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# PRE-PLANNED STARVATION AND ADVANCED DEMENTIA — IS THERE A CHOICE?

COLLEEN DAVIS\*

*Canadian Margot Bentley's thoughts on Alzheimer's disease were quite clear. In a written statement of her wishes, she said, 'I want it to be known that I fear degradation and indignity far more than death.' She repeatedly made her wishes known to her family, verbally and in two written documents. However, judges refused to enforce Mrs Bentley's directive that food and drink be withheld when the disease progressed to the point that she no longer recognised her family. The reasons for the court's decision are relevant to Australians who want to pre-plan a death from starvation, in the event that they develop Alzheimer's and the disease progresses to a pre-determined stage. This paper considers the legislative scheme in Queensland for health care decision-making for a person without capacity and concludes that the outcome in a case with facts similar to Mrs Bentley's would probably be the same.*

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## I INTRODUCTION

As a nurse in her younger years, Margot Bentley saw firsthand how dementia progressively robbed patients of their cognitive and physical abilities, along with their independence and dignity. She was adamant that she did not want to suffer a similar fate. When Mrs Bentley was diagnosed with Alzheimer’s some years later, her family did everything they could to give effect to her written and verbal instructions that food and water be withheld when the disease reached an advanced stage. They even sought a court order to force care facility staff to comply. Despite the family’s efforts, the end of Mrs Bentley’s life was exactly what she had feared. She spent her final years in an emaciated, vegetative state, unable to speak or move, and incontinent — a far cry from the dignified death she had planned.

Although the tragedy of Margot Bentley’s final years played out in Canada, the case is a caution for Australians who want to plan their deaths if they develop Alzheimer’s. Although courts in both countries have recognised the right of people with full capacity to refuse sustenance,<sup>1</sup> and to be kept comfortable and sedated until they die,<sup>2</sup> the position

<sup>1</sup> This paper will use the term ‘sustenance’ to refer to nutrition and hydration.

<sup>2</sup> See, eg, *Manoir de la Pointe Bleue (1978) Inc c Corbeil*, 1992 CarswellQue 1623 (CS) (Quebec Supreme Court); *Brightwater Care Group Inc v Rossiter* [2009] WASC 229.

is not so clear when a person with capacity leaves instructions that sustenance be withheld in the event of later progressive cognitive decline. This paper will explore this issue, using the legislative scheme in Queensland as an example.<sup>3</sup> It begins by providing a brief outline of Margot Bentley's case and the progression of Alzheimer's before considering whether the problems highlighted by Greycliff J in the Supreme Court of British Columbia in *Bentley v Maplewood Seniors Care Society*,<sup>4</sup> and then affirmed by the Court of Appeal for British Columbia,<sup>5</sup> would be relevant to a Queenslanders in a position similar to that of Mrs Bentley. It argues that the outcome would be the same in Queensland. The paper concludes that it may not be possible for people to plan to starve to death if they develop Alzheimer's disease at a later date and are no longer able to care for themselves or to recognise family members. However, if the disease progresses to the point where the person is in a vegetative state or is kept alive by tube-feeding, the position may be different.

## II THE BENTLEY CASE

In 1991, Margot Bentley signed a document, witnessed by two people, requesting that if the time came when there was 'no reasonable expectation of my recovery from extreme physical or mental disability', she be 'allowed to die and not be kept alive by artificial means or heroic measures'. She also requested 'no electrical or mechanical resuscitation of my heart when it has stopped beating', 'no nourishment or liquids', and euthanasia in the event she was unable to recognise members of her family due to mental deterioration.<sup>6</sup>

Mrs Bentley was diagnosed with Alzheimer's in 1999, and she made her family promise that her wishes would be honoured.<sup>7</sup> They cared for her at home for five years and then moved her to a care facility. Within two years, Mrs Bentley was no longer able to recognise her family. Twelve years after diagnosis, Mrs Bentley spent her days lying

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<sup>3</sup> Each Australian jurisdiction has different provisions for health decision making when an adult does not have capacity. It is beyond the scope of this paper to compare how the decision in the *Bentley case* might affect a case with similar facts in the various Australian jurisdictions.

<sup>4</sup> *Bentley v Maplewood Seniors Care Society* (2014) BCSC 165 (British Columbia Supreme Court).

<sup>5</sup> *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91 (British Columbia Court of Appeal).

