those who are too frail or fearful for whatever reason, to speak for themselves. Advocates provide information sessions to people receiving aged care services to empower them to speak up and assert their rights, or to seek assistance with raising their concerns or a complaint.

Seniors Rights Service is the NSW member organisation of the Older Persons Advocacy Network (OPAN).



Russell Westacott CEO

Seniors Rights Service

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