Consent and Capacity Board
Commission du consentement et de la capacité

Ontario

21-5796-01
21-5796-02

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

AND IN THE MATTER OF
SG
A patient at
TRILLIUM HEALTH PARTNERS – MISSISSAUGA SITE
MISSISSAUGA, ONTARIO

REASONS FOR DECISION

PURPOSE OF THE HEARING

The Board convened a hearing by videoconference at the request of Dr. Amanda Young, a physician at Trillium Health Partners – Mississauga Site ("Trillium") and the health practitioner who had proposed a plan of treatment for SG. SG had been found incapable to consent to treatment. Her substitute decision-makers ("SDMs") did not consent to the proposed plan of treatment. Dr. Young brought a Form G application to the Board under s. 37(1) of the *Health Care Consent Act* ("*HCCA*") to determine whether or not SG's SDMs had complied with the principles for giving or refusing consent to treatment set out in s. 21 the *HCCA*.

The *HCCA* provides in s. 37.1 that a Form G application is deemed to include an accompanying application, under s. 32 of the *HCCA*, requiring the Board to review Dr. Young's finding that SG was incapable of consenting to treatment (referred to as the "deemed Form A" application). The two applications were heard together.

DATES OF THE HEARING, DECISIONS AND REASONS

The hearing took place on January 22, 23, 24, 27 and 28, and February 7, 2022, and the panel released its Decisions on February 8, 2022. On February 9, counsel for Dr. Young requested written Reasons for Decision, which were released on February 15, 2022 (and are contained in this document).

LEGISLATION CONSIDERED

The *Health Care Consent Act*, sections 4, 21, 37(1) and (3), and 37.1

AUTHORITIES CONSIDERED

M.A. v. Benes, 1999 ONCA 4236
I.T. v. L.L. 1999 ONCA 4237
Conway v. Jacques 2002 ONCA 59 O.R. (3d) 737
Cuthbertson v. Rasouli 2013 SCC 53
Scardoni v. Hawryluck, 2004 ONSC O.J. No. 300
Re SH 2019 Canlii 79248 (CCB)
Re MO 2019 Canlii 110013 (CCB)
Re SS 2015 Canlii 44140 (CCB)
Re DW 2011 Canlii 18217 (CCB)

PARTIES TO THE DEEMED FORM A APPLICATION

SG, the person found to be incapable to consent to treatment

Dr. Young, the health practitioner proposing the treatment

PARTIES TO THE FORM G APPLICATION

SG, the person found to be incapable to consent to treatment

Dr. Young, the health practitioner proposing the treatment

BR, son of, and substitute decision-maker for, SG

SR, daughter of, and substitute decision-maker for, SG

All of the parties except SG attended the hearing

PANEL MEMBERS

Nina Lester, senior lawyer and presiding member
Elizabeth Harvie, senior lawyer member
Partha Datta, physician member

APPEARANCES

SG was represented by counsel, Maureen Addie
Dr. Young was represented by co-counsel, Christine Wadsworth and Christine Windsor
BR and SR were represented by co-counsel, Anita Szigeti and Maya Kotob

PRELIMINARY MATTERS

Language Interpretation

During the entire hearing interpretation was provided in the Afghani Pashto language for the benefit of one party and one witness who did not speak English. For the majority of time interpretation was performed simultaneously with the use of telephone; when the Pashto-speaking party and witness testified, interpretation was performed consecutively.

Witness Exclusion

At the request of counsel for Dr. Young and counsel for SG, the non-party witness (SH) was excluded from the proceeding during BR's and SR's testimony. SH was permitted to observe the hearing at other times.

Bedside Visit

With the consent of SG's family, Dr. Young arranged for a nurse at SG's bedside to call into the hearing videoconference with a tablet, in order to allow the panel to "meet" SG and briefly observe her presentation and surroundings. Dr. Young provided commentary on the equipment and methods operating to sustain SG's life. This occurred at the very beginning of the hearing. The video connection lasted approximately 10-15 minutes and SG remained asleep throughout.

Plan of Treatment

The treatment plan proposed by Dr. Young and the Trillium ICU team was documented in a letter from Dr. Young to SG's family dated December 17, 2021 (Ex.2A, p.21), as reproduced here:

> **Proposed Treatment Plan:**
>
> As we have attempted to discus with [SDMs], the clinical team believes a palliative care plan is in your mother's best interests given her condition and prognosis. The specific plan we propose is:
>
> - No attempts at cardiac resuscitation in the event of a cardiac arrest. This includes, but is not limited to, no chest compressions (pressing on the chest to pump for the heart), defibrillation (shocking the heart to restart it), vasopressors or inotropes (medications to raise the blood pressure if shock develops), intubation/ventilation, chest tubes (to drain air outside the lung or fluid) or dialysis. A DNR Order would be written on her chart.
>
> - No ventilation: Withdrawal of the ventilator. If in the usual course of treatment she has been liberated from her ventilator by the time of the CCB hearing (which is incredibly unlikely), the clinical team would not restart ventilation.
>
> - No dialysis: No renal replacement therapy of any kind in the event of kidney failure.
>
> - Palliative care, including any medications necessary to relieve discomfort or symptoms caused from ventilator discontinuation (if necessary).
>
> - No invasive suctioning unless perceived to be alleviating discomfort.
>
> - No surgery.
>
> - Discharge from ICU and will not be readmitted to the ICU. She will still be cared for in the hospital.

When this treatment plan was formally proposed in December 2021, SG's SDMs did not consent to any part of it and Dr. Young and her team decided to proceed with a Form G application to the Board, giving rise to this hearing. As the hearing commenced on January 22, 2022, counsel for the SDMs announced that the SDMs now consented to the first paragraph of the proposed treatment plan (the "DNR") but no other part of it. The panel asked Ms. Wadsworth if this development might be a basis for potential settlement of the matter. Ms. Wadsworth replied that Dr. Young's position would not change unless the entire plan was consented to. The hearing thus proceeded with the understanding that the SDMs were willing to consent to the "DNR" aspects of the treatment plan but not to the withdrawal or withholding of any other treatments.

