



Response to the Initial  
13 Findings & 6 Recommendations  
of  
*The Safe Approach to End of Life Choices*  
(Minority Report for the  
Joint Select Committee on End of Life Choices  
by The Hon Nick Goiran, MLC)

28 August 2020

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## Introduction

The Western Australian Parliament charged the Joint Select Committee on End of Life Choices with (amongst other things) inquiring into the state of palliative care in the state in early 2018.

The Committee published their findings in a report called *My Life, My Choice: The 1<sup>st</sup> Report of the Joint Select Committee on End of Life Choices* in August 2018.

A member of the Joint Select Committee, The Hon Nick Goiran MLC, released a minority report entitled *The Safe Approach to End of Life Choices: Licence to Care, Not Licence to Kill*.<sup>1</sup>

On 30 July 2020, Will Hallahan (Project Officer, Palliative Care) and Dr Paula Moffat (Director of Palliative Medicine and Palliative Medicine Consultant) of Bethesda Health Care testified before the Joint Select Committee on Palliative Care in Western Australia, which was established by Parliament in May 2020.

At the hearing, the Hon Nick Goiran MLC asked Bethesda Health Care to provide a written response to the first 13 findings and 6 recommendations of *The Safe Approach to End of Life Choices*, and indicate whether any of these should be endorsed by the Joint Select Committee on Palliative Care in Western Australia.

## Bethesda Health Care

Bethesda Health Care is a Christian organisation established to actively contribute and to make a difference in our community and the world in which we live.

Our mission is 'to deliver the highest quality healthcare experience for our patients', and our values are:

- teamwork – creating an environment of unity and togetherness
- respect – recognising and acknowledging the uniqueness and value of every individual
- integrity – demonstrating honesty and trustworthiness
- compassion – expressing God's love through a caring, kindness, tolerance and tenderness
- excellence – excelling in all that we do so that we can promote our mission
- professionalism – taking pride in our work.

Bethesda operates a medium-sized licensed hospital at Claremont which offers privately-funded medium-acuity surgical services and inpatient care, and publicly- and privately-funded inpatient care palliative care.

We are also contracted by the Western Australia Department of Health to manage the Metropolitan Palliative Care Consultancy Service (MPaCCS), which provides consultancy support, education, and ongoing clinical support to residential care facilities (aged care, mental health, disability and correctional) throughout Perth.

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<sup>1</sup> Goiran (2018) *The Safe Approach to End of Life Choices: Licence to Care Not Licence to Kill – Minority Report by Hon NP Goiran MLC for the Joint Select Committee on End of Life Choices*

# Response to Selected Findings & Recommendations

## Finding 1

*Specialist palliative care is a relatively new discipline within the medical profession.*

Bethesda agrees with this finding.

The modern palliative care movement dates back to the late 1960s and early 1970s. During this early period the concept was championed by a small number of visionary pioneers, often working within non-government organisations, sometimes funded only by charitable contributions, frequently operating without robust evidence about the benefits of the overall approach or specific therapies.

It has taken several years for palliative care to be fully integrated within healthcare systems around the world,<sup>2</sup> including the Australian healthcare system. In a short space of time, evidence-based palliative care practices have been developed (and continue to be developed),<sup>3</sup> and the principles of palliative care are increasingly routinely included in the education of healthcare providers,<sup>4</sup> while general community awareness and understanding<sup>5</sup> of palliative care is slowly growing.

## Finding 2

*Palliative care is poorly understood within the Western Australian community.*

Bethesda agrees with this finding.

In our experience, many members of the community understand 'palliative care' to apply only in the terminal phase (the final days or hours of life), although the evidence clearly demonstrates palliative care can provide great benefits early in an individual's end-of-life journey.<sup>6,7,8</sup> We observe that some associate palliative care with lesser levels of care, choice and hope.<sup>9</sup>

In addition, many people assume palliative care is only relevant for people with a primary diagnosis of cancer,<sup>10,11</sup> even though a wealth of policy and science emphasises the value of this approach to care for people with non-cancer life-limiting illnesses.<sup>12</sup>

## Finding 3

*The provision of quality palliative care affirms a patient's right to choose their therapy, decline futile treatment, choose their place of dying, receive the best possible relief of symptoms and to refuse to prolong the dying process.*

Bethesda agrees with this finding.

