

# **Dementia, Decision-Making, and the Modern (Adult) Guardianship Paradigm: *Bentley v Maplewood Seniors Care Society***

**Margaret Isabel Hall\***

*This paper considers the meaning of decision-making, including substitute decision-making, for persons with dementia. The paper discusses the historical development of adult guardianship, from the King's stewardship of the property of "fools" and "lunatics" to the modern mechanisms of substitute decision-making, and the relationship between substitute decision-making and a particular ideal of autonomy. The paper concludes with a discussion of Bentley v Maplewood Seniors Care Society, a case concerning the present choices of a woman with dementia, the decisions set out in the "living will" she drafted many years earlier (prior to dementia), and the decisions made by the woman's (purported) representatives on her behalf. The case invites us to consider whether the decisions of the former, mentally capable self can ever trump the choices of the current self with dementia.*

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\* Assistant Professor, Faculty of Law, Thompson Rivers University.

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## I. Introduction

The case of *Bentley v Maplewood*<sup>1</sup> raises a number of profound questions about the nature of self in dementia, the nature and significance of “decisions” and “decision-making,” and the role of substitute decision-makers (including the former self through an advance directive) *vis-à-vis* the person with dementia. What is the nature of consent for an individual with advanced dementia, who departs in dramatic physical and mental ways from the norm (including his or her former “normal” self), and how can it be recognised? Should consent ever be separated from decision-making and if so, why and under what circumstances? What are the ethical implications of enabling a former self to make life terminating decisions on behalf of a fundamentally changed present self? What is the role of the individual’s representative in this situation? As Ronald Dworkin would have it (see discussion, *infra*), should a person’s prior (intellectual) decision override contrary (embodied) behaviour by the present self-with-dementia? What is “decision-making” and why does it matter?

This article considers the issues raised by the *Bentley* case, as they both illustrate and challenge the modern adult guardianship paradigm.

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1. 2014 BCSC 165 [*Bentley*].

## II. Autonomy Through Decision-Making: The Modern Adult Guardianship Paradigm

The modern adult guardianship paradigm is predicated on a particular theory about autonomy, individualism, decision-making, and the relationship between them. “Decision” (for the purposes of this theory) refers to a specific kind of choice, a “conclusion or resolution reached after consideration”;<sup>2</sup> *mere* choices are not decisions. A conclusion arrived at through this process of consideration (*because* it has been arrived at through this process) is understood to be the person’s “own” free, and therefore autonomous, decision. Control of one’s own decisions and decision-making process is essential to one’s identity as an individual; the individual, in turn, tends to make the kind of decision that is consistent with his or her identity. The ability to make a different out-of-character kind of decision, however, for whatever reason, is integral to personal freedom and must be respected.

In this account, the ability to carry out the *process* of decision-making is essential to both autonomy and individual identity. “Mental” or “decision-making capacity” (sometimes referred to as competence) refers to this ability. The *content* of decisions arrived at through this process is irrelevant so long as one is capable of making a “real” decision about the matter at hand: “[t]he right knowingly to be foolish is not unimportant; the right to voluntarily assume risks is to be respected. The State has no business meddling with either. The dignity of the individual is at stake.”<sup>3</sup> Autonomy in this sense (as exercised through autonomous decision-making) is a core legal value, long recognised by the common law and equity (through the doctrines of undue influence and duress)<sup>4</sup> and protected by the right to life, liberty and security of the person guaranteed by section 7 of the *Canadian Charter of Rights and Freedoms*.<sup>5</sup>

2. Oxford Dictionaries, *sub verbo* “decision”, online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/decision>>.
3. *Koch (Re)* (1997), 33 OR (3d) 485 (Gen Div) at para 17, Quinn J.
4. Which recognize that, in certain factual situations, an otherwise mentally capable person’s ability to make free decisions may be overborne.
5. *R v Morgentaler*, [1988] 1 SCR 30 at 171, Wilson J, concurring (the majority agreed with Justice Wilson on this point); *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B

Consent refers to a particular type of decision; to allow something that would otherwise be un-allowed. As with other kinds of decisions, the person who does not have the mental capacity required to consent cannot, truly, consent. The doctrine of informed consent<sup>6</sup> is premised on the idea that a person cannot make her “own” “real” decision about a matter if she lacks the information she needs to understand the choice involved, and the implications of making it.

The person who is identified as unable to carry out the decision-making process (as lacking mental or decision-making capacity) poses a problem for this account. On the one hand, to hold a person to the consequences of a decision that is not really her “own” seems unfair. On the other hand, making decisions *for* that person negates her identity as autonomous.

The modern guardianship paradigm appears to resolve this problem through the mechanisms of substitute and supported decision-making. Substitute decision-making enables the autonomy of the person whose decision-making processes are impaired by enabling her substitute to effect the decisions she *would have made* if able to do so. The substitute is not a replacement; he or she operates as a kind of decision-making amanuensis, effecting decisions that “really” belong to the other. Proceeding on the basis that persons generally make decisions like those they have made in the past, the substitute is able to maintain the identity of the individual by perpetuating this kind of consistent decision-making. Supported decision-making is a variation on this idea, providing a less intrusive mechanism for enabling autonomous decision-making.<sup>7</sup> The objective in both cases is the same: to enable the individual to formulate and express his or her “own” decisions and to have those decisions recognized and enforced by the law.