EVIDENCE

The evidence at the hearing consisted of the oral testimony of five witnesses: Dr. Young, Dr. Neil Antman, BR, SR, and SH (another child of SG) and the following documents entered as Exhibits:

1	Clinical Summary prepared by Dr. Amanda Young, January 13, 2022 (10 pages)
2A	Documentary Brief presented on behalf of Dr. Young, volume 1 of 3 (60 pages)
2B	Documentary Brief presented on behalf of Dr. Young, volume 2 of 3 (1661 pages)
2C	Documentary Brief presented on behalf of Dr. Young, volume 3 of 3 (386 pages)
3	Supplementary Brief presented on behalf of Dr. Young (152 pages)
4	Clinical notes by Dr. Neil Antman, January 20, 2022 (11 pages)
5	Brief submitted on behalf of substitute decision-makers (8 pages) including links to videos shown as Exhibit 7
6	Social Work Notes written by Rakhi Mistry, January 20, 2022 (2 pages)
7A	Video taken at bedside of SG, December 20, 2021
7B	Video taken at bedside of SG, January 18, 2022

INTRODUCTION

SG was an 84-year old widow with seven adult children and some grandchildren. Most of the family lived together in a duplex in Toronto. The family was originally from Afghanistan and their native language was Afghani Pashto. The family was devoutly Muslim. The family members immigrated to Toronto at different times – some, including SG, after many years in Pakistan. BR settled in Toronto in 2000; SG and SR arrived in 2014. BR was fluent in English; SR and SH understood a little English; SG did not understand a word of English, nor was she able to understand Urdu or the Pashto dialect spoken in Pakistan; nor was she able to read or write in any language.

On July 2, 2021, SG suffered a stroke and was brought to Trillium for emergency treatment. A surgical procedure to remove a blood clot from her brain was only partially successful but she recovered from surgery and was transferred to a medical ward on July 3. Due to SG's inability to swallow resulting from the stroke, a naso-gastric feeding tube was inserted. Apparently, SG pulled out the NG tube two days later, and in the course of re-insertion a nurse inserted the tube in the lung, a known risk associated with NG tube insertion. This caused SG's lung to collapse and she was transferred back to the ICU and placed on mechanical ventilation through a breathing tube. On July 23 SG received a tracheostomy in order to remain on mechanical ventilation. SG remained in the ICU with the ventilator and other life sustaining equipment and treatments up to the day of the hearing.

On August 29, 2021 Dr. Young held a family meeting with BR and SR, along with a social worker and the hospital ethicist. At the time Dr. Young believed SG had four children, of whom only two attended the meeting. Dr. Young reviewed SG's medical condition and told the family it was very unlikely SG would ever be able to breathe without a ventilator or leave the hospital. Dr. Young explained the role of SDMs under the *HCCA*, and discussed the possibility of withdrawal of life support although it was not proposed at that time. By December 17, 2021 the proposal to withdraw life support was formalized in a letter delivered to the family. The family refused consent to the proposal. On December 30, 2021 Dr. Young made an application to the Board under s. 37(1) of the *HCCA* to determine whether or not the SDMs were complying with the principles for giving or refusing consent set out in s. 21 of the *HCCA*. Following several pre-hearing case conferences, the Board convened a hearing on January 22, 2022 to determine the matter.

THE LAW

General

At a hearing for a Form G application, the onus is on the health practitioner to satisfy the Board that the SDM (or, in this case, SDMs) in question has not complied with the principles of substitute decision-making under the *HCCA*. For the accompanying deemed Form A application, the onus is on the health practitioner to prove that the person is incapable of making treatment decisions according to the test for capacity set out in the *HCCA*. The standard of proof in either case is proof on a balance of probabilities. The Board must be satisfied on the basis of clear, cogent and compelling evidence that the health practitioner's onus has been discharged. There is no onus whatsoever on the SDM or the person who is the subject of the applications. The Board must consider all evidence properly before it. Hearsay evidence may be accepted and considered, but it must be carefully weighed.

Capacity to Consent to Treatment

Under the *HCCA* s. 4(2), a person is presumed to be capable to consent, or refuse consent, to treatment, and the onus to establish otherwise rests with the capacity evaluator. The test for capacity is set forth in s. 4(1) of the *HCCA*, which states:

> ***4.(1) Capacity.*** *– 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.*

In other words, a person will be found incapable of consenting to treatment if that person fails either part of the two-part test set out in s. 4(1).

Principles for Giving or Refusing Consent

Section 21 of the *HCCA* sets out the principles for giving or refusing substitute consent on behalf of an incapable person:

> ***21. (1) Principles for giving or refusing consent. –*** *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.*

> ***(2) Best interests.*** *– 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.*

Section 37 of the *HCCA* allows a health practitioner to apply to the Board if he or she believes that a substitute decision-maker is not adhering to the principles contained in s. 21:

> ***37.(1) Application to determine compliance with s. 21. –*** *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) Parties.*** *– 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) Power of Board.*** *– 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) Directions. –*** *If the Board determines that the substitute decision-maker did not comply with section 21, it may give him or her directions and, in doing so, shall apply section 21.*
>
> ***(5) Time for compliance. –*** *The Board shall specify the time within which its directions must be complied with.*
>
> ***(6) Deemed not authorized.*** *– 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).*
>
> ***37.1 Deemed application concerning capacity. –*** *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 consent 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.*

ANALYSIS

Deemed Form A: Capacity to Consent to Treatment

Before any Form G application can be decided, the *HCCA*, s. 37.1, requires the Board to first determine whether the person subject to the treatment in question remains incapable at the time of the hearing. If the person is found to be capable of consenting to treatment, the Board must dismiss the Form G application. Upon hearing evidence regarding SG's cognitive function the panel determined that SG was incapable to consent to treatment. This issue was not contested by any of the parties at the hearing.

Did the evidence establish that SG was unable to understand the information relevant to making a decision about treatment, or unable to appreciate the reasonably foreseeable consequences of a decision or lack of decision about treatment?

The evidence on this point was incontrovertible. Both Dr. Young and Dr. Antman testified that SG was unable either to understand information relevant to decision making, or to appreciate the consequences of her decisions. She had been incapable to consent to treatment since the first day of her admission following her stroke.

SG was not totally unconscious, but in a minimally conscious state with very limited ability to communicate. She slept most of the time with occasional bursts of alertness. For instance, when Dr. Antman examined SG on January 20, 2022 she opened her eyes at the sound of her name and moved her hand to mimic the doctor's gesture, but five minutes later she was unresponsive even to the voice of a Pashto interpreter. When her son BR spoke to her, SG was able to respond to simple commands such as raise your hand, open your eyes, stick out your tongue (Exhibits 7A and 7B). She could also nod her head or shake her head to indicate "yes" or "no" when asked simple questions like "are you cold?" or "are you in pain?" Because SG had a tracheostomy, she could not vocalize sounds, so it was unknown whether she was capable of forming words. Even if she were capable of mouthing some words, the doctors' evidence was that SG's neurological function was not intact enough to carry on a back and forth conversation, nor could she stay alert long enough to receive and process information, especially complex medical information.