Bethesda subscribes to the World Health Organisation's definition of palliative care.<sup>13</sup>

We also assert that quality care at the end-of-life is only possible when it conforms with the individual's values and preferences.

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<sup>2</sup> Floriani & Schramm (2012) 'Routinisation and medicalisation of palliative care: Losses, gains and challenges' - *Palliative Supportive Care* - doi: 10.1017/S1478951511001039

<sup>3</sup> Tieman et al (2008) 'Changes in the quantity and level of evidence of palliative and hospice care literature: The last century' - *Journal Clinical Oncology* - doi: 10.1200/JCO.2008.17.6230

<sup>4</sup> Fitzpatrick et al (2017) 'Palliative care in undergraduate medical education: How far have we come?' - *American Journal Hospice Palliative Care* - doi: 10.1177/1049909116659737

<sup>5</sup> O'Connor et al (2019) 'A tripartite model of community attitudes to palliative care' - *American Journal Hospice Palliative Medicine* - 36(10)

<sup>6</sup> Zambrano et al (2016) 'The impact of early palliative care on the quality of care during the last days of life: What does the evidence say?' - *Current Opinion Supportive Palliative Care* - 10(4)

<sup>7</sup> Davis et al (2015) 'A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illness' - *Annals Palliative Medicine* - 4(3)

<sup>8</sup> Haun et al (2017) 'Early palliative care for adults with advanced cancer' - *Cochrane Database Systematic Reviews* - 12(6)

<sup>9</sup> Collins et al (2017) 'Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers' - *Palliative Medicine* - doi: 10.1177/0269216317696420

<sup>10</sup> Oishi & Murtagh (2014) 'The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and healthcare professionals' - *Palliative Medicine* - doi: 10.1177/0269216314531999

<sup>11</sup> Russ et al (2015) 'Staff perceptions of palliative care in a public Australian, metropolitan emergency department' - *Emergency Medicine Australasia* - doi: 10.1111/1742-6723.12428

<sup>12</sup> Mitchell et al (2010) 'Palliative care beyond that for cancer in Australia' - *Medical Journal Australia* - 193

<sup>13</sup> World Health Organisation, United Nations (2002) *WHO Definition of Palliative Care* @ [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/) accessed 18 Aug 20

Many people with life-limiting illnesses do not wish to avail themselves of invasive or burdensome therapies and treatment directed at the prolongation of life if quality of life is impaired, and most wish to choose where they are cared for, and where they might die.<sup>14,15</sup>

Furthermore, people approaching the end-of-life want to:<sup>16,17</sup>

- be free from pain and other troubling symptoms
- be in the company of their family and friends,
- maintain their function
- receive culturally sensitive care
- be treated as a whole person
- have the opportunity to prepare for death
- have coordinated, undisrupted care
- have trusting relationships with the staff looking after them.

Bethesda notes that artificial hydration and nutrition (ie feeding tubes and drips) have long been considered medical treatments, which a person may refuse.

Dying in one's preferred place of death is often cited as a key element of a 'good death' (although a lively debate surrounds the idea,<sup>18</sup> and it is not necessarily as important to patients and family carers as other factors<sup>19</sup>).

A majority of Australians die in hospitals,<sup>20</sup> although most – when well – say they would prefer to die at 'home'.<sup>21</sup> For many people dying in an acute hospital is a potentially poor outcome: numerous barriers<sup>22</sup> inhibit the provision of the type of care that patients and those close to them value most highly,<sup>23</sup> and the risk of receiving non-beneficial treatments is high.<sup>24</sup>

## Finding 4

*Medical treatment, including palliative care is an end of life choice currently available in Western Australia, however:*

- a) *patients with non-malignant diseases are under-represented in palliative care in WA; and*
- b) *access to good quality palliative care across the State is, in any event, currently highly variable.*

### Finding 4a

Bethesda agrees with this finding.

