Consent and
Capacity Board

Commission du consentement
et de la capacité

Ontario

18-5916-01
18-5916-02

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

AND IN THE MATTER OF
SH
A PATIENT AT
LONDON HEALTH SCIENCES CENTRE - UNIVERSITY HOSPITAL
LONDON, ONTARIO

REASONS FOR DECISIONS

PURPOSE OF THE HEARING

A panel of the Board convened a hearing at the request of Dr. R. Butler, the health practitioner who was treating SH. Dr. Butler 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-maker ("SDM") for SH, who was her husband, FH, 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 SH 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 was held on May 8, 2019. The Decisions were released the following day, May 9, 2019. Reasons for Decisions, contained in this document, were requested by Mr. Squire (on behalf of SH) at the hearing and were released on May 14, 2019.

DECISIONS

After carefully considering the evidence, the submissions of the parties and the law, the panel unanimously concluded that SH was not capable of consenting to a plan of treatment involving the withdrawal of life support measures and the ongoing provision of palliative care measures.

Further, the panel unanimously determined that the SDM had not complied with the principles of substitute decision-making as required by section 21 of the *Act*. The panel directed the SDM to consent to the following plan of treatment:

- Life support measures would be withdrawn, including the withdrawal of mechanical ventilation and the discontinuance of hemodialysis;
- No resuscitative measures would be provided if SH suffered a cardiac arrest; and,
- The focus of treatment would be on palliative measures that will be provided as needed to minimize discomfort to SH.

The SDM was ordered to comply by May 23, 2019 at 4 pm.

LEGISLATION CONSIDERED

Health Care Consent Act (“*HHCA*”), including sections 20, 21, 37 and 37.1.
Statutory Powers Procedure Act (“*SPPA*”), including section 9.

PANEL MEMBERS

Glenn Stuart, senior and presiding lawyer member
Eva Hodgson, public member
Henry Pateman, public member

PARTIES & APPEARANCES

SH, the patient, did not attend the hearing but was represented by counsel, Mr. P. Squire.

Dr. R. Butler, the health practitioner, attended the hearing and was represented by counsel, Mr. B. Hodge.

FH, the SDM and SH's husband, attended the hearing and was represented by counsel, Ms. N. Circelli.

PRELIMINARY MATTERS

Request for Exclusion of Observers from Hearing

At the outset of the hearing, Ms. Circelli requested an order excluding witnesses. The other parties did not oppose this request. The panel ordered that any witnesses, other than parties, be excluded until they had given evidence. Counsel confirmed that there were no intended witnesses other than parties.

Ms. Circelli then asked the panel to order that the observers in the room also be excluded. She submitted that this was necessary for two reasons. First, the sensitive nature of the evidence meant that the hearing should proceed in the absence of the public to protect the privacy interests of SH and FH. Second, the individuals included members of SH's care team (which was not disputed), and their treatment of SH could be negatively affected if they heard the evidence. The other parties opposed this request relying both on the presumption in favour of public hearings and the fact that the hospital was a teaching facility that relied on the public hearings as educational opportunities.

In the panel's view, it was well-established that there was a strong presumption in favour of hearings being open to the public, and that presumption could only be overcome in the exceptional circumstances outlined in decisions from the Supreme Court of Canada and in the *SPPA.* Section 9(1)(b) of the *SPPA* provides that a hearing will be public unless "intimate financial or personal matters or other matters may be disclosed at the hearing of such a nature, having regard to the circumstances, that the desirability of avoiding disclosure thereof in the interests of any person affected or in the public interest outweighs the desirability of adhering to the principle that hearings be open to the public". In hearings before the Board, it is inevitable that intimate personal information regarding one’s medical condition will be disclosed. However, the Legislature has not directed that the hearings before the Board always be held in the absence of the public. The question then was whether information would be disclosed at this hearing that was *more* intimate than in other hearings. There was no indication before the panel that that would be the case. In the absence of that threshold being met, the panel was not satisfied that it had the jurisdiction in this case to make the order sought. In this regard, the panel found that there was no need to assess the balance between educational value and privacy rights.

With regard to the second argument, the panel found that there was no evidence that there was a risk that the members of the care team would be negatively impacted by, or misuse, any of the evidence to be heard. In the absence of specific evidence of such a risk, the panel concluded that it could rely on a presumption that these health care professionals would act appropriately and in accordance with their professional obligations. The panel denied the request to remove any observers from the hearing room.

INTRODUCTION

SH was, at the time of the hearing, a 75-year-old woman. She was described as very social and “bubbly”. She was a kind person who loved life. Her husband said that people liked to be in her company all the time because she was so happy. She spent much of her life as a teacher and a community member trying to make things better for children. She enjoyed animals, walking in the park with her dog and husband, and spending time with others.

SH had been married to her husband, FH, for 41 years. They had no children. FH said that he loved SH more than anything. There can be no doubt of that. It was overwhelmingly clear throughout the hearing that FH loved SH very deeply. FH described SH as his wife, his friend and his only family in Canada. FH spoke about their life together, as they lived in various locations across Ontario over the years. He told the panel that he had never said no to her, and they had never had an argument. He said that, if he could change places with her, he would in a second, if it meant that SH would live. Unfortunately, that profound love and commitment could not remedy the irreversible health problems that SH faced at the time of the hearing. It also could not, in itself, define what treatment decision was in SH’s best interests given her condition and the weight of the evidence before the panel.

For some time, SH had lived with, and been treated for, a number of serious medical problems: end stage kidney disease, which had been managed with hemodialysis; atrial fibrillation, which required her to have a pacemaker; hypertension (high blood pressure), including pulmonary hypertension, which involved high arterial blood pressure around her lungs; and, longstanding diabetes, which had damaged her nerves and the retinas of her eyes.

In 2017, SH had been hospitalized at the London Health Sciences Centre - Victoria Hospital. After being placed in an induced coma, she remained in the Victoria Hospital for a period of approximately six months. It was unclear whether she was unconscious throughout that period, although she was on life support, including mechanical ventilation, for a significant part of that time. SH eventually recovered, with the care she received from the health care team and the support of FH. She returned to live at home with FH, where, according to FH, she was very grateful for the care and support he had provided her during her hospitalization.

On August 13, 2018, SH was brought to the Emergency Department at the University Hospital after suffering a cardiac arrest at home due to elevated levels of potassium in her system. She had no pulse on arriving at the hospital. SH was resuscitated at the hospital and transferred to the Intensive Care Unit (“ICU”) where she received urgent hemodialysis to reduce her potassium levels, as well as life support and standard treatments following a cardiac arrest, including “therapeutic hypothermia”. This process involved, in effect, the lowering of her body temperature while SH was unconscious to allow an opportunity for her brain to recover from the effects of the cardiac arrest and hopefully avoid or mitigate potential brain injury. After the cardiac arrest, there was a concern among the health care team that SH had suffered a significant anoxic brain injury, meaning an injury resulting from the lack of oxygen to the brain in response to diminished blood flow during the cardiac arrest. A series of neurological tests that were performed on SH indicated that she had suffered an extensive brain injury due to the lack of oxygen to her brain during her cardiac arrest.