The Glasgow Coma Scale ("GCS") was a diagnostic tool used measure a patient's level of consciousness. SG was tested regularly, scoring between 8 and 11 (out of a maximum of 15) depending on the day. The GCS was not a measure of capacity but it indicated impaired cognition in SG's case.

BR and SR were the only people who were able to carry on meaningful communication with SG. (The hospital had tried to engage an interpreter to speak to SG but she did not respond to his voice, possibly because he spoke a different dialect of Pashto.) BR testified that he did not think SG was able to understand sufficient information to make decisions about her complex medical care. Nobody at the hearing contested Dr. Young's finding that SG was incapable to consent to any of the treatment she was receiving, nor the proposed treatment plan. The panel confirmed Dr. Young's finding of incapacity.

Form G: Application re Compliance with Principles for Giving or Refusing Consent

Board's Powers

A Form G application under the *HCCA* requires the Board to determine whether a SDM is acting in accordance with the principles for giving or refusing consent on behalf of an incapable person, as enshrined in s. 21. The principles for substitute decision-making consist of two branches: first, whether the incapable person, while previously capable, expressed a wish applicable to the circumstances (which is a paramount consideration); and second, if the first branch is not satisfied, whether the SDM is making decisions in the incapable person's best interests. If the Board determines that the SDM has not followed these principles, it may substitute its own opinion for that of the SDM and direct the SDM to comply with s. 21.

It is important to highlight a fundamental difference between a capable person making treatment decisions on his or her own behalf, and a SDM making decisions on behalf of an incapable person. In the first instance, it is commonly known that a capable person has the right to make foolish decisions – this is an inviolable attribute of individual liberty and personal autonomy protected by our laws. Nobody has the right to interfere with a capable person's treatment decisions, whether or not those decisions are judged by others to be in the person's best interests. In other words, a capable person is the sole arbiter of his or her own best interests. In contrast, a SDM does not have the right to make unwise or unreasonable decisions on behalf of an incapable person; a SDM must make correct decisions in accordance with the principles of consent set out in the *HCCA*, i.e. in accordance with the incapable person's prior capable wish applicable to the circumstances, or the incapable person's best interests, judged objectively. This removes a fair amount of discretion on the part of the SDM to decide what is best for the incapable person. The SDM is not the sole arbiter of the incapable person's best interests. If the SDM strays from the *HCCA* principles, the Board is empowered to intervene and compel the SDM to comply with those principles, in accordance with Board's objective perception of the person's best interests, as revealed by the evidence.

The SDM's role and the Board's role were considered in the twin decisions of *M.A. v. Benes,* 1999 ONCA 4236 and *I.T. v. L.L.* 1999 ONCA 4237 (decisions issued by the same Court of Appeal panel on the same day). The Court of Appeal stated that the SDM must not only act in good faith and reasonably, but must also stive to make the best decision possible for the incapable person. This is the standard of "correctness." If the Board feels the SDM did not weigh the best interests factors appropriately and they made a poor decision, despite best efforts and intentions to act in the incapable person's best interests, then the Board should substitute its own decision for that of the SDM. The Court felt that the Board is well-positioned to make the best decision for the incapable person, having listened to all of the evidence from both sides, because the Board is neutral and objective, per *Benes*:

> [46] The disagreement between the S.D.M. and the health practitioner potentially creates tension and the Act recognizes this by providing for a neutral expert board to resolve the disagreement. Indeed, after hearing submissions from all parties, the Board is likely better placed than either the S.D.M. or the health practitioner to decide what is in the incapable person's best interests. Thus, the Board should not be required to accord any deference to the S.D.M.'s decision.

Background: SG's medical condition and prognosis

SG's medical condition was outlined in Dr. Young's clinical summary (Exhibit 1) and reviewed in her oral testimony at the hearing. SG's stroke had left her paralyzed on her left side and her head permanently turned to the right. She could not move her eyes and could not swallow. She had significant cognitive impairment. The neurologists determined there was no possibility of neurological recovery.

Since July 5, 2021, SG had needed a ventilator to assist her breathing and since July 23, 2021 SG drew air via a tracheostomy. She'd had several trials off the ventilator using a "trach mask" but these always resulted in the need to go back on the ventilator due to respiratory failure caused by irreversible loss of muscle mass. The trach tube required suctioning every 2-4 hours, which was an uncomfortable procedure. By early December 2021 it was apparent to the treatment team that SG would never be able to wean off the ventilator and breathe independently. Moreover, SG could not be transferred to a chronic ventilation facility due to the other complications she would inevitably experience. SG would have to remain in the ICU for the remainder of her life.

SG had suffered multiple infections, including sepsis, since July 2021, described in detail in Exhibits 1 and 2B. Some infections were due to the injury to her lung caused by the NG tube insertion, some were associated with the ventilator and trach-mask trials. These infections resolved with courses of antibiotics however some of the infections were antibiotic-resistant requiring prolonged treatment and additional life support in the form of vasopressor medications to boost blood pressure. Dr. Young was certain that more infections would recur regularly.

Due to being prone in bed for months, SG had developed several pressure ulcers (bed sores). By the time of the hearing these were classified as “stage 4 ulcers” being the most severe category – down to the bone. These wounds would not heal, but would continue to grow progressively worse. They required cleaning and dressing changes at least once per day, which was painful to SG.

Occasionally SG’s blood pressure would drop so as to be life-threatening and she was treated with adrenaline. She suffered from atrial fibrillation and was resuscitated during a cardiac event in September. She suffered a seizure in October. She required five blood transfusions due to low hemoglobin. SG’s limbs were extremely swollen due to fluid retention (edema), to the point that her skin continuously secreted fluid.

In addition to being hooked up to a ventilator through a trach tube, SG was also attached to a heart monitor and oximeter, and was fed by a naso-gastric tube, and had an intra-venous port for administration of antibiotics when needed. A central line was inserted to manage her sepsis infection. Her one mobile arm had to be restrained to prevent her from pulling at the tubes. She had a foley catheter to collect urine and was bowel-incontinent. SG had to be turned in her bed every two hours, suctioned every 2-4 hours, wounds cleaned and changed 1-2 times per day, and hygiene maintained regularly. Throughout the day there were nurses and clinicians touching her, monitoring her, cleaning her, and many machines humming and beeping around her. Dr. Young and Dr. Antman described this as an intolerable, undignified and distressing existence for SG, who was alert enough to sense what was going on but too cognitively impaired to understand why she was in this situation.

Dr. Young also described the pain SG must have been experiencing. The care of her pressure ulcers caused SG the most pain, and she was often observed grimacing or crying while her dressings were changed. The trach suctioning also caused her pain, and likely the turning as well. SG was given pain medication as needed, ranging from Tylenol to morphine. Of course SG could not communicate her pain, so there was guess-work involved. The nurses tried to give pain medication in advance of painful procedures but it was impossible to get the timing or dosage exactly right, so breakthrough pain was inevitable.

