Consent and
Capacity Board

Commission du consentement
et de la capacité

Ontario

18-5097-01
18-5097-02

IN THE MATTER OF
the ***Health Care Consent Act, 1996***
S.O. 1996, c.2, Sch. A
as amended

AND IN THE MATTER OF
HC
A PATIENT AT
OTTAWA CIVIC HOSPITAL – CIVIC CAMPUS
OTTAWA, ONTARIO

REASONS FOR DECISIONS

PURPOSE OF THE HEARING

A panel of the Board convened a hearing at the request of Dr. G. D'Egidio, the health practitioner who was treating HC. Dr. D'Egidio had brought an application to the Board (a "Form G" application under section 37(1) of the *Health Care Consent Act* ("*HCCA*" or the "*Act*") for a determination as to whether or not the substitute decision-makers ("SDMs") for HC had complied with section 21 of the *Act*. An application to the Board under section 37 is deemed, pursuant to section 37.1 of the *Act*, to include an application to the Board under section 32 of the *HCCA* by HC with respect to her capacity to consent to the proposed treatment. The panel considered and determined both issues.

DATES OF THE HEARING, DECISIONS AND REASONS

The hearing commenced on March 13, 2019 by teleconference to hear a motion. The matter continued March 18, 19, 20, 21 and 22 in person in Ottawa and concluded on March 25 at the Consent and Capacity Board offices in Toronto. The Decisions were released March 26. The panel unanimously held that HC was not capable of consenting to a palliative plan of treatment including the use of antibiotics, dialysis, vasopressors, cardiac or respiratory resuscitation, artificial nutrition and medications for comfort.

Further, the panel unanimously determined that the SDMs (two of HC's sisters and her mother, identified in a Power of Attorney for Personal Care) had not complied with the principles of substitute decision-making as required by section 21 of the *Act*. We directed the SDMs to consent to the following plan of treatment:

- No further antibiotics will be offered in the event of and for the treatment of aspirations although these may be offered as required for comfort measures to relieve discomfort;
- No dialysis will be offered;
- No vasopressors will be offered;
- No CPR and no mechanical ventilation will be offered;
- Feeding will cease if any of the above treatments are required but for the operation of this order. All investigations and other interventions will cease.
- Comfort measures consisting of the administration of medications to ease suffering, pain, shortness of breath, anxiety, nausea, or any other symptoms, including bacterial infections, will be provided.

The SDMs were ordered to comply by April 5, 2019 at 12pm. Reasons for Decisions, contained in this document, were requested by Mr. Handelman (on behalf of the health practitioner) at the hearing and were released on April 2, 2019.

LEGISLATION CONSIDERED

Health Care Consent Act (“*HHCA*”), including sections 2, 4, 20, 21, 37 and 37.1.

PANEL MEMBERS

Lora Patton, senior and presiding lawyer member
Glenn Stuart, senior lawyer member
Gary Strang, public member

PARTIES & APPEARANCES

HC, the patient, was represented by counsel, Mr. E. Atnikov.
Dr. D’Egidio, the health practitioner, was represented by counsel, Mr. M. Handelman.
SD, LF and SM, the SDMs (SD was HC’s mother, LF and SM were two of her four sisters), were represented by counsel, Mr. H. Scher and Ms. K. Naugler.

The Euthanasia Prevention Coalition, granted limited party status to intervene on a question of jurisdiction, was represented by counsel, Mr. J. Campion and Mr. J. Nehmetallah.

All parties, other than SD and HC, attended throughout the hearing.

PRELIMINARY MATTERS

Request to Intervene:

The Euthanasia Prevention Coalition (“EPC”) sought limited party status in this matter for the purposes of intervening on the issue of the Board’s jurisdiction with respect to the withdrawal of artificial nutrition and/ or hydration. Limited party status was granted and, following hearing the motion on this issue on March 13th, the panel issued the below order, its ruling on the motion reproduced (although anonymized) for ease of reference:

1. *The hearing of this matter commenced on March 13th to hear a motion by the Euthanasia Prevention Coalition ("EPC") that it be named a party for the purposes of intervening in the hearing on a specific issue of jurisdiction: whether or not artificial nutrition and hydration were treatments as defined in the HCCA and, therefore, whether or not the Board could consider these elements in this case.*

2. *Participating in the teleconference were Mr. Campion & Mr. Nehmetallah (counsel to the EPC), Mr. Handelman (counsel to the attending physician), Mr. Scher (counsel to the SDMs) and Mr. Atnikov (counsel to HC).*

Revision of the motion:

3. *After discussion amongst the parties, Mr. Campion agreed to clarify his motion and narrow its scope. Following the conclusion of the motion, Mr. Campion filed a letter with the clarified language. He indicated that, if accepted as a party, EPC sought an order that "nutrition and hydration are not treatments within the meaning of the Health Care Consent Act in the context of this case and accordingly the Board does not have jurisdiction to decide on the withdrawal of nutrition and hydration."*

Proposed participation of EPC:

4. *Mr. Campion confirmed that his intended participation would be limited to cross-examination of some witnesses of no more than 15 minutes and submissions (I had identified 20 minutes for submissions during the motion but, in fairness, note that no such mention is made in the letter). He would not call witnesses. Further, he undertook that EPC would not initiate an appeal of this matter.*

Position of the other parties:

5. *Mr. Scher consented to the motion. Mr. Atnikov took no position except to note the importance of efficiency in resolving his client's health care. With the various revisions identified and the undertaking to not initiate an appeal, Mr. Handelman took no position on the motion.*

Determination:

6. *Although the panel was hesitant to add EPC as there was a lack of clarity as to its "useful and distinct contribution to the Board's understanding of the issues" (CCB Rules of Practice 5.2(e)) we recognized that none of the other parties were opposed, that the decision at issue was significant and that the requested participation was strictly limited such that it would not significantly delay the conclusion of the matter.*

7. *Consequently, the panel orders that EPC is added as a party for the sole purpose of intervening on the question of the Board's jurisdiction vis-à-vis nutrition and hydration*

and, specifically whether or not nutrition and nutrition and hydration are treatments within the meaning of the Health Care Consent Act in the context of this case.

8. *The panel further orders that EPC's participation:*
    - *Will include the cross-examination of witnesses, for a duration of 15 minutes;*
    - *Will include submission on the issue identified in paragraph 7 for a time period*
    - *determined by the panel;*
    - *Will not include the ability to call witnesses;*
    - *Will not include, by virtue of the undertaking, an ability to initiate an appeal of the Decisions.*

Motion about the Board's jurisdiction to consider the withdrawal of artificial nutrition and/ or hydration:

Prior to the outset of the hearing, the respondents gave notice that they would be raising as a preliminary issue a question as to whether the provision of nutrition and hydration to HC by way of a feeding tube constituted "treatment" within the meaning of the *HCCA.* The respondents took the position that nutrition and hydration were necessities of life, not treatment. Under the provisions of the *HCCA,* the panel's jurisdiction was limited, on the current application, to "treatment" as defined in the *HCCA.* If the panel concluded that the provision of nutrition and hydration by way of a feeding tube was not treatment, the panel would have no jurisdiction to determine the question of HC's capacity to consent to the provision of nutrition and hydration and no jurisdiction to review any decision by the SDMs in that regard. In other words, the panel would be limited to considering the other elements of the treatment plan. The EPC supported the respondents' position; at the hearing, the respondents made limited submissions on this issue and adopted the position of the EPC. HC took no position. Dr. D'Edigio maintained that nutrition and hydration were treatment.

The parties agreed that, although this issue was a preliminary issue for the panel's consideration, it would be argued at the conclusion of the hearing based on all of the evidence presented at the hearing.

For the following reasons, the panel unanimously concluded that the provision of nutrition and hydration constituted treatment within the definition in section 2(1) of the *HCCA.* Given this conclusion, the panel considered whether HC was capable with respect to the provision of nutrition and hydration through a feeding tube and whether the withdrawal of nutrition and hydration, in the circumstances set out in the treatment plan proposed by Dr. D'Egidio, was in the best interests of HC.

Counsel for the EPC, Mr. Campion, submitted that the issue of whether nutrition and hydration were treatment was one of statutory interpretation. The panel agreed with this submission and considered the issue with the framework of the language of the *HCCA.* Although the EPC and the respondents introduced a significant amount of material that set out the perception of nutrition as a necessity of life in many religious communities, the panel found that this provided little assistance in interpreting the relevant provisions of the *HCCA.* The panel accepted that nutrition was a necessity of life; the question remained whether it also amounted to treatment under the *HCCA.*

> "Treatment" is defined in s. 2(1) of the *HCCA.* The relevant provisions are the following:
>
> *"treatment" means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan, but does not include,*
>
> > . . .
> > *(f) a personal assistance service,*
> > *(g) a treatment that in the circumstances poses little or no risk of harm to the person,*
> > . . .

The EPC advanced two principal arguments: first, that nutrition and hydration were sustenance and *not* treatment; and, second, under the *HCCA*, nutrition and hydration were personal assistance services, not treatment. The panel did not accept either argument.

