File Number LO-10-3602
LO-10-3603

AND IN THE MATTER OF
The ***HEALTH CARE CONSENT ACT***
S.O. 1996 c.2,
As amended

AND IN THE MATTER OF
JM
A PATIENT AT
LONDON HEALTH SCIENCES CENTRE – CHILDREN'S HOSPITAL
LONDON, ONTARIO

REASONS FOR DECISION

PURPOSE OF THE HEARING

JM was a patient at London Health Sciences Centre – Children's Hospital (LHSC). JM suffered from a severe and progressive neurodegenerative disease from which Dr. F, his attending physician, said there was no hope of recovery. Dr. F proposed a treatment plan to which the parents of JM refused to consent.

Dr. F applied to the Board to determine if the refusal of JM's parents was in accordance with the principles for giving or refusing consent to treatment as set out in The *Health Care Consent Act* (*HCCA*).

DATES OF THE HEARING, DECISIONS AND REASONS

The hearing took place on January 18, 2011. At the end of the hearing, the panel requested written submissions from the parties with submissions and replies to be delivered to the

Board on or before 2:00 p.m., January 24, 2011. Thereafter, the panel deliberated on the matter and released its decisions and amended decision before 9:30 AM on January 26, 2011. In his submissions, Mr. S, on behalf of MM and SN, requested written Reasons for Decision which Reasons were released on January 31, 2011.

LEGISLATION CONSIDERED

The *Health Care Consent Act*, *1966*, S.O. 1996 c.2, as amended including ss. 4(1), 20, 21, 37, and 37.1.
The *Consent and Capacity Board Rules of Practice*, Rule 29.1.

PANEL MEMBERS

Mr. BC, Senior Lawyer-Presiding Member
Dr. RC, Psychiatrist Member
Ms JCB, Community Member

PARTIES

JM, the patient
Dr. F the health practitioner
MM and SN, the parents and substitute-decision makers of JM

APPEARANCES

For Dr. F, Ms JZB, lawyer
For JM, Ms DE, lawyer
For MM and SN, Mr. S, lawyer

PRELIMINARY MATTERS

This matter was scheduled for hearing on December 13, 2010 and at that time MM advised that he required an Arabic translator. Even though he spoke and understood English reasonably well, he requested such a translator in the event that he had difficulty understanding certain

phrases or phrasing by any of the parties, their lawyers or the panel. MM advised the panel that SN, who was not present on December 13, did not require a translator. After two adjournments at the request of MM, the matter proceeded on January 18, 2011 with an Arabic translator present for MM. There were no other preliminary matters.

THE EVIDENCE

The evidence at the hearing consisted of the oral testimony of Dr. F, MM and SN as well as seven exhibits:

1–Clinical Summary– Dr. DF – December 11, 2010 (4 pgs.);

2– Clinical Summary Addendum – Dr. F– January 17, 2011 (2 pgs.);

3 –Growth Chart for JM;

4 – Two MRI reports – JM – October 25, 2010 & October 18, 2010 (4 pgs.);

5 – EEG reports – November 17, 2010, November 10, 2010, October 19, 2010 & January 4, 2011 (5 pgs.);

6 – Clinical Notes – various dates (8 pgs.);

7 – MRI report – ZM –August 15, 2002 (3 pgs.).

INTRODUCTION

JM was born in late January 2010. In his clinical summary (exhibit 1), Dr. F said that JM suffered severe and progressive neurodegenerative disease. Dr. F proposed a removal of endotracheal tube (breathing tube) without replacement, a do not resuscitate order (DNR) and palliative care.

MM and SN, the parents and substitute decision-makers (SDM's) of JM did not consent to the proposed treatment. Consequently, Dr. F brought a Form G application to the Board under the *HCCA* to determine if the SDM's were acting in accordance with the principles for giving or refusing consent. That application prompted a hearing under the Act to determine if the patient was capable of consenting to his own treatment. This deemed capacity hearing was a condition precedent to the hearing under the Form G application.

THE LAW

The relevant sections of the *Health Care Consent Act* are as follows:

4. (1) 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.