Prognosis: during the seven months SG had been in the ICU her condition had not improved and she had endured numerous complications. Although she had not had any serious infections since late November 2021, her ulcer wounds had worsened and she had lost more muscle mass. Even with full life supporting measures her condition was deteriorating and would continue to do so, leading to her death, likely within 6-12 months. The most likely cause of her death would be an infection leading to sepsis and organ failure. She might also suffer sudden cardiac arrest. All physicians agreed there was no chance that SG's condition would improve.

The proposed treatment plan and discussions with SDMs

The treatment plan proposed by Dr. Young on behalf of the entire team of ICU physicians was reproduced above under "Preliminary Matters." Dr. Young testified that the nine ICU physicians tasked with caring for SG on a rotating basis were unanimous that the proposed treatment was in SG's best interests. Essentially, they were in favour of removing the ventilator while keeping SG comfortable and pain-free, with the expectation that she would die within hours. Dr. Young's premise was that SG was suffering pain, indignity and psychological distress, with no hope of medical recovery. Her suffering was likely to increase as her physical condition continued to deteriorate. The life supporting measures in place were prolonging her suffering, with no expected improvement in her condition, thus the harm they caused SG outweighed any benefit. Removing the ventilator would end SG's suffering and therefore be a net benefit to her. The physicians believed that in a situation such as SG's, death was preferable to an intolerable existence.

SG's family of seven adult children were close-knit and very supportive towards SG. From the beginning of her admission to Trillium in July 2021 SG's children visited at her bedside and were involved in decision-making, some more than others. BR and SR emerged as the "spokespeople" for the family and the other five siblings eventually recused themselves from decision-making although, according to BR, he and SR kept the siblings informed and obtained consensus on every major decision. Throughout SG's hospitalization the covid-19 pandemic restrictions limited family visitors to two people, and only one at a time, an additional source of sadness and stress for the family. Due to a surge of covid infections in the community, visiting was cut off completely on January 5, 2022. From that day on BR and SR were able to "see" their mother only by videochat through an ipad held by nurses in SG's room.

Dr. Young and her team engaged BR and SR in discussions about goals of care for SG from early on in her admission. Dr. Young's summary (Exhibit 1) included a brief summation of these discussions, with more detailed notes contained in Dr. Young's documentary briefs (Exhibits 2A-C). It must be noted that there was a language barrier between the physicians and the SDMs. Although BR was very proficient in English, some of his siblings were not – including SR – with BR acting as interpreter for the family as well as spokesperson. Occasionally BR misunderstood certain words or nuances, for example when he mistook the identity of substitute decision-maker with that of *visitor* to the hospital, or when he did not understand the concept of "palliation" when first introduced by Dr. Murthy. Ms. Addie aptly commented in her submissions that, overall, communication between the treatment team and the family was weak due to language and cultural barriers and the hospital would have been well-advised to have retained an Afghani Pashto interpreter for family meetings as well as examinations of SG. The pandemic restrictions placed an additional strain on communication and collaboration between the team and the family.

The treatment team met with family members formally around once per month, and informally at the bedside more often. As early as August, 2021, Dr. Young and Dr. Murthy introduced the idea of palliation as opposed to active life support, given that there was no hope of meaningful recovery. In November Dr. Antman recommended a "do not resuscitate" order ("DNR") in case of cardiac arrest. BR, as spokesperson for the family, consistently refused to alter SG's care level down from full code. The reasons for his insistence are explored fully below.

In December Dr. Young communicated to the family that she and the other physicians felt the SDMs were not acting in accordance with the principles of substitute decision-making, and that she had no choice but to bring an application to the Board make a determination. It then lay with the Board to decide whether the SDMs' decision to refuse the proposed palliation plan was made in accordance with the principles set out in the *HCCA*.

Prior Capable Wish

Section 21(1) of the *HCCA* requires a SDM to give or refuse consent in accordance with a wish that the incapable person previously expressed while still capable, if the wish is determined to be applicable to the circumstances and possible to fulfill. This is sometimes referred to as an "advance directive." If the evidence proves the existence of an applicable capable wish, the analysis ends there, the wish must be implemented, and there is no requirement to consider what would be in the incapable person's best interests.

Did the evidence establish that SG had expressed a wish, while she was capable, that was applicable to the circumstances?

Counsel for BR and SR argued that SG had clearly expressed a wish while she was still capable, to remain on any and all life sustaining mechanisms for as long as possible, until her last dying moment. The evidence supporting this wish came in two forms: SG's own words, repeated at different times in a variety of circumstances, and SG's rigid adherence to the practices of Islam which placed paramount importance on sustaining life at all costs, using all possible treatments.

Counsel for Dr. Young (counsel for SG concurring) submitted that neither SG's verbal pronouncements nor her profound religious faith crossed the high evidentiary threshold to establish a prior capable wish applicable to the circumstances. After lengthy deliberation on the issue, the panel agreed with Dr. Young.

The evidence regarding SG's verbal expression of a wish to remain on life support did not rise to the level of a prior capable wish applicable to the circumstances. SG's capacity at the time was not in question, but her verbal pronouncements were made at times when she could not have foreseen her current circumstances.

BR and SR presented three examples when SG told members of her family that she would want treatments and/or machines to keep her alive as long as possible. First, when SG's sister-in-law had suffered a stroke and kidney failure and was bed-ridden for fifteen years, and her husband wanted to let her die a natural death instead of taking her to the hospital for treatment. SG apparently persuaded the husband to take her to the hospital and try every means possible to keep her alive, or else God would hold him responsible for her death. The sister-in-law was treated and lived a little longer. Second, a brother-in-law who had lost limbs in a rocket attack and later developed cancer wanted to let himself die, but SG persuaded him to get treatment and he survived. SG told him to never give up on life. Third, was an incident early in the covid pandemic when SG and SH were watching videos on the internet about covid victims being hospitalized and intubated. SH explained to SG that the ventilators in the videos were "breathing machines" to keep people alive who could not breathe for themselves. SG adamantly stated to SH that she would want to be kept alive on a ventilator if she caught covid and could not breathe for herself.