The theoretical account outlined above is a story; a story about how people think and about how they behave. It is a story which resonates, profoundly, with broader cultural and political values. But, however

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to the *Canada Act 1982* (UK), 1982, c 11.

6. *Malette v Shulman* (1990), 72 OR (2d) 417 (CA).

7. The supported decision-making model was developed within the developmental disability community, for whom the “substitute” model is much less coherent (there being no former “competent” identity to perpetuate).

attractive the narrative, it is not real. It is a social construct, and its application, to be justified, depends on its workability:

If ideas, meanings, conceptions, notions, theories, systems are instrumental to an active reorganization of the given environment, to a removal of some specific trouble and perplexity, then the test of their validity and value lies in accomplishing this work. If they succeed in their office, they are reliable, sound, valid, good, true. If they fail to clear up confusion, to eliminate defects, if they increase confusion, uncertainty and evil when they are acted upon, then are they false. Confirmation, corroboration, verification lie in works, consequences ... By their fruits shall ye *know* them.<sup>8</sup>

### III. Historical Context: Situating the Modern Paradigm

The modern adult guardianship paradigm is the most recent iteration of a very old concept: that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability.

The English system of guardianship, from which the Canadian system derives, originated sometime before the 13<sup>th</sup> century as a personal obligation of the King.<sup>9</sup> The obligation was limited to the protection and stewardship of property, and distinguished between “idiots” or “fools” (individuals never having possessed the mental ability required to manage their property) and “lunatics” or *non compos mentis* (those losing this ability as adults). *Non compos mentis* individuals were treated by the law

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8. J Dewey, *Reconstruction in Philosophy* (Boston: Beacon Press, 1948) at 156 [emphasis in original].

9. The obligation is first mentioned in, although apparently not created by, the *Statute De Prerogativa Regis* in the late thirteenth century. Doug Surtees provides an excellent summary of the murky origins of the Crown’s jurisdiction, which replaced the feudal arrangement whereby the Lord of the Manor assumed control of the property of persons of “unsound mind.” This assertion of Kingly jurisdiction has been explained as a response to abuses of this power committed by the lords, or, alternatively, as part of the general extension of centralised Crown jurisdiction during this period; D Surtees, “How Goes the Battle? An Exploration of Guardianship Reform” (2012) 50:1 *Alta L Rev* 115. Prior to assumption by the King at some point during the reign of Edward I (1272- 1307); see also Lawrence B Custer, “The Origins of the Doctrine of *Parens Patriae*” (1978) 27:2 *Emory LJ* 195 at 195.

as if they could regain mental capacity in the future (whether or not they currently enjoyed “lucid” moments) and, accordingly, the Crown was required to manage the property of such a person on that person’s behalf, taking no profits. Having “once lived his life on an equal mental footing with others ... there was always that glimmer of hope that he would do so again,”<sup>10</sup> and should a lunatic regain lucidity (either permanently or episodically) his property and profits would be returned. The property of fools, on the other hand, who would never regain capabilities they had never enjoyed, was managed on behalf of the Crown. The profits from their estates became the king’s property, subject only to the king’s duties to provide the incapable individual with the necessities of life, not commit waste or destruction, and to pass the estate to any heirs upon death.

The Crown’s “power of administration” over the property of both lunatics and fools was delegated personally to the Lord Chancellor (and, later, to the Lord Justices of Appeal in Chancery), as opposed to the equitable jurisdiction of the Chancellor regarding children. Over time, however, it appears that this power of administration developed in practice into something like an equitable jurisdiction, “[by] virtue of [the Chancellor’s] general power, as holding the great seal, and keeper of the King’s conscience.”<sup>11</sup> Also over time, the property of fools came to be managed according to the same standards as the property of lunatics, and the *de facto* distinction between the two categories withered away. No precise moment or mechanism through which this change took place is apparent; Professor Surtees, in his account, directs the reader to Blackstone’s comment that “the ‘clemency of the crown and pity of juries’ gradually assimilated the condition of idiots to that of lunatics.”<sup>12</sup> In a similar way, over time and with no marked turning point, the Crown

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10. Louise Harmon, “Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment” (1990-91) 100:1 Yale LJ 1 at 16.

11. *Ibid* at 19, citing Joseph Story, *Commentaries on Equity Jurisprudence: as Administered in England and America*, 12th ed (Boston: Little Brown, 1877) at 608.

12. Surtees, *supra* note 9 at 117; see also Sarah Burningham, “Developments in Canadian Adult Guardianship and Co-Decision Making Law” (2009) 18 Dal J Leg Stud 119.

(through the Chancery) assumed responsibility for the personal care and wellbeing of both lunatics and fools, in addition to property stewardship (although personal responsibilities were most often in fact carried out by families).