20. (1) If a person is incapable with respect to a treatment, consent may be given or refused on his or her behalf by a person described in one of the following paragraphs:

1. The incapable person's guardian of the person, if the guardian has authority to give or refuse consent to the treatment.
2. The incapable person's attorney for personal care, if the power of attorney confers authority to give or refuse consent of the treatment.
3. The incapable person's representative appointed by the Board under section 33, if the representative has authority to give or refuse consent of the treatment.
4. The incapable person's spouse or partner.
5. A child or parent of the incapable person, or the children's aid society or other person who was lawfully entitled to give or refuse consent of the treatment in the place of the parent. This paragraph does not include a parent who has only a right of access. If a children's aid society or other person is lawfully entitled to give or refuse consent to treatment in the place of a parent, this paragraph does not include the parent.
6. A parent of the incapable person who has only a right of access.
7. A brother or sister of the incapable person.
8. Any other relative of the incapable person.

(2) A person described in subsection (1) may give or refuse consent only if he or she,

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

(3) A person described in a paragraph of subsection (1) may give or refuse consent only if no person described in an earlier paragraph meets the requirement of subsection (2).

(4) Despite subsection (3), a person described in a paragraph of subsection (1) who is present or has otherwise been contacted may give or refuse consent if he or she believes that no other person described in an earlier paragraph or the same paragraph exists, or that all those such a person exists, the person is not a person described in paragraph 1, 2 or 3 and would not object to him or her making a decision.

(5) If no person described in subsection (1) meets the requirements of subsection (2), the Public Guardian and Trustee shall make the decision to give or refuse consent.

21. (1) a person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after obtaining 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 obtaining 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) 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.

37.(1) if consent to a treatment is given or refused on an incapable person's behalf by his or her substitute decision-maker, and if the health practitioner who proposed the treatment is of the opinion that the substitute decision-maker did not comply with section 21, the health practitioner may apply to the Board for determination as to whether the substitute decision-maker compliant with section 21.

(2) The parties to the application are:

1. The health practitioner who proposed the treatment.

2. The incapable person.

3. The substitute decision-maker.

4. Any other person whom the Board specifies.

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

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

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

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

(6.1) If, under subsection (6), the substitute decision-maker is deemed not to meet the requirements of subsection 20(2), any subsequent substitute decision-maker shall,

subject to subsections (6.2) and (6.3), comply with the directions given by the Board on the application within the time specified by the Board.
(6.2) If a subsequent substitute decision-maker knows the wish expressed by the incapable person with respect to the treatment, the substitute decision-maker may, with leave of the Board, apply to the Board for directions under section 35.
(6.3) Directions given by the Board under section 35 on a subsequent substitute decision-maker's application brought with leave under subsection (6.2) prevail over inconsistent directions given under subsection (4) to the extent of the inconsistency.
(7) If the substitute decision-maker who is given directions is the Public Guardian and Trustee, he or she is required to comply with the directions, and subsection (6) does not apply to him or her.

37.1 An application to the Board under section 33, 34, 35, 36 or 37 shall be deemed to include an application to the Board under section 32, with respect to the person's capacity to 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

We carefully considered the oral evidence of the parties, the various exhibits and the written submissions made by their lawyers on their behalf.

We noted the kindness and compassion that Dr. F displayed while he gave his evidence. He advised that he was a medical doctor and that he had obtained a PhD in neuroscience from the University of Calgary. He said that he was certified by the College of Physicians and Surgeons as a specialist in pediatric and critical care medicine. He was a consultant and trauma team leader for the pediatrics division at LHSC. At the University of Western Ontario, he was an associate professor in pediatrics, physiology, pharmacology and clinical neurological sciences.

Dr. F said that he was directly involved with the care of JM since his admission on October 17, 2010 to LHSC, having been transferred from the Ingersoll emergency department via the transport team of the pediatric critical care unit (PCCU) of LHSC. Dr. F said that he was one of five intensivists who had continually looked after JM. There were also consultations with three neurology physicians and the director of the critical care unit at Toronto’s Hospital for Sick Children.

Did JM have the capacity to consent to his own treatment*?*

In his clinical summary, Dr. F said that "JM's age does not allow him to contribute to treatment decisions." All parties, by their lawyers, agreed that JM did not have the capacity to consent to his own treatment.

Since JM, at the time of the hearing, was only approximately 1-year-old, we agreed with the parties. We held that it was impossible for JM to have the ability to understand the information relevant to the treatment proposed for him, nor was it possible for him to have the ability to appreciate the reasonably foreseeable consequences of consenting to or refusing the treatment proposed for him. The panel held that JM was incapable of consenting to his own treatment pursuant to the provisions of section 4(1) of the *HCCA*.