SG's belief in taking all possible treatment to stay alive was in keeping with her Muslim faith. SG devoutly adhered to Muslim practices and beliefs: she prayed five times a day and two extra optional times per day, attending mosque daily. She followed fasting rules rigidly during Ramadan. Although illiterate she had memorized much of the Quran, reciting prayers multiple times daily. Her entire life was determined by Islam. For SG, Islam was the way of life and she often said "I will live by Islam and die by Islam." SG's late father was a "Mullah" – a religious scholar and teacher – who had home-schooled SG in the teachings of Quran. One of her father's pupils in turn became a spiritual leader in their town in Afghanistan, who still served as SG's spiritual guide. We heard much evidence from the family about Islamic doctrine regarding the sanctity of life and never giving up on life regardless of suffering (this will be revisited below in these Reasons under "values and beliefs"). SG's children consulted the spiritual leader in Afghanistan, who confirmed their belief that SG's faith required them to keep her on life support as long as possible.

In an interesting twist, the Afghani spiritual leader also advised BR and SR that it was permissible to consent to the DNR without contradicting the fundamental principle of preserving life. The rationale was that performing CPR on SG would cause her harm by way of cracking her ribs – she was too frail to withstand the intervention – and in that case the DNR was justifiable.

Ms. Szigeti posited that SG's supreme level of devotion to Muslim practices and faith rose to the level of a prior capable wish. In other words, because SG's understanding of Islamic teachings made it necessary to accept all forms of life support treatment up to the bitter end, and because SG would have devotedly followed Islamic teachings no matter what her circumstances, therefore her inclination towards staying on life support should be considered tantamount to a previously expressed capable wish.

The panel considered caselaw interpreting the prior capable wish provisions in *HCCA* s. 21(1). The Court of Appeal, in *Conway v. Jacques* 2002 ONCA 59 O.R. (3d) 737, addressed the question of when a prior capable wish might, or might not, be determined to be applicable to new circumstances not contemplated when the wish was expressed, stating: "[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."

The *Conway* reasoning was confirmed by the Supreme Court of Canada in *Cuthbertson v. Rasouli* 2013 SCC 53 in which the Court found that if an incapable person expressed a prior wish that life support not be withdrawn, the intended meaning and scope of the wish must be carefully considered to determine if applies to the incapable person's current circumstances. Changes in the person's condition, prognosis, and treatment options may all bear on the applicability of a prior wish. A wish that is unclear, vague, or lacks precision may be held inapplicable to the circumstances:

> [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….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….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.

The panel determined that when SG expressed her wish to be put on a ventilator if she needed help to breathe, or when she referred to Islamic doctrine to preserve life at all costs, she was expressing a general wish or philosophy of life, without any way of anticipating her eventual circumstances. SG's wish was not precise, clear and specific to the medical conditions she would develop.

SG did not know she would end up paralyzed in bed, fully-dependent on mechanical ventilation for the rest of her life, unable to speak or swallow, with bedsores down to the bone, and no hope of recovery. She stated a wish upon seeing images of anonymous patients on a screen, with commentary in a language she did not understand, with no prior knowledge of what mechanical ventilation implies or requires, only her daughter interpreting the scene. At the time she was healthy and could not have anticipated her current predicament. She did not have the benefit of being able to ask a physician or a technician the risks and benefits of being on a ventilator indefinitely, and the inevitable complications that would entail. Because SG had no way of foreseeing her severely deteriorated medical condition at the time she expressed her wish for life sustaining measures, the panel determined that her prior wish was *not applicable to the circumstances* in which she found herself in 2022.

To borrow the words of Justice Sharpe in *Conway*, to apply SG's prior stated wish literally and mechanically, without regard to the change in her circumstances, would be a great disservice to SG for she might not have wished to remain on life support under her current circumstances. Nobody, not even BR and SR who knew her well, could accurately guess what SG would have wished for in the current circumstances, therefore it was incumbent on her SDMs, and on the Board, to move to an analysis of her best interests.

The panel also determined that SG's devout adherence to Islamic doctrine did not rise to the level of a prior capable wish. To adopt that reasoning would be to remove agency and autonomy from a devotee of a particular faith. Even a person who is strictly and determinedly religious should be allowed to stray from the tenets of their faith in exceptional circumstances. A person whose faith advocates for life sustaining measures may ultimately change their mind if they are in extreme pain, for instance, or feel they are a burden to their loved ones.

The panel's decision that SG did not have a clearly expressed prior capable wish applicable to the circumstances was consistent with several CCB precedents, for example: *Re SH* 2019 Canlii 79248 and *Re MO* 2019 Canlii 110013. In *SH* the panel found that previous pronouncements made by the patient lacked precision and were made under different circumstances such that the panel could not place much weight on them. In *MO* the patient, who suffered from ALS, a debilitating and terminal disease, told his doctors he wished to stay on life support until the very end, in keeping with his strong Christian faith. However, he subsequently suffered a heart attack that left him in a persistent vegetative state with no hope for neurological recovery. The panel in *MO* determined that MO's previously expressed wish about goals of care was expressed when he had contemplated end-stage ALS, where a patient can typically still hear voices and form thoughts; he had not foreseen ending up with anoxic brain injury which left him completely unable to see, think, or communicate. The panel held that MO's previously expressed capable wish was no longer applicable to the unforeseen circumstances that had developed.

There are cases in which the Board has confirmed an incapable person's previously expressed capable wish, for example in *Re JEP*, 2017 Canlii 49299 and *Re GG*, 2020 Canlii 36914. In each of these cases the person deliberately wrote down his very precise wishes in contemplation of the ailments that would cause their ultimate incapacity. In one case the person was a medical doctor, in the other case a lawyer, and the panel found that in both cases the person understood very well what he was signing.

This was not to say that SG's previously expressed wish and her religious beliefs were discounted altogether, far from it. The *HCCA* pays suitable tribute to wishes, values and beliefs held by an incapable person in s. 21(2). Once it was determined that SG did not have a clear prior capable wish that should be given deference in the circumstances, the analysis turned to her best interests, paying heed to those very wishes, values and beliefs.

Best Interests

When there is no prior capable wish applicable to the circumstances, the law requires a SDM to make decisions in the incapable person's best interests, according to the factors set out in *HCCA* s. 21(2). There are three factors that must be balanced in determining an incapable person's best interests: (a) the values and beliefs the person held while capable and would still act on, if he could; (b) any wishes expressed by the person that do not qualify as prior capable wishes applicable to the circumstances; and (c) Whether the person's condition and well-being would be better off with, or without, the proposed treatment, weighing the expected benefits and harms of the proposed treatment. These factors are weighed according to the strength of the evidence; the legislation does not establish a hierarchy among the various considerations.

The panel first reviewed the contrasting positions of the parties and then applied its own analysis of the evidence and submissions to decide which course of action would accord with SG's best interests. Ms. Addie, as uninstructed counsel for SG, did not take a position until the very end of the hearing. Ultimately, she felt that the evidence weighed in favour of Dr. Young's position.