The core tenets of the modern adult guardianship paradigm began to take shape with the *Imperial Lunacy Act* of 1890.<sup>13</sup> First, a new unified category of the “mentally infirm” removed altogether the archaic distinction between lunatics and idiots. Second, the Act effectively privatised the formerly public obligation, setting out procedures for appointing an agent to manage the property of the infirm.<sup>14</sup> Third, by permitting the use of medical evidence (provided through affidavit) in place of a full judicial inquiry, the Act effectively medicalised the guardianship process; although both the declaration of disorder/incapacity justifying guardianship and the appointment of a guardian remained the responsibility of the court (with the exception of “statutory guardianship” where applicable<sup>15</sup>) medical evidence of decision-making capacity is virtually always determinative.

Substitute decision-making had been introduced earlier in the 19<sup>th</sup> century in the case of *Ex parte Whitbread*<sup>16</sup> as a means of allowing the law to effect what could not otherwise be done: to make a distribution of property from the estate of a wealthy “lunatic” to his impecunious, but competent, relative.<sup>17</sup> Such a distribution, with the court taking the private property of one person for the benefit of another, conflicted with the core liberal legal value of private property ownership. It would also

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13. 53 & 54 Vict c 5.

14. Burningham, *supra* note 12.

15. “Statutory guardianship” refers to the mechanism whereby the Public Guardian or Trustee (or analogous body depending on the language of the jurisdiction) may be appointed as guardian of property or estate through medical evidence only. The process in British Columbia (originally developed to apply where an individual had been institutionalised) allows for the Public Guardian and Trustee to be appointed as guardian of estate on the basis of a Certificate of Incapacity issued by the director of a Provincial mental health facility or psychiatric unit designated for this purpose under the *Mental Health Act*, RSBC 1996, c 288 and/or under the *Patients Property Act*, RSBC 1996, c 349.

16. 35 Eng Rep 878 (Ch 1816) [*Ex Parte Whitbread*].

17. Harmon, *supra* note 10.

appear to have been prohibited by the court's mandate (as descended from the King's obligation) to preserve the lunatic's estate in his or her interests.<sup>18</sup> The "fiction" of substitute decision-making allowed the court to "discover what the lunatic himself probably would have done" and carry out those "probable desires" through the adoption of an "internal, subjective point of view."<sup>19</sup> According to this fiction, the gift to the niece was "really" in her uncle's interest because it was "really" what he would have decided to do had he been mentally capable of making that decision. The closeness of the family relation together with "[e]vidence of the lunatic's former intentional states" were essential to this exercise.<sup>20</sup>

These 19<sup>th</sup> century innovations – privatization, medicalization, and substitute decision-making – comprise the conceptual core of the modern adult guardianship paradigm. All three are connected to, and dependent upon, one another. The substitute decision-making model has come to define adult guardianship in terms of both purpose (as a response to impaired decision-making) and function (the implementation of autonomous decision-making mechanisms). The legal requirement of "finding" decision-making impairment (as a pre-requisite to appointing a substitute or supportive decision-maker) has, in turn, enhanced medical control over the process. Medically produced evidence of decision-making capacity, presented in hard and scientific language of the "bio-fact,"<sup>21</sup> is seldom questioned by legal decision-makers when legal decision-makers

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18. *Ibid* ("[T]he Court... has nothing to consider but the situation of the Lunatic himself, always looking to the probability of his recovery, and never regarding the interest of next of kin" at 22, citing Lord Eldron's judgment in *Ex Parte Whitbread*, *supra* note 16). The jurisdiction of the Courts, descended from the King's delegation of his personal responsibility to the Lord Chancellor, developed into something like an equitable jurisdiction "by virtue of [the Chancellor's] general power, as holding the great seal, and keeper of the Kings conscience." *Ibid* at 19, referring to Story's *Commentaries on Equity Jurisprudence as Administered in England and America* (12th ed, 1877) 608. See also Surtees, *supra* note 9.

19. Harmon, *supra* note 10 at 22.

20. *Ibid* at 25.

21. See discussion in Margaret Isabel Hall, "Mental Capacity in the (Civil) Law: Capacity, Autonomy and Vulnerability" (2012) 58:1 McGill LJ 61 at 71-74.

are involved in the process.<sup>22</sup> The increasing privatization of the once public guardianship process through the rise of the enduring power of attorney and other “personal planning” instruments such as health directives (in British Columbia, the representation agreement) has made the involvement of the courts increasingly less likely. These private instruments provide for the individual him or herself to appoint a remedial decision-maker of some kind (substitute or supportive) without public oversight, a “least interventionist” alternative. Within the conceptual framework of the substitute decision-making model, the friend or family member appointed through a private process is best placed to know the individual’s “prior intentional states” and to effect the decision that individual *would have made* if able to do so. The result of these processes has been a dwindling of the public/legal role in the guardianship process, and a transformation (in accordance with the liberal conceptualization of liberty and individualism) of the old idea that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability to harm.

The rise of the advanced directive expands on, and in a sense perfects, these processes, directly enforcing the individual’s “former intentional state” regarding a particular kind of decision – decisions about health care – without the need for a third person intermediary or amanuensis. Within the limited scope of decisions to which it applies, the advanced directive maximizes autonomy by enabling the individual to directly effect his or her own “real” decisions, regardless of decision-making capacity, up to the point of death. The process is a legal one only to the extent that it is enabled by legislation, and the private nature of the advance directive as a direct exchange between individual and physician is intended to construct, in so far as possible, a “normal” medical decision (as if the patient were any other “normal” decision-competent individual).