<sup>6</sup> *Bentley v Maplewood Seniors Care Society* (2015) BCCA 91, [2] (British Columbia Court of Appeal).

<sup>7</sup> Katherine Hammond, 'Kept Alive — The Enduring Tragedy of Margot Bentley' (2016) 6(2) *Narrative Inquiry in Bioethics* 80.

‘motionless in bed, contracted and spastic, unable to speak or to move, eyes closed most of the time, essentially unresponsive and diapered’.<sup>8</sup>

Mrs Bentley’s husband found a second document in 2011, in which Mrs Bentley stated that if she was in a state of severe physical illness with no reasonable prospect of recovery, she did not wish to be kept alive ‘by artificial means such as life-support systems, tube feeding, antibiotics, resuscitation or blood transfusions’ and that ‘any treatment which has no benefit other than a mere prolongation of my existence’ should be withheld or withdrawn.<sup>9</sup>

At this point, Mrs Bentley’s family asked that the care facility honour the ‘Living Will’—that staff stop force feeding Mrs Bentley but keep her comfortable with medication and sedation and allow her to die.<sup>10</sup> However, the care facility, supported by the local Health Authority, refused saying it had a legal duty to provide care to Mrs Bentley, and this included feeding her.<sup>11</sup> The care facility also refused to release Mrs Bentley into the care of her family so they could take her home or move her to another care facility. The family then sought a court declaration that Mrs Bentley not be given nourishment or liquids, in accordance with her wishes.<sup>12</sup>

Justice Greycell, in the Supreme Court of British Columbia, refused to grant the declaration sought. His Honour found that Mrs Bentley’s acceptance of sustenance offered by spoon touched to her mouth indicated consent and that she had the capacity to consent to assisted feeding. Further, such consent would override any earlier instructions that sustenance be withheld. His Honour indicated that the outcome would be the same if it was found that Mrs Bentley did not have capacity. First, the legislative regime covering health directives would not apply because spoon-feeding is personal care and not health care.<sup>13</sup> If this was not correct, the inconsistencies between the two written documents signed by Mrs Bentley meant that there was no valid advance directive that could be followed.<sup>14</sup> Justice Greycell then considered whether Mrs Bentley’s husband could make

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<sup>8</sup> Ibid [81].

<sup>9</sup> *Bentley v Maplewood Seniors Care Society* 2015 BCCA 91, [7] (British Columbia Court of Appeal).

<sup>10</sup> Hammond, above n 7, 81.

<sup>11</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [148] (British Columbia Supreme Court).

<sup>12</sup> Ibid [1].

<sup>13</sup> Ibid [77].

<sup>14</sup> Ibid [111].

this decision on her behalf. He said that Mr Bentley would not have the legal authority to 'make a binding decision [to withdraw assisted feeding] when her health care providers believe it is medically inappropriate'.<sup>15</sup>

The Court of Appeal upheld Greyell J's decision.<sup>16</sup> The reasons given by Greyell J for refusing the declaration sought suggest that it may not be possible for a person to direct that sustenance be withheld at a nominated point before Alzheimer's disease progresses to its final stages.

Margot Bentley's case is not an isolated one. In Oregon, Nora Harris was diagnosed with Alzheimer's in 2009 and signed an Advance Health Directive stipulating that she was not to be provided with care to prolong her life. When the disease progressed to the point where Nora could no longer communicate, recognise family members, or feed herself, her husband sought a court order preventing nursing home staff from spoon-feeding her, in accordance with Nora's wishes.<sup>17</sup> The court refused, for essentially the same reasons as in the *Bentley case*.<sup>18</sup> The next part of the paper considers whether the impediments raised by Greyell J would apply to the legislative scheme in Queensland.

### III ALZHEIMER'S DISEASE AND DEMENTIA

Dementia refers to a collection of symptoms rather than one specific disease. These symptoms include changes in thinking, behaviour, and the ability to perform everyday tasks. Dementia has many causes; Alzheimer's disease is the most common form of dementia and accounts for 60 to 80 per cent of dementia cases in Australia. More than 50 per cent of people in residential aged care facilities have dementia. The cost of dementia to the community in 2018 will be more than \$15 billion.<sup>19</sup>

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<sup>15</sup> Ibid [120].

<sup>16</sup> *Bentley v Maplewood Seniors Care Society* 2015 BCCA 91, [7] (British Columbia Court of Appeal).

