Consent and Capacity Board
Commission du consentement et de la capacité

Ontario

18-4190-01
18-4190-02

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

AND IN THE MATTER OF
PL
A patient at
MARKHAM STOUFFVILLE HOSPITAL
MARKHAM, ONTARIO

REASONS FOR DECISION

PURPOSE OF THE HEARING

The Board convened a hearing at Markham Stouffville Hospital ("MSH") at the request of Dr. Datta, the health practitioner who had proposed treatment for PL. PL had been found incapable of consenting to treatment. Dr. Datta had brought a Form G application to the Board under s. 37(1) of the *Health Care Consent Act* ("*HCCA*") to determine whether or not PL's substitute decision-makers ("SDMs") had complied with the principles for giving or refusing consent 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 Form A application by PL, under s. 32 of the *HCCA*, requiring the Board to review the finding of incapacity. The two applications were heard together.

DATES OF THE HEARING, DECISIONS AND REASONS

The hearing took place on January 22 and February 7, 2019, and the panel released its Decisions on February 8. On February 11, counsel for PL requested Reasons for Decision (contained in this document), which were released on February 18, 2019.

LEGISLATION CONSIDERED

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

PARTIES TO THE DEEMED FORM A APPLICATION

PL, the person found to be incapable for treatment decisions
Dr. Datta, the health practitioner proposing the treatment

PARTIES TO THE FORM G APPLICATION

PL, the person found to be incapable for treatment decisions
Dr. Datta, the health practitioner proposing the treatment
ML, substitute decision-maker for PL
SWL, substitute decision-maker for PL
All of the parties except PL attended the hearing

PANEL MEMBERS

Nina Lester, senior lawyer and presiding member
Andrew Hackett, psychiatrist member
Anthony Warr, public member

APPEARANCES

PL was represented at the hearing by counsel, Janet Gillespie
Dr. Datta was represented at the hearing by counsel, Leah Ostler and Erica Baron
ML and SWL were not represented by counsel

2019 CanLII 39117 (ON CCB)

PRELIMINARY MATTERS

Proposed Treatment

Dr. Datta proposed a treatment plan for PL that was, at times, referred to as "Level 2" care, which included receiving fluids and nutrition, hygiene and wound care, some medications (including antibiotics), and any comfort measures required to keep PL pain-free and comfortable, but which did not include any invasive or aggressive treatments such as mechanical ventilation, vasoactive drugs, dialysis, surgery, or cardio-pulmonary resuscitation ("CPR"), (the "treatment plan"). The treatment plan was set out in a letter from Dr. Datta to the SDMs dated November 26, 2018.

Interpretation

A Korean language interpreter was present throughout the hearing to interpret the proceedings for the benefit of SWL and ML.

EVIDENCE

The evidence at the hearing consisted of the oral testimony of Dr. Datta, ML and SWL (PL's mother and father, his SDMs), and HL and DL (PL's sisters) and the following documents entered as Exhibits by counsel for Dr. Datta:

1. Summary of Records Brief prepared by Ms. Ostler on behalf of Dr. Datta, January 20, 2019 (6 pages).
2. Binder containing Dr. Datta's evidence (136 pages) arranged in tabs as follows:
    - 2.1. MSH Medical Consultation and Progress Notes by various authors written between October 29, 2015 to November 18, 2018
    - 2.2. MSH Physiotherapy Reports written between December 22, 2015 to September 26, 2018
    - 2.3. MSH Occupational Therapy Reports written between October 31, 2015 to September 25, 2018

  - 2.4. MSH Social Work Notes recording family meetings written between November 6, 2015 to December 17, 2018
  - 2.5. Letter from Dr. Datta to ML and SWL, outlining proposed treatment, November 26, 2018
  - 2.6. Blank Consent and Direction for Treatment Form, undated
  - 2.7. Form G application submitted by Dr. Datta to CCB, December 5, 2018.