SH's condition did not improve or change over time, leading to the conclusion that her condition was permanent. As a result, Dr. Butler and the health care team talked to FH about SH's condition and her prognosis. Although the physicians maintained that SH was in an irreversible vegetative state, FH insisted that she would recover, as she had when admitted to the Victoria Hospital in 2017. As a result, he insisted that SH received full life support and that all resuscitative measures be provided if she had a crisis or a cardiac arrest – what is known as "full code". This is the level of care provided until a different type of treatment is instructed by the person or her SDM. To provide these supports, a tracheotomy had to be performed in order to connect SH to a respirator by inserting a breathing tube into her throat. To ensure adequate delivery of nutrients, a feeding tube had to be inserted through her skin into her stomach. Despite efforts to remove her from the respirator, SH remained fully dependent on the respirator to breathe.

Dr. Butler indicated that, by the time of the hearing, SH's condition had been stable, but her neurological condition had not improved. In February 2019, Dr. Butler and the ICU physician team proposed a treatment plan that would involve the withdrawal of life support and resuscitative measures and the reliance on palliative measures to ease discomfort. FH refused consent to the proposed plan, insisting that SH would recover and she needed more time to do so. When FH's consent was not obtained to the plan of treatment, Dr. Butler brought this Form G application.

THE EVIDENCE

The evidence at the hearing consisted of the oral testimony of Dr. Butler and FH, along with the following nine exhibits:

1. Consent and Capacity Board Summary, dated March 22, 2019, by Dr. Butler ("CCB Summary");
2. Collection of Clinical Records, dated August 21, 2018 to March 8, 2019 (63 pages);
3. Letter, undated, from FH to Whom It May Concern;
4. Letter, undated, from FH under title "The London Connectivity Table", enclosing letter, dated March 2, 2019, from FH to University Hospital;

5. Letter, dated April 6, 2019, from FH to Whom It May Concern;
6. Letter, dated February 26, 2019, from the Extended Intensive Care Unit Physician Team to FH;
7. Consent to Treatment Form, dated April 4, 2019, signed by FH;
8. Clinical Progress Record, dated April 4th [2019], by Cathy Mawdsley; and,
9. Last Will and testament of SH, dated June 4, 2015.

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 standard of proof is proof on a balance of probabilities. The Board must be satisfied on the basis of cogent and compelling evidence that the physician's onus has been discharged. There is no onus whatsoever on the patient. The Board must consider all evidence properly before it. Hearsay evidence may be accepted and considered, but it must be carefully weighed.

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* sets out a framework for people to make treatment decisions for a person who has been found incapable with respect to treatment. Section 20 lists the priority in which people can become a substitute decision-maker for another person. After the categories of people who may be appointed by a formal legal document, the first person to be considered as a substitute decision-maker on the basis of their relationship to the incapable person is the incapable person's spouse. Section 20(2) of the *SPPA* sets out the requirements to be a substitute decision-maker:

> *20. (2) A person described in subsection (1) may give or refuse consent only if he or she,*
> *(a) is capable with respect to the treatment;*

> *(b) is at least 16 years old, unless he or she is the incapable person's parent;*
> *(c) is not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf;*
> *(d) is available; and*
> *(e) is willing to assume the responsibility of giving or refusing consent.*

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.
(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.

(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.

(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.

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

(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).

(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.

(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.

(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.

(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.

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.

SH's CAPACITY TO CONSENT TO THE PROPOSED TREATMENT

Did the evidence establish that SH was unable to understand the information relevant to the treatment decision?

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

Dr. Butler proposed a treatment plan that involved the withdrawal of life support to SH, beginning with a withdrawal of mechanical ventilation, along with a discontinuance of hemodialysis. If SH were to suffer a cardiac arrest, he proposed that no resuscitative measures would be used, so that SH could be permitted to die without the additional suffering that would be caused by those measures. The focus of care would be providing SH with as much comfort as possible. Consequently, if SH was unable to breath without the ventilator, she would be provided with palliative care to prevent discomfort, but she would otherwise be allowed to die.

Dr. Butler had not reviewed any information about this treatment with SH because he had concluded that she was unable to receive and understand any information. Dr. Butler indicated that SH had demonstrated no cognitive functioning over the course of her hospitalization as a result of her brain injury. He summarized the testing she had undergone in his CCB Summary (Exhibit 1, page 2). On the two days following her admission, SH had Computertized Tomography ("CT") scans of her head. These tests showed evidence of a "diffuse hypoxic brain injury". Dr. Butler stated that the health care team had wanted to do further imaging by a Magnetic Resonance Imaging ("MRI") Scan to allow them to give a better prognosis, but that was not possible because SH had a pacemaker, which could not be put through an MRI Scan. Neurologists assessed SH and found that she had minimal response to painful stimuli. EEG (or electroencephalogram) exams conducted on August 17 and 27, 2018, showed very limited brain activity. Further tests, known as Somatosensory Evoked Potentials, were conducted to see if her brain responded to various types of stimuli, but no readings could be obtained that were sufficient for the health care team to interpret. By the end of August 2018, the neurologists had concluded, based on the information they were able to gather, that it was unlikely that SH would recover her brain activity. As a result of the brain injury, it was likely that she would be dependent on others for all of her activities of daily living, she would be unable to live anywhere other than a hospital or chronic care home and she would be unable to communicate with those around her.

Dr. Butler candidly acknowledged that there was some uncertainty in the assessment of SH's prognosis in August 2018 due to the limits of the tests that they were able to perform, but that this uncertainty would reduce over time. Dr. Butler indicated that the lack of improvement in SH's condition over the nine months leading up to the hearing had eliminated any uncertainty in the conclusion that she was in an irreversible vegetative state. Although he did not accept the conclusion that SH's condition was irreversible, FH agreed that SH's condition had not improved or changed since August 2018. Dr. Butler stated that the team of physicians in the ICU all agreed that, at the time of the hearing, SH's brain injury was irreversible. This was reflected in the letter, dated February 26, 2019 (Exhibit 6), that was delivered to FH by Dr. Butler on March 6, 2019.

SH's neurological condition had been unchanged since August 2018. Dr. Butler stated that SH had periods of wakefulness and she would open her eyes to stimuli from sound or touch, but she did not focus or track objects with her eyes. He indicated that her movements, including the opening of her eyes in response to sound, were characteristic reflexive responses to painful stimuli. SH was also unable to obey directions, and she was unable to make deliberate or purposeful movements with her limbs or face. Dr. Butler said that these factors created a clinical picture that SH was in a vegetative state. She was unable to meaningfully communicate with her environment, including the people in it, and she was unable to make, or attempt to make, words. He said that this condition would continue without improvement.

Dr. Butler made similar observations in a clinical note, dated March 8, 2019 (Exhibit 2, page 62), with respect to an assessment of SH's capacity, in concluding that SH was "unable to meaningfully interact with environment or communicate" and therefore "incapable to make decisions". The note indicated that SH opened her eyes to voices at times and in response to painful stimuli, but she did not focus or track with her eyes. Her eyes would randomly dart about sometimes. She was not responsive in her limbs or her face, and she held her hands and arms bent against her body, a reflection of the extent of her brain injury. FH also noted that SH held her hands bent in towards her body, although he believed that could be corrected by massage. It was indicated that these observations were consistent with previous assessments.

