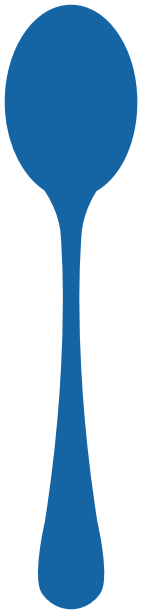
Margot Bentley Case | references from judgement & recommendations



Many people, particularly in British Columbia, have heard about and followed the story of Margot Bentley. Margot Bentley has advanced dementia and her family says she is being spoon fed without her consent, according to wishes she expressed when capable in a 1991 "Statement of Wishes."

A recent documentary by Karin Wells, '**In the presence of a spoon**,'[1] which aired on CBC radio Sunday Edition on June 14, 2015, brought the story to national attention.

The family asked the staff at the facility to honour Mrs. Bentley's wishes and to stop giving her food and liquids. The facility refused. The family (petitioners) challenged the facility, Maplewood Seniors Care Society, as well as Fraser Health Authority (respondents) in BC Supreme Court.

1 http://www.cbc.ca/radio/thesundayedition/in-the-presence-of-a-spoon-a-karin-wells-documentary-1.3111456?autoplay=true

THE LAW FOUNDATION OF BRITISH COLUMBIA

Thank you to the Law Foundation of BC for the small project grant to provide information on consent rights and planning tools for health and personal care.

Nidus followed the Margot Bentley case and you can read about the Court process, the parties involved and the original materials presented by each side at **www.nidus.ca** > AskJoanne in the right sidebar. Select category.

THINGS TO NOTE

- This case was about Margot Bentley's capability to consent to being spoon fed and honouring her "Statement of Wishes" if she is found incapable of consent.
- The case was not a test of the current legislation for personal planning such as Representation Agreements, although comments were made about the current laws and their relationship to Mrs. Bentley's "statement."
- The Representation Agreement Act was initiated and is promoted by citizens and community groups to provide a way for BC adults to authorize someone—a representative—to make health and personal care decisions during incapacity and at end-of-life.
- Nidus (a non-profit, charitable organization) was set up by seniors and disability groups to be a resource on Representation Agreements. Our legal practice group has studied the Bentley case and is concerned about the uncertainty that may have been created by the judge's comments in this case. See our analysis and recommendations on pages 7-8.

ISSUES RAISED AT THE HEARING IN BC SUPREME COURT

On December 17, 2013, the hearing of Bentley v. Maplewood Seniors Care Society began in the Supreme Court of BC with the Honourable Mr. Justice Greyell presiding.

The judge summarized the issues raised by the Petitioners and Respondents.

1. **"Is Mrs. Bentley currently capable of making the decision to accept nourishment and assistance with feeding?**
2. **Does assistance with feeding fall within the definition of health care or personal care?**
3. **If Mrs. Bentley is not currently capable of making the decision to accept nourishment, who has authority to make the decision?**
4. **Would failure to provide assistance with feeding constitute neglect within the meaning of the Adult Guardianship Act?**
5. **Would failure to provide assistance with feeding contravene a criminal prohibition?"**

QUESTION #1 – IS MARGOT BENTLEY CURRENTLY CAPABLE OF MAKING THE DECISION TO ACCEPT NOURISHMENT AND ASSISTANCE WITH FEEDING?

The BC Court rules Margot Bentley is capable of giving consent

On February 3, 2014, Judge Greyell of the Supreme Court of BC released his ruling in the case of Bentley v. Maplewood Seniors Care Society, **2014 BCSC 165—Reasons for Judgement**.[2]

Petitioners seek order to stop spoon feeding

In their Petition, Margot Bentley, represented by her daughter, and the family asked the Court to rule that Margot Bentley's verbal and written wishes not to be fed nourishment and liquids be honoured. Since Mrs. Bentley's "Statement of Wishes" was written in 1991, they asked the judge to order that it be recognized under the current legislation, which came into effect much later.

Respondents oppose the petitioners' requests

As Respondents, Fraser Health Authority and the Province of BC provided written responses to the Petition. Fraser Health opposed each of the orders sought by the Petitioners and made its own arguments about why the staff of Maplewood could not stop feeding Mrs. Bentley.