Dr. Young's position

As stated earlier in these Reasons, Dr. Young's position was that the medical treatments currently being provided to SG were only serving to prolong her pain, indignity and psychological distress, without any medical benefit since she was not expected to recover, only to continue deteriorating until her inevitable death in a matter of months. Her suffering was likely to increase as her physical condition continued to deteriorate. The proposed treatment would keep her comfortable and pain-free while removing the ventilator and causing her immediate death. In Dr. Young's calculation, prolonging SG's life was prolonging her suffering, thus causing her harm. Whereas expediting her death would end her suffering, thus provide a benefit. She believed that in a situation such as SG's, death was preferable to an intolerable existence. The factual basis for Dr. Young's belief that SG was suffering in a variety of ways under her current treatment was elaborated earlier under the heading "*SG's medical condition and prognosis*."

BR and SR's position

Ms. Kotob submitted that SG's SDMs weighed all the best interest factors in *HCCA* s. 21(2) but placed the greatest weight on her previously expressed wish and her strongly-held values and beliefs, and thus determined it was in SG's best interests to stay on the ventilator and other life-sustaining treatments indefinitely, under any and all circumstances (with the exception of resuscitation during cardiac arrest, explained earlier).

The panel's determination

After hearing six days of evidence and submissions from the parties, the panel concluded that BR and SR did not consider all of the best interests factors as they were called upon to do under s. 21(2). The panel found that BR and SR were so fixated on honouring their mother's wish, values and beliefs, that they stopped short of truly considering the pain and suffering she was experiencing, and which would only worsen in the foreseeable future. BR and SR did not factor the medical considerations set out in s. 21(2)(c) into their decisions and thus fell short of their responsibility as SDMs. They were so convinced that SG had expressed a capable wish applicable to these circumstances, they did not think they needed to proceed to the best interests factors.

The Supreme Court of Canada, in its majority decision of *Cuthbertson v. Rasouli* 2013 SCC 53, provided a succinct interpretation of the SDM's duty to make decisions in an incapable person's objectively interpreted best interests:

> [88] The substitute decision-maker is not at liberty to ignore any of the factors within the best interests analysis, or substitute her own view as to what is in the best interests of the patient. She must take an objective view of the matter, having regard to all the factors set out, and decide accordingly. This is clear from the mandatory wording of the opening portion of s. 21(2): the decision-maker "shall take into consideration" the listed factors. The need for an objective inquiry based on the listed factors is reinforced by s. 37, which allows the decision of the substitute decision-maker to be challenged by the attending physician and set aside by the Board, if the decision-maker did not comply with s. 21. The intent of the statute is to obtain a decision that, viewed objectively, is in the best interests of the incapable person.

The panel and the treatment team all recognized that BR and SR were acting in good faith and with the best of intentions towards their beloved mother. Throughout their testimony, and that of their sister SH, it was evident that SG's children loved, respected, and honoured her deeply. They were inquisitive about her care and visited her frequently. Nobody at the hearing questioned their sincere desire to make decisions according to what they believed SG would want. However, as the Court stated in *Benes* and *IT*, it is not enough for the SDM to act in good faith and reasonably, they must also strive to make the most *correct* decision for the incapable person, taking into account all of the factors in s. 21(2).

Ms. Wadsworth took Dr. Young through the documented evidence regarding the meetings between SG's ICU physicians and the SDMs (contained in Exhibit 2A). According to Dr. Young the principles for substitute decision-making were explained to BR as early as July and August. The notes from the meeting on August 29, 2021 state that these principles were explained and the SDMs were given opportunity to ask questions. From that meeting up until the hearing BR and SR maintained they were acting in accordance with their perception of what their mother would want: to continue all forms of treatment indefinitely. BR's and SR's testimony indicated their belief that SG had expressed a wish to be kept on life support and they had no choice but to honour that wish.

The panel agreed with Ms. Addie's submission that BR and SR genuinely believed they were following SG's prior capable wish under s. 21(1) and therefore they did not need to proceed to an analysis of best interests under 2. 21(2).

In their first meeting on August 29, 2021, BR and SR disagreed with Dr. Young's medical evidence regarding SG's loss of muscle mass and the likelihood she would never wean off the ventilator. In a meeting held on December 25, 2021, BR claimed that all of SG's organs were functioning and disagreed that SG would develop further complications and infections. Despite being confronted repeatedly with evidence of their mother's deteriorating condition, the SDMs steadfastly maintained SG's wish to "use machines" and to "leave her fate in God's hands." They appeared impervious to consideration of her medical reality. BR also testified that he would *never* change his position, no matter what medical problems ensued in the future, because he based his decision on SG's wishes – this indicated that BR was not even considering the medical factors included in best interests.

The evidence showed that BR repeatedly told SG's physicians he would consider their proposal for palliation together with his siblings and get back to them, but he did not follow up with the physicians. This avoidance was understandable, given the painful choices before him and his siblings, but did not accord with his role as SDM, to engage with physicians about all of the medical evidence and all of the treatment options on the table. The panel felt that BR and SR were closed-minded about the proposed treatment plan. They had made up their minds that maintaining life support was the only viable option for SG and did not weigh all of the benefits and harms as they were tasked to do as SDMs.

The evidence showed that BR considered removal of life support as "euthanasia" or "murder" and that SG should be allowed to die a "natural death" while being supported on a mechanical ventilator and all manner of tubes, lines, and medications. The panel could not find logic in this sentiment. Objectively, SG's life was being maintained in a most unnatural and artificial way – a "natural" death would have been to remove machines and let nature take its course. BR and SR were not open to that point of view.

Although the SDMs did not execute their role in accordance with the principles set out in the *HCCA*, the panel upheld their decision. On performing its own analysis of SG's best interests, taking into account all of the factors in s. 21(2), the panel arrived at the same conclusion: that it was in SG's best interests to remain with the treatments she was currently receiving, i.e. life support measures with the exception of resuscitation in case of cardiac arrest. Therefore, the panel did not order the SDMs to consent to Dr. Young's proposed treatment plan.

Panel's analysis: applying the evidence to best interests factors contained in HCCA s. 21(2)

For the reasons stated above the panel found that BR and SR were not making decisions in accordance with the best interests principles set out in s. 21(2) of the *HCCA*. The panel set about objectively analyzing SG's best interests, balancing all of the factors in s. 21(2)(a), (b) and (c).

The values and beliefs that SG held while she was capable and would still act on if she were capable.

