# Optimising Person- and Family-Centred End-of-Life Care during a pandemic

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## **CONTEXT FOR THIS STATEMENT**

The Coronavirus Pandemic (COVID-19) is challenging health care systems worldwide. From the day the first case of COVID-19 was reported in Wuhan in November 2019, to the declaration of a pandemic in March 2020,<sup>1</sup> COVID-19 has developed as an unparalleled and extraordinary public health emergency.<sup>2</sup> Mortality associated with COVID-19 has been described as a tsunami of death,<sup>2</sup> with estimates that eight out of ten deaths have been among people aged 65 and older.<sup>3</sup> There are a number of unique challenges associated with providing end-of-life care for people during the COVID-19 pandemic. End-of-life care is almost always complex, yet there is limited information to date to guide care and support during the pandemic.

Australian measures designed to contain and minimise the spread and impact of COVID-19 have been relatively successful compared to other countries,<sup>4</sup> although the persistence of community transmission and ongoing outbreaks across the country are a reminder that this pandemic is especially difficult to control and that the health and economic effects will continue for an extended period. This statement identifies the challenges associated with providing end-of-life care during the COVID-19 pandemic and outlines actions required to support the provision of high-quality endof-life care across multiple practice settings.

## **AUSTRALIAN COLLEGE OF NURSING'S POSITION**

The Australian College of Nursing (ACN) acknowledges that safe and high-quality end-of-life care is a human right that must be available to every individual at the time and in the place it is needed. During the COVID-19 pandemic, access to quality end-of-life care has been impacted by enhanced public health and infection prevention and control measures and restrictions associated with COVID-19.

To ensure access to appropriate end-of-life care, ACN supports:

- Nursing practice that integrates a person- and family- centred approach to end-of-life care as a core component of a health and aged care service response for managing the COVID-19 pandemic, including effective symptom support, timely communication inclusive of informal carers (including family members, surrogates and informal support persons), and ensuring care aligns with the person's values and preferences;
- Adequate prioritisation of psychosocial and existential support for people at end of life, and their informal carers including access to psychological and social supports for people at end of life and their families;
- Resourcing of flexible and innovative communication mechanisms within all care settings that facilitate meaningful interactions between the person and informal carers at the end of life;
- Initiatives that support nurses providing end-oflife care for people during the COVID-19 pandemic across all practice settings, including:
- -Specific and targeted opportunities to upskill in providing person- and family-centred care at the end of life, and infection prevention and control where required
- -Access to personal protective equipment
- -Measures which promote self-care and access to employee support services which acknowledge the stressors experienced by nurses.



# BACKGROUND

# End-of-Life Care Needs associated with COVID-19

A COVID-19 diagnosis is associated with significantly higher risk of death, especially for older people.<sup>5</sup> Cough, breathlessness, fatigue and myalgia are significant symptoms<sup>6</sup> often leading to hospitalisation.<sup>5</sup> Dyspnoea is the most significant symptom in the dying phase, with respiratory and/or heart failure the predominant causes of death associated with COVID-19.<sup>6</sup> Agitation is also commonly experienced towards the end of life.<sup>7</sup> Such physical symptoms are associated with a high level of distress.<sup>7</sup>

Sources of distress associated with dying, however, extend beyond physical symptoms to also include social isolation,<sup>8</sup> fear and stigma<sup>9</sup> associated with the virus and its management, and the sometimes invasive clinical interventions that are employed in an effort to manage the effects of COVID-19. Moreover, people who die from COVID-19 can include those for whom intensive treatment has not been successful, those who are not candidates for intensive treatment, or who choose not to have a life-prolonging intervention.<sup>10</sup> This means that understanding the person's preferences for care, particularly at the end of life is essential.<sup>11</sup>

# Unique issues related to setting of care – acute care and residential aged care

Quality end-of-life care during the COVID-19 pandemic is required within all healthcare settings – hospitals, at home and within residential aged care facilities (RACFs). People will continue to die from a range of life limiting conditions during this period, and the provision of quality care, including end-of-life care should continue to be a priority in all care settings. However, such care is challenged by the overriding public health and heightened infection prevention and control measures necessary to minimise transmission, protect healthcare workers and the greater community.<sup>12-14</sup>