The judge's ruling

Judge Greyell ruled that "Mrs. Bentley is capable of making the decision to accept oral nutrition and hydration and is providing her consent through her behavior when she accepts nourishment and liquids." [para 153]

He ordered that Mrs. Bentley must continue to receive assistance with feeding. The judge considered a number of factors in his ruling:

- The presumption of capability is an important principle and the petitioners (Margot Bentley's family) are responsible for proving that Mrs. Bentley is not capable of making the decision to give or refuse consent to eat or drink. The judge found that they did not provide sufficient proof to rebut this presumption. [para 59]
- The judge was presented with different opinions on Mrs. Bentley's ability to give consent. There was no disagreement that she has advanced dementia (characterized as "stage seven," and the final stage).
- Dr. Andrew Edelson has known Mrs. Bentley for some 30 years and been her primary physician since 2011. His evidence, via affidavit, was that Mrs. Bentley's response to prompting with a spoon or glass is simply reflex and not a 'conscious decision.' [para 22]
- The judge noted that Dr. Edelson did not have specific expertise in Alzheimer Disease or assessments of incapacity. [para 21]
- Fraser Health Authority provided evidence from Dr. Neil Hilliard, a hospice palliative care physician, who assessed if Mrs. Bentley fit the criteria to be transferred to hospice care. He reported that she is clearly choosing to eat and is not "actively dying." [para 24]
- Fraser Health also presented an opinion from Dr. Deborah O'Connor, a professor in the School of Social Work at the University of British Columbia and an Incapacity Assessor with the Office of the Public Guardian and Trustee. [para 25]
- Dr. O'Connor determined that Mrs. Bentley had preferences for certain foods and made clear when she did not want more. Although there was some 'grey space' in that the responses to prompting may be reflexive, there was 'some capacity' and staff should decrease the number of tries to get Mrs. Bentley to continue to eat. [para 30] (These conclusions seem to be from a one-time observation made March 5, 2013. [para 26])
- The judge stated that he favoured the evidence from Dr. O'Connor over that by Dr. Edelson. [para 59]

BC COURT OF APPEAL AFFIRMS JUDGE GREYELL'S RULING ON CAPABILITY TO CONSENT

The family appealed Judge Greyell's decision. They said that the judge was incorrect in three aspects.

2 https://www.canlii.org/en/bc/bcsc/doc/2014/2014bcsc165/2014bcsc165.html?autocompleteStr=Bentley&autocompletePos=23

1. **The judge did not discuss whether Margot Bentley is giving consenting to be spoon fed;**
2. **The judge put the responsibility on the Petitioners to prove Mrs. Bentley is clearly refusing consent; and**
3. **If Mrs. Bentley is not consenting the judge should have ruled that prodding her with a spoon is battery.**

The BC Court of Appeal dismissed the appeal (March 3, 2015) on all grounds and agreed that Judge Greyell did address how Mrs. Bentley is giving consenting to eat. The Appeal Court re-affirmed that the judge did not require the Petitioners to prove Mrs. Bentley is refusing consent, instead they were required to counter the presumption that Mrs. Bentley is capable of giving consent. See **2015 BCCA 91**[3] at paragraphs 10, 14 and 17.

Judge Greyell's decision and his order to continue spoon feeding is binding on the parties in this case, although the Bentley family could appeal the issue of capability to consent to the Supreme Court of Canada.

OTHER COMMENTS BY JUDGE GREYELL—SUPPOSING MRS. BENTLEY WAS FOUND INCAPABLE OF CONSENT...

When Judge Greyell found that Margot Bentley is capable of giving consent and ordered that she continue to be fed, there was no reason to address any other issues.

However, Judge Greyell went on to talk about what might happen if he had made the opposite decision and found Mrs. Bentley incapable of giving consent. These additional comments are not binding on the parties; they are his opinions, also known as 'obiter dicta.' These cannot be appealed.

QUESTION #2 – IS SPOON FEEDING HEALTH CARE OR PERSONAL CARE?

What if Mrs. Bentley was found not capable of giving consenting to eat? Is spoon feeding health care?