Treatment and sustenance, or necessities of life, are not exclusive categories. The broad terms of the statutory definition of treatment on their face include in their scope not only interventions that may be of "medical benefit" or assist with the curing of disease. The language used also encompasses measures that maintain – or sustain – life. As noted by the Supreme Court in *Rasouli (Litigation Guardian of) v. Sunnybrook Health Sciences Centre,* 2013 SCC 53 ("*Rasouli*"), the definition of treatment under the *HCCA* encompasses all actions that are done for a "health-related purpose". Chief Justice McLachlin, writing for the majority, discussed the clear choice made by the Legislature in the language used in the definition of treatment in the *HCCA* at paragraphs 36 to 44*:*

> *[36] The concept of "medical benefit" is a clinical term used by physicians to determine whether a given procedure should be offered to a patient. This clinical term has legal implications for the physician's standard of care. If a treatment would be of medical benefit to the patient in this sense, the physician may be required to offer that treatment in order to comply with his standard of care. Whether a given treatment offers a medical benefit requires a contextual assessment of the patient's circumstances, including the patient's condition and prognosis, the expected result of treatment for that patient, and any risks of treatment for that patient: A.F., at para. 44.*
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> *[37] The concept of "health-related purpose", by contrast, is a legal term used in the* HCCA *to set limits on when actions taken by health practitioners will require consent under the statute. "Treatment" is "anything that is done" for one of the enumerated purposes (therapeutic, preventive, palliative, diagnostic and cosmetic) or "other health-related purpose". Under the* HCCA, *only acts undertaken for a health-related purpose constitute treatment, and therefore require consent. The concept of health-related purpose in the* HCCA *does not interfere with a physician's professional assessment of whether a procedure offers a medical benefit. Its only function is to determine when the actions of health care practitioners require patient consent.*
>
> *[38] The issue here is not the correctness of the physicians' professional opinion that sustaining life in Mr. Rasouli's situation confers no medical benefit. In fact, their opinion appears to reflect a widely accepted view in the medical community.* ***The issue at this stage of the argument is whether maintaining Mr. Rasouli's life serves a health-related purpose within the meaning of the HCCA.***
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> *[39] The wording of the* HCCA *does not limit "health-related purpose" to what the attending physician considers to medically benefit the patient.* ***The HCCA does not use the terms "medical benefit" or "medically indicated". The legislature could easily have taken this approach but instead chose to define "treatment" more broadly with a wide-ranging and non-exhaustive list of health-related purposes.***
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> *[40]* ***The words of the HCCA on their face cover provision of life support that is effective in keeping the patient alive and forestalling death. Life support arguably falls within "therapeutic" and "preventive" purposes, listed in the definition of "treatment" in s. 2(1).***
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> *[41] The* New Oxford Dictionary of English *(1998), defines "therapeutic" as "relating to the healing of disease", but also as "having a good effect on the body or mind" (p. 1922). Maintaining life support for Mr. Rasouli does not serve the purpose of "healing of disease".* ***However, it can be argued that maintaining life support has a "good effect on the body", in the sense of keeping it alive.***

> *[42]* ***The same dictionary defines "preventive" as describing a medicine or other treatment "designed to stop disease or ill health from occurring" or "designed to keep something undesirable such as illness, harm, or accidents from occurring" (p. 1469). If death is considered harmful or a manifestation of ill health, then life support serves a preventive purpose so long as it is effective in preventing death.***
>
> ***[43] Inclusion of life support in "treatment" is also generally supported by the objects of the HCCA. It provides consistency with respect to consent, protects autonomy through the requirement of consent, and provides a meaningful role in the consent process for family members.*** *An interpretation of "treatment" that is confined to what the medical caregiver considers to be of medical benefit to the patient would give these statutory purposes short shrift. The legislature cannot have intended such a crabbed interpretation of "treatment".*
>
> *[44] Reading the words of the statute in their ordinary sense and in their context, and having regard to the objects and scheme of the Act, I cannot accept the physicians' argument that "treatment" and "health-related purpose" are confined to procedures that are of medical benefit in the view of the patient's medical caregivers.* [Emphasis added.]

The panel noted that, although the Chief Justice used the term "life support", the interventions in that case included mechanical ventilation and "artificial nutrition and hydration, delivered through a tube inserted into his stomach" (paragraph 5). In the panel's view, the decision of the Supreme Court in *Rasouli* provided a full answer to the argument that sought to exclude nutrition and hydration delivered through a tube inserted in the stomach from the definition of treatment.

Counsel for the EPC took the position that the decision in *Rasouli* was not a complete answer to the interpretation question. They relied heavily on the agreement by most witnesses that the nutrition provided through a feeding tube served the same purpose as food presented on a spoon. On a fundamental level, that was true. Both provided nourishment to the human body. Implicitly, if nutrition through a tube was the same as food eaten on a spoon, the reasons of the Supreme Court in *Rasouli* could not be read as including nutrition as treatment, but only the collective package of interventions referred to as "life support". Put another way, if nutrition through a feeding tube and eating from a spoon were analogous, all eating would constitute treatment, and that defied common sense. Therefore, nutrition as a distinct element of life support had to be considered differently, and not as treatment.

The panel did not accept this line of reasoning for two reasons. First, the elements of the treatment provided to Mr. Rasouli were identical to those provided to HC, except that there was no mechanical ventilation provided to HC at the time of the hearing. While the collective effect of those interventions was to prevent death, this was also the effect of each individual intervention. Each element, including nutrition or hydration, contributed to the health related purpose of preventing Mr. Rasouli's death. Consequently, the panel concluded that the rationale set out by Chief Justice McLachlin applied equally to each element of life support, including nutrition and hydration. Nutrition through a feeding tube serves a health-related purpose because it "serves a preventive purpose so long as it is effective in preventing death." Applying this rationale, nutrition provided through a feeding tube had to constitute treatment.

Second, the analogy drawn between nutrition through a tube and spoon feeding was a very superficial one that does not bear scrutiny on all of the evidence. The evidence of Dr. D'Egidio made clear that nutrition provided through a feeding tube had all of the indicia that would reasonably be attached to a "treatment". Specifically, a licensed health care professional had to determine the rate at which nutrition was provided, the concentration (and content) of the nutrition provided and the duration for which it was provided. Put another way, the nutrition provided by feeding tube was prescribed by a health care professional, or, in this case, a collaborative team of health care professionals, including a physician and a dietician. Although Dr. Lebowitz suggested that these decisions might be made by other staff in his jurisdiction in the United States, this was contrary to the practice and regulatory requirements in Ontario, based on the evidence Dr. D'Egidio and Ms. Golka, a registered dietician.

Under the *HCCA*, treatment lies within the exclusive responsibility of health practitioners, as reflected by the fact that only health practitioners can make a finding of incapacity with respect to treatment: s. 10, *HCCA*. Food eaten by a person from a spoon does not need to be prescribed in most cases, although Dr. D'Egidio did indicate that food could form part of a treatment plan in some instances where the rate, concentration and duration of feeding were prescribed. One example was the case of someone being treated for diabetes through diet. The uncontradicted evidence of Dr. D'Egidio was also that feeding through a tube could pose a number of risks to the health of HC, which would not be the case in most circumstances with spoon feeding. He indicated that the Canadian Geriatric Society did not recommend tube feeding for patients with advanced dementia in part due to these risks. These factors made feeding through a tube placed in HC's stomach more analogous to the provision of medications, which were also prescribed, than the food that one may consume as nourishment outside hospital and without the direction of a health care provider. Thus, while food consumed in other settings separated from the health care environment may not fall within the definition of treatment, the nutrition provided to HC constituted treatment for the purposes of the *HCCA* because the circumstances of its provision established a health-related purpose. The fact that nutrition was also a necessity did not change the conclusion that it was treatment in these circumstances.

On the evidence in this case, there was a further consideration following from the statutory language. Dr. D'Egidio indicated that, once HC went into distress again, in that she would require further interventions, the act of feeding her through a tube would be detrimental to her well-being since it created an overriding risk of aspiration as her body's other functions shut down. This risk was in addition to other risks of harm that could arise from the feeding tube. At that point in time, the withdrawal of nutrition itself would become a treatment because that withdrawal had the health-related purpose of preventing further injury to HC.

The second argument raised by the EPC was not explicitly addressed in *Rasouli.* In effect, the argument was that, even if nutrition through a feeding tube amounted to treatment under the first part of the statutory definition, it was expressly exempted from the definition as a personal assistance service. Personal assistance service is defined in the *HCCA* as "**assistance with or supervision of** hygiene, washing, dressing, grooming, **eating, drinking**, elimination, ambulation, positioning or any other routine activity of living . . ." [Emphasis added.] The EPC took the position that this included all forms of the provision of nutrition, including nutrition through a feeding tube.

The panel considered the language of the *HCCA* in light of the principle reiterated in *Rasouli,* at paragraph 32, that the "basic rule of statutory interpretation is that "the words of an Act are to be read in their entire context, in their grammatical and ordinary sense harmoniously with the scheme of the Act, the object of the Act, and the intention of Parliament". . . . Every statute "shall be given such fair, large and liberal interpretation as best ensures the attainment of its objects": *Legislation Act, 2006*, S.O. 2006, c. 21, Sch. F, s. 64(1)." Applying this standard, the panel concluded that nutrition through a feeding tube did not fall within the definition of personal assistance service. First, the relevant activities identified in the list in the definition are eating and drinking. In the panel's view, eating and drinking are to be distinguished from the broader concepts of nutrition and hydration. Both of these terms suggest active participation by the person receiving this assistance. In this case, the evidence demonstrated that HC was unable to eat or drink orally. Eating is a narrower term than feeding or nourishing. Drinking is a narrower term than hydrating. If the Legislature had intended more inclusive concepts to form part of the definition, it could have chosen terms such as feeding or nutrition. It did not. Rather, the Legislature chose the terms that reflect functions requiring the active participation of the recipient. The plain language used must be given effect as a matter of statutory interpretation. Second, the definition refers to "assistance with and supervision of" the listed activities. These terms also suggest support provided to a person who has some physical ability to perform the listed activities. It would be a distortion of the plain meaning of these terms to read them as contemplating the provision of something such as nutrition through a feeding tube when the mere existence of such a tube indicates that the person is unable to participate in the activity of eating. It was not disputed that HC was unable to eat, even with assistance. She had to be nourished through the feeding tube. Her role in that process was aa passive one.