3. Two additional MSH Consultation Notes by Dr. Datta, November 19, 2018, and by Dr. Fernandes, January 20, 2019, respectively (2 pages).

INTRODUCTION

On September 26, 2015, PL, aged 36, collapsed suddenly and was rushed to Mackenzie Health Centre for emergency care. He had suffered spontaneous bleeding in the brain resulting from a previously undetected malformation of the blood vessels in his brain referred to as “AVM”. He was quickly transferred to St. Michael’s Hospital for emergency neurosurgery. He was unconscious, with a Glasgow Coma Scale (“GCS”) score of 3 – the lowest possible score. The surgery was not successful in reviving PL and he suffered a series of complications while at St. Michael’s, described in Exhibit 2, pp 1-3. PL was transferred to MSH on October 29, 2015 and returned to St. Michael’s at the end of November, 2015 for a further procedure to relieve fluids gathering in the cranium, then transferred back to MSH on December 2, 2015, where he remained until the commencement of this hearing. PL never regained consciousness; he remained at a GCS of 3 throughout his three-year hospitalization.

PL’s SDMs were his parents, ML and SWL. They had divorced approximately five years earlier however from all accounts they both remained close to PL and to his sisters. ML and SWL were extremely devoted parents, visiting PL almost daily throughout his hospitalization. Sisters HL and DL also visited often.

PL developed a great many complications while in hospital, described in detail in the clinical notes contained in Exhibit 2. These medical problems included: a variety of infections treated with antibiotics, acute kidney injury, hyperkalimia (high potassium), diabetes, hypotension, skin breakdown with several stage 4 bedsore wounds reaching the bone, respiratory failure requiring tracheostomy and occasional mechanical ventilation, frequent mucus plugging of the tracheostomy tube causing pneumonia, significant loss of muscle mass, and cerebral atrophy and encephalomalacia, meaning that brain tissue was softening or disappearing.

For most of the three plus years at MSH, PL was treated in the General Medicine Unit (“GMU”), with some periods spent in Complex Continuing Care (“CCC”) when he was considered more stable, and intermittent transfers to the Intensive Care Unit (“ICU”) when he was in crisis or required intensive intervention. The transfers to ICU occurred with greater regularity in 2018. In the GMU, PL was cared for by a team of 15 physicians and other medical staff. In the ICU there were four intensive care physicians on rotation, Dr. Datta being one of them. PL’s most recent admission to the ICU was on November 2, 2018, to address bleeding around the tracheostomy. He was stabilized and transferred back to GMU. While PL was under Dr. Datta’s care in the ICU in November 2018, Dr. Datta questioned whether PL’s SDMs were making decisions in PL’s best interests. Dr. Datta felt that PL was undergoing undue suffering, with no hope of recovering neurological function. He proposed a treatment plan that would avoid future visits to the ICU for aggressive treatments that would prolong PL’s suffering without any prospect for recovery. Dr. Datta consulted the other physicians in the ICU, and some of the physicians in the GMU, who all concurred. Dr. Datta presented the proposed treatment plan to PL’s SDMs by letter dated November 26, 2018. The SDMs did not consent to the proposed treatment plan.

Dr. Datta made an application to the Board under s. 37(1) of the *HCCA* (“Form G”) to determine whether or not ML and SWL were complying with the principles for giving or refusing consent set out in s. 21 of the *HCCA*. The Board convened a hearing on January 22, continuing on February 7, 2019. On the first day of the hearing the parties and witnesses presented their evidence; on the second day the panel heard submissions.

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).

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.*

At any hearing under *HCCA* s. 37(1), the Board will first hear evidence concerning the deemed Form A application under s. 37.1. If the person is found to be capable of consenting to treatment, the Board must dismiss the Form G application.

ANALYSIS

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.