In an entry in the Clinical Progress Record, dated March 1, 2019 (Exhibit 2, page 57), a member of the health care team indicated that SH had periods of “wakefulness” when her eyes were open, but she demonstrated no indication of any awareness. The writer described her clinical state as “vegetative”. In a note, dated February 6, 2019, on page 5 of the records marked as Exhibit 2, Dr. David Leasa indicated that SH’s neurological state remained unchanged. He noted that SH opened her eyes to voices or touch, but she did not track or respond to further stimuli.

Based on the observations of her condition, Dr. Butler indicated that SH was unable to understand any information about her condition or otherwise relevant to a decision regarding treatment, as a result of her brain injury. He stated that she was also unable to appreciate the consequences of a decision regarding treatment for the same reasons. Dr. Butler indicated that he had seen SH on the morning of the hearing and her condition remained the same at the time of the hearing.

FH stated that, contrary to the evidence of Dr. Butler, he had observed SH crying in pain and he said that she turned her head to look at him when he entered the room. The panel did not question that this may have been what FH perceived to have happened and what he honestly believed had happened. It was clear to the panel that FH was a man of great personal integrity. But, the panel also found that he was a man whose perceptions in relation to the wife that he loved and had loved for 41 years were distorted by what he wanted to see. This factor influenced many aspects of the evidence and required the panel to carefully assess FH’s evidence where it contradicted the clinical record.

In the panel’s view, FH’s perceptions of SH’s cognitive ability were skewed by his emotional attachment to his wife and his boundless hope that she would recover. In a note, dated February 5, 2019 (Exhibit 2, pages 4-5), one of the nurses, Ms. Mawdsley, indicated that FH had reported that he had seen SH cry and that she had demonstrated other pain behaviours. He had also told her that SH was trying to talk to him, and, consequently, he wanted the health care team to remove her breathing tube so that she could talk. However, Ms. Mawdsley indicated that, when she assessed SH, SH was turned to the window with her eyes open and moving without direction. She noted that SH was not tracking to the sound of either her voice or FH's voice. In her note, Ms. Mawdsley also indicated that SH's facial expression was relaxed, and she was not grimacing or shedding tears.

In another entry on an undated nursing assessment sheet (Exhibit 2, page 6), the nurse indicated that FH had reported that SH had withdrawn her hand and then squeezed his hand. But, the nurse was unable to reproduce this reaction. At the same time, it was noted on page 63 of the clinical notes (Exhibit 2) that FH required supervision when visiting SH because "at times he does get frustrated when she doesn't respond the way he wants. In the past, I had to tell him to stop tapping her face."

Dr. Butler and Ms. Mawdsley met with FH on November 15, 2018, as reflected in a UH ICU Family Meeting Record, of that date (Exhibit 2, pages 31-33). FH insisted at the time that SH was improving after dialysis because she had pulled his hand to her chest (specifically the heart area) and she had blinked her eyes when he had asked her to do so. FH stated to the panel that SH had communicated with him during her previous admission to Victoria Hospital by blinking, so this was significant to him. Dr. Butler had explained that FH had observed spontaneous or automatic movements by SH (such as blinking), and that SH remained unable to do more complex actions, such as squeezing her eyes shut or responding to commands. Although FH maintained that SH was responding to him, Dr. Butler confirmed that there had been no observations of coordinated brain activity by SH. Dr. Butler had told FH that there was no improvement in SH's condition.

In a meeting with Dr. Leasa and three nurses on February 8, 2019, reflected in a UH ICU Family Meeting Record, of that date (Exhibit 2, pages 34-37), FH again told the health care team that SH was communicating with him through her eyes. He said that he asked SH the day before to blink twice if she had pain and she did. The team members asked FH to demonstrate this communication. FH asked SH to squeeze his hand. SH did not open her eyes to the sound of FH's voice or move her hand. When Dr. Leasa told FH that SH could not communicate and that there would be no further improvement, FH refused to accept that conclusion. When Dr. Leasa offered to repeat a trial done the previous day to show that SH could not breathe without the respirator, FH refused to remain for the trial. His response, as recorded in the Meeting Record, gave insight into his perceptions: “I can’t see this. She is my life.”

The panel was satisfied that the clinical records accurately described SH’s condition and FH’s observations at the time. Where FH’s perception conflicted with the clinical record, the panel accepted the description in the clinical record. The clinical record presented consistent observations of SH’s condition, which were made at the time of the events. The records contained significant details of the observations and the related discussions with FH. Those observations were made over a prolonged period of time by a number of health care providers. The clinical record had all of the hallmarks of a reliable source of information. In each instance where the health care team sought to have the action that FH had reported reproduced, it could not be done. At the same time, the panel accepted that the emotional devastation that FH was confronting could well lead him to perceive things inaccurately or interpret his perceptions inaccurately, in a way that was consistent with his overriding hope that SH would recover and speak with him.

In assessing the evidence of SH’s neurological condition, the panel also considered FH’s evidence that he only visited SH for five to ten minutes at a time, after security had been assigned to accompany him when he was in the hospital. Security had been arranged early in SH’s admission because some of the health care team felt that they were at risk due to FH’s behaviours and threatening comments, including threat to the families of the treating doctors. The short duration of these visits, typically less than 10 minutes and sometimes only one or two minutes, was also confirmed in the clinical notes (Exhibit 2, for example, pages 6 and 9). The panel understood that FH’s visits were brief for many reasons, including the presence of security and the lack of responsiveness of SH. But, in the panel’s view, FH would not have had a meaningful opportunity to observe SH in the course of these short visits. The nursing staff, which monitored SH around the clock, were better able to make these observations. These observations were reflected in the clinical records and Dr. Butler’s evidence.

The panel also concluded that, in some instances, FH’s perceptions of SH’s actions may have been accurate, but he may have interpreted them incorrectly to suggest brain activity that did not exist. To the extent that SH may have shown reactions such as gripping a hand placed in hers, opening her eyes in response to sound, or even blinking, Dr. Butler stated that these would be reflexive actions that did not reflect any awareness by SH of her environment. This view appeared to be shared by the rest of the health care team treating SH. The panel accepted this interpretation.

The panel determined that the evidence clearly established on a balance of probabilities that SH was unable to understand information relevant to the treatment decision. Dr. Butler's evidence about SH's level of brain functioning was clear and cogent. It was corroborated throughout the clinical notes at Exhibit 2, which showed that his assessment was mirrored by the other doctors involved in SH's care. The panel accepted the evidence of Dr. Butler and the health care team that SH's brain function was so impaired from her brain injury that she was unable to receive and process any information about her condition or the proposed treatment. Given that SH was incapable of understanding information relevant to the treatment issue, it was unnecessary for the panel to consider the second branch of the capacity test.

APPLICATION TO DETERMINE COMPLIANCE WITH THE *HCCA*

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

Section 21(1) 1 of the *HCCA* requires that a substitute decision maker must act in accordance with "a wish applicable to the circumstances that the incapable person expressed when capable". As suggested by Ms. Circelli, treatment decisions are so fundamental to a person's bodily integrity and autonomy that a capable person must consent to treatment before treatment will be permitted by law. The corollary to that position is that where a person is no longer capable but had expressed a wish when capable that applies to the circumstances facing the person, that wish must be considered determinative of the decision by the substitute decision-maker. This proposition is recognized by s. 21(1)1 of the *HCCA.*

In this case, a consideration of SH's prior capable wishes was complicated by the fact that the evidence suggested that there were two prior wishes by SH that were, arguably, applicable to the circumstances. These wishes were contrary and led to different conclusions regarding treatment.