<sup>17</sup> JoNel Aleccia, 'Despite Advance Directive, Dementia Patient Denied Her Last Wish, Says Spouse', *USA Today* (online), 21 August 2017 <<https://www.usatoday.com/story/news/health/2017/08/20/despite-advance-directive-dementia-patient-denied-her-last-wish-says-spouse/570585001/>>.

<sup>18</sup> See *Re Nora Harris* (Oregon, Jackson City Circuit Court No 13-107-G6, 13 July 2016).

<sup>19</sup> See generally Dementia Australia, *What is Dementia?*

<<https://www.dementia.org.au/information/about-dementia/what-is-dementia>>; Alzheimer's Association, 'Alzheimer's and Dementia in Australia' (2017) <<https://www.alz.org/au/dementia-alzheimers-australia.asp#about>>; 'Dementia' on *Mayo Clinic* (2 August 2017) <<https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447>>.

According to Dementia Australia, there are three phases of dementia: early, moderate, and advanced.<sup>20</sup> The early phase is usually very gradual, and signs include losing interest in activities, inability to adapt to change, poor judgment and decision-making, losing things, and forgetfulness. The signs are more apparent during the second phase and include confusion, forgetting the names of or confusing family members, leaving pots on the stove, wandering, and inappropriate behaviour. When the disease reaches its final stage, the person requires total care. The person often cannot remember things for even a few minutes, does not recognise friends or family, is completely dependent on others for daily activities, and becomes incontinent, disoriented, and confused. The person may become immobile and bedridden and struggle to communicate.<sup>21</sup>

In the final stages of the disease, people have little interest in food and have difficulty swallowing. Nutrition can be administered via a percutaneous endoscopic gastrostomy (PEG), a tube that is inserted directly into the stomach through an incision in the abdomen. However, the focus of this paper is on people whose wish is to die when they become unable to care for themselves and not on palliative care in the final few weeks of the disease. As in Margot Bentley's case, a high-care patient with dementia can remain alive for several years.

#### IV WITHHOLDING SUSTENANCE FROM A PATIENT

A person who has full capacity can refuse sustenance, and this decision must be respected by healthcare givers and others.<sup>22</sup> Capacity for this purpose in Queensland means that the person is capable of understanding the nature and effect of decisions about treatment or choosing a person to make decisions on his or her behalf, freely and voluntarily makes such decisions, and communicates the decisions in some way.<sup>23</sup>

Clearly, a person in an advanced stage of Alzheimer's would not have the requisite capacity to understand the serious implications of a request that food and water be withheld. However, it is unclear whether a court can uphold such a directive where it was

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<sup>20</sup> Dementia Australia, *Progression of Dementia* <<https://www.dementia.org.au/about-dementia/what-is-dementia/progression-of-dementia>>.

<sup>21</sup> *Ibid.*

<sup>22</sup> See *Brightwater Care Group Inc v Rossiter* [2009] WASC 229.

<sup>23</sup> *Guardianship and Administration Act 2000* (Qld) sch 4 (definition of 'capacity'); *Powers of Attorney Act 1998* (Qld) sch 3 (definition of 'capacity').

made while the person had capacity, with the intention that the directive should operate at a later date if the person becomes incapacitated.

*A When a Patient with Capacity has Left Clear Advance Health  
Directive Instructions and Later Becomes Incapacitated*

The *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld) set out a comprehensive legislative scheme for Queensland healthcare decision-making for a person without capacity. The scheme allows a person with capacity to set out his or her wishes in advance, in the form of an Advance Health Directive ('AHD') with the intention that the directive is to come into operation should the person lose capacity at some time in the future. The legislation also sets out a hierarchy of people who can make healthcare decisions for a person without capacity, in the event that the person did not leave valid instructions.

### 1 Advance Health Directive

One way for people to direct that sustenance be withheld should they develop a particular condition that involves a loss of capacity is to complete an AHD. In the directive, they can specify what medical treatments should be carried out and also which treatments should be withheld. Provided the requirements and formalities set out in the legislation are met, professionals generally must comply with the directive when a patient loses capacity.<sup>24</sup>

However, it is important that a person's instructions are set out clearly. If the instructions are uncertain or unclear, health care professionals do not have to fully comply.<sup>25</sup> In the *Bentley case*, the 1991 statement included a direction that she did not wish to be kept alive by 'artificial means or heroic measures' if she developed an extreme mental or physical disability from which there was no reasonable expectation of recovery. However, a little later on in the same document, Mrs Bentley directed that she not be given 'nourishment or liquids'. In the second document, found in 2011, she again asked that she be allowed to die and not be kept alive by artificial means such as tube feeding. She indicated that she would, however, accept basic care. Justice Greyell interpreted these

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<sup>24</sup> *Guardianship and Administration Act 2000* (Qld) s 66(2) makes it clear that if an adult has made an AHD giving a direction about a health matter, the matter may only be dealt with under the direction.