We proceeded to hear the evidence as to whether the refusal by the parents to consent to the treatment proposed for JM was in accordance with the principles for giving or refusing consent pursuant to the *HCCA*.

JM's Medical History, Status, Prognosis and the Treatment Plan

Dr. F filed his clinical summary (Exhibit 1) and his addendum to his clinical summary (Exhibit 2). Those documents set out in great detail the medical history, current status, prognosis, proposed treatment and the risks and benefits of that treatment.

Dr. F, in his clinical summary and orally, gave clear, cogent and compelling evidence. In his clinical summary, Dr. F said that JM was born via C-section on January 22, 2010. His mother, SN, had been administered oxycontin for various painful health problems. He said that JM's initial development was reported as normal except for a complication with opiad withdrawal. He said "JM was monitored for the first few months of life by a pediatrician for developmental problems given the history of a sibling who had died from a severe and progressive neurodegenerative disorder."

He said that "JM's neurological abnormalities became apparent on May 31, 2010." He was taken to an emergency room in Windsor where they found seizure activity and then was transferred to

Michigan Children's Hospital where an MRI “showed a reduction in brain size associated with cells dying from metabolic stress.” He said that a further note from Michigan dated June 15, 2010, “noted severe swallowing difficulties resulting in a gastrostomy tube placement through the abdominal wall into the stomach.” Dr. F said that this latter problem suggested an inability of the brain to control the muscles required for coordinated swallowing.

Dr. F became involved with JM on October 17, 2010 and was his main treating physician up to the date of the hearing. JM apparently stopped breathing while travelling in an automobile with his parents. He was taken to Ingersoll emergency by ambulance and from there transported by the PCCU team to LHSC where he remained as a patient up to the date of hearing.

Dr. F, in his clinical summary, stated: “JM remains ventilated in the pediatric critical care unit. His nutrition is entirely via gastrostomy tube. JM's head is small for his age. He has occasional spontaneous eyelid opening and movements of his lower extremities. His pupils do not react to light and he has neither visual fixation nor following. His brainstem reflexes are either abnormal or absent. He exhibits limb withdrawal to pain, but no purposeful response to pain. He demonstrates facial grimacing with secretions and stimulation (i.e. suctioning, repositioning, changing diaper). In summary, his neurological examination remains grossly abnormal and the clinical findings reflect a severe and widespread neurological injury. JM has failed removal of the breathing tube previously requiring replacement (November 8-11, 2010). He remains on a ventilator with a background rate. Many attempts have been made to allow him to breathe spontaneously on the ventilator; however, within short periods of time, the ventilator reverts to a backup rate due to prolonged periods without breaths.”

Under prognosis in his clinical summary, Dr. F said: “Repeated neurological assessments based on both clinical examination and supportive testing (MRI and EEG), demonstrate that JM has a severe and progressively deteriorating neurological state. JM's MRI is, in fact, remarkably similar to his deceased sister ZM. There is unanimous agreement among five PCCU and three neurology physicians that there will be no recovery and no treatment options exist for this progressive neurodegenerative disorder. JM will not interact meaningfully with his environment. He will require ongoing gastrostomy tube feeding and he will always be bedbound. He will require support for cough and pulmonary secretion clearance. It is likely that he will require

ongoing ventilation. JM is at risk for infectious complications, such as pneumonia, and ongoing pulmonary aspirations, bedsores and skin breakdown. A second opinion was requested from the Hospital for Sick Children in Toronto. All relevant material was sent for expert review. The director of the critical care unit in Toronto provided us with the following opinion: (1) that tracheostomy and ventilation would be futile and (2) to proceed with Consent and Capacity Board."

Under proposed plan in his clinical summary, Dr. F highlighted the plan as follows: "removal of endotracheal tube (breathing tube) and do not resuscitate (DNR)." He described the plan in detail and said: "given JM's severe and progressive neurodegenerative disease, we have not offered tracheostomy and home ventilation. We are proposing to not resuscitate, including breathing tube removal without replacement. We would not provide resuscitative measures in the event of cardiac or respiratory arrest. If JM were to continue breathing comfortably, he will be offered palliative care options and transitioned home with the parents at their wishes. If removal of the breathing tube results in inadequate respirations, he could be treated with medications to provide optimal palliative care, to prevent any possible discomfort, with the full expectation that JM would die."