Moreover, a disproportionate number of deaths from COVID-19 have been associated with older people, particularly those living in RACFs. Older age is a significant risk factor for morbidity in COVID-19,<sup>15, 16</sup> and older people are also at greater risk of death due to age-related health conditions and multimorbidity.<sup>17</sup> In environments like RACFs, where older people live communally and social distancing is difficult to maintain due to the nature of the personal care provided,<sup>18</sup> and the design of facilities, the risk of adverse outcomes and mortality is greatest.<sup>19</sup>

For these reasons the World Health Organization (WHO)<sup>13, 14</sup> released Infection Prevention and Control (IPC) guidelines to provide detailed guidance on IPC measures during the COVID-19 pandemic. These guidelines, <sup>13, 14</sup> and those from the Australian Government<sup>20</sup> recommend restricting or avoiding visitors as much as possible, or complete closure of health care facilities,

particularly RACFs. While these measures are designed to protect residents, families and staff,<sup>19</sup> the resultant impacts on optimal family-centred end-of-life care for people dying with COVID-19, and those dying from other causes during the COVID-19 pandemic, are stark and therefore planning to enable high-quality care within this context is essential.

# Providing quality end-of-life care for people during the COVID-19 pandemic

Current responses to Humanitarian (sic) emergencies and crises rightfully focus on saving lives, but for both ethical and medical reasons, the prevention and relief of pain, as well as other physical and psychological symptoms, social and spiritual distress, are also imperative.<sup>21</sup>

Quality end-of-life care requires access to appropriate symptom control, access to essential medicines and expert nursing care.22 Additionally, whilst public health and infection prevention and control measures are essential to minimising risks associated with COVID-19, care considerations extend far beyond these. Recent international debate has focused on the need to balance infection prevention and control measures, designed to protect individuals and minimise the spread of COVID-19,23 with consideration of potential psychological and social impacts of such measures.23 Prior to COVID-19, social isolation was already a serious public health concern amongst older populations,24 contributing to the cycle of illness, increased healthcare utilisation, increased depressive symptoms in older people<sup>24</sup> and cognitive decline.<sup>25</sup> Restricting visitor access to RACFs during the pandemic has likely exacerbated these issues, through lost reduced access to previously established support networks, such as family, as residents are now spending increased time alone.26

Informal carers such as family members, who are commonly considered part of a person's care team<sup>23</sup> not only provide social connection and support,<sup>27</sup> but also assist to ensure care is personand family-centred, an approach to care that is more, not less important during a pandemic.<sup>23</sup> Person-centred care is about protecting a person's dignity, and respecting a person's rights and preferences.<sup>28</sup> COVID-19 has placed limitations on treatment and end-of-life care options,<sup>29</sup> emphasising the importance of opportunities for informal carer involvement and collaboration where possible<sup>30</sup>. Nurturing the family unit and maintaining family relationships and connection is key to the health and welfare of individuals and families alike.<sup>30</sup>

For some individuals diagnosed with COVID-19, there is also a need for skilled conversations about withdrawing and withholding life support.<sup>11, 16</sup> These conversations are difficult at the best of times, but pose new difficulties when family and appointed alternative decision-makers are not able to be present due to enhanced public health and infection prevention and control requirements.





#### Family-centred approaches to end-of-life care

Significant media attention has focused on informal carer and family members' responses to limited communication from care providers to family members and the restricted access to health and aged care facilities during the COVID-19 pandemic.<sup>31, 32</sup>In response, there are multiple media stories and reports of clinicians and care workers using alternate and innovative means to support and facilitate communication and family connection. In the height of the COVID-19 surge in Italy, one ICU team initiated daily video calls with family to enable family connection and provide opportunity for informal carers and families to receive an update from clinicians.33 Similar programs are now being used in RACFs in Australia so that older people can connect with family, and to reduce feelings of loneliness and isolation.<sup>34</sup> An online telehealth counselling and support service, staffed by psychology students has also been established to support older Australians living in residential aged care.<sup>35</sup> Despite these welcome initiatives, restrictions to visitation has been most deeply felt towards the end of life and into bereavement.