Did the evidence establish that PL 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 clear and uncontested. PL had been unconscious, in a persistent vegetative state since his initial brain hemorrhage in September 2015. PL was unable to receive information or communicate in any fashion. A neurologist, Dr. Hui, examined PL on December 3, 2015 and reported: PL was "not responsive to verbal or tactile stimuli. There was no eye opening or verbal output…eyes were directed in central gaze" (Exhibit 2, p. 18). Dr. Datta stated that PL's lack of consciousness was confirmed over and over with a variety of CT scans, MRIs, and clinical assessments by specialists, and it remained constant throughout his hospitalization. PL never scored higher than 3 (the lowest possible level) on the GCS.

PL's parents did not agree that PL was "unresponsive" to his environment, however they did not doubt the finding that he was incapable of consenting to his own treatment. The evidence was clear, cogent and compelling in support of Dr. Datta's finding that PL was unable to understand information and unable to appreciate the consequences of any decision about his treatment. PL remained incapable throughout his hospitalization.

Application to Determine Compliance with Principles for Giving or Refusing Consent

A Form G application under the *HCCA* requires the Board to determine whether a SDM is acting in accordance with the principles of giving or refusing consent enshrined in s. 21. If the Board determines that the SDM has not followed such principles, it may substitute its own opinion for that of the SDM and direct the SDM to comply with s. 21. Here follows an analysis of whether ML's and SWL's refusal to consent to Dr. Datta's proposed treatment plan for PL was in compliance with the principles of substitute decision-making, which consist of two branches: first, whether the incapable person expressed a prior capable wish applicable to the circumstances (which would be a paramount consideration), and second, whether the SDM's decision is in the incapable person's best interests.

It is important to underscore 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 final 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 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 or objective best interests. This removes a fair amount of discretion on the part of the SDM to judge what is best for the incapable person. The SDM is not the final 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 perception of the person's best interests, as revealed by the evidence.

Summary of PL's Medical Condition

PL never recovered any neurological function following the massive brain hemorrhage he experienced on September 26, 2015. He underwent emergency surgery to stop the bleed in September 2015, and a second operation to relieve fluid buildup in November 2015. PL remained unconscious, in a persistent vegetative state, with a GCS rating of 3, for over three years since his initial collapse. PL was unresponsive to stimuli and unable to interact with his surroundings. He was unable to move any part of his body or his face in a purposeful way. Sometimes his muscles twitched involuntarily, and his eyes opened and shut but without seeing. PL was alive, but had no brain function, completely unaware of his environment. Furthermore, brain scans indicated that PL's brain tissue was gradually softening and shrinking (encephalomalacia) as a result of the trauma suffered, making the prospect of recovery ever more remote.

It was not only Dr. Datta's opinion, but that of every physician caring for PL, including neurologist Dr. Hui, that PL would never recover brain function. Exhibit 2 contained multiple reports and notes by many different physicians all agreeing with the same conclusion. PL would never again talk, walk, feed himself, attend to bodily functions, or have any meaningful interaction with other people. The medical evidence was overwhelmingly persuasive that there was zero chance of his recovery. Dr. Datta testified that in cases of brain hemorrhage, if recovery is to occur, it should happen in the first couple of days; any realistic hope of recovery fades after one month post-trauma. In PL's case he had gone over three years with no sign of recovery. It was simply inconceivable that he would recover at this late stage; to the contrary, evidence showed his neurological function was gradually deteriorating.

PL's medical problems were not limited to his neurological condition. He suffered a litany of ongoing and recurring medical complications, including frequent infections (some of which were antibiotic-resistant), mucus plugging of his tracheostomy requiring frequent suctioning, skin breakdown with stage 4 bedsore wounds that had gone to the bone causing infection within the bone (osteomyelitis), diabetes, anemia requiring frequent blood transfusions, and tachycardia requiring daily medication. All of PL's bodily functions were managed artificially: a trach tube for breathing, PEG tube into the stomach for feeding, PICC line in the arm to supply fluids straight to his artery, catheters into urethra and rectum for eliminating. He received continuous prodding, turning and cleaning from multiple nurses all day for wound care of his ulcers, suctioning his trach, turning him in bed, and managing his hygiene. For the most part his treatment and care were managed in the GMU but occasional medical crises necessitated transfer to the ICU for more aggressive interventions, for example, mechanical ventilation. PL had been transferred to the ICU three times in the latter half of 2018.