Mr. Campion argued that the inclusion of eating and drinking in the definition of personal assistance services meant that those activities were excluded from treatment. Given the panel's conclusion that the language used excluded nutrition and hydration, it was not necessary to consider this argument further.

The panel's interpretation of the definition of personal assistance services coincides with the overall scheme of the *HCCA*, which generally considers personal assistance services to be provided in the context of long-term care facilities rather than care in a hospital. This limitation is not found in the definition of personal assistance services. However, under the definitions in s. 2(1) of the *HCCA*, a "recipient" is defined as one who receives personal assistance services in a long-term care home or other prescribed facilities. This definition effectively restricts the provisions of the *HCCA* with respect to personal assistance services to persons in a long-term care home. Findings of incapacity with respect to personal assistance services are made by an evaluator, not the more limited definition of a health care practitioner who assesses capacity with respect to treatment decisions: s. 57, *HCCA.* This suggests a limited application of personal assistance services in a hospital setting.

Perhaps most significantly, given the structure of the *HCCA*, if a person receiving nutrition through a feeding tube in a hospital was receiving a personal assistance service, not treatment, significant protections in the *HCCA* would not be available to them. The *HCCA* would not allow a SDM to make decisions for an incapable person, since SDMs are only engaged for *recipients* of those services: sections 56 to 62, *HCCA.* Findings of incapacity regarding personal assistance services, can only be challenged by a *recipient* of those services: sections 65, *HCCA*. Other applications, including an application to determine whether the decision by an SDM is in compliance with the *HCCA*, are also restricted to recipients: sections 66 to 69, *HCCA.* As noted, recipients are restricted to persons in long-term care homes – not hospitals. Although Mr. Handelman suggested in closing submissions that Dr. D'Egidio could challenge the instructions of the SDMs regarding nutrition provided through the feeding tube if nutrition was a personal assistance service, this challenge would not be permitted under the scheme of the *HCCA.* The deprivation of all of these protections would run contrary to the purpose of the *HCCA.* As held in *Rasouli*, at paragraph 43, the importance of these protections would support the conclusion that the provision of nutrition and hydration through a tube constitute treatment.

Although the provision was not addressed by counsel, the panel observed that the definition of treatment under the *HCCA* also excluded "a treatment that in the circumstances poses little or no risk of harm to the person." One could argue, following from the position of the EPC, that nutrition, as something required by all people, was something that posed little or no harm to HC. As noted above, that argument was not supported by the evidence. The evidence was clear that aspiration of substances, including food or other forms of nutrition, into HC's lungs was a significant risk, if not the most significant risk, of harm to HC and her well-being. On the facts here, this exception was not applicable.

Proposed Expert Witnesses on the issue of Disability:

Mr. Scher sought to introduce expert evidence on the issue of disability and systemic discrimination in the health care industry, as well as the lived experience of persons with disabilities in relation to health care. After considering the affidavits and supporting materials and hearing submissions from both Mr. Scher and Mr. Handelman, the panel declined to receive the evidence. The panel determined that although social science evidence may be of assistance in determining some context for the decisions to be made in this matter, the panel was capable of taking notice of the historic and current systemic factors impacting the lives of persons with disabilities in relation to health care. Further, notice could be taken of these contextual factors in interpreting the legislation, in particular, the meaning of well-being. As a statutory tribunal designed to resolve issues in a manner that is timely (the legislation requires commencing applications within 7 days, decisions within a day of conclusion and reasons for decision within 4 business days), embarking on complex inquiries such as may be appropriate in another forum would not achieve, in most cases, the timely resolution of applications. Regardless, the panel determined that such evidence was unnecessary on the facts of the matter before us.

Notice of Constitutional Question:

Prior to the commencement of hearing, Mr. Scher filed a Notice of Constitutional Question raising matters under sections 2, 7 and 15 of the *Canadian Charter of Rights and Freedoms (“Charter”)*. At the outset of the hearing, Mr. Scher fairly conceded that the Board does not have jurisdiction to hear or determine constitutional issues seeking relief under either s. 24 or 52 of the *Charter*. However, Mr. Scher asked the panel to interpret the applicable provisions of the *HCCA* in a manner consistent with “*Charter* values”, even if it was not applying a formal *Charter* analysis. The law in this regard was confirmed by the Court of Appeal in *ES v Joannou*, 2017 ONCA 655. After concluding that the Board did not have jurisdiction to provide relief under the *Charter*, the Court outlined, at paragraphs 98 to 100, the role that “*Charter* values” ought to play in the Board’s decision-making:

> *[98] Even though the Board does not have s. 24(1) Charter jurisdiction, it is not prevented from taking the Charter into account in applying the statutes under which it operates and exercising the discretion it has under those statutes. The Board’s authority*

> *derives from statute, which should not be interpreted as conferring the power to infringe the Charter, unless this power arises by necessary implication. Statutory discretion must, therefore, be exercised in a way that complies with the Charter, interfering with its protections no more than necessary given the statutory mandate:* Slaight Communications Inc. v. Davidson, *1989 CanLII 92 (SCC), [1989] 1 S.C.R. 1038, at pp. 1077-78;* Loyola High School v. Quebec (Attorney General)*, 2015 SCC 12 (CanLII), [2015] 1 S.C.R. 613, at paras. 39-40.*
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> *[99] The Board's decisions often have a direct impact on fundamental Charter rights, such as the right not to be detained and the right to control one's body. See* Gligorevic v. McMaster*, 2012 ONCA 115 (CanLII), 109 O.R. (3d) 321, at para. 60. In deciding issues of detention and consent to treatment, the Board is often engaged in balancing Charter rights, such as those under s. 7 of the Charter, against the objectives of the statutes which the Board is mandated to apply. This balancing reflects the Board's obligation to exercise its discretion in a Charter-compliant way. Thus, while the Board does not have s. 24(1) Charter jurisdiction, it is not precluded from considering the impact of its decisions on Charter rights.*
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> *[100] Moreover, as explained in* Conway*, at para. 103, Charter rights can be effectively vindicated without separate applications, through the exercise of the statutory powers and processes of the Board. Where the facts underlying a Charter breach are otherwise relevant to the statutory discretion of the Board, they may be taken into account in the exercise of that discretion: see* R. v. Nasogaluak*, 2010 SCC 6 (CanLII), [2010] 1 S.C.R. 206, at para. 47. In the present case, the Board found that the facts at issue were not relevant to the discretion it was exercising under the Mental Health Act.*

The panel proceeded on the basis of the foregoing framework and concurred with the position of the Attorney General for Ontario who understood our role as taking "the *Charter* into account in applying the statutes" and "by considering the impact of [our] decisions on *Charter* rights." As such, our consideration of the impact of our decision on any Charter rights is embedded in the panel's Reasons for Decisions as set out and is not addressed separately from our discussion of the applicable statutory criteria.

By contrast to the application of the *Charter* to a matter before the Board, the Board has the jurisdiction to interpret and apply the *Ontario Human Rights Code ("OHRC")* in determining a matter that is otherwise properly before it: *Tranchemontagne v. Ontario (Director, Disability Support Program)*, 2006 SCC 14 (CanLII), [2006] 1 S.C.R. 513, at paragraphs 34 to 39. There were no specific issues raised by the respondents that were relevant to the matters before the panel that triggered a formal discrimination analysis under the *OHRC.* For this reason, the panel did not undertake the formal analysis framed by the Supreme Court of Canada in *Moore v. British Columbia (Ministry of Education)*, 2012 SCC 61, 2012 CarswellBC 3446. However, as with the *Charter,* even if a formal *OHRC* analysis did not apply, the panel was obliged to interpret the *HCCA* in a way that was consistent with the *OHRC,* given its quasi-constitutional nature and the corresponding need to develop legal principles taking the *OHRC* into account. In other words, the panel was obliged to interpret and apply the *HCCA* in a manner that would not amount to discrimination under the *OHRC* in its effect.