Apart from identifying what SH's wishes were, the issue before the panel was whether any wishes that SH expressed applied to the situation in which she found herself at the time of the hearing. The case law is clear that this question must be considered with careful attention to the wish as expressed and the person's circumstances. The relevant principles were summarized by Chief Justice McLachlin, speaking for the majority of the Supreme Court of Canada in *Rasouli (Litigation Guardian of) v. Sunnybrook Health Sciences Centre,* 2013 SCC 53 ("*Rasouli*"), at paragraphs 80 to 83:

> *[80] If the substitute decision-maker knows of a prior wish regarding treatment that the patient expressed when capable and over 16 years old, and that is applicable in the circumstances, the wish must be followed: s. 21(1). This reflects the patient's autonomy interest, insofar as it is possible.*
>
> *[81]* ***While the HCCA gives primacy to the prior wishes of the patient, such wishes are only binding if they are applicable to the patient's current circumstances****. This qualification is no mere technicality. As the Ontario Court of Appeal held in Conway v. Jacques (2002), 2002 CanLII 41558 (ON CA), 59 O.R. (3d) 737, at para. 31:*
>
> > *. . .* ***prior capable wishes are not to be applied mechanically or literally without regard to relevant changes in circumstances. Even wishes expressed in categorical or absolute terms must be interpreted in light of the circumstances prevailing at the time the wish was expressed.***
>
> *[82] Needless to say, where an incapable patient has expressed a prior wish that life support not be withdrawn, the intended meaning and scope of the wish must be carefully considered: see Fleming, at p. 94.* ***The question is whether, when the wish was expressed, the patient intended its application in the circumstances that the patient now faces:*** *see Conway, at para. 33; Scardoni, at para. 74.* ***Changes in the patient's condition, prognosis, and treatment options may all bear on the applicability of a prior wish:*** *Conway, at paras. 37-38.* ***For example, had Mr. Rasouli expressed a prior wish regarding life support, his substitute decision-maker would have to consider whether, when the wish was expressed, Mr. Rasouli intended the wish to apply if he were in a permanent vegetative state, with recovery extremely improbable according to medical evidence, and facing the health complications associated with long-term provision of life support.***
>
> *[83] A prior wish need not identify every possible future development in order to be applicable: Scardoni, at para. 74; K.M.S. (Re), 2007 CanLII 29956 (Ont. C.C.B.).* ***However, a wish that is unclear, vague, or lacks precision may be held inapplicable to the circumstances. On this basis, the Board has found there were no prior wishes relating to life support applicable to the existing circumstances in numerous cases****: D.D. (Re), 2013 CanLII 18799; P. (D.), Re, 2010 CarswellOnt 7848; E.B. (Re), 2006 CanLII 46624; G. (Re); E. (Re), 2009 CanLII 28625; H.J. (Re), 2003 CanLII*

> *49837.* ***I have been unable to locate any case in which there was a prior expressed wish opposing withdrawal of life support that was held to be applicable and therefore binding in the circumstances.*** *[Emphasis added.]*

There was no prior capable wish expressed by SH in writing. Although SH's will was tendered in evidence (Exhibit 9), it did not contain any wishes that related either generally to health care or specifically to the continuation or withdrawal of life support. The panel had only oral evidence of wishes to consider.

FH took the position that SH had expressed a prior capable wish that life support be maintained for her. FH stated that SH had told him that she wanted him to do anything that he could for her (presumably to keep her alive). He said that SH had said she wanted him to "do the best you can". He said that this statement had arisen in one or more discussions, including discussions after she had been discharged from her lengthy admission in Victoria Hospital, when she had been on life support. FH indicated that SH also believed that only God could take away human life, and he interpreted her wish in light of this stated belief. He also emphasized that SH had been very grateful to him for supporting her throughout her admission at Victoria Hospital and told him that she wanted him to stand by her and be beside her 24 hours a day, as he had been during that admission.

After considering the evidence of FH on this point, the panel concluded that the evidence did not demonstrate that SH had expressed a prior capable wish applicable to the circumstances that indicated that life support should be continued. While recognizing the difficulty in relying on memory alone for the details of conversations in the past, the panel was not satisfied that the general terms recalled by FH amounted to a specific wish that applied to the issue of whether life support should be withdrawn. As noted by the Supreme Court, a wish that was vague or lacked precision could be found to be inapplicable. The panel found that it was difficult, if not impossible, to interpret what the stated wish meant in these circumstances. One could persuasively argue both that it meant that she wanted FH to make a decision that reduced her suffering and that she wanted him to seek all life support measures simply to keep her alive.

The panel was also concerned by the limited scope of the evidence regarding this purported wish. FH did not identify any other discussions or events over 41 years together where SH had discussed the specific issue of life support, including in the two years since her admission in Victoria Hospital, in the context of these specific circumstances. The absence of such evidence limited the weight that the panel could put on the general evidence that was provided.

In the panel's view, the statement as recalled also did not amount to a clear wish that life support would be continued in any circumstance, and specifically a circumstance where SH was in a permanent vegetative state with a number of physical health problems that would require the rest of her life to be spent in an ICU. To the extent that the wish had been expressed with reference to SH's prior hospitalization, the stated wish clearly did not take into account the very different circumstances that SH faced at the time of the hearing. FH indicated that the withdrawal of life support was never discussed during SH's admission to Victoria Hospital. This was understandable given that SH had not suffered a catastrophic brain injury at that time, leaving her in a very different situation from the present. There was no evidence to suggest that SH had contemplated her current circumstances when she made any of the statements to FH that he described to the panel. In all of these circumstances, the panel concluded that there was no prior capable wish applicable to SH's circumstances that directed the continuation of life support.

On the other hand, Dr. Butler and the panel considered whether there was a prior consistent wish by SH that she did not want to remain on life support if she was going to require "machines", such as a ventilator, and intensive care for the rest of her life. Although the evidence of FH fluctuated on this point, the panel found the evidence in support of this wish significantly more extensive than the evidence of the contrary wish. The clinical record had many references to FH, or others, indicating that SH did not want life support to continue if she was going to require life support for the rest of her life. The panel noted the following references in particular:

- In the UH ICU Family Meeting Record, dated August 22, 2018 (Exhibit 2, page 17), FH was reported to have said "[SH] has said that she wouldn't want to live on machines".
- In a Patient/Family Meeting Note, dated September 1, 2018 (Exhibit 2, page 20), Dr. Hegazy indicated that a "second generation cousin" of SH had indicated that FH had agreed with her that SH did not want to live in a nursing home. As Ms. Circelli pointed out, however, a further note (Exhibit 2, page 27) indicated that this cousin was not close to SH and she had not discussed health issues with SH. This reduced the weight of the

cousin’s assessment of SH’s wishes, although it did not impact her confirmation of FH’s statement in that regard.