Cancer is still the leading cause of death for most Western Australians (29.4%),<sup>25</sup> although the death rate from cancer has generally decreased in the last 50 years, and the Australian Institute of Health and Welfare predicts it will drop further between 2014 and 2025.<sup>26</sup>

<sup>14</sup> Gerber et al (2019) "It all depends!": A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers' – *Palliative Medicine* – doi: 10.1177/0269216319845794

<sup>15</sup> Agar et al (2008) 'Preference for place of care and place of death in palliative care: Are these different questions?' – *Palliative Medicine* – doi: 10.1177/0269216308092287

<sup>16</sup> Sutton & Coast (2006) 'Older people's preferences at the end-of-life: Developing attributes of a good death' – *Palliative Medicine* – 22(4)

<sup>17</sup> Meier et al (2016) 'Defining a good death (successful dying): Literature review and a call for research and dialogue' – *American Journal Geriatric Psychiatry* – 24(4)

<sup>18</sup> For example: Leiter (2019) 'Is dying at home over-rated?' – *New York Times* – 03 Sep 19

<sup>19</sup> Meier et al (2016) 'Defining a good death (successful dying): Literature review and a call for research and public dialogue' – *American Journal Geriatric Psychiatry* – 24(4)

<sup>20</sup> Productivity Commission, Australian Government (2017) 'End-of-life care in Australia' – *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services – Productivity Commission Inquiry Report* – # 85

<sup>21</sup> Swerissen & Duckett (2015) 'What can we do to help Australians die the way they want to?' – *Medical Journal Australia* – 202(1)

<sup>22</sup> Gardiner et al (2011) 'Barriers to providing palliative care for older people in acute hospitals' – *Age Ageing* – 40(2)

<sup>23</sup> Virdun et al (2015) 'Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end of life care that patients and their families rank as being most important' – *Palliative Medicine* – 29(9)

<sup>24</sup> Cardona-Morell et al (2016) 'Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem' – *International Journal Quality Health Care* – doi: 10.1093/intqhc/mzw060

<sup>25</sup> Australian Bureau of Statistics, Australian Government (2019) 3303.0 *Causes of Death, Western Australia, 2018* (Excel spreadsheet)

<sup>26</sup> Australian Institute of Health and Welfare (2015) *Cancer Mortality Trends and Projections: 2014 to 2025* @

[www.aihw.gov.au/reports/cancer/cancer-mortality-trends-and-projections-2014-to-2025/contents/all-cancers-combined](http://www.aihw.gov.au/reports/cancer/cancer-mortality-trends-and-projections-2014-to-2025/contents/all-cancers-combined) accessed 05 Feb 18

By comparison, 42.5% of foreseeable deaths in the state care caused by non-cancer conditions,<sup>25,27</sup> This is likely to increase over time because age is a major risk factor for the development of chronic illness, multimorbidity and frailty, and our population is ageing.<sup>28</sup>

People with non-cancer life-limiting illnesses, and their family carers, have similar palliative care needs to those with cancer.<sup>29,30</sup> People with these non-cancer terminal conditions may have unpredictable trajectories,<sup>31,32</sup> marked by irregular life-threatening exacerbations, ongoing dwindling,<sup>33</sup> and occasional rallies,<sup>34</sup> all of which can contribute to sub-optimal referrals to specialist palliative care.

People who die from a non-malignant condition are less likely to die in the place they prefer,<sup>35</sup> and more likely to die in hospital,<sup>36</sup> than those whose cause of death is cancer. A UK study calculated the average (median) duration from referral to death for people with non-cancer conditions in a community palliative care service was 22 days, compared to an average (median) duration of care for all patients of 46 days.<sup>37</sup>

Two important scientific papers about the rate of access by people with non-malignant life-limiting illnesses to specialist palliative care services in Western Australia have been published in the last twenty years.<sup>38,39</sup> While the findings in these articles are striking, they are – in 2020 – outdated.