During submissions, there were two *Charter* values raised as being applicable: the necessity for people to have equal benefit of the law without regard to any disability that people may have, and the necessity for people to be able to exercise freedom of religion. Given the factual findings of the panel regarding HC's religious beliefs, as set out below, the panel focussed its consideration on the former issue and the equal treatment of persons with a disability. In considering the emphasis that the *Charter* places on the substantive equality of people before the law, and the need to prevent discrimination by the law, the panel noted the underlying purpose of section 15(1) of the *Charter,* as summarized in *Law v. Canada (Minister of Employment & Immigration)*, [1999] SCR 497, 1999 CarswellNat 359, at paragraphs 42, 43, 46 and 48:

> *42 What is the purpose of the s. 15(1) equality guarantee? There is great continuity in the jurisprudence of this Court on this issue. In Andrews, supra, all judges who wrote advanced largely the same view. McIntyre J. stated, at p. 171, that the purpose of s. 15 is to promote "a society in which all are secure in the knowledge that they are recognized at law as human beings equally deserving of concern, respect and consideration". The provision is a guarantee against the evil of oppression, he explained at pp. 180-81, designed to remedy the imposition of unfair limitations upon opportunities, particularly for those persons or groups who have been subject to historical disadvantage, prejudice, and stereotyping.*
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> *43 Similarly, La Forest J., concurring with respect to the proper approach to s. 15(1), stated that the equality guarantee was designed to prevent the imposition of differential treatment that was likely to "inhibit the sense of those who are discriminated against that Canadian society is not free or democratic as far as they are concerned", and that was likely to decrease their "confidence that they can freely and without obstruction by the state pursue their and their families' hopes and expectations of vocational and personal development" (p. 197, quoting from Kask v. Shimizu, 1986 CanLII 100 (AB QB), [1986] 4 W.W.R. 154 (Alta. Q.B.), at p. 161, per McDonald J.). As discussed above, Wilson J. focussed upon issues of powerlessness and vulnerability within Canadian society, and emphasized the importance of examining the surrounding*

> *social, political, and legal context in order to determine whether discrimination exists within the meaning of s. 15(1).*
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> . . . .
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> *46 Similarly, in Eaton, supra, Sopinka J. applied a purposive approach to the determination of whether the state's failure to take into aHCount the underlying difference of the disabled qualified as differential treatment or inequality within the meaning of s. 15(1). Sopinka J. stated, at para. 66, that in light of the underlying context surrounding disabled persons in Canadian society, avoidance of discrimination on the ground of disability would frequently require formal distinctions in treatment to be made in order to effect substantive equality. He explained that "[t]his emphasizes that the purpose of s. 15(1) of the Charter is not only to prevent discrimination by the attribution of stereotypical characteristics to individuals, but also to ameliorate the position of groups within Canadian society who have suffered disadvantage by exclusion from mainstream society as has been the case with disabled persons".*
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> . . . .
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> *48 Similar observations were made in Miron, supra, by McLachlin J. and in Egan, supra, by L'Heureux-Dubé J. and Cory J., all of whom found that the fundamental purpose of s. 15(1) is the protection of human dignity. Cory J. stated in Egan, supra, at para. 128, that the equality guarantee "recognizes and cherishes the innate human dignity of every individual". As he explained, at para. 179, "the existence of discrimination is determined by assessing the prejudicial effect of the distinction against s. 15(1)'s fundamental purpose of preventing the infringement of essential human dignity". Similarly, in Miron, supra, at para. 131, McLachlin J. stated the overarching purpose of s. 15(1) as being "to prevent the violation of human dignity and freedom by imposing limitations, disadvantages or burdens through the stereotypical application of presumed group characteristics rather than on the basis of merit, capacity, or circumstance".*

The panel also took guidance with respect to the disadvantage faced by persons with disabilities, from the decision of the Supreme Court of Canada in *Eldridge v. British Columbia (Attorney General),* [1997] 3 SCR 624, 1997 CarswellBC 1939, a case that addressed barriers faced by deaf persons in relation to health care. Justice LaForest concisely framed the historical context of persons with disabilities, at paragraph 56:

> *It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions; see generally M. David Lepofsky, "A Report Card on the Charter's Guarantee of Equality to Persons with Disabilities after 10 Years -- What Progress? What Prospects?" (1997), 7 N.J.C.L. 263. This historical disadvantage has to a great extent been shaped and*

> *perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the "equal concern, respect and consideration" that s. 15(1) of the Charter demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms; see Sandra A. Goundry and Yvonne Peters, Litigating for Disability Equality Rights: The Promises and the Pitfalls (1994), at pp. 5-6. One consequence of these attitudes is the persistent social and economic disadvantage faced by the disabled. Statistics indicate that persons with disabilities, in comparison to non-disabled persons, have less education, are more likely to be outside the labour force, face much higher unemployment rates, and are concentrated at the lower end of the pay scale when employed . . .*

Exclusion of Witnesses:

Mr. Handelman sought an order excluding witnesses that were not family members. This was ordered.

THE EVIDENCE

The evidence at the hearing consisted of the oral testimony of Dr. D'Egidio, Ms. Golka (a registered dietician) and Mr. Barley (a registered nurse). In addition, in support of the SDMs, oral testimony was received from SM (SDM and sister), LF (SDM and sister), TG (cousin), MG (uncle and family Rabbi), MB (sister), Dr. N. Lazar, Dr. H. Lebowitz, and Rabbi B. Weiss.

Dr. N. Lazar was qualified as an expert in internal medicine, respirology and critical care. Dr. Lebowitz was qualified as an expert in critical care, long-term care and internal medicine. Rabbi Weiss was qualified in an expert in Jewish law and medical ethics in the Jewish context.

In addition, the following nine exhibits were received into evidence:

1. Document Brief of the applicant (54 pages);
2. Document Brief of HC (16 tabs);
3. Document Brief of the respondents (26 tabs);
4. Article "Intellectual and Adaptive Functioning in Individuals with Down Syndrome in Relation to Age and Environment Placement," Brown III et al. 1990 Pediatrics 450;

5. Package of material from the clinical record (individual date packages and flow sheets) from October 24, 2018 – November 26, 2018;
6. Richmond Agitation Sedation Scale chart and description;
7. Nursing notes from the clinical record March 9-18, 2019;
8. Progress notes from the clinical record March 9-18, 2019; and,
9. CV of Dr. Howard Harris Lebowitz.

INTRODUCTION

HC was, at the time of the hearing, a 62-year-old woman. HC was born with Down syndrome and had, by all accounts, flourished. She had lived in a supportive housing environment most of her life with friends and was proud of her ability to work in different jobs; she was a diligent worker who did not like to miss work. HC had participated in social activities, shopping and biking. HC was also close with her family, travelling to see her sisters and cousin and extended family to gather for Sabbath and holidays. She found joy in buying small presents for her family with her own money and in participating in her family's cultural and religious life. She was described as kind and strong-willed, with a wonderful sense of humour, an infectious laugh and a desire to please others.

In approximately 2013, HC was diagnosed with early onset dementia and was moved to a long-term care facility in Ottawa for increased support and care. In July 2018, HC was hospitalized due to aspiration, a complication of dementia caused by the diminished ability to co-ordinate swallowing. She was discharged after a short period of time to her long-term care facility but was readmitted with a second aspiration in September. A feeding tube was installed through her stomach, and HC was again discharged to long-term care. However, she was unable to remain out of hospital for more than three days. Beginning on October 18, 2018, HC began a difficult course in hospital following a further suspected aspiration. She was maintained in the intensive care unit for several weeks but stabilized such that she could be moved to step-down unit, where she received a level of care between that on a general ward and that in ICU. She remained in the step-down unit at the time of the hearing.

Dr. D’Egidio believed that HC was in end-stage dementia, and he proposed a palliative treatment plan in the event that various events occurred. It was his view that, if there was a further critical event, it would be evidence of her body dying. HC’s substitute decision-makers refused consent to the proposed plan, citing their orthodox Jewish faith and the importance of preserving every moment of life. When consent was not obtained to the plan of treatment, Dr. D’Egidio brought the Form G application.

THE LAW

Capacity to Consent to Proposed Treatment

Under the *HCCA*, a person is presumed to be capable to consent to treatment (Section 4(2)) and the onus to establish otherwise, in this case, rested with the health practitioner.

The test for capacity to consent to treatment is set forth in s. 4(1) of the *HCCA,* which states:

> *A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.*

Obligations of Substitute Decision-Making

The *HCCA* identifies the principles that substitute decision-makers must apply when making a decision about a proposed treatment. Those principles are outlined in Section 21:

> *21. (1) A person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:*
> *1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.*
> *2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests.*

> *21.(2) In deciding what the incapable person's best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,*
>
> *(a) the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;*
>
> *(b) any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1); and*
>
> *(c) the following factors:*
>
> *1. Whether the treatment is likely to,*
> *i. improve the incapable person's condition or well-being,*
> *ii. prevent the incapable person's condition or well-being from deteriorating, or*
> *iii. reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.*
>
> *2. Whether the incapable person's condition or well-being is likely to improve, remain the same or deteriorate without the treatment.*
>
> *3. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.*
>
> *4. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.*

In the event that a health practitioner believes that a substitute decision-maker did not comply with Section 21, he or she may apply to the Board for a determination. Section 37 addresses issues related to such an application:

> *37. (1) If consent to a treatment is given or refused on an incapable person's behalf by his or her substitute decision-maker, and if the health practitioner who proposed the treatment is of the opinion that the substitute decision-maker did not comply with section 21, the health practitioner may apply to the Board for a determination as to whether the substitute decision-maker complied with section 21.*
>
> ***Parties***
> *(2) The parties to the application are:*
>
> *1. The health practitioner who proposed the treatment.*
> *2. The incapable person.*
> *3. The substitute decision-maker.*
> *4. Any other person whom the Board specifies.*

Power of Board
(3) In determining whether the substitute decision-maker complied with section 21, the Board may substitute its opinion for that of the substitute decision-maker.

Directions
(4) If the Board determines that the substitute decision-maker did not comply with section 21, it may give him or her direction and, in doing so, shall apply section 21.

Time for compliance
(5) The Board shall specify the time within which its directions must be complied with.

Deemed not authorized
(6) If the substitute decision-maker does not comply with the Board's directions within the time specified by the Board, he or she shall be deemed not to meet the requirements of subsection 20 (2).

Subsequent substitute decision-maker
(6.1) If, under subsection (6), the substitute decision-maker is deemed not to meet the requirements of subsection 20 (2), any subsequent substitute decision-maker shall, subject to subsections (6.2) and (6.3), comply with the directions given by the Board on the application within the time specified by the Board.

