

### Editor's note:

Prof. Blair Henry (Sunnybrook Health Sciences Center): It is my honor to be named the inaugural chair of the newly created Ethics column for the *Annals of Palliative Medicine*. My motto has always been: Know better—do better! Palliative care and more specifically end-of-life care are natural nexus for ethical quandaries. In this column I hope to be able to provide our readers with interesting, topical and challenging ethical issues relevant to your clinical setting.

### Editorial on Ethics

## Evolving ethical and legal implications for feeding at the end of life

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Care decisions and choices at the end of life can confront patients and families with a myriad of challenges that could threaten their physical, psychological, social and spiritual well-being (1). Many individuals in society fear prolonged and painful deaths—and as such have placed reliance on the use of advance care directives and explicit conversations with family, to ensure their wishes are known and that their autonomy is preserved at that vulnerable moment and beyond, when they have lost decisional capacity and can no longer direct care for themselves.

This paper will examine the unique issues raised at the interface between law and ethics as it relates specifically to the controversial issue of alimentation (providing food and nourishment) at the end of life. This analysis will be based, in part, on a historical case involving Margot Bentley (MB), an 82-year-old Canadian residing in a long term care facility in British Columbia (2). MB is living with and dying from the end stages of Alzheimer's disease and in 2013 Margot, her family and the care facility she resides in were at the centre of a legal battle over the circumstances necessary to constitute an imposed duty on caregivers to provide the basic necessity of life (food). This case exposed a number of concerns: the questionable utility and limits of living wills, surrogacy decision making, the actual meaning of implied

consent, and what exactly constitutes medical treatment versus basic care. What is unique about this case is that it does show gaps in both ethical and judicial analysis which has resulted in a legal decision to provide a level of care the family believes would be untenable and lacking in dignity for MB.

### The nature of alimentation in the provision of end of life care

Food and water are basic requirements to sustain life. Under normal conditions, the intake of food/liquids is self-controlled and requires no assisted alimentation external to the individual involved (oral or natural feeding). This act is clearly not considered a medical treatment, however, at its extreme end—individuals at the end of life, unable to take food or liquid by mouth, may choose to accept artificial means of hydration to meet their basic requirements (enteral by intravenous, and parenteral by feeding tube). This form of alimentation assistance has clearly been identified as a form of medical treatment requiring informed consent prior to initiation (3).

What is not clearly delineated is the degree of alimentation assistance leading up to artificial/assisted

**Table 1** Potential issues related to food and drink approaching the end-of-life

Factors	Issues potentially needing to be reviewed and negotiated
Consumption	Natural reduction in the intake of food and drink expected—psycho-education support needed to normalize this process
Cultural/religious	Belief in the need or necessity to provide nutrition and hydration based on cultural, religious need to be considered
Risk	Aspiration due to dysphagia—assessments by speech language pathologist
Food consistency	Movement from regular food consistency to a mechanically modified intake (soft/minced/pureed)
Fluid consistency	Altered liquid requirements moving from nectar-thin, honey-like, spoon-thick consistency
Dietary considerations	Reduction in overall intake can be reviewed and use of supplements (Ensure®, etc.) can be added to support intake
Method of delivery	Oral preferred and artificial mechanism (enteral and parenteral)

feeding and hydration required to classify the act as a clinical intervention requiring informed consent to proceed. *Table 1* outlines the potential issues related to food and drink which can give rise to ethical issues when approaching the end-of-life. Does the necessity to monitor for swallowing safety by a speech language pathologist, the use of textured foods and thickened liquids fall more into the categorization of treatment or is this simply an extension of basic care requirement? For MB, the courts ruled that assisted feeding (bringing a spoon up to her lips) constituted basic care and was not a treatment—therefore not requiring compliance with the local consent to treatment legislation (2).

Given the lack of clinical, ethical and legal clarity in respect to this continuum of alimentation (at the point when verbal or strong communication and interaction is not possible with the client) an ethics mediation process is needed to assist in finding common ground. It is recommended that the particular context of a case should drive the decision making process. Insufficient evidence and consensus exist at this time for the creation of a specific policy or laws that could adequately address these unique and challenging dilemmas.

### The role of the court

Ultimately, in cases such as MB, the primary function of a court is to ensure that the rights of the incompetent are exercised properly. This judicial jurisdiction is typically referred to as *parens patriae* in legal parlance. The *parens patriae* doctrine of the state has had its greatest application in the treatment of children, mentally ill persons and other individuals who are legally incompetent to manage their

own affairs, and is based on the proscribed need to act for the protection of those who cannot care for themselves. In a notable Canadian case law the following judicial obligation is described for this duty:

*“...the scope of the parens patriae jurisdiction is unlimited, the jurisdiction must nonetheless be exercised in accordance with its underlying principle. The discretion given under this jurisdiction is to be exercised for the benefit of the person in need of protection and not for the benefit of others.”* (4).