» The judge found that BC's Health Care Consent and Care Facility Admission Act (HCCCFA Act) does not mention oral nutrition or hydration in the definition of health care. [para 63 and 65 - link at footnote 2]

» The judge noted that the term 'diet' is in the Representation Agreement Act, under the definition of personal care, along with shelter, dress, participation in activities, licenses and permits. [para 65]

NOTE

Those involved in the education and practice of Representation Agreements have used diet under the definition of personal care to discuss eating preferences (butter not margarine, rice not potatoes, hate liver) and lifestyle choices based on values and beliefs (Kosher or Halal diet, vegan, vegetarian). Issues concerning food allergies and diets related to medical diseases and conditions such as diabetes, would fall under health care. In the case of people with Parkinson's disease, it is a health care provider who assesses swallowing problems and prescribes thickeners for liquids and changes to food consistencies. This holds true for other eating problems and eating disorders.

Diet—eating and drinking—may be thought of as on a continuum. At times, diet is about personal care—based on individual preferences or belief systems. At other times, it is a health care issue. When a health condition requires interventions to one's 'diet'—thickening, puree, elimination of offending substances—it is not only a quality of life issue, it could be a life threatening situation. Other personal care matters, such as exercise and mobility, can become health care matters. For example, the health system took over falls prevention education for seniors, presumably because a fall usually leads to hospital admission. Doctors refer patients with osteoarthritis to programs involving physiotherapy (physiotherapists are health care providers) for exercises specific to the health condition. These programs usually also discuss nutrition because being overweight can increase the pain of osteoarthritis. Smoking and other addictions are seen as health care issues.

Personal care matters and health care matters may not be discrete and therefore classifying items as covered by one or the other needs to take the context into account.

3 http://www.canlii.org/en/bc/bcca/doc/2015/2015bcca91/2015bcca91.html

» The judge concluded that since a Representation Agreement can authorize decisions about personal care (as well as health care) and since nutrition, assistance with eating and meal planning as part of daily living are addressed in the legislation governing community care, assisted living and residential care this means eating and drinking must be personal care matters, not health care. [para 83]

NOTE

The judge referred to the Residential Care Regulation as a signal that eating or diet is not health care. However, the Regulation says that a health care provider or medical officer can request or require a review of a resident's nutrition plan and it must be done by a dietician. Dieticians are health care providers.

The Representation Agreement Act and Health Care Consent and Care Facility Admission Act were intended to work as a package. Unfortunately the Ministries of Health and Attorney General, who share responsibility for the legislative package, have not always worked together on implementation. The chance of gaps and inconsistencies are ever-present.

In addition, the Community Care and Assisted Living Act and Regulations were developed apart from the reform package.

Nidus proposed amendments to personal planning and related legislation in 2006. Charting the Course Ahead called on the Ministry of Health to make changes to legislation governing residential care—"the Regulations need to be updated to be consistent with not only the Representation Agreement Act but also with the Health Care Consent and Care Facility Admission Act and changes to the Adult Guardianship Act…the Regulations may also need to be reviewed for consistency with the HCCCFA Act regarding plans for minor health care and consent for immunizations."

» The judge concluded from his review that taking liquids or food by a spoon or glass is not health care, it falls under personal care or basic care. [para 77 and 84]

» The judge added that adults have a common law right to give or refuse consent to personal care matters. [para 84]

NOTE

The judge noted that Fraser Health Authority differentiated between types of assistance with feeding. They argued that prompting with a glass or spoon is personal care whereas assistance by artificial means (tube feeding) constitutes health care. (para 68)

Interestingly, no one makes this distinction for help with breathing. Mouth-to-mouth is not artificial assistance, nor are some other methods of resuscitation. Yet the law and practice considers any type of assistance with breathing to be health care. Eating and drinking are life supporting—just like breathing.

QUESTION #3 – IF SPOON FEEDING WERE HEALTH CARE, WHO DECIDES?

The judge went on to discuss how decisions would be made if Margot Bentley was incapable of giving consent and spoon feeding was defined as health care, not personal care. [para 86] He considered how the current law would apply to Mrs. Bentley's situation and therefore who can make decisions on her behalf.

1. Does Mrs. Bentley have a committee of person (court-appointed personal guardian)?

» The judge noted that Mrs. Bentley did not have a committee of person (personal guardian). [para 89]

NOTE

A spouse, family member or friend can apply to the BC Supreme Court to be appointed an adult's committee (kaw-mi-tay) of person. This cost can be $5,000 to $7,000 and it takes three to four months. At the Court hearing, the judge must first find the adult mentally incompetent. If yes, a committee of person is appointed and will have legal authority to make health and personal care decisions on behalf of the adult. Under this scheme the adult loses their rights, sometimes referred to as 'civil death.' In BC, Committeeship is the last resort.