Application for directions
(6.2) If a subsequent substitute decision-maker knows of a wish expressed by the incapable person with respect to the treatment, the substitute decision-maker may, with leave of the Board, apply to the Board for directions under section 35.

Inconsistent directions
(6.3) Directions given by the Board under section 35 on a subsequent substitute decision-maker's application brought with leave under subsection (6.2) prevail over inconsistent directions given under subsection (4) to the extent of the inconsistency.

P.G.T.
(7) If the substitute decision-maker who is given directions is the Public Guardian and Trustee, he or she is required to comply with the directions, and subsection (6) does not apply to him or her.

> ***Deemed application concerning capacity***
> *37.1 An application to the Board under section 33, 34, 35, 36 or 37 shall be deemed to include an application to the Board under section 32 with respect to the person's capacity to capacity to treatment proposed by a health practitioner unless the person's capacity to consent to such treatment has been determined by the Board within the previous six months.*

HC's CAPACITY TO CONSENT TO THE PROPOSED TREATMENT

Did the evidence establish that HC was unable to understand the information relevant to the treatment decision? Did the evidence establish that HC was unable to appreciate the reasonably foreseeable consequences of making a decision about the proposed treatment?

It was Dr. D'Egidio's uncontested evidence that HC was unable to understand information relevant to the treatment decision. It was his evidence that HC was unconscious and unresponsive, unable to follow commands or to track the presence of a person with her eyes. It was his view that HC's brain functions had significantly eroded over several months as a result of her dementia. Dr. D'Egidio described HC as "profoundly encephalopathic", meaning that her brain function largely deteriorated. He explained that, as illustrated by a CT scan conducted in the preceding weeks, the degenerative process of dementia had shrunk HC's brain tissue, leaving enlarged ventricle space. This, in his description, indicated significant brain dysfunction and precluded HC from understanding information.

There was some evidence from HC's sister's and cousin that HC had responded to their visit, squeezing TG's hand when asked and turning her head when hearing a song she had known from family celebrations when she was younger. Dr. D'Egidio thought that this behaviour was unlikely indicative of a conscious response but more likely a reflex. The inconsistent evidence on this point did not address HC's ability to understand information regarding her treatment in the panel's view.

The panel determined that the evidence clearly established on a balance of probabilities that HC was unable to understand information relevant to the treatment decision. Dr. D'Egidio's evidence about HC's level of consciousness was clear and cogent. It was corroborated throughout the clinical notes at Exhibit 7 (found on the second page of the nursing flow sheet), which showed that HC's Glasgow Coma Scale results were between 4 and 9, indicative of minimal consciousness. Although HC may have been conscious at some points in the recent past, the panel accepted Dr. D'Egidio's findings that HC's brain function was so impaired from dementia that she was unable to receive the complex information about the proposed treatment, and she was very clearly unable to retain or process that information. HC was heavily sedated so that she could remain comfortable. The sedation did not appear, based on the evidence, to impact HC's ability to understand information as Dr. D'Egidio testified that she would have been incapable in any event due to the underlying brain dysfunction. HC was incapable of understanding information relevant to the treatment issue and it was unnecessary for the panel to consider the second branch of the capacity test.

APPLICATION TO DETERMINE COMPLIANCE WITH THE *HCCA*

Did HC express an applicable Prior Capable Wish (HCCA, section 21(1))?

Section 21 of the *HCCA* includes two references to the wishes, values or beliefs that the individual held when *previously* capable. The first is the requirement in s. 21(1) 1 that a substitute decision maker must act in accordance with "a wish applicable to the circumstances that the incapable person expressed when capable". The second is the requirement in section 21(2)(a) that "the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable". Both of these provisions require a consideration of the person's capacity at the time the particular value, belief or wish was held.

Mr. Handelman submitted to the panel that the onus rested on the respondents to prove both that the wish, value or belief was expressed or held by HC and that HC was capable at the time it was made. He relied in this submission on authorities that arose in the context of the interpretation of powers of attorney or wills: namely, *Vout v. Hay*, [1995] 2 SCR 876, 1995 CanLII 105 ("*Vout*"); and, *Barbulov v Cirone*, 2009 CanLII 15889 (ON SC) ("*Barbulov*").

The *Barbulov* decision involved an appeal from a decision of this Board. There was an issue as to whether a power of attorney with respect to personal care reflected the grantor's prior capable wishes. The Court found that it did not because the grantor did not know and approve of the contents of the document, even though the power of attorney was formally valid and the grantor had capacity to sign a power of attorney (paragraph 61). The Court found that this was a different question from the capacity of the person; rather, it related to the scope of the wish (paragraph 44). On the facts of that case, the portions of the judgment relied upon by Mr. Handelman with respect to the onus of proof did not impact on the ultimate decision of the Court. In other words, they were *obiter.* The onus of proof was not determinative of the case, and, in fact, the issue was not mentioned outside of the cited passage (paragraph 45). Instead, the Court focussed on the fact that the evidence that was adduced by the party seeking to rely on the wishes in the document demonstrated a set of circumstances that indicated that the grantor did not "know or approve of the contents" of the wish.

Even if the onus of proof had been the determinative question in *Barbulov*, the panel found that the decision was distinguishable from the facts of this case for two reasons. First, the panel found that a written document that purported to express the wishes of the grantor was significantly different in its nature from expressions of values and beliefs by HC through spoken word or actions. A question may arise as to whether a person knows the contents of a document; that same question cannot arise in considering a person's spoken word or action. As there was no evidence before the panel that HC had expressed a prior capable wish in a power of attorney or other written document, the Court's analysis in *Barbulov* did not assist in the present case.

Second, the Court was clear (at paragraph 45) that a person was presumed to know and approve of the contents of a power of attorney unless there was evidence to indicate to the contrary. Assuming that knowing and approving the contents of a document could be equated to an understanding of oral statements, there was no clear and convincing evidence that HC did not understand her wishes, values and beliefs at the time she made any statements, so as to trigger any onus on the SDMs to rebut that evidence and prove she was capable. The panel's reasons for this conclusion are set out below. However, in the panel's view, the *Barbulov* decision could be distinguished from the present case for this reason as well.

The panel concluded that the *Vout* case was distinguishable on the basis that it arose in the context of a will, outside the statutory scheme of the *HCCA*, and also that it considered the onus of proof surrounding a will after there had been proof of "suspicious circumstances" around the execution of the will. This panel heard no evidence suggesting "suspicious circumstances" surrounding the expressions of HC's wishes, values and beliefs. More importantly, as noted elsewhere in these reasons, the panel was bound to the consideration of the requirements of the *HCCA* in determining this application. Jurisprudence arising outside of that context, without the constraints of the statutory presumption of capacity, did not assist the panel.

It is fundamental to the scheme of the *HCCA* that an individual is presumed to be capable with respect treatment decisions unless the evidence demonstrates on a balance of probabilities that the individual is *not* capable, as that term is defined in section 4(1) of the *HCCA*. This presumption is explicitly set out in section 4(2). As a result of this presumption, it is well-established that the onus of establishing that a patient is incapable is on the physician seeking to rebut the presumption: *Starson v. Swayze*, [2003] 1 SCR 722, 2003 SCC 32 (CanLII) ("*Starson*"), at para. 77. In this case, that meant that the onus was on Dr. D'Egidio.

It was not contested that the onus to prove that HC was incapable with respect to treatment at the time of the hearing rested on Dr. D'Egidio. However, the panel could find no provision in the *HCCA* or any other principled reason set out in any binding jurisprudence to shift that onus away from Dr. D'Egidio in relation to HC's capacity prior to her current admission when she may have expressed values and beliefs that may have been relevant to the panel's decision. While there was necessarily some onus on the respondents to bring forward evidence that a prior wish, value or belief was held by HC, this rationale did not extend to proving her prior capacity. On the other hand, there was a compelling reason to leave the onus on Dr. D'Egidio. That reason derived from the *OHRC* and the values underpinning the *Charter*, as discussed below.

Dr. D'Egidio indicated that HC had not been capable since 1992. As he had only been involved in HC's health care since late 2018, he relied on the opinion expressed by Dr. Marilyn Crabtree in her letter, dated February 21, 2019 (Exhibit 1, page 37). In that letter, Dr. Crabtree, who had been HC's family doctor from 1992 to 2013, expressed the view that HC had not been "capable of providing informed consent for any significant medical procedure during the time she was under my care." Dr. Crabtree provided no further details of any assessments of HC's capacity that were performed during this period of time, although she specifically referred to three letters to support that view. In response to questions by counsel for HC, Dr. D'Egidio acknowledged that the three letters did not indicate that there had been an assessment of HC's capacity or that HC had been found to lack capacity. The first two letters, contained at Exhibit 2, Tab 2, pages 1 and 2, were prepared by Dr. Bruce McCreary, a psychiatrist, and confirmed that no signs of dementia had been identified. The third letter (Exhibit 2, Tab 2, pages 5 and 6) from the Neurology Clinic at Ottawa Civic indicated that HC's memory had declined and she had more difficulty following instructions, and this reflected a "mild cognitive impairment" that had been progressive over time. At that time, HC scored 16/30 on a Mini-Mental status examination.

A further mini-mental examination was conducted on February 23, 2011 (Exhibit 2, Tab 1, page 16). HC scored 7/30 on that examination. Apart from the assessments conducted during the current admissions, there was no evidence that HC's capacity was ever assessed.