Recent information is available from the Palliative Care Outcomes Collaboration. Their report *Patient Outcomes in Palliative Care in Western Australia – July to December 2019* – provides data on 4,618 episodes of care provided by 18 participating services.<sup>40</sup> These data reveal people with a primary diagnosis of cancer accounted for 58.3% (n = 2,698) of episodes of care.

Of the remaining 41.5% (n = 1,920) of episodes – which were for people with non-cancer conditions – one service (the Metropolitan Palliative Care Consultancy Service, managed by Bethesda Health Care) provided 37.3% (n = 717),<sup>41</sup> all delivered in residential care facilities (principally aged care).

Spilsbury et al<sup>42</sup> analysed cost data from WA in 2009-10, and observed that people with non-cancer palliative care compatible conditions who accessed community palliative care (Silver Chain) incurred an average of 27% less hospital cost than those who did not.

## Finding 4b

Bethesda agrees with this finding.

Recent investments by the Western Australian Country Health Service (WACHS) will go some way to improving this situation. Regional palliative care services across the state have been expanded and consolidated, and their clinical governance structures have been strengthened. These are welcome initial steps – more will need to be done as rural and regional populations grow.

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<sup>27</sup> The remaining 28.1% of deaths are mostly unexpected and from causes (eg accidents or sudden acute events) which are not amenable to palliative care.

<sup>28</sup> Australian Bureau of Statistics, Australian Government (2017) *2017.0 – Census of Population and Housing: Reflecting Australia – Stories from the Census, 2016* @

[www.abs.gov.au/ausstats/abs@nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14](http://www.abs.gov.au/ausstats/abs@nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14) accessed 06 Jul 20

<sup>29</sup> See et al (2019) 'Symptom burden in malignant and non-malignant disease on admission to a palliative care unit' – *BMJ Supportive Palliative Care* – doi: 10.1136/bmjspcare-2018-001560

<sup>30</sup> Moens et al (2014) 'Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review' – *Journal Pain & Symptom Management* – 48(4)

<sup>31</sup> Barclay et al (2014) 'Living in uncertain times: Trajectories to death in residential care homes' – *British Journal General Practice* – 64(626)

<sup>32</sup> Murray et al (2005) 'Illness trajectories and palliative care' – *British Medical Journal* – doi: 10.1136/bmj.330.7498.1007

<sup>33</sup> Finucane et al (2017) 'Gradual physical decline characterises the illness trajectories of care home residents' – *International Journal Palliative Nursing* – 23(9)

<sup>34</sup> Lynn & Adamson (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age* – RAND Health White Paper

<sup>35</sup> Billingham & Billingham (2013) 'Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: A systematic review and meta-analysis' – *BMJ Supportive Palliative Care* – 3

<sup>36</sup> Reeve et al (2017) 'Health care use and costs at the end of life: A comparison of elderly Australian decedents with and without a cancer history' – *BMC Palliative Care* – 17(1)

<sup>37</sup> Bennett et al (2016) 'What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city' – *BMJ Open* – 6(12)

<sup>38</sup> McNamara & Rosenwax et al (2004) *Who Receives Specialist Palliative Care in WA – And Who Misses Out?*

<sup>39</sup> Rosenwax et al (2016) 'A retrospective population-based cohort study of access to specialist palliative care in the last year of life: Who is still missing out a decade on?' – *BMC Palliative Care* – 15(46)

<sup>40</sup> Palliative Care Outcomes Collaboration (2020) *Patient Outcomes in Palliative Care in Western Australia – July to December 2019*

<sup>41</sup> Palliative Care Outcomes Collaboration (2020) *Metropolitan Palliative Care Consultancy Service Patient Outcomes in Palliative Care – July to December 2019*

<sup>42</sup> Spilsbury (2017) 'Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life' – *BMC Palliative Care* – 16(1)

As made clear in Bethesda's written submission and in-person evidence to the Joint Select Committee Inquiry into Palliative Care in Western Australia, access to specialist services in metropolitan Perth remains patchy.