Committeeship (adult guardianship) is difficult to reverse. For example, if an adult no longer needs a committee (after recover from a stroke) the adult has to apply to court to regain their decision making rights.

A committee of person would not have greater scope for decision making than a representative under a Representation Agreement Section 9. However, their duties are different. A committee's duty is to do what they think is best for the adult; a representative's duty is to follow the adult's wishes and values.

Statement of Wishes

Mrs. Bentley made a "Statement of Wishes," which is like a "Living Will" and is not a legal document under BC legislation. The lawyer for Margot Bentley and her family asked the Court to make an order that her "statement" be treated as a Representation Agreement or, if not, as an Advance Directive under current legislation.

2. Could Mrs. Bentley's Statement of Wishes be considered a Representation Agreement?

» The judge considered whether Mrs. Bentley's "statement" made in 1991 could be considered a Representation Agreement appointing her husband and daughter as representative and alternate.

» The judge said Mrs. Bentley's "statement" would not be a valid Representation Agreement. Even if the problems with signing and witnessing are set aside, her document did not clearly authorize her "representatives" (her husband and daughter) to refuse consent to health care necessary to preserve life. [para 101]

NOTE

A Representation Agreement is a legally enforceable document under BC legislation that you can use to authorize someone—your representative—to assist you with health or personal care decisions and act on your behalf.

The Representation Agreement Act was passed in 1993 and came into effect on February 28, 2000. Although the government partnered with community groups to create the legislation, government has yet to invest in education on Representation Agreements.

Not only is it difficult for the public to find out about Representation Agreements and their benefits. There is also considerable misinformation.

A Representation Agreement Section 9 (RA9) can be made when you are mentally capable. It gives your representative the authority to have the final say to refuse consent to health care necessary to preserve life if you are incapable at the time. No legal professional is required to make a Representation Agreement and Nidus has forms on its website.

3. Could Mrs. Bentley's Statement of Wishes be considered an Advance Directive?

» The judge noted that Mrs. Bentley's "statement" did not include wording required of an Advance Directive that no one would be selected as a Temporary Substitute Decision Maker (TSDM). Her statement contradicted this because it indicated her husband and daughter should act as decision makers on her behalf. [para108]

NOTE

Advance Directive legislation came into effect in BC on September 1, 2011. An Advance Directive (AD) can only cover health care, not personal care matters. It does not appoint a person; it is only for writing an instruction while you are capable and may be used as consent in the future if you are incapable.

It is unlikely that a document made before September 1, 2011 would be recognized as a valid AD since the requirements are very specific. For example the AD must include wording that the adult knows no one will be selected to make decisions (a Temporary Substitute Decision Maker) for matters covered in the AD.

» The judge also found that "the instruction 'No nourishment or liquids', when read in the context of the 1991 'Statement of Wishes,' is so unclear that even if this document could be considered a valid Advance Directive, this instruction could not be taken as consent." [para 112]

» While many would assume 'no nourishment or liquids' is a clear instruction, the judge was concerned about the circumstance when this would apply. Earlier in her "statement" Mrs. Bentley wrote that she did not want to be kept alive by artificial means or heroic measures.

The judge argued that there must be some relationship between these two aspects of the "statement." Since spoon feeding is not an artificial means of giving nourishment (like a feeding tube) and it is difficult to know what a particular person considers "heroic" the judge said he could not interpret the instruction as refusal of eating or drinking in the current circumstance. [para 111] It seemed that the wording in Mrs. Bentley's "statement" was contradictory.

NOTE

There are some fundamental challenges with using an Advance Directive alone (without an RA9). There is no wording in the legislation for instructions and therefore it is difficult to know what would be binding on different health care providers and across different health settings. This makes an Advance Directive of limited use and open to different interpretations.

An instruction alone—giving consent to specific health care or refusing consent—is likely not sufficient; you would also have to include specifics about the circumstance when it applies. For example, you could make an AD prior to your surgery based on a discussion with your surgeon about the risks and possible outcomes in the specific circumstance. But the AD/instruction would only apply to that surgery/ circumstance.

