Consent and Capacity Board   Commission du consentement et de la capacité

Ontario

15-0538-01
15-0538-02

2015 CanLII 44140 (ON CCB)

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

AND IN THE MATTER OF
SS
A PATIENT AT THE HOSPITAL FOR SICK CHILDREN
TORONTO, ONTARIO

REASONS FOR DECISION

PURPOSE OF THE HEARING

A panel of the Board convened at the Hospital For Sick Children, (Sick Kids) on May 15th, 2015, to hear an application, brought by Dr. Peter Cox that the substitute decision makers for SS, (his parents) were not complying with the principles for providing consent to treatment under the *Health Care Consent Act*. This triggered a deemed application to determine whether SS was capable of making his own decisions regarding capacity. The proposed treatment was removal of extracorporeal membrane oxygenation.

DATES OF THE HEARING, DECISIONS AND REASONS

The matter continued on May 22nd, 2015 and after deliberations on May 23rd, 2015, the panel released its decisions. Reasons for Decisions (contained in this document) were requested on behalf of Dr. Cox and released on May 29th, 2015.

LEGISLATION CONSIDERED

The *Health Care Consent Act, 1996*, S.O. 1996 c.2, as amended including ss. 4(1), 4(2) 20, 21, 22, 37, and 37.1.

PANEL MEMBERS

Carolyn L. Jones, Senior Lawyer-Presiding Member
Sabita Maraj, Public Member
Anthony Warr, Public Member

PARTIES

SS, the patient
RF and LMS the substitute decision makers, (to the Form G application)
Dr. Peter Cox, the health practitioner, who made the finding of incapacity and brought the Form G application.

APPEARANCES

SS, was represented by counsel, Mr. D'Arcy Hiltz
RF and LMS were represented by counsel, Ms. Mercedes Perez
Dr. Cox was represented by counsel, Ms. Daphne Jarvis

PRELIMINARY MATTERS

Ms. Perez wished to file certain documents to which Ms. Jarvis objected. These included what Ms. Jarvis submitted were non-scientific journal articles as well as newspaper articles about persons who had survived extracorporeal membrane oxygenation. Ms. Jarvis acknowledged such materials may be introduced through cross examination of Dr. Cox but submitted they should not in and of themselves be accepted as exhibits at the outset of the hearing.

We ruled we had jurisdiction under the *Statutory Powers Procedure Act* Section 15 to accept such documents and to then determine the weight to be placed upon them. It was up to Ms. Perez to decide if she wished to put the documents to Dr. Cox in her cross-examination.

THE EVIDENCE

The evidence at the hearing consisted of the oral testimony of five witnesses, Dr. Cox, Dr. Mema, Dr. Koudys, RF and LMS and 18 exhibits:

1. Exhibit Brief – including – tab 1 Clinical Summary for the Hearing signed by Dr. Cox and dated April 14, 2015, -tab 2 sub tabs A to O, Progress Notes, various authors, Sick Kids covering April 14, 2015 to May 10, 2015, -tab 3 Diagnostic Image Reports signed by Dr. Yoo and dated April 15, May 6 & 8, 2015, -tab 4 Consultation from Pediatric Lung Transplant Team signed by Dr. Solomon and dated May 8, 2015, and –tab 5 Consultation of Dr. Ferguson dated May 11th, 2015;
2. A document titled, "Guidelines Re: Use of ECMO Re: SS signed by Dr. Cox and dated May 14, 2015;
3. Addendum to Clinical Summary, signed by Dr. Cox and dated May 14, 2015;
4. Email from Dr. Monica Kleinman to Dr. Cox dated May 14, 2015;
5. Curriculum Vitae, Dr. Peter Cox dated May 13, 2014;
6. A document titled, "Progress Note" Irina Eremeeva, RN dated April 14, 2015;
7. A document titled, "Progress Note", various authors, dated April 22, 2015 12:02 to 13:02;
8. A document titled, "Progress Note", various authors, dated May 5, 2015;
9. A document titled, "Progress Note", Lori Hamilton, dated May 6, 2015;
10. A document titled, Extracorporeal Life Support Organization (ELSO) - General Guidelines for all ECLS Cases, version 1.3 dated November 2013;
11. An article titled, 'Prolonged extracorporeal membrane oxygenation for children with respiratory failure", authored by Dr. Borgan et al and reported in the Pediatric Critical Care Medicine Journal, 2012, Col 13, No. 4;
12. An article titled, "Prolonged Duration ECMO for ARDS: Futility, Native Lung Recovery", authored by A. Rosenberg et al, and reported in ASAIO Journal , November-December 2013, Volume 59 Issue 6;