He went on to describe that an alternative plan, which the parents wanted but the hospital medical team would not offer, would be tracheostomy and ventilation and that with that plan JM "would progress to a full vegetative state and eventual death."

Dr. F outlined carefully the risks and benefits of the proposed plan and the alternate plan. He said: "the risk of our proposed plan, removal of the breathing tube without replacement and DNR is that JM would not breathe adequately and would die shortly after extubation. This proposed plan avoids the further trauma, medical and surgical interventions and represents a minimally invasive approach to dealing with a severe and progressive neurodegenerative disease. It is the view of the PCCU and Neurology staff that ongoing life support and extension of treatment with tracheostomy is not in JM's best interest given his current condition and ultimate prognosis."

He went on to say: "The plan alternative would be a surgical tracheostomy and ongoing

ventilation, as the breathing tube cannot be left in the airway indefinitely due to risk of lung and sinus infection, tissue erosion and scar tissue formation in the airway. Tracheostomy includes a surgical and anesthesia risk. Once the tracheostomy is placed, the risks then include ongoing infectious risks (pneumonia), tube blockade with secretions, tube dislodgement, and tissue breakdown resulting in the tracheostomy tube invading the areas beyond the trachea (i.e. neck structures, esophagus, lungs, and chest). JM's airway would require frequent suctioning of oral and pulmonary secretions. A tracheostomy would likely provide for a longer period of life, however, in our view would not result in improvement of well-being and could reduce quality of life."

Exhibit 2 was an addendum to the clinical summary dated January 17, 2011 and signed by Dr. F. In that document, he said that JM had been reassessed by the PCCU and neurology physicians multiple times over the approximate four weeks preceding the date of his report. He said there were four notable recent events which he described as follows:

"First, JM is now showing poor ability to regulate his (1) temperature and (2) the sodium in his blood, likely both secondary to further brain injury. For his temperature dysregulation, he has received multiple courses of antibiotics, but all tests for infection have been negative. For his sodium dysregulation, he now requires regular sodium supplements added to his feeds and frequent blood draws by venous puncture to measure and maintain his sodium levels at a safe level.

Second, there has been further loss of cranial nerve function, also indicating progressive brain injury. All cranial nerve functions are now absent.

Third, JM has had an increase in clinical motor seizures. A fourth EEG was completed and was also grossly abnormal. The EEG again demonstrated no brain reaction to external stimulation.

Fourth, JM suffered several sudden dislodgements of the endotracheal (breathing) tube. The PCCU staff was alerted immediately and on examination without the breathing tube, JM could not tolerate his oral secretions or in one instance, he did not breathe adequately to sustain life. The breathing tube was almost immediately reinserted on both occasions.

JM has not had any signs of clinical improvement, only deterioration, supporting the diagnosis of a severe and progressive neurodegenerative disease. His head size is grossly small for age and his head has not grown in the 3 months during his hospital admission, indicating no brain growth. JM remains in a persistent vegetative state."

In his oral testimony, Dr. F reiterated what he said in his two clinical summaries. He explained the medical evidence in easy to understand terms. He indicated that the MRIs and EEGs confirmed that there was a significant loss of neuronal content in JM's brain. He said that neurons do not repopulate. He referred to Exhibit 6 which contained various clinical notes from the attending physicians on the treatment team. At page 1 of that exhibit, he pointed out that it was a note from Dr. L who he said was an expert in brain development and seizure activity. Dr. L concluded his report by saying that there was "severe diffuse neurological damage." On page 2 of that exhibit, Dr. F pointed out that a neurological assessment of JM was completed by Dr. P on December 20, 2010. He said that Dr. P was an expert in brain growth, seizure and metabolic diseases of the brain. In that report, Dr. P said that JM "remains severely impaired-as in a vegetative state."

Dr. F referred to page 3 of that exhibit and a report from Dr. L on December 27, 2010. Dr. L said: "the examination is unchanged except I am unable to elicit corneal reflexes bilaterally." Dr. F said that JM was missing all five of the brainstem reflexes critical for life which he said were gag, cough, eye movement, pupil and cornea responses.