4. Could Mrs. Bentley's husband or daughter refuse health care on her behalf as 'next-of-kin?'

» The judge noted that even if Margot Bentley's husband or if he was unwilling then Margot's daughter was selected as a Temporary Substitute Decision Maker, a TSDM can only refuse consent to health care necessary to preserve life if a majority of the medical team agrees.

» Except for Mrs. Bentley's family physician, the rest of the medical team did not agree. Therefore the TSDM scheme would not have allowed Mrs. Bentley's husband or daughter to refuse nutrition or liquids, according to her wishes. [para 119]

NOTE

If an adult is incapable of informed consent for health care and the adult did not authorize a representative in a Representation Agreement or make an Advance Directive with adequate or applicable instructions, a health care provider must apply the default scheme when obtaining consent.

This involves selecting someone to be a Temporary Substitute Decision Maker (TSDM) for health care decisions.

The law sets out a ranked list starting with spouse, then adult child and other next-of-kin, then close friend or in-law. The Public Guardian and Trustee (government official) is the last resort if there is no one else available or willing on the TSDM list.

» In reviewing the current legislation, the judge recognized the Representation Agreement as the primary document for appointing a decision maker in BC. [para83]

NOTE

If Margot Bentley was mentally capable today and wanted to plan for incapacity, end-of-life and other future unknowns, what could she do under the current law in BC? Margot Bentley could make a Representation Agreement Section 9 (RA9) to authorize her husband and daughter to make health and personal care decisions on her behalf. An RA9 gives the representative the authority to refuse health care according to the adult's wishes, even if they might die. A representative authorized in an RA9 does not require the agreement of the medical team to refuse care.

QUESTION #4 – IF SPOON FEEDING WERE PERSONAL CARE, WHO DECIDES?

1. If, as the judge suggests in answer to question #1, spoon feeding in Mrs. Bentley's case is considered personal care and not health care, what might happen if Mrs. Bentley was considered mentally incapable of consent?

- As described under question 1 (page 2), the judge suggested assistance with oral nutrition and hydration is personal care, not health care.
- The judge noted that under BC law, only a Representation Agreement (or court-ordered committee of person) can address personal care matters. [para 122] An Advance Directive and a TSDM do not cover personal care.
- The judge also made clear that consent is required for personal care decisions under common law even if there is no legislation (no Act) that outlines 'personal care consent' like there is for health care consent. He said that, if an adult is incapable of making a personal care decision and there is no committee of person or Representation Agreement, at least family and friends should be consulted along with any written wishes. [para 124] But in this case, the Petitioners (family) have a different interpretation of Mrs. Bentley's wishes than the Respondents (Maplewood staff and Fraser Health Authority). [para 125 and 126]

2. If there is no legislation specific to giving or refusing consent to personal care, would stopping spoon feeding be considered neglect under BC's Adult Guardianship Act?

- The Adult Guardianship Act details definitions and responses to abuse, neglect and self-neglect.
- This Act states that it does not apply if an authorized representative or committee of person refuses health care, according to the adult's wishes, even if in the adult dies. There is no such exemption for refusing personal care. The judge, who classified spoon feeding under personal care, believed that stopping it would be considered neglect under this Act. [para 144-145]

NOTE

Under the Adult Guardianship Act, if someone is suspected of neglecting an adult, a designated agency (e.g. Health Authority) must determine if the adult needs support and assistance. If yes, the agency may investigate. An outcome of an investigation may be an application to court for an interim order to restrict the person, found to be neglecting an adult, from having contact with the adult.

QUESTION #5 – WOULD IT BE A CRIMINAL ACT TO STOP PROVIDING ASSISTANCE WITH FEEDING?

The respondents raised the issue that assistance with feeding is classified as 'basic care' and falls under Section 215 of the Criminal Code of Canada requirement to provide the necessaries of life. Maplewood and Fraser Health Authority said they fear prosecution under this or other sections of the Criminal Code if they stopped spoon feeding Mrs. Bentley.

Judge Greyell did not comment on this issue. He does not believe a civil court can or should give a judicial opinion on criminal liability. [para 152]

WHAT DOES THIS ALL MEAN?