The consultation liaison teams in tertiary hospitals are short-staffed, Silver Chain's community service does not have the ability to consistently provide early palliative care, the current Metropolitan Palliative Care Consultancy Service is subject to a funding cap (which was exceeded in the year ending 30 June 2020), public inpatient palliative care services delivered by non-government organisations run at a loss and are understaffed, while people in the outer suburbs must travel substantial distances to access them.

## Finding 5

*Data from the Palliative Care Outcomes Collaboration (PCOC) can be useful in comparing one service provider with another but it is not, nor is it intended to be, an academically rigorous tool to assess palliative care generally.*

Bethesda agrees with this finding.

While the Palliative Care Outcomes Collaboration is designed as a benchmarking and quality improvement collaborative, it remains the only rigorous large-scale data collection about palliative care outputs and outcomes in Australia. Bethesda has integrated PCOC concepts and language into our service provision models and processes, and PCOC outcomes data are a key element of our improvement efforts.

PCOC also incorporates a casemix classification, which means that the outcomes scores are presented for different classes of patients, to permit valid comparisons across the participating service cohort.

Shortcomings of which we are aware (some may be rectified in coming years) include that:

- not all specialist palliative care services participate
- some important symptoms experienced at the end-of-life are not routinely assessed (eg delirium) and outcomes data are therefore not available
- the range of available diagnoses does not include important (emerging) categories such as frailty, multimorbidity, and different types of dementia
- assessment data are not available (in outcomes reports) for the end of the terminal phase (ie 'Symptom distress at the beginning of a phase' is reported, but symptom distress at the end of a phase is not, so the outcomes of effective care interventions are not shown).

## Recommendation 1

*The Minister for Health should consult with the Palliative Care Outcomes Collaboration (PCOC) and service providers to determine a data collection methodology that would set the lowest figures for unmanaged pain symptoms as the aspirational standard for every service provider.*

Bethesda supports this recommendation.

The management of pain and other troubling symptoms is a cornerstone of palliative care.

Well-designed quality standards can improve performance and outcomes in healthcare.<sup>43</sup>

Suffering is entirely subjective. The existing PCOC Symptom Assessment Scale (SAS) seeks to measure the level of *distress* a symptom gives the individual (ie a person may seem to have trouble sleeping, but this may not distress them, so they would record a low score for this symptom). This approach to the symptom measurement is essential, and should be adopted in any new standards initiative.

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<sup>43</sup> Brand et al (2008) 'Standards for health care: A necessary but unknown quantity' - *Medical Journal Australia* - 189

Additionally, the concept of ‘total pain’ demands that healthcare providers assess and address the physical, psychological, emotional, existential and social factors that contribute to an individual’s suffering.<sup>44</sup> A patient with significant physical pain may indeed have significant underlying spiritual or psychological distress.

Symptom management methods must always be acceptable to the patient and other stakeholders (such as family members). For example, use of a medication associated with a significant risk of sedation in order to minimise the pain of a patient who values interactions with family and friends is not quality care. New initiatives must not perversely incentivise providers to disregard the patient’s values and preferences in order to meet a minimum standard.

## Recommendation 2

*The Minister for Health should consult with palliative care service providers to ascertain the current deficit in capacity preventing equitable provision of specialist palliative care across Western Australia.*

Bethesda supports this recommendation.

Bethesda notes that in mid-2020 the Perron Institute was commissioned to review models of specialist palliative care service provision in Western Australia, and this research project will include sector consultations.<sup>45</sup>

## Recommendation 3

*The Minister for Health should assess the recommendations made by Western Australia’s peak body for palliative care and report to Parliament with a plan to:*

- a) *utilise co-design workshops*
- b) *progress the Compassionate Communities model*
- c) *introduce shared-care models*
- d) *increase the capacity of the Silver Chain Hospice Care Service model of care*
- e) *build the capacity of existing outpatient clinics to facilitate advance care planning*
- f) *increase the availability and flexibility of telehealth.*

Bethesda supports all these recommendations.