#### **IV. Situating Dementia: Margo’s Story**

Harmon discusses at some length how the doctrine of substitute decision-making came to provide the basis for “substitute” health care

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22. See Glyn Davies & Lesley Taylor, “Private Committeeship in British Columbia: A Study of Due Process” (1989) 8:1 Can J Fam L 185.

decision-making on behalf of developmentally disabled persons. The fiction lost all coherence in this context, according to Harmon; unlike the wealthy, lunatic uncle in the *Ex Parte Whitbread* case, there could be no evidence of such a person's "former intentional state" from which to draw conclusions about what he or she *would have done*. Indeed, there was no former "real" self on whose behalf the substitute could act; the real self was the present self. Harmon provides several examples of purportedly "substitute" decisions that were dramatically *contra* the interests of the (present-self) individuals on whose behalf they had been made.<sup>23</sup> Harmon argues that substitute decision-making operated in this context as a blatant and self-serving fiction, employed for the purpose of benefitting (through organ transplant, for example, and the refusal of life saving treatments) other persons at the expense of the incapable individual.<sup>24</sup>

Dementia poses other difficulties for the substitute decision-making model. In one sense (and unlike the developmentally disabled person) the person with dementia falls into the category of persons formerly characterised as lunatics, for whom evidence of former intentional states can be found. Unlike the lunatic (in the archaic distinction), however, there is no "glimmer of hope" that the individual with dementia will be restored to her or his former self. Indeed the very nature of dementia entails the progressive movement away from that former self, ending in death. Is this process a loss of self (the "living death" or zombie trope) or a changed self? And if the substitute decision model (in all of its modern iterations) works as a mechanism for enacting the "would-have-been" "real" decisions of the individual, how does that mechanism protect the autonomy of an individual with no or little current connection to that past self?

Ronald Dworkin and Rebecca Dresser have both considered this question through the story of Margo, a woman with Alzheimer's disease whose story was originally told by Andrew Firluk in a *Journal of*

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23. These developments comprise the focus of her article.

24. And the incoherence of substitute decision-making may be a key reason for the development of supportive decision-making by and on behalf of the developmentally disabled community (and the relative incoherence of supported decision-making in the context of dementia).

*the America Medical Association* column called “A Piece of my Mind.”<sup>25</sup> Firlik describes Margo as “undeniably one of the happiest people I have known,” absorbed in reading and re-reading of her novel and painting abstracts in warm and rosy colours:

There is something graceful about the degeneration [Margo’s] mind is undergoing, leaving her carefree, always cheerful. Do her problems, whatever she may perceive them to be, simply fail to make it to the worry centers of her brain? How does Margo maintain her sense of self? When a person can no longer accumulate new memories as the old rapidly fade, what remains? Who is Margo?<sup>26</sup>

In his response to Margo’s story, Ronald Dworkin considers the following moral and ethical dilemma: what if Margo, prior to her mental “degeneration,” had expressed a desire to have her life ended in the event that she developed Alzheimer’s disease?<sup>27</sup> Dworkin concludes that Margo’s previous wishes should be honoured regardless of Margo’s current contented state of mind. Honouring Margo as an autonomous being, in Dworkin’s account, requires honouring her interest in “living her life in character,” a “critical” interest of higher value than the mere “experiential” interests all humans enjoy as sentient beings (the taste of delicious food; listening to agreeable sounds). Those with the mental capacity to do so construct their identity as autonomous beings through the choices they make throughout their lives; the autonomous character of “Ronald Dworkin” is the outcome of this process, and “Ronald Dworkin” has a critical interest in constructing and maintaining this autonomous self. Acting in Margo’s best interests requires maintaining the autonomous self that Margo constructed while she was capable of doing so; once Margo loses the capacity to, effectively, change her storyline, there is no one else qualified to do that on her behalf, and the most accurate information

25. AD Firlik, “Margo’s Logo” (1991) 265:2 *The Journal of the American Medical Association* 201. The immediate concern of both Dworkin and Dresser is substitute decision-making in the context of health treatment – specifically, end of life decision-making, extending to euthanasia. The essential terms of the argument apply to the workability and moral justification of substitute decision-making generally in the dementia context, however.

26. *Ibid* as cited in Rebecca Dresser, “Dworkin on Dementia: Elegant Theory, Questionable Policy” (1995) 25:6 *Hastings Center Report* 32 at 32.