Judge Greyell's comments speculating on the outcome if Margot Bentley was found incapable of consenting to spoon feeding are NOT a ruling or binding decision from the court. However, these remain 'on the record.' The comments cannot be appealed by the parties in this case. These could be debated in future cases but it would depend on the facts of those cases and the knowledge and experience of the lawyers involved.

ANALYSIS BY NIDUS' LEGAL PRACTICE GROUP

Nidus' legal practice group, made up of community and legal experts, has studied the Bentley case. Our analysis is based on 20+ years of experience in the development and practice of the legislation governing Representation Agreements, health care consent and adult guardianship.

- We are surprised that this situation ended up in court action.
- We believe the judge did not have the full arguments in front of him when commenting on issues related to BC's current legislation. This is an emerging area of law and BC's legislation has undergone a lengthy and convoluted implementation. The legal experts in this field and those involved in the development and implementation of the current legislation were not party to this court case or involved as a resource.

» We believe that this case has caused some concern and uncertainty for British Columbians who want to plan for the future. Particularly worrisome are the comments that eating and drinking may be considered personal care, not health care.

» A representative authorized in an RA9 is able to refuse health care necessary to preserve life according to the adult's wishes even if it means the adult's death. According to this judge's opinion, spoon feeding is not health care but rather personal care. Therefore refusing personal care necessary to preserve life could be considered neglect and subject to actions under the Adult Guardianship Act. Although just an opinion, it raises questions and concerns.

RECOMMENDATIONS

We believe any uncertainty must be remedied as soon as possible and we have put forward recommendations for minor amendments to reflect the intent of the Representation Agreement Section 9. You can read more about this in our presentation to the Standing Committee on Health, BC Legislative Assembly – **Nidus Recommendations to Improve Best Practices in End-of-Life Care**.[4]

Nidus recommends that the government make minor amendments at the earliest opportunity to include reference to 'personal care' in Section 45 (2)(b) of the Adult Guardianship Act and Section 9 (3) of the Representation Agreement Act.

LESSONS AND STEPS FOR PERSONAL ACTION

This case brings home some important lessons for those who are mentally capable now and want to plan for the future.

1. Wishes alone are not enough.

» If you only have written wishes, then the health care provider must select someone to be your Temporary Substitute Decision Maker (TSDM).

» Under the TSDM scheme, the medical team has a veto over decisions involving the refusal of health care necessary to preserve your life.

2. Make a Representation Agreement Section 9 (RA9) for health and personal care—give your representative as much authority as possible.

» As the judge noted, the Representation Agreement is the primary planning document in BC and covers health care and personal care matters. He pointed out some of the limitations of using an Advance Directive including that it does not apply to personal care.

» Your spouse and other family members have more legal authority as representatives than they would have under the TSDM scheme. But you can choose anyone as your representative. It does not have to be family.

» Don't wait for a crisis to make an RA9 as it may be too late. If capable, you can revoke (cancel) an existing RA9 and make a new one. No legal professional is required; find RA9 forms at nidus.ca—Planning for the Future.

» Register your completed RA9 with the Personal Planning Registry so it is available when needed.

3. Talk with your representative about your wishes, values and beliefs.

» If you want to write your wishes down, do it on a separate piece of paper. Give the page to your representative (and alternate) to use when they believe it is appropriate for the circumstance.

» As the judge noted, there are different ways of interpreting wishes and instructions. The representative is someone who knows you and who you have chosen. They will be the continuity and certainty in your life and over time.

4. Subscribe to the Nidus newsletter to keep informed and up-to-date about the law, educational resources and the Registry.

» **Sign up for our newsletter.** Visit www.nidus.ca, then click on "Subscribe to Our News" in the right sidebar.

This analysis was informed by Hugh McLellan's webinar presented with Nidus to practicing lawyers through Courthouse Libraries BC on May 12, 2015. Mr. McLellan is a partner in the law firm McLellan Herbert and recognized as an expert in the areas of personal planning, adult guardianship, and wills and estate litigation. He has been involved in the reform of adult guardianship legislation since the late 1980's.

Thank you also to Audrey Jun for consultation and review of this post and to Katharine Wong, UBC ProBono Law Student for proofreading and editing.

4 http://www.nidus.ca/PDFs/Nidus_Recommendations_End-of-LifePlanning.pdf