<sup>25</sup> *Powers of Attorney Act 1998* (Qld) s 103(1).

documents to mean that Mrs Bentley did not want artificial delivery of nourishment or liquids through measures like a feeding tube. Eating from a spoon or drinking from a glass, even with assistance, was not, in His Honour's opinion, artificial.<sup>26</sup> Therefore, His Honour's interpretation of Mrs Bentley's instructions was that they did not cover spoon-feeding.

Clearly, problems of interpretation like this can be cured by careful drafting of an AHD. Nonetheless, there are three reasons why even a well-drafted document might not operate where a person develops Alzheimer's disease.

The first reason is that a directive refusing life-sustaining treatment can only operate in Queensland where the person has a terminal illness and death is expected within a year, is in a persistent vegetative state, is permanently unconscious, or has a severe condition and there is no reasonable prospect of recovery to the point where life-sustaining measures would no longer be required.<sup>27</sup> A person with advanced dementia can live for many years. The position might be different when the disease reaches its final stages and the person is in a vegetative state.<sup>28</sup> However, people might want nutrition and hydration withheld at an earlier stage in the disease process in a deliberate effort to hasten death.<sup>29</sup> Margot Bentley, for example, nominated failure to recognise family members, and not progression to a vegetative state, as the point where she wanted her life to end.

The second reason is that an AHD covers only health matters.<sup>30</sup> In *Bentley v Maplewood Seniors Care Society*,<sup>31</sup> Greyell J found that 'providing oral nutrition and hydration by prompting with a spoon or glass is not health care' within the meaning of the relevant legislation.<sup>32</sup> Therefore, it was instead a form of personal care or basic care.<sup>33</sup> It is possible that a Queensland court may come to a similar conclusion. However, the

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<sup>26</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [111] (British Columbia Supreme Court).

<sup>27</sup> *Powers of Attorney Act 1998* (Qld) s 36.

<sup>28</sup> *Ibid* s 36(2).

<sup>29</sup> JoNel Aleccia, 'Should Patients with Dementia Be Able to Decline Spoon-Feeding?', *National Public Radio* (online), 3 November 2017 <<https://www.npr.org/sections/health-shots/2017/11/03/561393940/should-dementia-patients-be-able-to-decline-spoon-feeding>>.

<sup>30</sup> *Powers of Attorney Act 1998* (Qld) s 35.

<sup>31</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165 (British Columbia Supreme Court).

<sup>32</sup> *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, ch 181 s 1 (definition of 'health care'): Means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic, or other purpose related to health and includes a series or sequence of similar treatments or care administered to an adult over a period of time for a particular health problem or deals with one or more of the health problems that an adult has.

<sup>33</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [77] (British Columbia Supreme Court).

definition of health care in Queensland legislation is not identical to that in British Columbia. Health care in Queensland includes 'care or treatment of, or a service or a procedure for, the adult (a) to diagnose, maintain, or treat the adult's physical or mental condition; and (b) carried out by, or under the direction or supervision of, a health provider'.<sup>34</sup>

It could be argued that this definition could extend to cover spoon-feeding, which would be a 'service' necessary to 'maintain ... physical condition', and if the patient was in a nursing home, this would be done by a 'health provider'.<sup>35</sup> However, in the *Bentley case*, a definition of healthcare that included anything for a therapeutic, preventive, or other purpose related to health and both 'treatments or *care* administered to an adult over a period of time for a particular health problem',<sup>36</sup> was held not to encompass spoon-feeding. Both Canadian and Queensland legislation define personal care to include matters respecting diet and dress.<sup>37</sup> While this could be interpreted to refer to the choice of what will be in a person's diet, rather than the manner of ingestion, it could also cover spoon-feeding of someone unable to feed themselves. In the *Bentley case*, Greyll J adopted the latter interpretation, and it is likely that Queensland courts would do the same.