27. R Dworkin, *Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (New York: Alfred A Knopf, 1993).

available resides in Margo's previously expressed wishes (a time when she was still "Margo" and still able to make the kinds of decisions that would determine who "Margo" would be – in Dworkin's scenario, "Margo" would *not* be a woman with dementia). If Margo did not leave instructions before losing the capacity to do so, according to Dworkin, "the law should so far as possible leave decisions in the hands of [her] relatives or other people close to [her] whose sense of [her] best interests [in Dworkin's sense of maintaining Margo's autonomous character]... is likely to be much sounder than some universal, theoretical, abstract judgment."<sup>28</sup>

Rebecca Dresser has responded to and rejected Dworkin's argument on the basis (in her terms) of either "wisdom or morality."<sup>29</sup> Prior to developing dementia, Dresser notes, it is highly doubtful that Margo had any real understanding of what her lived experience of dementia would be (apart from the mainstream narrative of "horrifying disease"). More fundamentally, Dresser writes, "Dworkin assumes that Margo the dementia patient is the same person who issued the earlier requests to die, despite the drastic psychological alteration that has occurred."<sup>30</sup> That assumption is not self-evident, and the morality of imposing the will of a now disappeared self onto the life of a current and existing self is problematic,<sup>31</sup> either directly (as through an advance directive) or through the "substitute" decisions of a guardian.

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28. *Ibid* at 213.

29. Dresser, *supra* note 26 at 34; see also Rebecca Dresser, "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46:2 Rutgers L Rev 609.

30. *Ibid* at 35.

31. See also James Lindemann Nelson & Hilde Lindemann Nelson, eds, *Meaning and Medicine: A Reader in the Philosophy of Health Care* (New York: Routledge, 1999) at 47-56; Allen Buchanan, "Advance Directives and the Personal Identity Problem" (1988) 17:4 Philosophy and Public Affairs 277; Seana Valentine Shiffrin, "Autonomy, Beneficence, and the Permanently Demented" in Justine Burley, ed, *Dworkin and His Critics: With Replies by Dworkin* (Malden, MA: Blackwell Publishing, 2004) 195.

## V. *Bentley v Maplewood Seniors Care Society*

*Bentley v Maplewood Seniors Care Society* engages, implicitly, with the fundamental questions of consent and autonomy which substitute decision-making appears to resolve, and the extent to which that (apparent) resolution loses coherence in the context of dementia.<sup>32</sup> What is the relationship between autonomy, the self-with-dementia, and the former self? Are the decisions of the former self “real” (the result of reflection and, through that process, the deliberate adoption of identity) in a way that the choices of the self-with-dementia are not? Is it a betrayal of that real self (and therefore an abnegation of the individual’s true autonomy) to prefer and give effect to the choices of the self-with-dementia? What are the obligations of a substitute decision-maker in this situation?

The case concerned Margot Bentley, a resident at the Maplewood care facility. Mrs. Bentley had been diagnosed as suffering from advanced Alzheimer’s disease. Mrs. Bentley is described in the case as having “very few physical movements,” “occasionally rub[bing] the back of her hand, arm, or face” with “[h]er eyes ... closed much of the time. She has not spoken since 2010. She does not indicate through her behaviour that she recognizes her family members or any other person.”<sup>33</sup> The British Columbia Supreme Court agreed with an assessment carried out by a hospice care physician that Mrs. Bentley was not dying, “[d]espite her cognitive and physical disabilities”; if the petitioners’ application was granted she would die from starvation or dehydration, rather than from any effect of Alzheimer’s disease.<sup>34</sup>

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32. Oxford Dictionaries, *sub verbo* “dementia”, online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/dementia>>. “Dementia” here refers to “[a] chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning” and includes, but is not limited to, Alzheimer’s. The *Bentley* case concerns an individual with Alzheimer’s, but the issues raised by the case apply to dementia more broadly.

33. *Supra* note 1 at para 18.

34. *Ibid* at para 33.

Staff at Maplewood “assisted” Mrs. Bentley with eating and drinking by:

[P]lacing a spoon or glass on her lower lip. When she opens her mouth to accept nourishment or liquid, the care attendant places the nourishment or liquid in her mouth and Mrs. Bentley swallows it. When she keeps her mouth closed despite being prompted, the care attendant will try again. If she keeps her mouth closed despite a couple of attempts, the care attendant makes no attempt to force her to accept nourishment or liquid.<sup>35</sup>

Conflicting medical evidence was provided regarding Mrs. Bentley’s apparent “choice” to participate in the spoon feeding. A hospice palliative care physician who assessed Mrs. Bentley concluded she was “clearly” (if non-verbally) “choos[ing] to eat.”<sup>36</sup> An assessment of Mrs. Bentley’s decision-making capacity was also carried out by an Incapacity Assessor with the Office of the Public Guardians and Trustee. The assessor agreed that Mrs. Bentley was choosing to eat, and found that her behaviour (opening her mouth in response to dessert after refusing the final portion of her dinner) conveyed Mrs. Bentley’s choices about *what* food to eat. Although Mrs. Bentley “does not make eye contact or appear to respond in other ways when people try to interact with her” she did “grasp the hands of people who speak to her” and “convey[ed] when she is in pain by moaning and tightening her facial muscles.”<sup>37</sup> Mrs. Bentley’s condition was described by her GP, in contrast, as “a vegetative state.”<sup>38</sup> In the opinion of the GP “any response Mrs. Bentley has when she is prompted with a spoon or glass is ‘a reflex and is not indicative of any conscious decision about whether to eat or not’ ... [s]he does not function mentally in any discernible way.”<sup>39</sup>

Mrs. Bentley, through her litigation guardian,<sup>40</sup> together with her husband and daughter, now sought a declaration from the Court that Maplewood stop the spoon feeding. Maplewood, the Fraser Health Authority (“FHA”), the Province of British Columbia (the “Province”), and the intervenor, Euthanasia Prevention Coalition of British Columbia

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35. *Ibid* at para 19.