Prior Capable Wish

Section 21(1) of the *HCCA* requires a SDM to respect a wish, applicable to the circumstances, that the incapable person expressed while still capable.

Had PL expressed a wish, while he was capable, that was applicable to the circumstances?

There was no evidence to suggest that PL had ever expressed a wish applicable to his current circumstances. His four family members stated that such matters had never been discussed with

PL. None of them ever contemplated the scenario they found themselves in. There was no guidance available to PL's SDMs from any wish or intention previously expressed by PL.

Best Interests

When there is no known prior capable wish, the law requires a SDM to make decisions in the incapable person's best interests. The factors to consider in determining an incapable person's best interests are set out in *HCCA* s. 21(2), and analyzed below. These factors are weighed according to the strength of the evidence; the legislation does not establish a hierarchy among the various factors. The panel first acknowledged the positions of the three parties: Dr. Datta, ML and SWL, and then applied its own analysis of the evidence in deciding whether ML and SWL were acting in PL's best interests.

Dr. Datta's Position

The first important point to clarify is that Dr. Datta was acting as a representative of PL's entire treatment team at MSH. PL did not have a primary physician at MSH. During more than three years of hospitalization PL had been under the care of multiple physicians, nurses, therapists, social workers, and staff in the GMU, the ICU and CCC unit. Exhibit 2 contains many reports notes written by a wide variety of health practitioners, an indication of the vast number of professionals involved in PL's care. Dr. Datta was one of four ICU physicians who rotated weekly, and had cared for PL during several of his admissions in the ICU. Dr. Datta had last treated PL for one week in November, 2018, when PL was transferred from GMU to ICU to treat severe bleeding around his tracheostomy. It was at that time that Dr. Datta formed the opinion that continued aggressive intervention was not in PL's best interests.

Dr. Datta testified that he had canvassed his colleagues in the ICU, and many of the physicians in the GMU, and all were unanimous that continued aggressive intervention was not in PL's best interests. When asked why he, Dr. Datta, was the one who applied to the Board with Form G, Dr. Datta replied that any of the physicians caring for PL could have applied, but it was a time-consuming and draining process that no other physician felt they had time for. All the physicians he spoke to supported and encouraged Dr. Datta in his application. Furthermore, Dr. Datta testified that the ICU physicians, not the GMU staff, were the ones who were called upon to administer the most aggressive treatments and interventions whenever PL was in crisis, thus they had a better grasp of the extreme level of pain and suffering, and affront to his dignity, that PL endured in times of medical crisis. Dr. Datta emphasized that the proposed treatment plan, and the evidence presented at the hearing, reflected the consensus of all the physicians he consulted, and his Form G application was made on behalf of the entire treatment team at MSH.

Dr. Datta began his letter to PL's parents dated November 26, 2018, by saying "I am writing as one of the physicians caring for your son" and throughout the letter he used "we" to indicate that the letter represented the opinions of all the physicians who cared for PL. The panel accepted Dr. Datta's evidence that he spoke for the entire treatment team at MSH, and that the consensus on the proposed treatment plan expressed in the November 26 letter was unanimous.

Dr. Datta's premise was that PL was suffering, and that life-saving interventions increased or prolonged his suffering, with no potential medical benefits since PL had no prospect of neurological recovery. Dr. Datta believed that PL's suffering was the result of the myriad physical intrusions and indignities he was subject to on a daily basis, combined with his absolute inability to enjoy any aspect of living, and the potential pain he experienced from his deteriorating condition. Dr. Datta conceded that if there were any hope even of minimal recovery, the pain and suffering might be justifiable, but absent that hope, it was not in PL's best interests to prolong his life only to prolong his suffering. In essence, Dr. Datta believed that PL should be allowed to die peacefully and naturally, and that only death would end his suffering. The treatment team would not do anything to accelerate his death, but would refrain from aggressive life-saving measures, letting nature take its course, while keeping PL as comfortable as possible.