Dr. F said that JM was at the time of the hearing in a persistent vegetative state. He said that he showed ongoing severe, progressive neurological deterioration. He said that JM was blind and deaf. He said that JM had no proper reaction to pain except an automatic reflex. He said that JM's father wanted everything done for JM. He said that MM agreed to have a second opinion. Dr. B of Toronto's Hospital for Sick Children provided that opinion. Dr. F said that Dr. B was a world renowned pediatric critical care specialist. Dr. B spoke to Dr. S on November 29, 2010, referenced by a note at page 7 of Exhibit 6 and Dr. B, having examined all of the documents forwarded to him, agreed with the position taken by Dr. F's treatment team at LHSC.

Dr. F said that there was no way of proving or disproving pain for JM. He said that they had erred on the side of caution by giving occasional mild pain medication at the request of the father.

Dr. F discussed the condition of ZM, the sister of JM, who died in infancy after a prolonged stay at LHSC. He said that her MRI and MRS were remarkably similar to those completed on JM. He said that Dr. S was involved in ZM's case and that the doctors reluctantly agreed to give her a tracheostomy and send her home. He said that in retrospect that decision was being questioned as to whether it was correct. At the time of JM's hospitalization, Dr. F said that they were better able to investigate and that knowledge had increased substantially. He said that the tracheostomy only prolonged life and that "now we know that decision for JM is not right." He said that the benefit of the tracheostomy would prolong life but that action was not good for the well-being of JM. He said that a tracheostomy is prone to erosion, which could promote discomfort. He said that it would not improve the well-being of JM and would not prevent the ongoing rate of deterioration. To questions from Mr. S, Dr. F said that a tracheostomy and ventilation would delay death but the risks were unacceptable. He said that the process could not be reversed. To a question from the Board, Dr. F said that the neuron loss in JM's brain was a widespread problem. There was no improvement and there were no therapies to improve it. He said that the tracheostomy and ventilator would not improve JM's condition or well-being. He said that that treatment would not prevent JM from deteriorating. As well, it would increase the risk of infection and pneumonia.

The Position of the Parents

SN, the mother of JM, gave evidence. She said that JM was still breathing, that he didn't like her to touch him with her cold hands as he moved his hand away. She said that when she talks to him that he knows her voice. She said that JM's sister who died some years ago was more severe than JM. She said that she wanted to have JM home for whatever time he had. She knew that there was no cure and no treatment that would help him.

On examination by Ms ZB, SN said that she knew that JM was not going to improve and that death would be the end result. When asked about her daughter ZM, she said that she was

transferred from Windsor hospital to their home in Windsor. Asked if she had to return to the hospital, SN said that ZM “kept having pneumonia” and had to be taken to hospital. She said that the doctor wanted to put ZM on a respirator but SN refused.

To questions from Ms E, she said that she no longer spoke to Dr. F because “I can't talk to a killer.” She was asked if all the doctors felt the same as Dr. F about her son's condition and she acknowledged that they did but she said: “JM is not their son.” She said that if they were in her position they would not approve of killing their own son. She said that she took care of her daughter who was much worse than JM and didn't have a problem doing so. She said that her daughter was alive for five months at home with them and it helped “both of us-her and me.” She said that they could hope for a miracle but she knew that JM was very sick. She said that she wanted the tracheostomy done “so I can have more time before he dies.”

When questioned by the panel, SN said that the doctor told them nine years earlier that it was better for their daughter to have a tracheostomy and to be at home. She said that “the doctors are now saying that things have changed, that science has changed.”

MM gave evidence and said that over the last couple of weeks preceding the hearing his son was breathing by himself, that he felt pain, that he felt his hand and that he felt safe when somebody held him or was with him. He said that his son is breathing but there is secretion and it was very hard to put the tube in his mouth to get the secretion out. He said that he knew that his son was very sick. He said that if he was home that “he would pass away when God says he should.” He said he understood that his son was in critical condition, that his daughter passed away in his hands like a sleeping baby and that is what he wanted for his son. He said: “my son is still feeling, still moving, still feeling pain, and still alive inside. I am not a judge about his life.” He said that he would feel guilty if he agreed with the doctors. He said that his daughter died peacefully and that she died “when her time was done. When I see her picture I feel very comfortable-- that's what I want to see for JM.”

The panel asked if there was anything that the treatment team could tell him and he said that he could not change his mind. He said: “I won't change my mind. I don't want to feel guilty. I don't

want to kill my blood." He was asked if he thought JM's brain will grow and he will get better. He said: "I believe in God. I trust in Him. If nothing changes, then he dies."