Dr. D'Egidio conceded that he was not an expert in Down syndrome, but he said that he had treated a number of patients with Down syndrome and none of them had the capacity to consent to end of life treatment. He also referred to a 1990 study in the journal *Pediatrics* that indicated that persons living with Down syndrome experienced a deterioration in their cognitive abilities over time (Exhibit 4). As a result, and relying on Dr. Crabtree's letter, he had concluded that HC had never had capacity with respect to treatment. In response to a question from Mr. Atnikov, he conceded that he did not know before reaching this conclusion that HC had been high functioning. He maintained that this did not change his assessment.

In addition, Mr. Handelman fairly conceded that Dr. D'Egidio was not taking the position that the power of attorney signed by HC was invalid. In other words, he was not arguing that HC lacked the capacity to execute the power of attorney. This concession was based, in part, on the fact that the power of attorney did no more than identify the SDMs, and the named SDMs were the same as they would have been under the statutory hierarchy in section 20(1) of the *HCCA.*

For that reason, the panel did not place any weight on the concession in its consideration of HC's prior capacity.

It was suggested that, in the past, HC's health care providers and SDMs proceeded on the assumption that HC did not have capacity. As a result, HC's parents, or later the SDMs, may have made decisions for HC. HC did not object to those decisions. However, the panel could not infer from these actions, which were based on an untested assumption about HC's capacity, that HC did not have capacity at the time.

The panel was satisfied that there was no clear and convincing evidence from before HC's current admission that demonstrated that HC was not capable between 1992 and her current admission. In particular, there was no evidence that HC's capacity had been assessed during this period. The only evidence to support a finding of incapacity was Dr. Crabtree's bald statement that HC had been incapable since 1992, and Dr. D'Egidio's adoption of that conclusion. However, the conclusion was not supported by any other evidence, including the letters specifically identified by Dr. Crabtree. The conclusion appeared to be based on an assumption about HC's capacity. On the evidence before the panel, the only way that the panel could conclude that HC lacked capacity at all times back to 1992 was if the panel accepted the premise that HC could never have had capacity because she had Down syndrome and therefore lacked the cognitive ability necessary to establish capacity. The panel was not willing to accept that premise.

The panel concluded that the evidence did not demonstrate that HC had been incapable since 1992 for two reasons. First, there was an absence of evidence indicating either that HC's capacity had actually been assessed, based on her individual characteristics, or that HC was specifically found to have lacked capacity at the time of any statements she may have made with respect to her wishes, values and beliefs. Given the panel's conclusion regarding the onus on Dr. D'Egidio, this absence of evidence meant that the presumption of capacity was not overcome.

Second, the panel found that any conclusion based on an assumption that HC lacked capacity simply because she suffered from Down syndrome would not only be contrary to the scheme of the *HCCA* but would reflect a discriminatory view contrary to the *OHRC* and *Charter* values. The intersection of these issues was identified by the Supreme Court, in the majority reasons of Justice Major, at para. 77:

> *As a result, patients with mental disorders are presumptively entitled to make their own treatment decisions. Professor D. N. Weisstub, in his* Enquiry on Mental Competency: Final Report *(1990), at p. 116 ("Weisstub Report"), notes the historical failure to respect this presumption:*
>
> > *The tendency to conflate mental illness with lack of capacity, which occurs to an even greater extent when involuntary commitment is involved, has deep historical roots, and even though changes have occurred in the law over the past twenty years, attitudes and beliefs have been slow to change. For this reason it is particularly important that autonomy and self determination be given priority when assessing individuals in this group.*
>
> *The Board must avoid the error of equating the presence of a mental disorder with incapacity.*

When Dr. D'Egidio first approached the SDMs about the proposed treatment plan, both sisters candidly acknowledged that HC had not made any specific statements about the care she would want to receive; in a telephone call with the doctor, LF stated that "there was no need" to have these discussions (Exhibit 3, Tab 25, page 21). She explained in her testimony that this was because HC was never sick but also because everyone understood that Jewish law would dictate these decisions. Although HC had completed a Power of Attorney for Personal Care in 2011, she did not provide any directions in that document (Exhibit 3, Tab 24, page 11).

HC's family was devoutly orthodox and strictly followed Jewish law. The family members who gave evidence testified about the fact that HC's father was an orthodox Rabbi, that he had survived the Holocaust but lost much of his family, and that this had influenced his views and his teachings to his children on faith. HC's three sisters and RG described a devout home, committed to upholding Jewish values and a strict interpretation of the faith; a faith that HC's sisters had embraced in their adult lives. Jewish law set out expectations in the realm of end-of-life care based on the pre-eminent principle that every moment of life is sacred and a gift from God. For the family, only God could end life and, at times, suffering was required at the end of life as part of God's unknowable will. In turn, the family's orthodox faith did not account for suffering in the context of end-of-life decisions.

It was within this context that HC's family testified that HC may have made prior capable wishes about her current circumstances. LF's evidence was that when HC's grandmother was unwell HC "made very clear that we should do everything possible to keep bubbie alive because that was what the Torah said" and that she further told LF that "she would want the same treatment for herself if she was sick like bubbie" (Exhibit 3, Tab 1, paragraph 27). Similarly, MB's evidence was that HC had known about her father's feeding tube and that "she was happy that he was being supported and kept alive" and that "she would want the same treatment if she was sick" (Exhibit 3, Tab 4, paragraph 39). SM also indicated that HC had made statements about end of life treatment noting that, when HC's grandfather was in hospital, it was important "that all steps should be taken to keep him alive for as long as possible because that is what God wanted" (Exhibit 3, Tab 5, paragraph 19).

Over the course of their oral evidence, HC's family members acknowledged that HC had generally been unable to express complex ideas but that they witnessed her faith and beliefs more through her actions rather than her words. They had inferred wishes from the rather limited statements HC had made, interpreting these within the context of their own faith. It became clear in questioning the family witnesses that HC did not appreciate that either her grandparents or father were dying or very unwell when she found out that they were sick, or that choices had been made by them or for them about the health care that they were to receive. The evidence did not demonstrate that HC knew that they would not get better and join the family again for the holiday celebrations in which she enjoyed participating. More critically, the evidence made clear that HC was protected by her family from difficult issues; they did not want to cause her pain, so they did not describe Jewish laws around suffering and when they discussed health matters, framed issues in ways that they believed she would understand. For example, LF acknowledged that when HC visited her father in hospital, he would have appeared comfortable and not in any distress, so there was no need for HC to have asked about whether suffering was a necessary part of his life and death, and it was not discussed. MB stated that they did not discuss her father's illness with HC other than that he was very sick. When asked about having indicated in her will say statement, which was admitted in evidence on consent, that HC had said she would want everything done for her father, MB acknowledged that HC had not expressly stated this and that she was, rather, simply talking about him getting better. Similarly, when her uncle was asked about whether he thought that HC had been upset at the time of her father's illness because her father was ill and dying or because he was suffering, he acknowledged that he could not say.

Although we concluded that HC was presumptively capable, we also determined that HC had not made a prior wish that was applicable to her current circumstances. The panel found that, to the extent that HC had made any statements about care in hospital, these were expressions of hope that the sick person would get better as she would also hope to get better if she were sick. HC had not been informed about the specifics of Jewish law surrounding health care and her family sheltered her from some of the more complex and difficult concepts. The panel was satisfied that evidence did not demonstrate that HC understood the concept of death. No one believed that HC had been involved in a conversation about remaining alive despite discomfort or pain or suffering or despite experiencing the ravages of late or end-stage dementia. Any of the referenced stated wishes were vague, uninformed as to the matters at issue, and not addressed to the specific circumstances HC was now in. As such, these statements were not prior capable wishes within the meaning of section 21(1) 1.

In the absence of a prior capable wish applicable to HC's present circumstances, s. 21 required the SDMs, and, in turn, this panel, to consider the best interests of HC as that concept was defined in s. 21(2).

What Values and Beliefs did HC hold when capable that she would still act upon if capable (HCCA, s.21(2)(a))?

The panel heard that when HC was 5 years of age she was placed outside her family home and, being too young at that point for a group home, was cared for in a private home by others. When old enough, at about 6 years of age, HC transitioned to a group home outside of Ottawa. As there were no Jewish homes at that time, she was placed in a secular facility. HC's father made arrangements so that HC would not receive pork products in her diet and would not attend church. However, HC's family acknowledged that HC would not otherwise be able to live there in accordance with kosher rules. HC's uncle also indicated that "to keep kosher was beyond [HC's] abilities". HC remained in group homes in the Ottawa area until 2013 – over fifty years - when she moved into a Jewish, long-term care home. At that time "her memory and mobility [had] started to decline and she was becoming more resistive to care" (Exhibit 1, page 42). Consent for her admission at that time was provided by her SDMs.

Although living away from home, HC was visited by her uncle who brought her kosher food that she enjoyed, and she travelled home or to relatives for the Sabbath approximately once a month and for high holidays. She was described as enjoying the rituals, songs and food of the Sabbath, and Passover in particular. HC was described as enjoying the songs of her religion, although sometimes singing songs during the wrong holiday or holding the prayer book upside down.

Her cousin, TG, described HC as being part of the festivities, imitating others so that she could be part of the family's faith practices to the degree that she was able. TG told the panel that HC would wear an apron as her grandmother had when preparing for the Passover Seder. She described one instance of HC taking care of a toy Torah that had fallen on the ground, picking it up and cradling it, recognizing its importance. HC would be at the table with her family for Passover Seder and would, with her sisters, listen to her father talk about Judaism, the Passover story, and answer questions of faith. When she was engaging in orthodox practices "she did so in her own way and at her own level" (Exhibit 3, tab 1, paragraph 22).