Queensland legislation goes on to specifically indicate that health care includes withholding or withdrawal of life-sustaining measures.<sup>38</sup> However, such measures are intended to sustain life and to take the place of vital bodily functions that are not working.<sup>39</sup> One of the examples given is *artificial* nutrition and hydration. A patient such as Mrs Bentley is able to take food orally, and therefore it is arguable that spoon-feeding would not be regarded as a life-sustaining measure. If, however, the patient's condition was to deteriorate to the point where sustenance has to be provided through artificial

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<sup>34</sup> *Powers of Attorney Act 1998* (Qld) s 5 (definition of a 'health provider'); *Guardianship and Administration Act 2000* (Qld) sch 2 (definition of a 'health provider').

<sup>35</sup> *Guardianship and Administration Act 2000* (Qld) sch 4 (definition of a 'health provider'): A person who provides health care, or special health care, in the practice of a profession or the ordinary course of business.

<sup>36</sup> *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, ch 181 s 1 (definition of 'health care').

<sup>37</sup> *Powers of Attorney Act 1998* (Qld) s 2 (definition of 'personal matter'); *Guardianship and Administration Act 2000* (Qld) sch 2 (definition of 'personal matter'); *Representation Agreement Act*, RSBC 1996, ch 405 s 1 (definition of 'personal care'); All definitions include diet of an adult.

<sup>38</sup> *Guardianship and Administration Act 2000* (Qld) sch 2 s 5A; *Powers of Attorney Act 1998* (Qld).

<sup>39</sup> *Ibid.*

means, such as tube-feeding, this would fall within the definition of healthcare, and a patient's directions about withholding or withdrawing sustenance would fall within the ambit of an AHD.

It is unclear, therefore, whether spoon-feeding would be regarded as health care or personal care in Queensland. If a Queensland court were to take the same approach as Greyell J in the *Bentley case*, an AHD could not be used to give directions about withholding of sustenance at a pre-determined point in the progression of Alzheimer's disease. Provision of sustenance by artificial means, on the other hand, would be covered. Nonetheless, a directive that such sustenance be withheld could only be followed when the disease progresses to its final stages, such that one of the conditions set out in s 36(2) of the *Powers of Attorney Act 1998* (Qld) for directions to withhold a life-sustaining measure would be met.

## 2 Substitute Decision Maker

If there is no valid AHD, a substitute decision maker can make healthcare decisions for a person who lacks capacity.<sup>40</sup> However, any substitute decision maker would face legislative constraints similar to those imposed on personal directives in an AHD, discussed above: the method of providing sustenance must fall within the definition of health care and the patient must have less than a year to live or be in a vegetative state. Furthermore, the decision must be consistent with good medical practice.<sup>41</sup> In the *Bentley case*, most of the health care providers looking after Mrs Bentley did not think it was medically appropriate to discontinue spoon-feeding.<sup>42</sup> In the absence of 'substantial agreement' among health care providers, Mrs Bentley's husband, her substitute decision maker, did not have the legal authority to direct that spoon-feeding be ceased.<sup>43</sup>

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<sup>40</sup> *Guardianship and Administration Act 2000* (Qld) s 66: Under the legislation, a person can appoint an attorney to make health decisions for him or her if the person later becomes incapacitated. If the person has not appointed someone to do this, the legislation provides for a statutory health attorney to do this; *Powers of Attorney Act 1998* (Qld) s 63 provides that a statutory health attorney is the first person on the list provided who is readily available and culturally appropriate to act. The list includes a spouse or de facto, a primary carer (unpaid and over 18), and a close friend or relative (but not a paid carer and over 18). If there is no one on the list who meets the criteria, the Public Guardian will fulfil the role.

<sup>41</sup> *Powers of Attorney Act 1998* (Qld) s 36(2)(b).

<sup>42</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [119] (British Columbia Supreme Court).

<sup>43</sup> *Ibid* [120].

Indeed, a substitute decision maker or medical professional who withdraws spoon-feeding could be found to be in breach of their legal duty to care for the patient and could face possible civil proceedings or manslaughter charges. This was the concern raised by the care facility in *H Ltd v J*.<sup>44</sup> It was held that there is no positive duty on care providers to forcibly hydrate or feed patients against their wishes.<sup>45</sup> However, the key difference between the facts in this case and one like Margot Bentley's is that the patient in *H Ltd v J* had capacity.