In relation to Recommendation 3(c), Bethesda notes that Silver Chain is not the only possible provider of specialist palliative care services in the community, and all services operating in this setting need to be appropriately resourced. Regarding Recommendation 3(e), we are of the view that while existing outpatient clinics need additional capacity, there is also value in starting new palliative care outpatient clinics in a range of community locations across Perth.

## Finding 6

*Loss of hunger and thirst occurs frequently as a normal part of the natural dying process.*

Bethesda supports this finding.

## Finding 7

*Refusal of nutrition and hydration is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.*

Compelling a competent individual approaching death due to the progress of a life-limiting illness to eat or drink (or to accept artificial feeding and hydration) is inconsistent with quality care. Such an intervention would directly contravene the individual’s values and preferences, would be unlikely to benefit the individual, and would more likely cause them harm.

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<sup>44</sup> Cherny (2010) ‘The problem of suffering and the principles of assessment in palliative medicine’ in Hanks et al (eds) (2010) *Oxford Textbook of Palliative Medicine: Fourth Edition*

<sup>45</sup> Perron Institute (2020) *Reviewing Perceptions of Palliative Care in WA* @ <https://perroninstitute.org/reviewing-perceptions-of-palliative-care-in-wa/> accessed 18 Aug 20

Bethesda agrees with the American Nurses Association, which states:<sup>46</sup>

*For voluntarily stopping eating and drinking (VSED) to be an informed decision, the patient must not be encumbered by depression or other factors that impede decision-making.*

Bethesda notes evidence provided by palliative care practitioners to the Joint Select Committee on End of Life Choices and cited in the Minority Report that refusal of food and drink by competent patients (as distinct from the loss of hunger and thirst commonly seen in the terminal phase and referred to above at Finding 6) is unusual.<sup>47</sup>

Some people who are not imminently dying may consider ceasing eating and drinking in order to hasten death. The desire to die may be caused by problems such as psychological, social, physical or spiritual suffering – all problems which can be effectively addressed by specialist palliative care, with the help of mental health services, in most instances.<sup>46,48,49</sup>

## Finding 8

*Refusal of medical treatment is an end of life choice currently available in Western Australia, however it is significantly distinguishable from assisted suicide as it is based on the right to inviolability and is in any case reversible.*

Bethesda supports this finding.

Bethesda understands that an adult with decision-making capacity has the right to refuse medical treatment in Western Australia,<sup>50</sup> and that artificial feeding and hydration (ie by tubes or infusions) are medical treatments.

The statement that the right to refuse medical treatment is based on the right to inviolability is confirmed out by the Australian Law Reform Commission.<sup>51</sup>

## Finding 9

*Palliative sedation, when competently administered, is a legal and ethical end of life choice currently available in Western Australia.*

Bethesda understands that so-called ‘palliative sedation’ is not illegal in Western Australia. The term is, however, often misused and misinterpreted by non-medical and medical staff.

In Bethesda’s view, sedation of the patient should not be a primary goal of care. Instead, it may be a secondary (but foreseeable) consequence of optimal management of an individual’s troubling symptoms (eg delirium), or of an effective response to a rare catastrophic terminal event (eg bleed, airway obstruction, seizure etc).

Best practice does not entail sedating a person solely because they are dying.

Our experience is that ‘terminal sedation’ is sometimes proposed by the family members or friends of dying people<sup>52</sup> who may be unfamiliar with death and distressed by what they see, even when the patient is dying peacefully. Onlooker distress can be effectively managed with clear and consistent education and excellent communications.

Bethesda supports Recommendation 10 of *My Life, My Choice, The 1<sup>st</sup> Report of the Western Australian Parliament’s Joint Select Committee on End of Life Choices*.

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<sup>46</sup> American Nurses Association (2017) *Nutrition and Hydration at the End of Life*

<sup>47</sup> Page 15 of the *Minority Report*.