Dr. Datta agreed that basic treatments available in the GMU, including antibiotics, should continue, and every available comfort measure should be offered (referred to as "Level 2" treatment) but that PL should no longer be transferred to the ICU for aggressive treatments (referred to as "Level 4" treatment). More specifically, Dr. Datta's proposed treatment plan excluded: mechanical ventilation, surgery, dialysis, vasoactive drugs, and CPR (the "excluded treatments"). Dr. Datta's rationale was twofold: first, some aggressive treatments such as mechanical ventilation and CPR caused additional discomfort and suffering, for example, broken ribs and injury to tissue and organs. Second, the aggressive treatments prolonged PL's suffering unnecessarily.

Several physicians in PL's treatment team broached the topic with family members in meetings (documented in Exhibit 2.4) beginning on January 7, 2016. The SDMs consistently requested maintaining PL on "full code" Level 4 care. On August 27, 2018 Dr. Sheikh and the hospital's ethicist met with the family to elucidate on PL's condition and prognosis, and to educate them further on their responsibilities as SDMs, asking them to consider transition to Level 2 care. At the next family meeting on October 17, 2018, the SDMs continued their call for Level 4 care. When PL was transferred to ICU to manage bleeding around the tracheostomy, on November 2, 2018, Dr. Datta expressed his views to ML, and informed her of his intention to make application to the Board. Dr. Datta's letter of November 26, 2018 (Exhibit 2.5) explicitly set out the hospital's position and the proposed treatment plan reducing care to Level 2. He proceeded with his Form G application on December 5, 2018. A further family meeting occurred on December 17, 2018, with Ms. Gillespie appointed to represent PL, however the SDMs were not comfortable agreeing to Level 2 care.

ML and SWL were convinced that PL's condition had improved over the three-year course in hospital, and were hopeful that he would continue to improve. They witnessed PL moving his eyes and sometimes his head and limbs, as signs of improvement and a will to live. Dr. Datta testified that even in a persistent vegetative state, PL did experience spasmodic muscular movement, but these were meaningless involuntary movements with no purpose or function. The medical staff did not bother to document such movements in PL's chart because they carried no significance. His eyes might open and shut, or produce tears, but he could not see or experience emotion. Dr. Datta believed that family members were reading meaning into PL's involuntary movements because of their emotional connection to PL, but that their observations were not based in science.

ML's Position

ML was PL's mother. Naturally, she was distraught and devastated to see her beloved son in such circumstances. It was understandable that she did not wish to let her son go. ML had faith that PL could recover some of his function, enough to enjoy life once again. She did not accept the physicians' evidence that PL's recovery was beyond hope. ML believed that PL was in fact improving – she felt him squeeze her hand once in 2018, and she was sure he could hear her, and he tried to communicate with his eyes. ML testified that she witnessed PL crying and turning his head towards family members. She was sure his movements had meaning and that he was trying hard to let his family know he had some awareness and a desire to live.

ML recollected that PL had been treated for leukemia when he was 16 years old, including a bone marrow transplant, so he was not new to suffering. He had fought for his life then and was fighting for his life now. ML testified that she knew in her heart that PL was not ready to give up on life.

ML believed that PL's life was worth living because there was always hope of recovery, she said that living, even in PL's condition, was better than dying. She did not consider loss of dignity to be a relevant factor. ML wanted the treatment team at MSH to continue life-saving measures indefinitely, with the exception of CPR, electric shock, and surgery, because they could cause him more pain. If PL required transfer to ICU for mechanical ventilation or for bleeding, as had happened in November 2018, ML wanted it to continue. ML said she hoped PL could go on living for ten more years with Level 4 care, but if they went to Level 2 she feared he would be dead within a year.