- In a clinical note of a meeting with FH on September 2, 2018 (Exhibit 2, page 42), Dr. Hegazy noted that FH told him that SH had told him never to put her in a nursing home. He also said that he would do anything for SH, and he insisted that she would get better.
- In a clinical note of a lengthy telephone discussion with FH on September 3, 2018 (Exhibit 2, page 44), Dr. Hegazy indicated that FH had been clear in the discussion that SH “would not want to live in a nursing home for the rest of her life.” FH also indicated that he promised he would not let her suffer (although the note did not indicate if SH agreed with this). As this discussion was before SH had a tracheotomy and feeding tube, Dr. Hegazy had questioned if those measures were against SH’s wishes, but FH insisted that those steps be taken. The care team later agreed that SH would have wanted those measures on a short term basis.
- Dr. K. Bosma indicated in an UH ICU Family Meeting Record, dated September 8, 2018 (Exhibit 2, page 24) that FH said to her during that meeting that “if his wife was never going to come off machines then she wouldn’t want that but right now she needed a trach + GI tube. She had one before [and] she woke up after several months.”
- Although FH disputed the closeness of the relationship between SH and her cousin, in a UH ICU Family Meeting Record, February 8, 2019, (Exhibit 2, page 37), DD (the husband of SH’s first cousin) said, after attending a meeting at SH’s bedside, that SH “wouldn’t want to live like this . . . she would say ’pull the plug’”.

In response to questions from the panel, FH denied that he had stated to the treatment team that SH would not want to live on machines forever (specifically referring to the clinical notes at pages 17 and 24 of Exhibit 2). However, in response to Mr. Squire, FH acknowledged that, if SH was not going to recover, she would not want to live in her present condition. FH said that SH would not want to live on machines.

The panel considered FH’s denial that he had told the treatment team that SH would not want to remain on life support indefinitely in light of his response to Mr. Squire and the extensive clinical record that set out the instances in which FH was purported to have made statements to that effect. In the panel's view, the number of entries reflecting statements to this effect, the detail of those records, the consistency of the statements, and the fact that they were drafted by different individuals made it highly unlikely that they were inaccurate. For these reasons, the panel concluded that FH had made the statements to the treatment team set out in the clinical records. As in other instances where the panel did not accept FH's evidence, this conclusion was not based on a finding that FH was being dishonest in his evidence. However, the panel found that FH's evidence was unreliable given the impact of his emotional turmoil and the stress of seeing his beloved wife in the condition she was in.

The panel also observed that FH declined to answer many of the questions asked to him regarding certain of SH's wishes. He did not answer when asked if she would want to have cardiopulmonary resuscitation ("CPR"). He said he did not know when asked if SH would want to live in her current condition – he only said that SH thought that life was beautiful. He also did not respond directly when asked what would happen if SH was moved to another hospital for a second opinion and that opinion was to withdraw life support. Given FH's stated commitment to telling the truth, which the panel did not question, the panel found the absence of answers to these questions significant. In the panel's view, FH chose not to answer these questions because he was committed to telling the truth, and he knew in his mind that the accurate answers to these questions could lead to the conclusion that he could not accept in his heart.

Although there was a significant amount of evidence that supported the conclusion that SH had expressed a wish not to remain on life support indefinitely, there was also evidence that raised some doubt in such a conclusion. As set out in the Patient/Family Meeting Note, dated September 1, 2018 (Exhibit 2, page 21), the doctor identified by FH as their family doctor, Dr. Izzeldin, indicated that he did not know what SH's wishes would be in this situation as he had only seen her for three visits and they had never discussed this topic. In a Case Conference Note, dated September 17, 2018 (Exhibit 2, page 25), Dr. Haddara indicated that FH was unable to say what SH would consider "an adequate trial of therapy, and whether she would be agreeable to continuation of life support indefinitely, including artificial feeding." More recently, in a UH ICU Family Meeting Record, dated February 26, 2019 (Exhibit 2, page 51), Dr. Champion reminded FH that he had previously indicated that SH would not want to live on a ventilator machine forever. FH denied saying this and suggested that it was only as a result of the doctor threatening him.

In considering all of the evidence regarding the prior wishes of SH, the panel was satisfied that there was evidence to suggest that SH had expressed a prior wish not to live on the life support if she was never to recover. However, given the contradictory nature of aspects of FH's evidence regarding SH's wishes, even accepting that he had made the statements that he had to the treatment team, the panel found that the evidence regarding SH's wish did not meet the level of clarity required to constitute a prior capable wish applicable to her circumstances. In addition, there was no evidence that SH had directly turned her mind to the circumstances in which she now found herself when she expressed these wishes. As a result, the panel concluded that SH had not made a prior wish that was applicable to her current circumstances within the meaning of section 21(1) 1.

Best Interests in the Absence of Prior Capable Wish

In the absence of a prior capable wish applicable to SH's present circumstances, s. 21 required the SDM, and, in turn, this panel, to consider the best interests of SH as that concept was defined in s. 21(2). One of the first issues the panel had to consider was whether FH had been able to consider SH's best interests given his devotion to her, which may have obscured his perceptions of her best interests. Ms. Circelli urged the panel to allow FH, or any SDM, latitude in how he assessed SH's best interests given the emphasis in the *HCCA* on an individual consenting to treatment. However, the *HCCA* and cases that have applied it such as *Rasouli* are clear that the SDM must exercise the ability to consent for an incapable person within the framework of the *HCCA.* Where an SDM cannot do that, the Board is called upon to intervene in order to find a decision that is in the best interests of the incapable person. The decision of the SDM is not entitled to any deference if it does not meet that threshold.

After considering all of the evidence, and in particular FH's evidence before this panel, the panel found that FH was unable to consider and assess SH's circumstances in the objective manner required of an SDM when considering the best interests of SH. There were several elements to the barriers that FH faced. The prospect of losing SH was clearly devastating to FH, the man who had loved her more than anything for 41 years. While one might want to think that a person could deal with that prospect objectively, it was equally possible that one could react with anger and avoidance as part of the grief process. The evidence demonstrated that unfortunately – but understandably – this was how FH reacted. This reaction was demonstrated during the course of FH's evidence before the panel. It was also seen in his refusal to engage in discussions with Dr. Butler and the other treating physicians about the proposed treatment. It was demonstrated throughout the clinical record of the proceeding months. For example, in a social work note, dated February 27, 2019 (Exhibit 2, page 53), the writer confirmed that FH refused to take part in end of life discussions. This refusal to discuss SH's situation impeded the ability of the treatment team to engage with FH and identify his understanding of the situation.

The situation was further complicated by the fact that when FH did speak with the health care team regarding SH's treatment, he was often either overtly hostile or overwhelmed by his beliefs that the doctors and the health care team were trying to deliberately harm SH, and to some extent himself. As noted, the hospital required security to be present whenever FH was in the facility due to the threats he had made to the treating doctors and their families. On a less physical level, Dr. Hegazy noted that a meeting on September 1, 2018, ended with FH threatening legal action and saying that he did not want to talk to the doctors (Patient/Family Meeting Note, dated September 1, 2018 (Exhibit 2, page 20)). Dr. Butler indicated that when he tried to discuss SH's prognosis with FH, it was difficult to keep FH focused on the discussion because FH would move on to making allegations about the health care team trying to kill his wife, arguing that SH was responding to him or insisting that SH would recover.

Although certain discussions between doctors and FH could possibly have been handled better to better recognize FH's reaction to the stress on him, the panel did not accept FH's argument that the health care team was trying to deliberately harm SH. In this regard, the panel gave weight to the fact that FH did not bring forward any of the evidence, such as third party assessments of SH's condition or audio recordings, which he said he had and would support his allegations. The panel also found that much of FH's evidence before the panel was not focused on SH's wishes or her actual condition, but on his allegations of improper conduct by the hospital. Some of these related to incidents that could have been the subject of different interpretations, such as a doctor following him to the elevator to obtain his consent. Others involved implausible allegations such as doctors calling him in the night to beat him up and that the hospital would receive money for people dying in their care. Unfortunately, FH's focus on these theories undermined his ability to address the question of SH's best interests.