When a person is dying, families wish to be kept informed<sup>36, 37</sup> and close to the dying person, to keenly observe, comfort and protect.<sup>38</sup> Communicating with cultural sensitivity<sup>39</sup> and enabling family to support culturally-specific practices are also important at death.<sup>40</sup> Death is a time of intimacy, vulnerability and poignancy.<sup>41</sup> Thus, the impact of restricted access to health care settings for the person and their family is likely to be profound, extending beyond the immediate grief and bereavement.<sup>18</sup> Given the nature of the relationship typically established between families and nurses, the nurse-family relationship is critical to perceptions of end-of- life care<sup>42</sup> and the provision of immediate grief and bereavement support.<sup>43</sup>

#### Support for nurses in the provision of end-of-life care

Australia's nursing workforce is highly educated, flexible and responsive to patient and community needs.<sup>44</sup> Registered nurses represent the largest group of health care professionals making up 55% of all health professionals, who provide care for life-limiting conditions across all care settings.<sup>22</sup> Nurses are central to responding to the range of physical, emotional, social and spiritual needs of people with life-limiting illness,<sup>22</sup> which includes extending care to family. Nurses are central to the inclusion of family and significant others in decision making and end-of-life care processes.<sup>29, 45</sup> Yet In a pandemic, it may not be possible or feasible to have meaningful conversations about a person's wishes, placing further strain on the role of nurses in collaborative teams with a diminished capacity for quality care at end of life.<sup>46</sup>

Nurses and other clinicians, personal care workers and nonclinical support staff will therefore also experience COVID-19 as a very intensive and traumatic time resulting in suffering and distress.<sup>9</sup> Early evidence from Wuhan, China demonstrated that frontline healthcare workers reported symptoms of depression, anxiety and distress.<sup>47</sup> Whilst Australian evidence is not yet available, large scale public health concerns including but not limited to COVID-19 significantly increase the potential for nurses and health care workers to experience compassion fatigue and burnout.<sup>48</sup> Thus, supporting nurses to provide end-of-life care during the pandemic, through actions including but not limited to peer support, debriefing and team support solutions is essential to preserving nurses' physical and psychological health and wellbeing.<sup>49</sup>

#### Implications

The experience of COVID-19 not only highlights immediate areas of concern for government, patients, residents, their families and carers, but also re-emphasises issues already identified by the Royal Commission into Aged Care Quality and Safety such as failings in the quality of the care provided for people who are close to death.<sup>50</sup> In relation to residential aged care, ACN has previously emphasised the need for regulation, legislation and policies that support appropriate staffing requirements in residential aged care, specifically for registered nurses to be on-site at all times.<sup>51</sup> ACN has also clearly documented the essential role that nurses play to ensure quality end-of-life care.<sup>22</sup>

Finding ways to address the current and underlying challenges associated with the provision of high-quality patient- and family-centred care at the end of life requires a resolution of all the known concerns, including staffing shortages, educational preparation and workers concerns over risk to themselves and their family.<sup>52</sup> Ensuring the needs of nurses and other health care workers are acknowledged and addressed is key.

#### CONCLUSION

The COVID-19 global pandemic presents significant challenges to enabling optimal person- and family-centred end-of-life care, irrespective of care setting. That said, there are several key areas of focus for healthcare leaders to analyse and address to support nurses in providing the best end-of-life care possible within a pandemic. This includes: ensuring adequate resourcing to enable impeccable nursing assessment, care planning and provision; innovative approaches for regular and meaningful information provision for individuals and families; innovative approaches for enabling remote family and informal carer connections as well as spiritual and cultural supports; upskilling for nurses in relation to the evolving nature of COVID-19; and resourcing to support nurse wellbeing and self-care within this context.

Further information about COVID-19 and end-of-life care is available at <u>CareSearch</u>.





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