36. *Ibid* at para 24.

37. *Ibid* at para 27.

38. *Ibid* at para 22.

39. *Ibid*.

40. Mrs. Bentley’s litigation guardian was also her daughter.

argued that to stop giving Mrs. Bentley nourishment or liquids would cause her discomfort and bring about her death through dehydration and starvation, constituting neglect within the meaning of the *Adult Guardianship Act*,<sup>41</sup> and possibly violating several criminal laws, including the prohibition against assisted suicide.

The petitioners argued that a “statement of wishes” written and signed by Mrs. Bentley in 1991 required Maplewood to stop providing her with liquids and nutrition, either directly as an “advanced directive” or through the substitute decision-making authority it conferred on them as her “representatives.” The statement of wishes provided that:

If at such a time the situation should arise that there is no reasonable expectation of my recovery from extreme physical or mental disability, I direct that I be allowed to die and not be kept alive by artificial means or “heroic measures”; that “no nourishment or liquids” be provided; and that “[i]n the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.”<sup>42</sup>

The statement of wishes also designated Mrs. Bentley’s husband as her “proxy for the purpose of making medical decisions on my behalf in the event that I become incompetent and unable to make such decisions for myself” and her daughter as alternative proxy.<sup>43</sup> A second, undated “statement of wishes” was subsequently found providing that:

If the time comes when I can no longer communicate, this declaration shall be taken as a testament to my wishes regarding medical care. If it is the opinion of two independent doctors that there is no reasonable prospect of my recovery from severe physical illness, or from impairment expected to cause me severe distress or render me incapable of rational existence, then I direct that I be allowed to die and not be kept alive by artificial means such as life support systems, tube feeding, antibiotics, resuscitation or blood transfusions: any treatment which has no benefit other than a mere prolongation of my existence should be withheld or withdrawn, even if it means my life is shortened.<sup>44</sup>

The specific reference to “nourishment or liquids” was omitted in this second statement. The petitioners argued that this second statement nevertheless did not contradict the first, and in fact reinforced it.

Advance directives were not provided for in legislation in British

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41. RSBC 1996, c 6.

42. *Supra* note 1 at para 5.

43. *Ibid.*

44. *Ibid* at para 9.

Columbia until September 2011;<sup>45</sup> representation agreements were not provided for until 2000.<sup>46</sup> The petitioners argued that Mrs. Bentley intended her statement of wishes to operate as a “living will” (although no such instrument was legally recognised in British Columbia at the time) and that the statement should now be treated as having effectively created *both* an advance directive and a representation agreement.<sup>47</sup> As an advance directive, the “statement of wishes” required Maplewood to stop feeding Mrs. Bentley. As a representation agreement, the statement required Mrs. Bentley’s representatives – her husband and then her daughter – to ensure that her wishes were carried out, therefore entitling them to demand an end to the spoon feeding.

The Court disagreed, on several bases. If the statement of wishes *were* to be treated as creating an advance directive, it was not clear that the refusal of “artificial means and heroic measures,” followed in the “statement of wishes” by a list of items including “nourishment or liquids,” was intended as a refusal of “heroic and artificial” *methods* of providing nourishment and liquids (such as tube feeding) or a refusal of liquid and nourishment *per se*. The “consensus in the medical community” (as attested to by a medical ethicist) was that “assistance with oral nutrition and hydration is neither artificial nor heroic.”<sup>48</sup> A health care provider could not obtain consent from an advance directive where “the instructions in an adult’s advance directive are so unclear that it cannot be determined whether the adult has given or refused consent to the health care,”<sup>49</sup> as in this case.

In any event, the “statement of wishes” was not an advance directive for several reasons. Advance directives and representation agreements

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45. *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996 c 181, Part 2.1 [*HCCCFA Act*].

46. *Representation Agreement Act*, RSBC 1996, c 405 [*RA Act*].

47. See *Health Care Consent Regulation*, BC Reg 20/2000, s 15: although legislation introducing advance directives was not proclaimed in British Columbia until 2011, “written instructions made by a capable adult as described in that section are deemed to be advance directives if made and executed in accordance with sections 19.4 and 19.5 of the Act, as if those sections had been in force at the time the written instructions were made.”

48. *Supra* note 1 at para 111.