<sup>48</sup> Porta-Sales et al (2019) ‘The clinical evaluation of the wish to hasten death is not upsetting for advanced cancer patients: A cross-sectional study’ – *Palliative Medicine* – doi: 10.1177/0269216318824526

<sup>49</sup> Hudson et al (2006) ‘Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals’ – *Palliative Medicine* – doi: 10.1177/0269216306071814

<sup>50</sup> White & Willmot, Australian Centre for Health Law Research, Queensland University of Technology (2020) *End of Life Law in Australia* – ‘Capacity and consent to medical treatment’ – @ <https://end-of-life.qut.edu.au/capacity> accessed 18 Aug 20

<sup>51</sup> Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws (DP81)* – ‘Informed consent to medical treatment’ @ [www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/10-review-of-state-and-territory-legislation/informed-consent-to-medical-treatment/](http://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/10-review-of-state-and-territory-legislation/informed-consent-to-medical-treatment/) accessed 18 Aug 20

<sup>52</sup> This seems to be a growing trend: Heijltjes et al (2020) ‘Changing practices in the use of continuous sedation at the end of life: A systematic review of the literature’ – *Journal Pain Symptom Management* – doi: 10.1016/j.jpainsymman.2020.06.019

## Finding 10

*An expanding evidence base has repeatedly confirmed that the appropriate use of sedating or pain-relieving medications does not hasten death.*

Bethesda supports this finding.

## Finding 11

*Palliative sedation does not hasten death.*

In Bethesda's view, given the wide and largely unregulated variation in the understanding and practice of 'palliative sedation', and the range of reasons for which it might be employed, we are not in a position to know, one way or the other, that it does not hasten death in the real world.

For patients under the care of palliative care specialists however, the use of medications to manage symptoms (of whatever cause) that may result in sedation, is carefully regulated and titrated to optimise symptom control. In these situations, it is clear that patients are dying from their underlying disease, and that such medications are used with the primary intention of optimising symptom control.

Bethesda notes and broadly endorses the evidence of palliative care doctors, Palliative Care WA, and others cited in the Minority Report that 'palliative sedation' in the context of 'good quality palliative care' does not hasten death.<sup>53</sup>

Bethesda agrees that the appropriate use of morphine and other opioids in palliative care does not hasten death. None-the-less, the perception that opioids are used to hasten death is common in the broader community.<sup>54</sup>

Opioid medications are seldom used to sedate a person approaching the end of life – benzodiazepines are more commonly chosen. It is important, in our view, to separate these two classes of drugs in any discussion of 'palliative sedation' and whether this practice hastens death.

## Finding 12

*Under-dosing and failure to make a specialist referral are problems that lead to unnecessary suffering and distress for patients and loved ones.*

Bethesda supports this finding.

The reader's attention is drawn to Bethesda's comments about Finding 33 of the *My Life, My Choice* report in our *Response*,<sup>55</sup> which cite the Joint Select Committee's findings about a wide variety of deficiencies in Western Australia's palliative and end-of-life care system that may directly result in intolerable suffering for individuals living with life-limiting conditions, and which emphasise that these deficiencies can and should be rectified.

Such conclusions are supported in the literature.<sup>56</sup>

## Finding 13

*Under-dosing and failure to make a specialist referral occur because of a lack of medical training and, in some cases, outdated teaching.*

Under-dosing and failure to refer patients with palliative care needs to specialist services can occur for a wide range of reasons, not just lack of or poor medical training.

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<sup>53</sup> Pages 23-24 in the *Minority Report*.

<sup>54</sup> Grant et al (2017) 'Morphine use in cancer care: A survey of attitudes and perceptions in general practice patients' – *Australian Family Physician* – 46(10)

<sup>55</sup> Bethesda Health Care (2018) *Response to My Life, My Choice: The 1<sup>st</sup> Report of the Western Australian Parliament's Joint Select Committee on End of Life Choices*

<sup>56</sup> Gallagher et al (2020) 'Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error' – *Medical Hypotheses* – doi: 10.1016/j.mehy.2020.109727

## Prescribing Opioids

Recognising the harms which can result from the misuse of opioid medications, the Australian Government updated prescribing regulations for this class of drugs in mid-2020.<sup>57,58</sup> In Bethesda's experience, general understandings of opioids, and prescribing regulations (including the updated regulations) – while necessary – have complicated the use of opioids in palliative care, and some GPs have become very reluctant to prescribe them for patients approaching the end-of-life.<sup>59</sup> This results in poor outcomes for patients.