SWL's Position

SWL had a slightly different perspective than ML. SWL recognized that PL was suffering in his current condition and he did not wish PL to suffer indefinitely. He conceded that with all the tubes going into and out of PL's body, PL was "not living properly". However, SWL concurred with ML that PL had showed signs of improvement and was trying to communicate with family members. SWL wanted PL to stay on Level 4 until his birthday on May 19, 2019, and after that SWL was willing to consent to Dr. Datta's treatment plan so as to end PL's suffering. SWL testified that he believed in "God's miracles" and he felt a miracle would happen prior to PL's birthday, and if it did not, he would follow the doctors' recommendations, and allow PL to "go to God". SWL referred to PL's earlier remission from leukemia as a "miracle" that could be repeated. SWL testified that PL's doctors had previously agreed to keep PL on Level 4 until his birthday, and that Dr. Datta was interfering with this prior agreement.

Panel's analysis, applying the principles contained in HCCA s. 21(2)

What were the values and beliefs that PL held while he was capable and would still act on if he were capable; had PL expressed any wishes with respect to his treatment, that were not prior capable wishes required to be followed? (*HCCA* s. 21(2)(a) and (b))

There was no definitive evidence presented about a specific belief system or set of values held by PL prior to his brain injury that would have guided his decision-making. PL never had the opportunity to express any wishes or preferences regarding the current circumstances because he was unconscious from the moment he was discovered collapsed on the ground. However there were two streams of evidence that suggested a possible inference of what PL might decide if he were capable.

It was evident that the family was close-knit and very loving towards one another. PL's sisters testified in support of their parents' decisions regarding PL. They did not offer their own opinions about PL's best interests, deferring entirely to the parents' views of PL's best interests. Ms. Gillespie ventured a submission that PL might also have deferred to his parents' decisions regarding his welfare, subjugating his own best interests in favour of their needs and wishes to keep him alive. Ms. Ostler replied that this was speculative, as there was no evidence to show that PL would have deferred to his parents' wishes. Also, ML and SWL's wishes were not entirely aligned – which parent's wish would PL defer to? The panel rejected Ms. Gillespie's argument for those reasons and one more: it was circular to suggest that PL's values would lead him to subjugate his own best interests to please his parents, when it was his parents' duty to make decisions in PL's best interests. To decide in the vein suggested by Ms. Gillespie would be to ignore the statutory mandate to make decisions to suit PL's best interests regardless of the needs or desires of his family members.

The second strand of evidence suggestive of PL's values and beliefs related to his previous battle with leukemia when he was 16 years old. His parents and sisters testified that PL was a "fighter" who courageously survived uncomfortable treatments in order to keep living, and therefore would want to do so again. The panel felt that the circumstances of PL's earlier battle with cancer were not analogous to his present condition. The former was not an end of life situation. Given that now PL had no chance of recovering to a full and normal life, as he had done before, the panel felt that no inference could be drawn from his past medical issues that would be applicable to his present circumstances.

In summary: the panel felt there was insufficient evidence regarding PL's values and beliefs to draw any meaningful conclusions to guide his parents' decision-making on his behalf. The panel turned its analysis to the best interests considerations.

Did ML and SWL consider whether the proposed treatment plan would likely improve PL's condition or well-being, prevent it from deteriorating, or reduce the rate at which it would likely deteriorate? Did ML and SWL consider whether PL's condition or well-being would likely improve, remain the same or deteriorate without the proposed treatment plan? Did ML and SWL consider whether the benefit PL was expected to obtain from the proposed treatment outweighed the risk of harm to him, and whether a less restrictive or less intrusive treatment would be as beneficial to PL? (*HCCA* s. 21(2)(c))

The wording of the *HCCA* requires a SDM to make decisions likely to improve the incapable person's condition or well-being. The term "well-being" has been interpreted by the Board and the Courts to include a person's dignity and quality of life.