The evidence on this issue was indisputable. SG strictly followed the Muslim faith as interpreted by a particular spiritual leader in her town in Afghanistan. SG's family was close-knit and they all espoused the same faith to varying degrees. The family all lived together in the same house in Toronto and SR had lived with SG her entire life, even the years in Pakistan. BR, SR and SH gave unwavering and credible testimony that according to SG's belief system she would want to use all forms of life sustaining treatment and equipment to stay alive as long as possible. They went so far as to contact SG's spiritual leader in Afghanistan for confirmation that the ventilator should stay in place even if there was no chance of recovery, and to help them assess how to address the DNR order.

The children's stories about SG's exhortations to her sick sister- and brother-in-law to seek medical treatment, and the story about SG's reaction to the video showing covid patients on ventilators supported their view that SG would want to continue treatment. According to BR and SR's testimony, SG believed that preserving life was the topmost priority and to refuse life-sustaining treatment would be a sin against God. Even if there was no hope for improvement treatment should be sought because every stage of life is important and precious.

The panel had no reason to doubt that SG's children understood SG's values and beliefs, and the evidence was persuasive that her values and beliefs spoke in favour of maintaining SG on life support indefinitely, even in the face of no chance for recovery.

Any wishes expressed by SG with respect to the proposed treatment, that were not required to be followed under s. 21(1).

This factor was difficult for the panel to assess. The Act does not explain which aspect of the person's wish would make it inapplicable under s. 21(1) and therefore applicable under s. 21(2)(b). Would it be a wish expressed by a person while incapable? A person under the age of 16? Or a general wish that was not applicable to the current circumstances? SG had not expressed a wish while incapable or while under the age of 16. However, she had expressed wishes that were found by the panel not to be applicable to her current circumstances. Should those wishes now be considered as a factor in weighing SG's best interests? The panel decided no, since her previously expressed wishes were deemed not applicable to her circumstances there was no justification to consider them as a factor in best interests. Those wishes were expressed in the context of her Muslim faith and were properly weighed as an ingredient in SG's values and beliefs.

Whether the proposed treatment plan would likely improve SG's condition or well-being, prevent it from deteriorating, or reduce the rate at which it would likely deteriorate; whether SG's condition or well-being would likely improve, remain the same or deteriorate without the proposed treatment plan; whether the benefit SG was expected to obtain from the proposed treatment outweighed the risk of harm to her, and whether a less restrictive or less intrusive treatment would be as beneficial to SG?

These questions were at the heart of Dr. Young's Form G application. SG's treatment team unanimously believed that the current treatment SG was receiving was causing her harm with no benefit. SG was enduring pain, indignity, and psychological distress due to her ailments, cognitive disability and medical needs, the many machines she was hooked up to, the many hands touching, prodding and turning her all day, and the fact that she could not even move, talk or swallow. Her condition would most certainly deteriorate further over time, on the way to a gradual death. The physicians believed it was an intolerable existence that no person would want to experience, let alone endure for months or years, with no hope for recovery. The physicians proposed what they considered to be the only ethical and humane option for SG's predicament: withdrawal of life support treatment together with comfort measures, allowing death to happen naturally and put a close on her suffering. She would not experience any pain, her tragic journey would end.

When Dr. Young filed the Form G application in December 2021, she and the other physicians were under the mistaken impression that SG was unresponsive. This was likely due to the fact that SG did not understand English and they had not attempted to communicate with SG with the assistance of a translator who spoke her dialect. Dr. Antman did see a minimal response from SG on January 20, 2022, and Dr. Young conceded that SG's response to BR's voice was substantial when she viewed the videos presented as Exhibit 7. This misunderstanding was an illustration of the poor communication between the family and the treatment team.

Dr. Young and Dr. Antman both stated that SG's responsiveness to voices did not change their view that she was suffering to an intolerable degree and that her life should be ended to alleviate her suffering. They did not think her level of consciousness was high enough to understand what was going on or to meaningfully interact with her environment, and they were sure it would not improve. Her minimal ability to interact with family members was not beneficial enough to justify her suffering.

Dr. Young and Dr. Antman also testified that SG's pain could not be adequately controlled unless she were permanently sedated. It was impossible for nurses to predict her level of pain and to treat it proactively. They did the best they could when they saw her grimace or cry. Dr. Antman stated that SG would always have some breakthrough pain with the amount of prn medication she was currently receiving. If they gave her enough pain medication to ensure no pain whatsoever she would be heavily sedated and her blood pressure would lower to a critical level – it could hasten her death. In order to keep her alive the administration of pain medication was a delicate balance.

Viewed from the physicians' vantage point, the proposed treatment would improve SG's condition and well-being because it would end needless suffering; it would prevent SG from the foreseeable deterioration she would suffer if the proposed treatment were not applied and she were to keep living. The physicians believed that death would be a benefit to SG whereas continuing life under the circumstances was to inflict further harm. There was no less intrusive treatment that could be as beneficial to SG as withdrawal of life support together with palliation.

SG's family members offered a diametrically different view of her condition and well-being, however. According to them, SG was living according to her faith and was thus not suffering. They did not view her life in the hospital as lacking in dignity or causing her distress – on the contrary, they said SG would be gratified to know she was receiving the best treatment and care available from top-notch professionals at an excellent hospital, and that this privilege would be a source of dignity for SG. She would be grateful for every minute of care that prolonged her life.

In terms of pain, the SDMs did not deny she was in pain some of the time, and it disturbed them. They said they had consented to pain medication without limitation; it was in line with SG's values and beliefs to keep her as comfortable as possible. They also stated that according to SG's faith pain and suffering were inflicted by God to cleanse one's sins and would be rewarded in the afterlife. Therefore, SG would bear her breakthrough pain with fortitude and view it positively as part of God’s plan. The SDMs acknowledged that SG’s pain would likely increase as her condition worsened over time, and they were in favour of administering more pain medication as needed, even if it resulted in heavy sedation.

BR and SR believed strongly that SG’s life was still worth living, not only due to her values and beliefs, but also because she still derived pleasure from being with her family members and from receiving tender care from nurses. Exhibit 5 contained multiple entries noting that SG smiled when nurses attended to her. SR testified that SG would smile when she entered the hospital room and extend her hand to greet her daughter. She was even happier when BR visited. When they asked if they should leave, SG would shake her head to say “no.” BR said that when he visited SG in December after a few days of vacation, she stretched out her hand for BR to grasp it and looked at him as if to ask “where were you?” The panel accepted the evidence indicating that SG had some (albeit limited) capacity to interact with others and obtained some pleasure in her interactions with her children and in being cared for with compassion.

BR and SR interpreted the doctors’ proposed treatment plan as a “mercy killing” intended to end SG’s perceived suffering. They refused to consent to it for three reasons: first, because it would constitute a sin in SG’s religious belief system, which would be the greatest affront and indignity that could happen to her; second, because they believed her life was still worth living even in her compromised state; and third, because any residual suffering she might experience would be rewarded later on. In their analysis, the proposed treatment would greatly harm SG’s well-being by ending her life, with no benefit since they did not perceive SG as unduly suffering.