## Palliative Care Services

Pippa Hawley argues palliative care providers give out 'mixed messages':<sup>60</sup>

*Refer early... but only when you are 100% sure your patient is dying.*

*Refer early... but we don't have room for any but the sickest.*

*Palliative care will make you feel better... but you can only have it when there's nothing else left to offer.*

*Palliative care is better at home... but you will have to do a lot of all the work and shoulder much of the cost.*

While such mixed messages seem to be the result of lack of resources, it is not to be wondered at that primary healthcare providers and other specialists can struggle to make appropriate referrals to specialist palliative care services, particularly for those patients who have unpredictable end-of-life trajectories.

## Recommendation 4

*The Minister for Health should facilitate and monitor an improved communication protocol, and if necessary, an improved communication pathway, between medical practitioners and specialist palliative care services.*

Bethesda supports this recommendation.

The evidence confirms that, in particular, the transition to palliative care can be disruptive, burdensome, confusing, and even traumatic for patients and their carers.<sup>61</sup> The UK's National Institute for Health and Care Excellence (NICE) states that the transition process should address 'the medical, social and psychological needs of a person as they move from one system or place to another.'<sup>62</sup>

Priority three of the *WA End-of-Life and Palliative Care Strategy 2018-2028* highlights the need for improved continuity of care at the end-of-life:

*My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.*

NICE guidelines for organising and delivering quality care at the end-of-life recommend the use of 'electronic information-sharing systems that are accessible between different services and organisations to enable information to be reviewed, updated and shared efficiently within and between multipractitioner teams, across different services and organisations.'<sup>63</sup> Bethesda clinicians – as employees of a non-government organisation – are unable to routinely access information about patients from WA Department of Health information systems.

<sup>57</sup> Department of Health, Australian Government (2020) *Prescription Opioids: Information for Health Professionals* @ [www.tga.gov.au/prescription-opioids-information-health-professionals](http://www.tga.gov.au/prescription-opioids-information-health-professionals) accessed 18 Aug 20

<sup>58</sup> Therapeutic Goods Administration, Australian Government (2020) *Revised Opioids PBS Listings for the Management of Severe Disabling Pain* @ [www.pbs.gov.au/news/2020/05/opioids-factsheet-files/opioids-factsheet-2020-v3.pdf](http://www.pbs.gov.au/news/2020/05/opioids-factsheet-files/opioids-factsheet-2020-v3.pdf) accessed 18 Aug 20

<sup>59</sup> Mitchell et al (2019) 'A perfect storm: Fear of litigation for end-of-life care' - *Medical Journal Australia* - 210(10)

<sup>60</sup> Hawley (2017) 'Barriers to access to palliative care' - *Palliative Care Research Treatment* - DOI 10: 1178224216688887

<sup>61</sup> Gardiner et al (2015) 'Exploring the transition from curative care to palliative care: A systematic review of the literature' - *BMJ Supportive Palliative Care* - doi: 10.1136/bmjspcare-2010-000001.rep

<sup>62</sup> National Guideline Centre, National Institute for Health and Care Excellence (2019) *NICE Guideline 142: End of Life Care for Adults – Service Delivery: Evidence Review – Optimal Transition and Facilitating Discharge*

<sup>63</sup> National Guideline Centre, National Institute for Health and Care Excellence (2019) *NICE Guideline 142: End of Life Care for Adults – Service Delivery: Guidance*

## Recommendation 5

*The Minister for Health should develop and roll out a community awareness program about specialist palliative care services.*

Bethesda supports this recommendation.

## Recommendation 6

*The Minister for Health should consult with palliative care specialists about mechanisms to improve the training and continuous professional education of all health practitioners about specialist palliative care services.*

Bethesda supports this recommendation.

## More Information

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