49. *HCCCFA Act*, *supra* note 45, s 19.8(1)(b).

are fundamentally different documents: an advanced directive cannot appoint a substitute decision-maker (as this document purported to do). Furthermore, advance directives can only direct *health* care decisions; the spoon feeding in this case was not “health care,” but “personal care.” More invasive methods of feeding such as tube feeding could be characterized as “health care,” but spoon feeding could not. The Court noted also Maplewood’s argument that the *Residential Care Regulations* (applying to nutrition, assistance with eating, and meal plans for adults living in assisted living and care settings) required that Mrs. Bentley be provided with liquid and nutrition.<sup>50</sup>

Of course, personal care also requires consent. In British Columbia, the *Representation Agreement Act*<sup>51</sup> sets out the mechanisms for appointing a substitute decision-maker for both personal and health care where a person is unable to consent.<sup>52</sup> There is no mechanism for creating a personal care advance directive, although a representative must consider the “previous intentional states” or wishes of the person on whose behalf he or she is acting and follow those wishes unless there are compelling reasons to do otherwise. Two kinds of representation agreements are available: a section 7 agreement (which can be made by a person with relatively lower mental capacity and which confers a more limited scope of decision-making authority on the representative)<sup>53</sup> and a section 9

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50. See *Residential Care Regulations*, BC Reg 96/2009, ss 66-67. The Regulations specify that a “licensee [Maplewood in this case] must ensure that each person in care receives adequate food to meet their personal nutritional needs, based on Canada’s Food Guide and the person in care’s nutrition plan”; that “a licensee must ensure that fluids are provided to persons in care in sufficient quantity and variation to meet the needs and preferences of the persons in care”; and that “a licensee must provide each person in care with ... eating aids, personal assistance or supervision, if required by a person in care who has difficulty eating, or the nutrition plan of a person in care.”

51. *Supra* note 46, s 1.

52. “Personal care” is defined in the *RA Act*, *ibid* to include matters respecting “the shelter, employment, diet and dress of an adult” (the emphasis is provided in the case), “participation by an adult in social, educational, vocational and other activities, contact or association by an adult with other persons, and licences, permits, approvals or other authorizations of an adult to do something.”

53. See *ibid*, s 7. A section 7 representative can also carry out financial

agreement (which authorises the representative “to do anything that the representative considers necessary in relation to the personal care or health care of the adult,” including giving or refusing consent to “health care necessary to preserve life.”)<sup>54</sup> Within these parameters the person making the agreement can confer more or less decision-making authority on the representative. If Mrs. Bentley had wanted to create a *de facto* representation agreement conferring personal decision-making authority on her “proxies,” she would have done so.

The petitioners argued that the statement of wishes should be construed as a representation agreement (presumably a section 9) and that their designation as “proxies” effectively appointed them as Mrs. Bentley’s health care and/or personal care substitute decision-makers.<sup>55</sup> If the statement *were* read as creating a representation agreement, however, it purported to appoint the two proxies as health care decision-makers only (“to serve as my proxy for the purpose of making medical decision on my behalf in the event that I become incompetent and unable to make such decisions for myself”<sup>56</sup>) with no mention of personal care. The authority to make one kind of decision could not be taken to imply the other and the statement could not be construed as conferring decision-making authority regarding personal care.

Most significantly, however, even if the “statement of wishes” could operate as either an advance directive or a representation agreement (or both), the Court concluded that Mrs. Bentley was capable of consenting to the spoon feeding and that, through her behaviour, she *did* consent to it.<sup>57</sup> The existence and content of any advance directive or representation

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management for the individual (a person who is not capable of appointing a power of attorney may appoint a section 7 representative).

54. *Ibid*, s 9.

55. Although the *RA Act* came into force in 2000 and the Statement of Wishes was completed in 1991, s 39 of that *Act* provides that “[a]n agreement that was made before this Act authorized the making of a representation agreement, and would have been a valid representation agreement if, at the time the agreement was made, this Act had authorized the making of a representation agreement, is valid and is deemed for all purposes to have been made under this Act.”

56. *Supra* note 1 at para 101.

57. The fact that Mrs. Bentley could not, currently, communicate as she did previously did not indicate an inability to consent; indeed, the *RA*

agreement she may have put in place was therefore irrelevant. The extent to which Mrs. Bentley's current consent contradicted any previously expressed wishes was also irrelevant:

It is entirely possible that the decisions Mrs. Bentley predicted she would make for herself in the future through her "proxies" and as set out in her statements of wishes are different than the decisions she is currently making. All adults are entitled to change their mind subsequent to creating written instructions, which is one of the risks associated with written instructions for the future. This Court must consider the possibility that Mrs. Bentley's previously expressed wishes are not valid in the face of her current consent.<sup>58</sup>

Mrs. Bentley's current consent must be respected, and the spoon feeding continued.

## VI. Conclusion

Mrs. Bentley's husband and daughter told the Court that they could "no longer see in Mrs. Bentley the active and creative person that they knew as their wife and mother,"<sup>59</sup> characterizing her as "vegetative."<sup>60</sup> She appeared to no longer recognize her family members, and could not speak. The "Margo Bentley" the petitioners knew had ceased to exist. That Margo, they now argued, deserved to have her autonomous voice heard and respected; the apparent choices of Mrs. Bentley's self-with dementia were not real decisions but reflexes. The Court disagreed.

Importantly, that conclusion was not justified on the basis that Mrs. Bentley's choices were in any way the product of a deliberate process of consideration. There is no reference in the judgment to the extent of her decision-making or mental capacity, only to her choices as indicated by her behaviours. The Court's decision implies that this process – that "decision-making capacity" – is not, in fact, the essential factor here; that where a living human being indicates an embodied choice, that choice must be respected as "real" regardless of the intellectual process

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*Act, Adult Guardianship Act, and HCCCFA Act* all include provisions indicating that an adult is presumed to be mentally capable and that difficulties with communication are not to be interpreted as indicating a diminishment of mental capacity.