Ought the Board view the patient, JM, interact with his parents?

In Mr. S's written submissions on behalf of the parents, he referred to the case of *EJG*, 2007 CanLII 44704 (ON C.C.B.). He submitted that the Board ought to see the child, JM, interact with his parents "following the procedure set out in page 3 of the EJG decision." While the Board viewed the patient in EJG, there was no precedent set nor was there any requirement that the Board view JM during the hearing of the evidence in this matter.

In replies to the submissions of the parties, both Ms ZB, on behalf of Dr. F and Ms E, on behalf of the patient JM, rejected Mr. S's submission.

Ms ZB, in her reply, said such a viewing ought not to be done after the evidentiary portion of the hearing was concluded. She submitted that neither JM's counsel, nor counsel for JM's parents, suggested this evidence be included at the time that evidence was being heard. She said that Dr. F relied on Rule 29.1 of the *Consent and Capacity Board Rules of Practice* that no new evidence may be presented during final argument.

Ms E made a similar argument in her reply.

Section 29.1, as referred to above states: "After all of the parties have had an opportunity to present evidence, the Board shall give all parties an opportunity to make a final argument in support of the decision or order they want the Board to make. No new evidence may be presented during final argument." We agreed with Ms ZB and Ms E that viewing the child with the parents ought not to be done. Even if we decided incorrectly that new evidence should not be introduced, it was our view that seeing JM was not relevant and/or necessary to our decision.

Are there wishes pursuant to Section 21(1) that are applicable?

JM was only one year old. Since he was under the age of 16 years, neither of the sub-parts under this section applied to him, as there could be no prior applicable wishes attributable to him.

Are there values and beliefs pursuant to Section 21(2)(a) that are applicable?

Since JM was only one year old, there were no values and beliefs that he could hold.

Are there any wishes pursuant to Section 21(2)(c) that are not required to be followed?

Since JM was only one year old, there could not be any such wishes.

Section 21(2) (c) Criteria for Best Interests

We considered the case law provided by counsel for the parties in their written submissions.

Ms ZB said that the Board could not ascribe beliefs of the parents to the child and referred to a decision of the Board cited as *E.J.G. (Re)*, 2007 CanLII 44704 (ON C.C.B.). In that case, the parents of a child, who was in a vegetative state from oxygen deprivation at birth, refused to allow the health care team to wean the child from his ventilator and allow him to die. The Board at page 16 of that decision, said as follows: "Unrelenting faith in divine intervention may be Mrs. G and Mr. G's belief. They were entitled to give primary importance to that faith in making their own treatment decisions but they made EJG's treatment (decision) based only upon their beliefs, not his. EJG did not have any values or beliefs." The panel noted that the *EJG* case was appealed and confirmed by the Superior Court with oral reasons. No written reasons were given.

Ms ZB, in her submissions, said that Dr. F's recommendation of withdrawal was made with reference to JM's 'well-being', a term used under ss. 21(2)(c), and considered by the Superior Court in the case of *Scardoni v. Hawryluk*, [2004] O.J. No. 300. He said that well-being should include an element of quality of life, involving considerations of personal dignity and levels of pain.

She submitted that Dr. F said that a tracheostomy would not improve JM's condition or well-being, that it would not prevent his condition or well-being from deteriorating, and would not reduce the extent or rate at which his condition or well-being was likely to deteriorate. He said it would merely prolong JM's life in a vegetative state. His condition was likely to deteriorate in spite of the tracheostomy. Because of the risks involved, the benefit of extended life did not outweigh the risk of harm to JM.

She said that although Justice Cullity reversed the Board's decision in *Scardoni v. Hawryluk*, that Justice Cullity approved the Board's recognition that ‘well-being’ could include considerations of a person's dignity.

Ms E, on behalf of JM, referred us to the same quote from the case of *EJG.* She submitted that the parents as substitute decision-makers were not acting in the child's best interests. She said that the hospital did not view the procedure that the parents wanted done as being in JM's best interest. She said that Dr. F said it is intrusive, risky and could result in numerous complications. She said that the hospital’s position was that with no improved quality in JM’s life, it was not worth putting JM through any more procedures. She said that the parents had their own views, opinions, values and beliefs. She said that to prolong JM's life served them and their needs. She submitted that JM didn't have values and beliefs, and that he could not think. She submitted that JM deserved to have his parents make decisions that put his best interests, ahead of their own. She said that they could not base a decision, for him, on their beliefs.