In the execution of its duty the judge, acting on behalf of the state is tasked with determining if the patient in fact requires the protection of the court, and if it did, to identifying what care would be in that patient’s best interest. In making that determination the court weighs the information and evidence provided by the petitioners and respondents; relies on expert testimony to provide clarity around medical issues; and based on this analysis applies known laws and prior court rulings to the issue at hand.

Of central importance is the issue of competency; the courts and regulations understand the importance of personal freedom and self-determination as a foundational right for the protection of human dignity. The question in this case separated specific “decisional capacity” from overall competence. MB was categorized, by medical experts, as having global incompetence given her advanced stage of dementia (stage 7 out of the seven stages of the Global Deterioration Scale for Assessment of Primary Degenerative Dementia) (2). However, an incapacity assessor with the Office of the Public Guardian and Trustee—provided expert opinion into evidence on this case—stating that MB, “*through her observations, has a means (by opening and closing her mouth to prompting by a caregiver) to*

*communicate her preferences*” (2). Regrettably the petitioners in this case were not advised to obtain a second, expert opinion on MB’s capacity to either verify or refute the initial findings that were offered to the court. A finding of capacity made strictly on an observed instinctive reaction (based on feelings or desires) is weak from an evidentiary perspective and should have been explored further in this case (5).

### Providing for the basics of life

Several statutes exist which govern the duties and responsibilities of residential care facilities to provide care to its residents. In the MB case, the guardianship act and the residential care regulations serve to identify what duties are implicit of the care providers (6). At the centre of the residential care act a facility “*must provide each person with adequate food and drink and to give assistance to persons with difficulty swallowing*” (7).

What appears to follow from the health authorities review of this case, and their reliance on the capacity assessment results, was to apply a decision (to contest the family’s directive to stop spoon feeding) based on the principle: “to err-on-the-side-of-life” (2). This principle is a particular application of the more general “err on the side of caution” principle of rational decision making in the face of uncertainty (8). However, this implicit value default would in itself be at the centre of the ethical conflict, wherein for MB, quality not quantity of life was her preferred wish in event of her not being able to recognize or interact with family.

In a separate legal analysis of this case, Dr. Downie questions why the health authority would have taken a position of having a duty under the criminal code to provide for the basics of life? Given that what they failed to consider was that a failure to provide for the basics of life would only constitute an offense if it were done without “lawful excuse” (9). In her report, Downie suggests that the absence of MB’s consent and the explicit references to food and nutrition in the original advance directives constitute sufficient defense to warrant a lawful excuse (9).

### Autonomy, advance directives and the duty of health care providers

In all jurisdictions across Canada, patients have the right to appoint a legal representative to make treatment decisions on their behalf when they lose decisional capacity to direct their own care. The status and legality of advance directives

is variable across the country. In British Columbia the use of advance directives was legalized with the amendment of the consent to treatment act in September 2011 (10). Directives written before that date are valid only if they meet the legal requirements outlined in the 2011 amendment. In the case of MB, her initial “statement of wishes” was completed in 1991. However, a second statement of wishes (incomplete) was found in 2011 which would have been executed at a later date and could potentially be a more recent reflection of her wishes—despite the family’s questioning of its authenticity.

In the context of advanced directives, it is always accepted that the wishes represent (at minimum) a point in time declaration—it can only speak to wishes declared at the time the document was written, and that anyone can change their wishes at any time. The discovery of a second directive (though not legally binding) offered a deviation in the wording used to address food and liquids, and arguably should have been sufficient to call for caution in proceeding forward.

Advanced directives should begin by thinking about one’s beliefs, values and wishes regarding future treatment and end with the proscriptions on how best to achieve those objectives in the context of the illness. What eventually happened in the MB case was that priority was given towards the semantics of the directives—and not its overall spirit. As noted by Pope, the fact that MB asked to be euthanized if due to mental deterioration she was unable to recognize any of her family—seemed not to have been a consideration in the deliberations (5). Additionally in situations of uncertainty the substitute decision maker should be called on to interpret beliefs/values and wishes applicable to the situation at hand.

The court decision sent a cautionary note to all Canadians who have or are considering the creation of an advance directive: make certain it is legally compliant in the jurisdiction you reside in—and that any such directives be kept current and updated if any changes occur!

### Summary

The MB case lives up to the legal maxim: hard cases make bad laws (11). Increasingly Canadians are demanding a voice in how they are going to die—noticeably in the recent flurry of right to die cases presenting at the highest courts. However, uncontested in this country has been the right for and expectation of a good death. The nature of MB’s death, by those who know and care for her most, would

contest that this basic right has been forfeited by the courts decision. Of note, in the opinion of one of her doctors: “...*despite her cognitive and physical disabilities, Mrs Bentley is not dying*” belies a common problem in the palliative care community—the lack of recognition that Alzheimer’s disease is a terminal illness and that MB is in fact in the latter stages of that illness and that she is dying. I believe that these cases points to the role for education and policy work to ensure concise goals of care conversations are documented for known issues not uncommon in cases of advanced dementia.

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None.

### Footnote

*Conflicts of Interest:* The author has no conflicts of interest to declare.

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