It would appear then that the current legislative regime in Queensland covering a person's direction for future health care and substitute decision making in the event of Alzheimer's-related incapacity would mean that the outcome in a case like *Bentley* would be the same in Queensland. However, even if a court were to determine that assisted feeding is healthcare and that a directive, from either the patient in an AHD or from a substitute decision maker, that sustenance be withheld from an Alzheimer's patient was valid, the *Bentley case* raises yet another hurdle that may be insurmountable: that a patient in an advanced stage of the disease can nonetheless still consent to being fed and has the capacity to do this.

### *B Dementia and Capacity to Consent to Sustenance*

Capacity is not an 'all or nothing' concept in law, and a person can have capacity to make one type of decision but not another. Clearly a higher level of capacity would be required where the decision is one with serious consequences, such as a directive that sustenance be withheld so that the person can die. On the other hand, a lesser level of understanding is required for minor decisions. The Queensland legislative scheme expressly recognises that the capacity of an adult with impaired capacity to make decisions may differ according to the type of decision to be made, including, for example, the complexity of the decision to be made.<sup>46</sup> Similarly, in the *Bentley case*, the local health authority (which opposed the declaration sought by the family) pointed out that Mrs Bentley 'could very well be incapable of making a complex decision, such as whether to undergo a risky

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<sup>44</sup> *H Ltd v J* [2010] SASC 176.

<sup>45</sup> *Ibid* [76] (Kourakis J).

<sup>46</sup> *Guardianship and Administration Act 2000* (Qld) s 5.

surgery, but capable of making a basic decision, such as whether she wants to eat or not'.<sup>47</sup>

In *Bentley*, the pivotal fact that led the judge at first instance, and then the Court of Appeal, to refuse the declaration sought by the family was the acceptance of medical evidence that Mrs Bentley was capable of deciding whether to accept food and drink offered to her and communicated her consent through behaviour.<sup>48</sup> Mrs Bentley's family, supported by some doctors, argued that acceptance of food, when a spoon was touched to her mouth, was a reflexive action. Her daughter, a nurse, said her mother would reflexively open her mouth if prodded with a spoon, and she believed this was akin to the basic rooting reflex of a newborn infant or a severely brain damaged infant. Further, the family had several legal opinions supporting their view that force-feeding of her mother was battery because she was being touched with a spoon without her consent and against her wishes, expressed previously.<sup>49</sup>

However, Greyell J also heard evidence that Mrs Bentley accepted more food or liquid on some occasions than others, with a spoon or glass touched to her lips. She sometimes refused by not opening her mouth and was more likely to accept sweet foods than other foods.<sup>50</sup> His Honour preferred this view and found that Mrs Bentley was 'communicating her consent' by accepting food and water. Therefore, care facility staff were under a legal duty to continue to 'offer' her assistance with feeding, in the form of prompting her with a spoon or glass,<sup>51</sup> and failure to do this would amount to neglect.<sup>52</sup> Likewise, in *Nora Harris'* case, it was found that the nursing home would be in violation of state law if it stopped spoon-feeding.<sup>53</sup>

The position is different during the terminal stages of Alzheimer's, when a person can have little interest in food and can have difficulty swallowing. Nutrition can be administered via a percutaneous endoscopic gastrostomy (PEG), a tube that is inserted directly into the stomach through an incision in the abdomen. Unlike spoon-feeding,

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<sup>47</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [43] (British Columbia Supreme Court).

<sup>48</sup> *Ibid* [12].

<sup>49</sup> Hammond, above n 7.

<sup>50</sup> *Bentley v Maplewood Seniors Care Society* 2014 BCSC 165, [49] (British Columbia Supreme Court).

<sup>51</sup> *Ibid* [60].

<sup>52</sup> *Ibid* [145].

<sup>53</sup> Alan Meisel and Kathy Cerminara, *The Right to Die, The Law of End-of-Life Decisionmaking*, Supplement 1A-191 (Aspen Publishers, 2017).

insertion of a PEG is a medical procedure and therefore falls within the ambit of an AHD. A person with capacity can stipulate in an AHD that such a procedure not be carried out. Likewise, a person with capacity can make it clear that no medical treatment, other than drugs to alleviate pain and discomfort, be provided in the event that the person loses capacity and develops an infection or illness which, if left untreated, would result in death. However, a wish that normal feeding be withdrawn at a nominated earlier stage in the progression of Alzheimer's is not medical treatment and therefore not covered by an AHD.