The crux of Dr. Datta's submission was that PL's condition was one of tremendous suffering with no hope of recovery, and further aggressive treatments would only prolong PL's current suffering, and possibly cause him even greater suffering, thus decreasing his well-being. The proposed treatment plan would alleviate PL's suffering sooner than if they continued with Level 4, thus it would be beneficial to PL's well-being.

ML and SWL believed that PL had made some improvement since the day of his admission, and they felt there was a possibility of further recovery, a “miracle”, and therefore they wished for Level 4 care to continue, to give PL the best chance to stay alive. PL’s parents were convinced that PL’s condition could improve, that he had some awareness, and was trying to communicate, but their belief ignored the indisputable medical evidence to the contrary.

The evidence presented in Exhibit 2 expressed the unanimous opinion of countless physicians who had treated PL over three years. The panel felt the evidence was clear, cogent and compelling that PL’s condition was irreversible, he would never regain neurological function, his brain condition was deteriorating due to encephalomacia, his bedsore wounds would continue to deepen, and he would continue to be plagued with a variety of infections as his organs also failed. The evidence showed that PL had no awareness of his own circumstances, and no ability to think or communicate, or interact with his environment. The panel preferred Dr. Datta’s extensive medical evidence about PL’s condition and prognosis over the family’s personal, lay observations. The panel was persuaded that PL had no quality of life in his current condition, and was suffering a great deal of indignity, and possibly pain. In other words, a negative quality of life. He had no chance of meaningful recovery and would likely deteriorate further. The panel agreed with Dr. Datta’s submission that aggressive life-saving measures would only prolong PL’s suffering, and thus worsen his condition and well-being. The proposed treatment plan aimed to alleviate PL’s suffering, which had already endured for over three years.

ML and SWL’s love for their son was unquestionable, their grief over his condition immeasurable. They hoped beyond hope for a different outcome, they were not willing to let go, give up hope. But as SDMs they had a responsibility to make decisions in PL’s best interests, taking into account all the considerations set out in the *HCCA*. The panel felt that the SDMs were not giving due consideration to the unequivocal medial evidence because it did not accord with their faith that PL could still make a miraculous recovery. They were ignoring key facts explained to them by medical experts, because their perspective was blinkered. As SDMs they had a duty to consider all of the information supplied to them, and weigh the risks and benefits of the proposed treatment plan from PL’s perspective, not from their own hopes and wishes. Their hope for PL’s recovery had no reasonable basis in fact. Their decision-making was not objectively rational.

In a moment of candour, SWL admitted that he would not wish to continue living in PL’s condition. Yet, he did not take that into account when he asked for Level 4 care to continue for three more months until PL’s birthday. The panel considered this request to be irrational; since PL was suffering and utterly unaware of his own birthday, there was no meaningful reason to delay the decision for three months.

The *HCC*A calls for SDMs to make decisions in an incapable person’s objectively interpreted best interests, taking into account all the factors listed in s. 21(2). This duty on the part of SDMs was expressed by the Supreme Court of Canada in its majority decision of *Cuthbertson v. Rasouli* 2013 SCC 53:

> [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 “<u>shall</u> 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.

As the panel determined that ML and SWL had not fulfilled their obligation to consider all of the relevant factors in making treatment decisions on behalf of PL, the panel substituted its opinion about PL’s best interests for that of his SDMs. The panel weighed all of the evidence presented by the parties, and decided that the proposed treatment plan was likely to improve PL’s well-being by reducing his overall suffering sooner than if he remained at Level 4 care. Without the treatment plan PL’s suffering would be prolonged unnecessarily. The risk of harm to PL, at Level 2 care, would be outweighed by the benefit of attenuating his suffering. There was no less restrictive treatment plan available to PL that would serve his best interests.

RESULT

The Board held that PL was not capable of consenting to any form of treatment. The Board also held that ML and SWL had not complied with the principles for giving or refusing consent set out in the *HCCA*, and ordered them to consent to Dr. Datta's proposed treatment as set out in his letter to them dated November 26, 2018.

Dated: February 18, 2019

Nina Lester
Presiding Member