58. *Supra* note 1 at para 54.

59. *Ibid* at para 56.

60. *Ibid* at para 57.

that produced it. The petitioners may be right, in other words, to the extent that Mrs. Bentley's current "consent" to the spoon feeding is not a decision (in the way that her "statement of wishes" is an expression of decisions). But those prior decisions do not override Mrs. Bentley's current choice in this context. It is right that embodied choices, even in the absence of rational decision-making processes, should determine what does and does not happen regarding the "personal care" of one's body.

The case has been widely discussed in the media as a "right to die" and "dying with dignity" case. The Vancouver Sun reported that "Bentley has been in a vegetative state since late 2011. Since then the family has pleaded for adherence to the living will. Her case has gained national attention and The Vancouver Sun has received many letters from readers, almost all of them outraged that the nursing home is not respecting Mrs. Bentley's wishes."<sup>61</sup> According to the Globe and Mail, Margo Bentley, a former nurse,

was determined not to die a slow, lonely, frightful death like so many of her patients. So she planned ahead. Bentley wrote a living will, one that clearly stated that, when her time came, she did not want heroic measures taken to keep her alive. She also discussed the issue with her children, fully and openly, and they were in agreement.<sup>62</sup>

Bentley did everything right. Yet today, the 82-year-old, who is in the final stages of dementia, is being kept "alive" against her wishes and those of her family. And the B.C. Supreme Court says that's okay.

How could this happen?

When will the wishes of patients finally and rightfully take precedence over the paternalistic prurience of the medico-legal establishment? When will we stop torturing people in the name of legalistic hair-splitting and fully embrace essential principles such as having treatment choices and death with dignity?<sup>63</sup>

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61. Tiffany Crawford, "Right-to-die: Fraser Health says it has a legal obligation to spoon-feed vegetative patient", *The Vancouver Sun* (12 September 2014) online: The Vancouver Sun <<http://www.vancouver.sun.com>>.

62. Andre Picard, "Margot Bentley case shows our health care system values its bureaucracy over its patients", *The Globe and Mail* (10 February 2014) online: The Globe and Mail <<http://www.theglobeandmail.com>>.

63. *Ibid.*

The public discourse around the Margo Bentley case essentially (if implicitly) adopts Ronald Dworkin's position regarding Firlík's "Margo." It demonstrates, powerfully, the cultural entrenchment of the modern adult guardianship paradigm, as a means of carrying the "real" self forward despite the embodied manifestation of the self-with-dementia. The dominant discourse that both constructs and surrounds dementia (the "living death" after the loss of self) is of a piece with these cultural values and beliefs (and, therefore, with the substitute decision-making model that is congruent with them). The decision of the British Columbia Supreme Court in *Bentley* provides an alternative account of the self-with-dementia as an *alternate* self (as opposed to non-self) that is capable of making choices of a certain kind; those choices look and almost certainly *are* different in kind from the decisions of the "normal" unimpaired self, and arrived at through different mental processes, but this difference does not negate their meaning. The implications of this account are potentially far-reaching, as society prepares for the "rising tide" of dementia.<sup>64</sup>

*Bentley* shows the court and the medical players – what the *Globe and Mail* refers to as the "medico-legal establishment"<sup>65</sup> – effectively exercising a public guardian-like role *vis-à-vis* Margo Bentley (although of course neither is acting as her actual guardian) in contravention of those who would assume that role in their private capacity (as Mrs. Bentley's representatives or through enforcement of an advance directive). "Guardian-like" here refers not to the legislated mechanisms of guardianship but to the old idea referred to at the beginning of this article, of which the modern adult guardianship paradigm is merely the latest (but almost certainly not the final) iteration: that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability to harm.

The modern idea (or paradigm)<sup>66</sup> of adult guardianship as a response

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64. Alzheimer Society of Canada, *Rising Tide: The Impact of Dementia on Canadian Society*, Alzheimer Society of Canada (2010), online: Alzheimer Society of Canada <<http://www.alzheimer.ca>>.

65. Picard, *supra* note 62.

66. The Oxford English Dictionary, *sub verbo* "paradigm", online: Oxford Dictionaries <<http://www.oxforddictionaries.com/definition/english/paradigm>>. "Paradigm" is defined as "a world view underlying the theories

to impaired decision-making is just that – an idea, neither natural nor inevitable. “Ideas are ... tools- like forks and knives and microchips- that people devise to cope with the world in which they find themselves,” and “their survival depends not on their immutability but on their adaptability.”<sup>67</sup>

The *Bentley* case suggests that the self-with-dementia needs a response of a different kind, a departure from the modern adult guardianship paradigm and from the theoretical hegemony of the decision.

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and methodology of a particular scientific subject.”

67. Louis Menand, *The Metaphysical Club* (New York: Farrar, Strauss and Giroux, 2001) at xi.