#### V CONCLUSION

If Greyell J's interpretation is correct, it would be very difficult for caregivers to give effect to the wishes of an Alzheimer's patient, expressed clearly, forcefully, and repetitively, in a written AHD and verbally to family members, that sustenance be withheld when the disease progresses to a particular point, such as failure to recognise family members. If a person has capacity to make a decision about a particular matter, such as whether or not to eat food offered on a spoon, substitute decision making is irrelevant. Furthermore, a care facility that fails to offer nutrition in this way will breach a duty of care to the patient. If, on the other hand, the patient refuses to accept sustenance offered by spoon and the patient is determined to have capacity to do this, the patient's decision must be respected, and force-feeding would amount to an assault.

Meisel suggests that a statement such as the following might provide clear guidance to caregivers:

When the time comes to implement my wishes, if my decision-making capacity is questionable and I appear to be resisting the implementation of my plan to end my life by voluntarily stopping eating and drinking, I nonetheless want my contemporaneous wishes to be ignored and my plan to end my life implemented.<sup>54</sup>

However, such a statement is likely to have little effect. If the patient has capacity to consent to food intake, regardless of his or her state of cognitive decline, that action will override any earlier written statement of wishes.

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<sup>54</sup> Ross Fewing, Timothy W Kirk and Alan Meisel, 'A Fading Decision' (2014) 44(3) *Hastings Centre Report* 16.

However, if the patient can no longer swallow safely, as sometimes happens in the weeks before death in Alzheimer's patients,<sup>55</sup> and nutrition and hydration are instead being provided by means of a tube, the position is different. The difficult question whether a person in an advanced state of cognitive decline can consent to receiving sustenance orally no longer arises. Further, as artificial feeding is often only needed in the final stages of the disease, the requirements regarding timing of withdrawal of life-sustaining measures, set out in s 36(2) of the *Powers of Attorney Act 1998 (Qld)*, would be met. However, what people like Margot Bentley want to avoid is allowing the disease to progress to this point.

It would seem then that, if a case with facts similar to those in the *Bentley case* were to arise in Queensland, the outcome would be no different. The impediments to a person setting out, in an AHD, a valid directive for withdrawal of sustenance leading to a dignified death at a pre-determined point in the progression of Alzheimer's disease appear to be insurmountable. There appears to be no way to 'provide a humane exit for people who, years later, no longer remember or understand why they wanted to use it' until the disease has reached its final stages.<sup>56</sup>

The only way people diagnosed with Alzheimer's disease can make sure they die before they reach the point where they no longer recognise their family or lose the ability to communicate is to take their own lives while they still have capacity. In so doing, they might deny themselves many years of fulfilling and worthwhile living, but this appears to be the only way to avoid the indignity and degradation of advanced Alzheimer's. It is somewhat ironic that decisions by persons to commit suicide before they are ready to die because they know it would be unlawful for someone to help them to die at a later point has been used to justify euthanasia in Canada under limited circumstances. The right to life was been interpreted as a right not to have to commit suicide prematurely in cases where progressive physical conditions would make it impossible for the person to commit suicide unaided at a later time.<sup>57</sup> However, it is unlikely that this reasoning would be

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<sup>55</sup> Alzheimer's Association, *Assisted Oral Feeding and Tube Feeding* (2015) <[http://mythoughtsondementia.com/Pamphlets/Assisted\\_Oral\\_Tube\\_Feeding.pdf](http://mythoughtsondementia.com/Pamphlets/Assisted_Oral_Tube_Feeding.pdf)>.

<sup>56</sup> John Schappi, *Advance Directives to Hasten Death in the Event of Dementia* Aging, AgeingCare.com <<https://www.agingcare.com/articles/advance-directives-to-hasten-death-in-the-event-of-dementia-179475.htm>>.

<sup>57</sup> *Carter v Canada (Attorney General)* [2015] 1 SCR 331, [58] (McLachlin CJ and LeBel, Abella, Rothstein, Cromwell, Moldaver, Karakatsanis, Wagner and Gascon JJ).

extended to cover Alzheimer's patients such as Margot Bentley, in light of Greyell J's finding that such patients have the capacity to consent to assisted feeding. Even if the problems with creating a valid AHD could be overcome, such consent effectively revokes any earlier direction that sustenance be withheld at a nominated point in the progression of Alzheimer's disease.

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