Mr. S, on behalf of the parents, referred to the *Scardoni* decision and the interpretation of the phrase ‘well-being’ by Justice Cullity in that decision. Mr. S took a different slant on the *Scardoni* decision and said that the “evidence given at trial by both Dr. F and the parents supports the parent’s position that a tracheostomy and home ventilation are in JM's best interest.” We could not agree with Mr. S’s submission as clearly, in our view, the evidence did not support the parents’ position. We accepted and agreed with the submissions of Ms ZB who referred us to the House of Lords decision, *Airedale NHS Trust v. Bland,* [1993] 1 All ER 821, a leading decision in England on the issue of withdrawal of treatment for patients in a persistent or permanent vegetative state. She submitted that what the Justices said about treatment of a person in a persistent or permanent vegetative state could offer guidance to the panel.

Respecting best interests, there are several important considerations enunciated in that decision.

At page 872, Lord Goff stated as follows:

“The truth is that, in the course of their work, doctors frequently have to make decisions which may affect the continued survival of their patients, and are in reality far more experienced in matters of this kind than are the judges. It is nevertheless the function of the judges to state the

legal principles upon which the lawfulness of the actions of doctors depend; but in the end the decisions to be made in individual cases must rest with the doctors themselves."

Certainly, in this matter, all expert physicians clearly supported the view that removal of the endotracheal tube and a DNR order was the correct course of treatment for JM.

At page 846, Lord Sloss said as follows:

"The quality of life has already been recognized as a factor and placed in the equation to allow a life not to be prolonged at any costs … To limit the quality of life to extreme pain is to take it demeaning view of a human being. There must be something more for the humanity of the person of a PVS patient. He remains a person and not an object of concern."

At page 848, he added the following:

"[The incompetent patient] has the right to be respected. Consequently he has a right to avoid unnecessary humiliation and the degrading invasion of his body for no good purpose… The considerations as to the quality of life of Mr. Bland now and in the future in this extreme situation are in my opinion rightly to be placed on the other side of the critical equation from the general principle of the sanctity and inviolability of life. In this appeal those factors which include the reality of Mr. Bland's existence outweigh the abstract requirement to preserve life... The duty of the doctors towards a PVS patient at the extreme end of the spectrum does not extend to prolonging his life at all costs."

At page 870 Lord Goff said:

"I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family - a stress which reflects not only their own feelings but their perception of the situation of their relative who was being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination."

In the matter before the panel, JM was in just that situation. Dr. F gave evidence that JM was in a persistent vegetative state. He had no quality of life. His physical condition was going to continue to deteriorate. There was no prospect that there would be any improvement in his condition. He would never recover. He would not get better. The artificial means by which he was being kept alive had no therapeutic purpose of any kind. As Lord Goff said; "… it is the futility of the treatment which justifies its termination." We agreed with Dr. F.

At page 839-840 Sir Thomas Bingham said:

"While the respect accorded to human life always raises a presumption in favour of prolonging it, that presumption is not irrebuttable. Mere prolongation of the life of a PVS patient such as Mr. Bland, with no hope of any recovery, is not necessarily in his best interests, if indeed such prolongation is in his interests at all. In making an objective judgment of Mr. Bland's best interests, account can be taken not only of pain and suffering which prolonged feeding and medication might cause but also wider, less tangible considerations…
I cannot conceive what benefit his continued existence could be thought to give him. It might be different where it possible to hope that, if he lived long enough, means might be found to restore some part of his faculties, but no grounds have been suggested for cherishing such a hope and the physiological findings appear to preclude it.

It is of course true that pain and suffering, which may (if the foregoing reasoning is sound) weigh in the balance against the presumption in favour of life, are here to be ignored because of Mr. Bland's insensible condition. An objective assessment of Mr. Bland's best interests, viewed through his eyes, would in my opinion give weight to the constant invasions and humiliations to which his inert body is subject …"

MM and SN gave evidence that they knew their son was going to die. They did not hold much hope in recovery, other than a miracle, from the disease that JM suffered and they knew that his death was inevitable. They wanted to take him home where they could care for him as they did his sister. Their hope and desire for JM to be home, obstructed them from seeing the "constant invasions and humiliations" (Sir Thomas Bingham) to which JM would suffer through the treatment plan they proposed. Having heard the evidence of Dr. F it was clear to us that the

family's hope was not at all realistic. JM had severe brain damage which was irreversible and no matter how long he was kept alive, there was no hope that any of his faculties would be restored. Prolonging his life would not allow JM the dignity that he deserved.