Dr. Butler indicated that the treatment team had difficulty in obtaining FH's consent even to proposed treatments other than the withdrawal of life support. In the fall of 2018, some of SH's teeth had loosened as a result of her unconsciously biting down. FH was reluctant to give consent to extract them, which was necessary to her care, because he believed someone had caused her teeth to loosen. In a UH ICU Family Meeting Record, dated October 9, 2018 (Exhibit 2, page 29) regarding this discussion, Dr. Champion conceded that it was "really impossible to know" what FH's current understanding of SH's health status was because he kept talking about how doctors were trying to kill her. Similarly, on April 4, 2019 (Exhibit 8), FH initially refused to consent to the replacement of an IV that had fallen out. This refusal was contrary to the idea that all measures be used to sustain SH, but again FH focused on perceived harms being caused to SH. Eventually, FH gave his consent so the tube could be reinserted (Exhibit 7).

Ms. Circelli suggested in her questioning of Dr. Butler that Dr. Butler had not provided FH with all of the relevant information regarding treatment decisions to enable FH to assess all of the factors an SDM had to consider and to make informed decisions with respect to treatment. In this respect, counsel noted that Dr. Butler had not responded to the letters from FH in writing. In addition, FH suggested that he had not been provided with even basic information regarding SH's condition. For example, FH said that he had never heard the term vegetative state. He stated to the panel that he had only been told once that SH had a serious brain injury. FH said that the doctor had never told him anything about his wife. Based on our review of all of the evidence, the panel rejected this submission and concluded that FH had received all of the relevant information regarding SH's proposed treatment, and he had done so several times prior to the hearing.

The panel relied on several considerations in reaching this conclusion. First, there was abundant evidence that Dr. Butler and the other physicians involved in SH's care had conveyed to FH the information relevant to the decisions regarding SH's treatment, including information FH denied receiving, on more than one occasion:

- In a UH ICU Family Meeting Record, dated August 22, 2018 (Exhibit 2, page 16), reflecting a meeting with FH, two physicians, a nurse and a social worker, the nurse recording the meeting confirmed that FH understood that SH's heart had stopped, the health care team had found a lack of response to testing and there were concerns about her brain function.

- In a UH ICU Family Meeting Record, dated August 30, 2018, (Exhibit 2, page 18), reflecting a meeting with four different members of the health care team, including SH's nurse, and a distant family member (but not FH), the resident recording the meeting noted that FH was aware, based on a conversation with SH's nurse the previous night, that SH's "neurological progress was poor".

- In a clinical note of a meeting with FH on September 2, 2018 (Exhibit 2, page 42), Dr. Hegazy indicated that he had explained to FH that SH would remain neurologically impaired, she would never go home or be independent, and she would need around the clock nursing care for her extensive needs.

- In a meeting held on February 26, 2019 with FH, two nurses and a social worker (UH ICU Family Meeting Record, Exhibit 2, pages 50-52), Dr. Champion confirmed to FH that SH had a bad brain injury that had not improved over the previous six months. SH was unable to be aware, and she was unable to communicate.

- The Extensive ICU Physician team prepared a letter, dated February 26, 2019, to FH (Exhibit 6). At the meeting on that date, FH refused the letter, but Dr. Butler gave it to FH on March 6, 2019. In the letter, the doctors reviewed that SH had suffered a devastating brain injury in August 2018 and FH had asked that she have time to recover. Before setting out the proposed treatment plan to withdraw life support, and after outlining the interventions that were in place, the doctors summarized SH's condition in the following terms:

  > She is bed-bound and completely dependent on health care providers for every aspect of her care. She is unable to speak for herself, or indicate her wishes.

> [SH]'s team of doctors has been caring for her for over 6 months, and because we have seen no improvement in her ability to be aware and interactive, we can be confident in her prognosis: that [SH] will never regain the ability to be interactive, communicate, to breathe independently without the ventilator or to leave the ICU. Her brain injury is permanent and she will not recover beyond her current state.

The doctors also reviewed their understanding of SH's wishes in the letter.

- Dr. Butler met with FH on March 6, 2019, to repeat the discussions that had occurred the previous week with Dr. Champion and FH. FH had asked to meet again with DD present at the meeting. As reflected in the UH ICU Family Meeting Record, dated March 6, 2019 (Exhibit 2, pages 58-61), Dr. Butler told FH that SH had suffered a cardiac arrest that had stopped the flow of blood to her brain. This lack of blood damaged SH's brain, and SH had a devastating brain injury. Dr. Butler reviewed the contents of the letter, dated February 26, 2019, with FH.

The records of these meetings and the letter, dated February 26, 2019, were consistent, and their reliability was not seriously challenged, other than by FH's bald denials. The relevant information regarding the proposed treatment and the factors to be considered in assessing whether the proposed treatment was in SH's best interests was set out in clear and simple language. For the reasons noted above, the panel was unable to rely on FH's evidence regarding his discussions with Dr. Butler and the other members of the medical team on these central points. In the panel's view, FH likely genuinely believed that he had not been told this information, but the pressure of his situation and his devotion to his wife had either clouded his perception or impaired his memory. Either possibility would be completely understandable to the panel. But, either demonstrated that FH's evidence was not reliable.

The panel concluded that, given the number of occasions on which the health care team had documented that the relevant information had been provided to FH and the fact that a number of different health care providers were involved in these discussions, FH had, in fact been provided with this information.

The factors reviewed above with respect to FH's hostility to the treatment team and his refusal to speak about the treatment plan with the doctors also impaired FH's ability to hear information that the treatment team provided.

Ms. Circelli raised a further question with Dr. Butler as to whether there was a language barrier preventing FH from understanding the information provided to him in English by the health care team. The panel was not satisfied that there was sufficient evidence to support this suggestion. In fact, other than one undated reference in the clinical record (Exhibit 2, page 8), there was no evidence that FH was unable to understand English. Dr. Butler was unaware of any concerns being raised about FH's ability to understand English. He had no interpreter at the hearing, despite one being offered to him. And, the letters he wrote to the doctors were fully fluent. Although English was not FH's first language, he had lived in various communities outside Toronto, but in Ontario, for at least 41 years. Perhaps most importantly, when he was asked the direct question, FH stated that he was able to understand English.

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

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. This can create some difficulty for an SDM because he or she must ensure that the incapable person's values and beliefs are considered - not their own. There is nothing in the statutory language that contemplates taking into account the values and beliefs of an individual's SDM, even when that SDM is a very devoted husband. Consequently, it was incumbent on the panel to ascertain, as best it could with the available evidence, SH's values and beliefs.

Ultimately, there was little evidence regarding SH's values and beliefs. FH said that SH loved life. The panel did not hesitate to infer from all of the evidence that she also loved FH. She wanted him to stand up for her, and stand by her. This reflected the devotion they had for each other.