MB described a story that HC's father had told the two of them during faith study. The story was about a man who was "near death" and whose relatives "pulled the plug" and caused him to die. The man returned to his family later to complain about his life being ended "prematurely" because this had "harmed his soul and ruined his afterlife" (Exhibit 3, tab 4, para 9). MB testified that in Jewish law and faith a person may be required to suffer to secure her place in the afterlife and that it was impossible for people to know the purpose of the suffering. LF testified that HC was being prayed for constantly and was accruing merits as a result – each merit advancing her placement in the afterlife. As such, every moment that HC was alive was more time for her to receive merits.

HC had a particularly close relationship with her grandmother, or her “bubbie”. HC’s bubbie was described as her friend and protector, reminding the family and others that HC’s differences were “not her fault as God had made her that way” and that HC was a special Jewish girl. HC’s grandmother would make mention of “going to Israel”, a concept that HC may have associated with dying or going to a peaceful place, and HC had indicated that she would want to go there too. Their closeness was such that the family purchased a cemetery plot in Israel beside bubbie for HC to be buried. When bubbie became sick HC “cried and prayed that her bubbie would get better and live longer so that we could be together more” (Exhibit 3, tab 2, para 27).

HC also had a close relationship with TG and RG, her cousin and uncle, respectively. RG would travel to HC’s home outside of Ottawa to visit with her. He testified that he would have to visit her in the evenings because HC was so committed to her work that she did not want to miss time. RG described HC as being in awe of his faith, that she would watch him pray and he would pray together with her, which pleased her. He told the panel that HC loved God. RG was able to visit HC more often when she was placed in long-term care as the facility was closer to him.

The panel was tasked with understanding who HC was based on her life story and how she had lived her life. Against this background, we had to discern her values and beliefs in the context of the proposed plan of treatment. The panel found that HC’s family held strong orthodox Jewish beliefs, and that HC’s family home was devout and committed to Jewish law. However, we determined that as an independent woman, HC had embraced not only elements of her Jewish faith but other values which were, at times, more important to her than strict compliance with religious doctrine.

Mr. Scher, on behalf of the SDMs, advanced the argument that the panel should infer that HC’s values and beliefs accorded with those of her family because she had not been able to express a complicated set of values as a result of her disability. Dr. Lazar, the expert presented by the SDMs, suggested that this assumption was applied in the case of children, with no lived experiences, and could be considered in the case of HC. The panel could not accept this proposition. Unlike a child, HC was a woman with more than 60 years of lived experience. To suggest that her values and beliefs had to accord with those of her family diminished her dignity as a person with a disability. Such a conclusion would be contrary to the *Charter* values that this panel was bound to, and did, consider.

The provisions of the *HCCA* are clear that the best interests test under s. 21(2) takes into account the values and beliefs of the *individual* who has been found to be incapable. There is nothing in the statutory language that contemplates taking into account the values and beliefs of that individual's *family.* As strong as the values and beliefs of HC's family may have been, that factor did not justify an assumption that they were HC's values. For the panel to look to the values and beliefs of HC's family, because she was limited in her ability to express her own values and beliefs due to her disability, would be to provide HC with a different protection of the law as a result of her disability. This result would be contrary to the equality values imbedded in the *Charter* and the *OHRC.* In the case of a person without Down syndrome, section 21(2) would direct the panel, and the SDMs, to the person's values and beliefs expressed when capable. Consequently, it was incumbent on the panel to ascertain, as best it could with the available evidence, HC's values and beliefs. The evidence was that HC would, when in the family home, participate as fully as she was able in the Jewish religion and traditions. HC's family home and the homes of her sisters were devout and would observe the Sabbath, keep kosher, attend synagogue and celebrate all Jewish holidays. However, HC lived at home only until she was 5 years old when she first went to a secular private home and then a secular group home. Notwithstanding her father's strong commitment to the faith, other factors were clearly considered when determining what was best for HC at the time. Although family visited periodically, their visits were relatively short and no one was able to describe what HC's day-to-day life was like with any degree of richness. All of the evidence suggested that for the fifty years HC lived in supportive housing, she did so largely in a secular way. The evidence did not demonstrate that during those years that HC kept kosher or took any steps to continue, even in a more minimal way, the religion that she practised when with her family. There was no evidence that HC observed the Sabbath unless she was with her family or attended synagogue. And, there was no evidence that she felt that these omissions were a loss.

The panel acknowledged that, when at home, HC participated alongside her family in religious activities. We also acknowledged the special relationship she had with her father, grandmother and uncle, all of whom were devout in their faith and who took great care to include HC in their faith and culture to the degree that she was able to do so. However, HC's identity clearly included the majority of the time she spent living much more secularly on her own.

The panel took particular note of the fact that HC rejected an opportunity to move to a Jewish home in Montreal when she had the opportunity. The evidence was that her uncle and father had continued to search for a Jewish home for HC throughout her life. Later in her life, and before her father's death, an opportunity arose for a placement in a home in Montreal that would provide HC with the opportunity to keep kosher, to keep Sabbath and to participate in Jewish life on a daily basis. The home was close to her cousin and uncle. (Her parents were living in Ottawa, but, at that time, HC's father was in hospital in Montreal where he remained until his death.) SM testified that HC had gone with her and RG to see the home and that HC very much liked it. However, when HC returned to her home, she decided that she would not move. She chose to remain in the home that she had made for herself and to continue with the secular lifestyle that she had built. The panel noted that the opportunity to be immersed in Jewish religion and to follow its principles was not determinative of the issue for HC; counsel for the SDMs acknowledged, in fact, that HC appeared to have weighed a number of factors including the importance of being close to her friends, her work and her home, as well as her wish to participate in Jewish life. The panel also noted that HC's strong wish to please family, to do good deeds (including being religiously observant) and to be rewarded for those deeds was not sufficiently compelling to make HC move at the time. The support workers at HC's housing unit also stated, and the family accepted, that HC was capable of making a decision about her living arrangements at the time.

The panel determined that HC was a complex woman with multiple values and beliefs that may have impacted her decision-making about her current treatment. For the same reasons as were set out above, we found that HC was presumptively capable during much of her adult life, including when she made the decision to forgo placement in a Jewish home. The panel rejected the SDM's submission that because of HC's intellectual disability, her religion and values and beliefs should be deemed consistent with those of her family. We found that such an interpretation was inconsistent with equality principles and disregarded the ability of HC to forge her own path – which she clearly had done throughout her life. Collective religious values did not usurp the emphasis on individual dignity and values inherent in the *HCCA*. We determined that her Jewish faith was not determinative of treatment choices nor was the value she placed on pleasing her family. These may have been factors in HC's values and beliefs but would not have resolved the issue in the manner advocated by the SDMs.

Were there any wishes expressed by HC that were not required to be followed under s. 21(1)(1) (HCCA, s. 21(2)(b))?

For the same reasons that were set out in relation to the determination relevant to section 21(1) of the *HCCA*, the panel also determined that the evidence did not establish that HC had expressed any wishes that were not required to be followed. Mr. Handelman raised an issue as to whether the wishes considered under this provision had to be prior capable wishes. Given its factual conclusions, the panel did not need to decide in this case whether prior incapable wishes could also be weighed under this provision.

What was the impact of the enumerated medical factors in determining HC's best interests (HCCA, s.21(2)(c))?

Dr. D'Egidio's evidence was that HC was in end-stage dementia and that this underlying condition was deteriorating and causing complications, including aspirations that jeopardized her health. It was his view that HC would continue to experience escalating complications such as infections (urinary tract infections, for example, as the result of the catheter), bed sores (as a result of being immobile) and shortness of breath or work of breathing (due to her collapsing windpipe, accumulation of secretions and exacerbated asthma). It was Dr. D'Egidio's evidence that nothing could be done to improve HC's underlying dementia or slow its degenerative course. He indicated that this assessment, and his proposed palliative treatment plan, was supported by the other twelve physicians in the critical care team.

Dr. D'Egidio's evidence was that HC would experience pain and suffering if she continued on the same plan of treatment of "full code." "Full code" meant that all measures would be implemented to sustain HC's life without consideration of the suffering that those measures may cause or their value in sustaining her life. Significant evidence was provided both by the doctor and by Mr. Barley (a registered nurse working in both the ICU and step-down units) about HC's difficult course in the intensive care unit for several weeks in the fall of 2018. HC was reportedly experiencing significant work of breathing on numerous occasions, often with her respiratory rate becoming extremely high as she struggled to take in air. HC was agitated on a number of occasions, pulling at her tubes and biting her ventilator. At times, she required physical restraints for her own protection. At times, HC required both physical and chemical restraint. Chemical restraint involved high levels of sedating medications being given to HC. (See Exhibit 1, updated Clinical Summary at pages 2-3 and Exhibits 7 & 8.) It was Mr. Barley's view that this type of course was quite unusual in the ICU setting, and HC appeared to be suffering. Mr. Barley acknowledged that, at the time of the hearing, HC appeared to be much more settled with little signs of significant distress, although he expressed his view that to be as sedated as HC would be suffering for many people.

Dr. Lazar and Dr. Lebowitz both gave expert evidence about persons in HC's condition. Although neither had treated HC, both had reviewed portions of her clinical record. Dr. Lazar's evidence focused largely on his understanding of the *HCCA*. To the extent that his evidence was premised on his incorrect belief that the law required that SDM direction be followed, his opinions were unhelpful. He did note that "trials" of ICU care, antibiotics and vasopressors could be appropriate, including for HC, although he acknowledged that he did not recall any references to shortness of breath, work of breathing, physical restraints or pain scores in the clinical record. Given the extensive references to these experiences in HC's clinical history, his opinion could be given little weight absent a consideration of these factors.