We compared the treatment plan proposed by Dr. F and the treatment plan proposed by the parents. We reviewed very carefully all of the criteria for best interests, as set out in ss. 21(2)(c) of the *HCCA*. In both cases there was nothing that would prevent JM's condition from deteriorating. We considered the term "well-being" as properly explained and accepted by Justice Cullity in *Scardoni*. We determined and held on a balance of probabilities that the treatment plan proposed by Dr. F met all of the criteria under ss. 21(2)(c) whereas the plan proposed by the parents did not. The dignity of JM had to be considered. The treatment plan that the parents proposed did not truly give consideration to the dignity for JM and in our view, for all the reasons cited above, that treatment plan did not meet the criteria in the HCCA.

Lord Sloss at page 847 referred to a passage from the American case of *Re Conroy* (1985) 98 NJ 321 at 398-399, wherein that court stated:

"The medical and nursing treatment of individuals in extremis and suffering from these conditions entails the constant and extensive handling and manipulation of the body. At some point, such a course of treatment upon the insensate patient is bound to touch the sensibilities of even the most detached observer. Eventually, pervasive bodily intrusions, even for the best motives, will rouse feelings akin to humiliation and mortification for the helpless patient. When cherished values of human dignity and personal privacy, which belong to every person living or dying, are sufficiently transgressed by what is being done to the individual, we should be ready to say: enough."

The foregoing quote from *Re Conroy* was cited with approval by a panel of this Board, in the decision of *EJG* (2007) CanLII 44704 (ON C.C.B.) at page 22.

In this matter, the parents were adamant that they wanted JM to live by any artificial means in the hope that there would be recovery. However, they knew that JM would not recover, as expressed by Dr. F and which he said all the other treating physicians concurred. We agreed with the expert evidence of Dr. F. There was no hope that JM would have any recovery. He had

absolutely no hope or chance of ever recovering. While we felt a great deal of empathy for the parents, we held that their view was not in any way realistic. MM and SN were blinded by their obvious love for JM and could not view his situation objectively nor were they able to put themselves into his position. After three months in hospital hooked up to tubes and machines, after suffering from the invasion of personal privacy, after suffering human indignities, and with the exacerbated difficulties that would arise because of the tracheostomy, it was time for the parents to say “enough”. In our minds, there was no disputing the clear, cogent and compelling evidence of Dr. F. We agreed with Dr. F that JM should be allowed to die with dignity and that the treatment for JM, in his best interests, would be removal of the endotracheal tube without replacement, a DNR order and palliative care.

It was clear to us from the cases cited by the lawyers for Dr. F and JM, that the parents could not ascribe their views to the child JM. This 12 month old child did not have any values and beliefs. The patient's best interests were served by accepting and adhering to the treatment plan proposed by Dr. F. We held, having taken into consideration all of the evidence, that MM and SN were not acting in accordance with the best interests of JM as set out in the section 21 criteria.

RESULT

The Board held that JM was not capable of consenting to the treatment proposed for him.

We granted Dr. F's application and determined that the refusal by MM and SN of accepting Dr. F's treatment plan for JM was not done in accordance with the principles for giving or refusing consent to treatment as set out in The *Health Care Consent Act* (*HCCA*). We directed MM and SN to consent to the proposed treatment plan, namely: removal of the endotracheal tube (breathing tube) without replacement, a do not resuscitate order (DNR) and palliative care.

We delivered the decisions to the parties by fax, before 9:30 a.m. on Wednesday, January 26, 2011.

We gave MM and SN until 10:00 a.m. on Friday, January 28, 2011 to consent to the treatment in accordance with our decision. The decision clearly set out that if they failed to comply with the Board's directions within the time specified, that they shall be deemed not to meet the

requirements for substitute decision-making as set out in Section 20(2) of the *HCCA*.

Dated at Chatham, Ontario, this 31st day of January, 2011.

BC, Presiding Member