The panel was tasked with assessing whether the proposed treatment plan would yield a net benefit or harm to SG under the “well-being” test. There was no universally-accepted standard of well-being to be used as a measure. Her children, who knew her better than anyone, insisted that SG’s well-being would be increased by staying alive. We acknowledged that SG must have been suffering physically and emotionally as described by Dr. Young, however we allowed the possibility that her faith gave her strength to endure the suffering and still derive some pleasure from seeing her children and feeling their presence. How could we measure the benefit SG would derive from remaining alive? It was an impossible calculation. The panel did feel that SG’s ability to interact with her children put her in a different plane than patients in a persistent vegetative state, with greater potential to derive benefit from staying alive.

The panel found the evidence inconclusive on whether the benefit SG was expected to obtain from the proposed treatment (ending of suffering) outweighed the risk of harm to her condition and well-being (certain death). The onus of proof lay with the Form G applicant – Dr. Young – to prove on a balance of probabilities that the benefit SG would gain from the proposed treatment outweighed the harm. The panel found that Dr. Young had not proven her case on the "well-being" part of the test.

The panel's conclusion was analogous to a previous CCB case: *Re SS* 2015 Canlii 44140 in which a six-year old boy on life support was found to derive enough pleasure in his parents' presence to outweigh the discomfort of his circumstances. Due to his young age, the boy did not have values, beliefs or wishes that played into the decision, it was based solely on the benefits and risks to his condition and well-being. The panel in *SS* found the evidence did not prove that his discomfort and pain outweighed the benefit of staying alive.

> The benefits he was experiencing with his parents outweighed the discomfort he felt by being confined attached to machines and related care. We accept generally he is peaceful except when strangers have to perform certain nursing and medical care such as suctioning and pulling up the blankets to change his diaper….Taking all of the factors set out in section 21(2) of the HCCA into account, the majority of the panel found there was not clear, cogent and compelling evidence presented that SS's parents were not applying the best interest test in keeping SS alive on ECMO [life support machine]. It is acknowledged that SS is undergoing an invasion of his personal privacy and suffered certain exacerbated difficulties due to ECMO, and is in some discomfort, but <u>it was not proven, on a civil balance of probabilities that SS no longer experiences pleasure or his level discomfort and pain has reached the point that it outweighs the benefit of this pleasure to the point SS's parents are required to say, "enough is enough"</u>. (emphasis added)

<u>*Weighing all the best interests factors*</u>

The panel had to weigh all of the considerations contained in subsections (a), (b) and (c) of *HCCA* s. 21(2). The difficulty of this task was expressed by Justice Cullity in *Scardoni v. Hawryluck*, (2004), O.J. No. 300 (ONSC):

> [60] Paragraph 21(2)(c) is concerned with the consequences of giving, or withholding, treatment on the patient's health and well-being. Although the evidence of health practitioners that reflects their expertise will inevitably be essential, the weighing of benefits and burdens under the section cannot be achieved scientifically. The imponderables involved – and the difficulty of the exercise – are increased significantly when the qualitatively different considerations referred to in s. 21(2)(a) and (b) are added to the scales.

In terms of subsection (c): weighing the benefits and harms of the proposed treatment to SG's condition and well-being, the evidence was inconclusive as there was no objectively satisfactory way to calculate the benefit of life to a sentient being, one who can hear and respond to, and take pleasure in, the presence of loved ones. In terms of subsection (b): an unenforceable wish, the panel found that SG had not expressed a wish with enough specificity to her current circumstances such that it should be considered. In terms of subsection (a): SG's values and beliefs – this factor weighed very heavily in favour of maintaining SG on life support. The overall calculation, therefore, weighed in favour of refusing the proposed treatment plan.

Dr. Young bore the onus of proving, on a balance of probabilities, that the SDMs' decision was not made in accordance with the principles of substitute decision-making. Although the process by which the SDMs arrived at their decision may have been incomplete because they did not accord due weight to SG's medical reality, their decision to refuse Dr. Young's proposed plan of treatment was in SG's overall best interests, in keeping with the purpose and intent of the *HCCA* to enhance an incapable person's autonomy, as expressed in *Scardoni*:

> [83] [*HCCA*] Sections 21(2)(a) and (b) reflect legislative acceptance that a person's personal beliefs, values and wishes are relevant to the statutory concept of their best interests. The provisions recognize, and reflect, the value to be attributed to personal autonomy by allowing the Board to look at the question of a patient's best interests from the viewpoint of the patient.

Dr. Young's submissions focused on one aspect of SG's existence: the pain, indignity and distress she must have objectively been suffering. The panel's analysis took the suffering into account along with SG's strongly-held values and beliefs that blurred the significance of her suffering and turned the analysis back to deciding what was in SG's <u>own</u> best interests. Looking at the choice from the viewpoint of SG, the evidence weighed in favour of refusing the withdrawal of life support.

The facts were analogous to the case of *Re DW* 2011 Canlii 18217 in which the panel was also called upon to incorporate the incapable person's values and beliefs into a calculation of his best interests:

> Dr. McConachie's evidence was quite clear that DW was in the terminal phase of advanced dementia, that he would continue to be bedbound and fully dependent and that he would suffer indignities and possible discomfort or pain from the on-going medical interventions and treatment for opportunistic infections. It was his position that DW's dignity and quality of life required that MW consent to the proposed plan of treatment. Had those issues been the only elements of DW's "best interests," we would have agreed.
>
> However, the *HCCA* also required the panel to consider DW's wishes, values and beliefs. Indeed, the court has noted the "value to be attributed to personal autonomy by allowing the Board to look at the question of a patient's best interests from the viewpoint of the patient" (*Scardoni*, at paragraph 83). In considering DW's best interests from his point of view, the panel agreed with MW [SDM] that DW's personal religious beliefs and values, particularly those that specifically addressed end of life treatment would have caused him to seek out aggressive treatment, regardless of his current circumstance and the medical realty. For DW, not [to] continue with aggressive treatment to maintain life was a sin.

RESULT

For the foregoing reasons the panel unanimously held that SG was not capable of consenting to any form of treatment. The panel also unanimously held that her SDMs had not strictly complied with the principles for giving or refusing consent set out in s. 21 of the *HCCA*, however the panel's own analysis of SG's best interests resulted in the same decision as that of the SDMs – to refuse consent to the proposed plan of treatment. Therefore, the panel made no order with respect to the proposed treatment plan.

Dated: February 15, 2022

Nina Lester, Presiding Member