Dr. Lebowitz provided care in a small hospital in the United States that specialized in chronic ventilator use and critical care. He noted that a quarter to a third of his patients had dementia, many were on ventilators, and a few had met the criteria for neurological determination of death and were still supported with ventilators and artificial nutrition and food. It was Dr. Lebowitz's view that families received great benefit from allowing a loved one to continue receiving medical care until their heart stopped – this prevented the family from feeling that the life had been ended prematurely. It was his view that great care could be taken of HC so that complications could be avoided for a lengthy period of time. He believed that, with careful care, HC could be kept comfortable as the trajectory of her underlying dementia continued. It was his position that vasopressors could be used for short periods of time to support blood pressure when necessary and antibiotics would often be used, even in palliative care, to eliminate the discomfort of infections. However, although Dr. Lebowitz acknowledged that HC had been well-cared for, the reality was that complications had recurred. The evidence was that these incidents caused a deterioration in HC's overall condition. The panel had to give less weight to Dr. Lebowitz's opinion in light of this evidence. Moreover, it was clear to the panel that Dr. Lebowitz practised within a different legal framework where the interests of the family were also considered. That was not among the principles underlying the *HCCA.*

The panel determined that HC was in end-stage dementia, a condition that could not improve and would continue to deteriorate, although the rate of that deterioration was unclear. The panel determined that, at the time of the hearing, HC was sedated sufficiently that there was much less indication of obvious pain or discomfort. However, she did experience some pain and would experience pain if her condition deteriorated through one of the critical events identified by Dr. D'Edigio. We also noted that HC's level of sedation was significant and that this alone may be seen as suffering for some individuals, particularly in light of the lack of consciousness or likelihood of improvement. This factor was not an element of her disability: it was a significant factor that arose wholly from the circumstances necessary for her treatment. There was nothing in the evidence to suggest that HC would not consider this overwhelming sedation to diminish her well-being or be suffering. We also determined that HC had experienced and would continue to experience complications from the manifestations of her deteriorated mental state due to dementia. It was likely that HC would experience a critical incident that would require ICU admission, mechanical ventilation or other interventions that were likely to significantly impact HC's well-being. These interventions, in turn, would hasten a deterioration in HC's overall condition.

The panel was cautious in considering the phrase "well-being" and recognized that concepts of quality of life and dignity may be fraught when applied, without context, to a person who has lived with a disability. We were equally aware that HC was entitled to the protections offered by the *HCCA* and to have decisions made on her behalf, when she was unable to do so, in accordance with the law, without diminishing her personhood or her values and beliefs.

The term "well-being" has been found to include not only the continuation of life, but the person's dignity, level of pain, contentment and good health, both physically and psychologically: *Scardoni v. Hawryluck,* (2004), 69 O.R. (3d) 700, 2004 CarswellOnt 424, at paragraphs 45-50. In the panel's view, this broad definition allowed for consideration of the person's lived experience and the significance that they placed on suffering and hardship. Fundamentally, the concept of "well-being" does not impose a single standard on all people. In this way, the perspective that a person who has lived with a disability can be weighed in the same way that the perspective of person without an identified disability would be. What constitutes well-being for each person may be different based on those experiences. Considering the context of the *Charter* values that focus on the elimination of disadvantage to persons with disability, the panel accepted that well-being had to be defined in such a way that considered HC's well-being through her eyes, insofar as that could be ascertained from the evidence, not the eyes of one who had never lived with Down syndrome or dementia. In making that assessment, the actual conditions that she experienced and the dignity of HC were paramount considerations.

In the panel's view, a definition of well-being that did not focus on life at all costs was consistent with the observations of the Supreme Court in *Carter v. Canada (Attorney General),* 2015 SCC 5, at para. 63:

> *This said, we do not agree that the existential formulation of the right to life requires an absolute prohibition on assistance in dying, or that individuals cannot "waive" their right to life. This would create a "duty to live", rather than a "right to life", and would call into question the legality of any consent to the withdrawal or refusal of lifesaving or life-sustaining treatment. The sanctity of life is one of our most fundamental societal values. Section 7 is rooted in a profound respect for the value of human life. But s. 7 also encompasses life, liberty and security of the person during the passage to death. It is for this reason that the sanctity of life "is no longer seen to require that all human life be preserved at all costs" (Rodriguez, at p. 595, per Sopinka J.). And it is for this reason that the law has come to recognize that, in certain circumstances, an individual's choice about the end of her life is entitled to respect. . . .*

Although HC was no longer able to exercise a choice about her treatment, her best interests under the *HCCA* could be assessed with these same values in mind.

We found that, at best, HC was minimally aware (if aware at all) of her environment. She was extremely unlikely to regain awareness for the balance of her life. She was alone in hospital, her family outside the province and limited to short trips to her bedside. Unless significantly sedated, HC struggled to breathe, was irritated by the tubes that were inserted into her body and bothered by the intrusive care that was provided (hand bathing by nursing staff, for example, as described by Mr. Barley). Although reasonably comfortable at the time of the hearing, it was likely that another critical incident would occur within the next several weeks requiring more invasive measures, causing HC to experience pain and discomfort as was evident in her most recent ICU stay. The panel was satisfied that, should a further critical incident occur, it would be evidence of HC's body dying, a process that should be allowed to occur in a manner that kept HC most comfortable. The panel was not satisfied that minor infections would be evidence of such a critical incident and, for this reason, excluded antibiotic care from the palliative plan as ordered. The evidence was ambivalent and suggestive that antibiotics could provide comfort in a palliative plan and, in any event, a urinary tract infection would not require the escalation of care to the point of discomfort for HC that an ICU stay would cause.

Taking into account HC's values and beliefs, there was no evidence that HC would want to have her life extended without consideration of her overall well-being, either because of how she envisioned herself as a woman with a disability or as a woman of faith. As HC's condition progressed, an assessment of her best interests obligated the panel to order that no further measures be taken to extend her life should another critical event occur. At the same time, it was clear that palliative care would enhance HC's dignity and diminish her suffering for the remainder of her life.

The SDMs, although out of love and concern for HC, were imposing their own values and beliefs on HC as though they were her own. They were, in many ways, unable to consider the elements of HC's best interest because they were unable to consider decisions that occurred without reliance on Jewish law – and they were unable to consider that HC was independent in her thinking and able to have values and beliefs that were distinct from their own. Indeed, the evidence demonstrated that the SDMs had not appreciated that the withdrawal of treatment being recommended would only come into effect upon the occurrence of another critical incident, not immediately. The SDMs were unable to ever consent to a plan that stopped escalation of treatment for HC as their own religious beliefs required that they follow Jewish law and the direction of religious authorities. We heard that HC would receive ongoing aggressive treatment until a Rabbi confirmed that she was within 72 hours of death. We did not believe that such a direction was consistent with HC's values and beliefs. It was certainly not in accordance with her well-being when that concept was considered on the basis of the medical evidence and HC's level of suffering.

It was also argued that the application was premature, that HC was resting comfortably and that no decision was required at the present time. The panel respectfully disagreed. HC appeared to be sufficiently sedated at the time of the hearing. However, her condition was precarious as noted by all physicians who testified. It was necessary for HC's health care team to have direction such that steps could be taken when a critical decision was required. It was clear that the parties would never reach an agreement given the fundamental issues that had to be determined. The panel was obligated to consider, as the Board has multiple times, what HC's plan of treatment would be in the coming weeks and months.

After carefully considering all of the factors set out in section 21 of the *HCCA,* hearing and assessing all of the evidence and submissions received, the panel determined that the SDMs had not exercised their decision-making authority in accordance with the principles in s. 21 and HC's best interests as that term is defined therein. The panel further concluded that it was in HC's best interest for the SDMs to consent to the clarified treatment plan set out in the panel's Decision. Given the importance of the terms of the Decision to all of the parties, the panel found it appropriate to reframe the plan of treatment in accordance with the evidence to avoid any ambiguities that may have existed in the language used in the written document.

Although neither impact directly on the panel's conclusion, it is important to clarify two points that arose in relation to the arguments concerning nutrition and hydration in this case. The first is that the hydration and nutrition were effectively the same process in this case as HC received both through her feeding tube. The other relates to the effect that the withdrawal of nutrition and hydration under the proposed treatment plan would have on HC. Dr. D'Egidio indicated that, where nutrition is withdrawn at a palliative stage of care, the patient does not feel hunger or any increased suffering due to the body's diminished desire for nutrition at that stage, which often leads people to refuse food and water provided orally. Similarly, with hydration, the body would not react to its withdrawal, except that a person would feel dryness as a result of oxygen intake. This would be addressed in palliative care through sponges or sprays applied to HC's mouth by staff or family or the use of fans. What is equally important to note, given some of the submissions to the panel, is that the evidence was clear that the lack of nutrition would not be the cause of HC's ultimate death if it was withdrawn.

RESULT

The panel determined that HC was incapable of consenting to a palliative plan of treatment and, further, that the substitute decision-makers had not complied with the principles for substitute decision-making set out in the *HCCA*. We ordered that the SDMs consent to the plan as set out in the Decision, as repeated above, by April 5th, 2019 at 12pm.

Dated: April 2, 2019

Lora Patton
Presiding Member

Glenn Stuart
Senior Lawyer Member