FH said that SH had a strong Christian faith. She prayed every night and read the bible. They regularly went to church together, although he was not Christian. FH said that SH believed, like he did, that people could not take away life – only God could decide when someone was to die. Ms. Circelli urged the panel to conclude that a decision to withdraw life support took the decision about SH's death from God and gave it to the doctors, contrary to SH's belief. In response to a question from Ms. Circelli, Dr. Butler emphasized that the withdrawal of these measures is not what would cause SH to die. SH was going to die as a result of her numerous serious medical conditions, including her permanent inability to breathe on her own. These measures were prolonging her life, and she would die without them. He indicated that this was not the same as their withdrawal causing her death.

While the panel accepted that SH believed that only God should decide when someone was to die, the panel did not accept that this led to the conclusion that the belief favoured the continuation of life support, which would only delay SH's death. To the extent that the withdrawal of life support would allow SH to die – as a result of the many serious medical conditions from which she suffered, the panel did not accept that the withdrawal usurped the natural course of SH's life. In other words, the withdrawal did not amount to the state or the doctors taking the decision as to the inevitability of SH's death from God. The withdrawal of life support was not analogous to the types of atrocities described by FH in his evidence where men had killed many others, including children, by deliberate acts of violence. The withdrawal was a passive, non-violent, step that allowed nature, or God, to take its course.

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

Although the panel was not satisfied that it amounted to a prior capable wish applicable to the circumstances that had to be followed under section 21(1) 1 of the *HCCA*, there was clear evidence, discussed above, that SH did not wish to remain on life support if she was not going to recover. Given the evidence of Dr. Butler, supported by the other treating physicians, that SH had permanently lost conscious brain function and would never leave ICU, the panel considered this wish to be highly relevant to this application, even if not determinative on its own.

At the same time, there was some indication of a wish that FH continue to stand by her. The limitations on this wish, and the issues regarding its meaning, were discussed above.

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

Section 21(2)(c) of the *HCCA* sets out a number of factors related to the impact, including the medical impact, of the proposed treatment on SH that are to be considered in assessing whether the proposed treatment is in SH's best interests.

(1) Whether the treatment is likely to improve SH's condition or well-being, prevent SH's condition or well-being from deteriorating, or reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate.

Dr. Butler stated that, after SH did not show any sign of recovery or improvement through the fall of 2018, the team treating SH met to assess her prognosis. The team agreed that her prognosis was fixed and there was no prospect that she would recover from her brain injury. Her condition was stable in the short term, and if the current treatment plan remained in place (requiring extensive life support), SH could subsist for months if not years, although her life expectancy would be shorter than if she were not on life support. FH agreed that SH's condition had not changed since August 2018, although he maintained hope that she would recover still.

Dr. Butler indicated that SH was dependent on mechanical ventilation and kidney hemodialysis. Her kidneys had no function remaining and every breath she took was due to the respirator. She had to be fed through a feeding tube into her stomach. He noted that her kidneys no longer functioned without hemodialysis. SH was also bedbound and could not move herself. He clearly indicated that these conditions had not improved during her nine months of hospitalization and would not improve and would continue until she died as a result of her irreversible brain injury. Her complex needs meant that she would need to continue to be in a hospital setting until she died so that those needs could be managed. SH's prognosis was summarized for FH in numerous meetings, as well as the letter, dated February 26, 2019 (Exhibit 6). In the UN ICU Family Meeting record, dated February 26, 2019 (Exhibit 2, page 52), Dr. Champion indicated that she told FH on that date that SH would never recover and she would never improve.

Dr. Butler stated that he considered SH to be suffering in this condition because she continued to physically exist although the person that she had been no longer existed. He observed that it was difficult for SH to maintain her dignity when all of her needs had to be tended to by other people. Dr. Butler indicated that the measures that were being used to keep SH alive in her current state would also be causing her discomfort. Measures such as repositioning her body every few hours to avoid pressure sores, suctioning her breathing tube, changing the dressing on her tracheotomy to avoid infection, and drawing blood several times a day would be uncomfortable. At the same time, SH lived with a significant risk of further complications, including infections of various sorts. These could include those that could arise in connection from the life support itself, such as infections around the tracheotomy incision. In addition, SH remained at risk of further consequences of her diabetes, from which she had already suffered damage to her eyes and nerves. Dr. Butler said that over time, SH's diabetes could cause further damage to her heart, skin and nerves (causing a loss of sensation in her extremities) and narrow her blood vessels. This would aggravate the coronary disease from which SH already suffered. Higher blood sugars also increased the risk of infections.

Dr. Butler noted that life support measures will always cause suffering, but people may think that suffering is justified if they get better, as SH had in Victoria Hospital. During the previous admission, SH had not suffered an extensive brain injury; the issue at that time had been an infection. Those circumstances were very different. An infection can be treated with antibiotics and cured; a brain injury such as the one SH had suffered could not be cured.

In these circumstances, Dr. Butler had proposed the removal of life support. He was clear in stating that SH would die during or shortly after the removal of ventilation. It may be obvious to say that death reflects a deterioration from being alive. But, in the panel's view, the fact that the proposed treatment would lead to SH's death was not the end of the consideration with respect to SH's condition and well-being. The Supreme Court of Canada touched on the complexity of this question, and the concept that withdrawal of life support may reduce suffering, in *Rasouli,* at paragraph 68:

> *In summary, withdrawal of life support aims at the health-related purpose of preventing suffering and indignity at the end of life, often entails physical interference*

> *with the patient's body, and is closely associated with the provision of palliative care. Withdrawal of life support is inextricably bound up with care that serves health-related purposes and is tied to the objects of the Act. By removing medical services that are keeping a patient alive, withdrawal of life support impacts patient autonomy in the most fundamental way.*

The Supreme Court has endorsed on other cases the view that the sanctity of life, which section 7 of the *Canadian Charter of Rights and Freedoms* seeks to protect, does not require the preservation of life at all costs, and without regard for suffering: *Carter v. Canada (Attorney General)*, 2015 SCC 5, at para. 63.

This principle is embedded in the term "well-being" in section 21(2)(c) of the *HCCA.* 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 other words, the SDM, and, in turn, the Board, had to consider not only the impact of the proposed treatment on the length of time SH may live, but the relative quality of that life, including the suffering and loss of dignity that may be entailed, over whatever amount of time it may continue.

Dr. Butler indicated that the proposed treatment would avoid the trauma to SH of further interventions. He acknowledged that an intervention such as CPR would cause significant injuries to SH, including bruising her lungs and breaking her ribs. There was an ongoing risk of infections. Dr. Butler anticipated that an infection would be the most likely cause of death of SH if she continued with life support treatment. These risks, and the related suffering, would be avoided by the proposed treatment. Dr. Butler maintained that the result would be that, while SH's life would be shorter, her well-being during that period would be enhanced. In other words, she would live less, but she would also suffer less.

In assessing the impact of the proposed treatment on SH's condition and well-being, the panel considered the impact of the alternative treatment on SH's condition and well-being. Dr. Butler indicated that the alternative to the proposed treatment, that is the withdrawal of life support, was to continue the various life supports, including mechanical ventilation, hemodialysis and nutrition through a feeding tube, in order to prolong her life through mechanical means.

At page 4 of his CCB Summary (Exhibit 1), Dr. Butler indicated that if this alternative treatment was pursued, “[a]t best, [SH] would remain in a persistent vegetative state and be dependent for all her care needs”. He indicated that SH’s life could be extended for months or even years in this way. But, during that time, her condition would not improve. As well, she would be at risk of cardiac arrest or of developing life threatening, and potentially painful, infections. In other words, SH’s quality of life – her well-being - would not be improved, she would not recover in any way from her brain injury, and she would be at risk of a deteriorated quality of life if and when she suffered further complications.

The panel was satisfied that, when considering SH’s condition and well-being broadly, the proposed treatment would cause deterioration in one aspect – the length of life – but increase her well-being in others. By contrast, the alternative treatment might enhance the length of SH’s life. But, it would not decrease her well-being, and it would not improve her underlying conditions, including her brain injury, her kidney failure, and her diabetes, among others.

(2) Whether the incapable person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment.

If the proposed treatment was not provided to SH, the only alternative would be to continue the life supports that were in place at the time of the hearing and the nine preceding months. It had been clearly demonstrated that SH’s condition was not changing in these circumstances. Dr. Butler’s evidence was very clear in this regard. Without the proposed treatment, SH’s condition would remain the same for an undetermined period of time, possibly months or years, until she suffered a critical incident, such as an infection or a cardiac arrest, and she would then die.

(3) Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her.

The principal benefit to SH in the proposed treatment is that she would not have to endure ongoing suffering without any prospect of ever recovering. She would also avoid the risk of increased suffering, and a potentially more traumatic death, as her body struggled with the risk of infections and the risk of the conditions that ravaged her body leading to other critical incidents.

In the panel’s view, this benefit outweighed the harm of the likelihood of an earlier death with the proposed treatment.

(4) Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.

Dr. Butler described his proposed treatment plan at page 4 of his CCB Summary (Exhibit 1) as “minimally invasive approach to dealing with the devastating consequences of the anoxic brain injury”. As discussed above, the evidence was clear that the treatments by which SH’s life would be prolonged would all involve further measures that would be significantly intrusive. This included the use of a respirator, feeding through a tube into SH’s stomach, dialysis three times a week, the prospect of measures such as CPR that could cause painful injuries to SH, and a care protocol that would require frequent handling of SH by nursing staff managing all of her bodily functions. Dr. Butler indicated that the treatment team had concluded that it was not in SH’s bests interests to continue with the highly intrusive measures required to continue SH’s life. The panel agreed. In the panel’s view, any benefit in terms of prolonged life would be diminished by the intrusive means that would be required to reach that goal.

In addition, the panel observed that the treatment SH would require could not be provided outside of the setting of the ICU. Dr. Butler indicated that the health care team had applied to transfer SH to Parkwood Hospital in their complex care ward. However, this application had been refused by Parkwood because SH’s combined treatment needs and her inability to engage with care providers to direct her own care exceeded Parkwood’s capabilities. FH was upset by that decision, but he had acknowledged that the application had been made and denied. The result of this was that any alternative treatment had to be provided in the restrictive confines of the ICU.

It was apparent in the evidence that FH was deeply conflicted about SH’s best interests as a result of his devotion to SH. He clearly did not want to see the woman that he had loved for 41 years die. To that end, he wanted life support to continue. But, at the same time, some of his answers suggested that he was aware that the life support measures that she required would cause her to suffer. When asked whether SH would want to have CPR, his first response was “don’t hurt that woman too much”. He was understandably concerned by his perception that SH was in pain, but he was unable to appreciate the role that ongoing life support played in that condition, if his perception of her pain was accurate.

Conclusion

The decision to be made in a case such as this was not taken lightly by the SDM, the treatment team, the participants in the process or the Board. But, in the midst of a complicated emotional context, the task of the SDM and the Board was to apply the statutory criteria in the *HCCA* to the circumstances of SH. Unfortunately, no decision could not change SH's medical conditions or tragic prognosis.

In considering the evidence of SH's values and beliefs, the panel concluded that the evidence indicated, on a balance of probabilities, that SH would not want to have her life extended if it meant that she would never leave the ICU or stop life support measures. The panel found that the incontrovertible evidence demonstrated that she would remain in a vegetative state permanently. In those circumstances, an assessment of SH's best interests obligated the panel to order that life support measures be withdrawn and no resuscitative measures be used. At the same time, it was important that palliative care was used to enhance SH's dignity and diminish her suffering for the remainder of her life.

FH had refused to accept that the proposed treatment could be in SH's best interests because he believed – as many who saw a loved one in SH's condition would – that she would recover. He was supported in that belief, in his mind, by her experience in her admission in Victoria Hospital. As reflected in the UH ICU Family Meeting Record, dated March 6, 2019 (Exhibit 2, pages 58-61) FH insisted that SH's situation was the same as when she had been admitted to Victoria Hospital in 2017, and she just needed more time to recover. In his evidence, FH said that the health care team at Victoria Hospital had told FH that SH was dead when she was first there. In his words, he was "like a stone" when they said that. But, he said that no one suggested that she be removed from life support. She recovered eventually. So, FH believed that there was still hope that SH would recover this time if she was treated properly.

As an act of devotion to his wife who had suffered a devastating brain injury on top of a collection of other serious conditions, FH's hope was both understandable and commendable.

However, it was contrary to his obligation to make a decision in SH's best interests based on all of the available medical evidence and the evidence of her wishes, values and beliefs. FH clearly hung onto the previous experience because within six months SH had recovered. But, that situation was very different, as demonstrated by SH being 9 months in a constant, vegetative, condition during this admission. FH's hope had to yield to that reality. In their meeting on March 6, 2019, Dr. Butler explained to FH that the health care team had agreed initially with FH's belief that SH may recover over time, but, after SH had been 6 months in the ICU, she had not improved at all. She was dependent of extensive life supports and was bedbound, and her condition would never improve: she would always remain in the state she was in. Dr. Butler stated that this admission was different from the 2017 admission because SH was not going to recover.

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 SDM had not exercised his decision-making authority in accordance with the principles in s. 21 and SH's best interests as that term is defined therein. The panel further concluded that it was in SH's best interest for the SDM to consent to the treatment plan proposed by Dr. Butler, as set out in the panel's Decision.

Date by Which the SDM Must Comply

One of FH's recurring comments during the hearing was that he just wanted more time for SH. He said he wanted her to have "one more chance". This plea had been raised with the treatment team previously. As Dr. Butler noted, the team had waited many months to see if SH's condition improved. It had not. FH said that he just wanted a couple of more months, and if there was no solution, he would listen to what a friend (apparently a doctor) at Victoria Hospital said. However, he had never asked his friend to examine SH. The panel observed that FH did not appear to have taken any steps to obtain such a third party opinion over the previous nine months. Assuming the Board had jurisdiction to give more time, which was doubtful, the panel was not inclined to grant more time. SH's best interests required a decision without more time.

That being said, the panel also considered it to be important, given FH’s numerous assertions during the hearing that he would challenge the Board’s decision, that he have an opportunity to make his decision in that regard after considering these reasons. In light of the emotional impact of this situation on FH, it would not be reasonable to expect him to make that decision immediately. The panel concluded that 14 days to comply with the direction in the decision allowed for this opportunity while accounting for SH’s best interests.

RESULT

The panel determined that SH was incapable of consenting to the proposed plan of treatment and, further, that the SDM had not complied with the principles for substitute decision-making set out in the *HCCA*. We ordered that the SDM, FH, consent to the plan as set out in the Decision, as repeated above, by May 23, 2019 at 4 pm.

Dated: May 14, 2019

Glenn Stuart
Presiding Member