13. An article titled, "Ovid: Probability of survival after prolonged extracorporeal membrane", Journal of Critical Care Medicine, volume 23163, June 1995;
14. A document titled, "Press Release - Seattle Girl Survives on Heart-Lung Machine Longer Than Any Child in the Northwest" Seattle Children's Hospital, dated March 2008;
15. A document titled, "Victor's war- 66 days on ECMO" Karolinski Universitejukhuset – Colume 112, Issue 1177, dated December 8, 2014;
16. A document titled, "Position Statement, Canadian Paediatric Society, Treatment decisions regarding infants, children and adolescents, authored by C. Harrison , Bioethics Committee, 2004,9(2);
17. A document titled, "Curriculum Vitae, Dr. Julie Koudys, PHD; and.
18. A series of Progress Notes Sick Kids - May 12, 2015 2:30 to May 19, 2015 3:48 (12 pages)

APPLICANT'S BRIEF OF AUTHORITIES

1. *Jansen v Janzen,*(2002), 44 ETR 217 (ONSC);
2. *RE: CA,* 2103 CanLII 76685, appeal dismissed in *Ackie v Manocha,* 2014 ONSC 669;
3. *RE EJC,* 2007 Can:LII 44704 (ON CCB), appeal to ONSC dismissed on Oct 17, 2007 by Whitten J (unreported);
4. *RE JM,* 2011 CanLII 7955 (ON CCB), appeal to ONSC dismissed on February 17, 2011 by Rady J (unreported, reasons transcribed);
5. *RE N,* 2009 CanLII 42576 (ON CCB);
6. *RE SR,* 2011 CanLII 79858 (ON CCB).

INTRODUCTION

SS is a six year old boy, who prior to his admission to the McMaster Children's Hospital paediatric unit, lived at home with his parents and one sibling. His family is originally from Columbia and his mother required a Spanish translator throughout the proceedings. SS was admitted to McMaster April 1st, 2015, due to inflammation of his gall bladder for which he received treatment with antibiotics. He developed an infection of his blood (sepsis) and went into Septic shock. He was given drugs designed to improve his blood pressure and heart function, but developed issues with his lung function - Acute Respiratory Lung Distress Syndrome (ARDS). Mechanical ventilation of his lungs was required as well as high frequency oscillation. SS reached the point that his condition was considered life threatening and Sick Kids was contacted by McMaster medical staff, to see if they would accept SS for treatment on a heart lung machine called extracorporeal membrane oxygenation (ECMO), in hope that his lungs may improve without the further damage that may be caused by the breathing machines.

Sick Kids, agreed to accept SS and in the evening of April 13 and early morning of April 14, 2015 SS was transferred to and admitted to the Intensive Care Unit at Sick Kids and with the consent of his parents, surgery was performed to hook him up to an ECMO machine. He has remained on the machine since that date. Initially the machine was hooked up with cannula (tubes) which were inserted into his neck and into the blue blood side of the heart, called veno-venous ECMO. The machine was unable to pump enough blood into his body and a change to veno-arterial ECMO and insertion of another tube into the right carotid artery, was made on April 29th, 2015. As there was no notable improvement in SS's lung function after three weeks on ECMO, the clinical team determined discontinuance of the ECMO machine should be recommended to the substitute decision-makers.

Dr. Cox and his team remain of the opinion it is not in the best interest of SS to remain connected to the machine and wish to disconnect it but to continue with all other treatments SS is receiving including mechanical ventilation and high frequency oscillation. SS's parents are of the opinion, it is in their son's best interest not to remove the machine at this time.

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.
>
> 4. (2) A person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services.
>
> 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 the incapable person's parent;
(c) is not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his or her behalf;
(d) is available; and
(e) is willing to assume the responsibility of giving or refusing consent.

(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.

22. Before giving or refusing consent to a treatment on a incapable person's behalf, substitute decision-maker is entitled to receive all the information required for an informed consent as described in subsection 11(2).

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 complied with section 21.
(2) The parties to the application are:
1. The health practitioner who proposed the treatment.
2. The incapable person.
3. The substitute decision-maker.
4. Any other person whom the Board specifies.
(3) In determining whether the substitute decision-maker complied with section 21, the Board may substitute its opinion for that of the substitute decision-maker.
(4) If the Board determines that the substitute decision-maker did not comply with section 21, it may give him or her 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

SS's Capacity to Consent to his own treatment.

Did SS have the ability to understand the information relevant to making a decision about the treatment proposed for her and did SS have the ability to appreciate the reasonably foreseeable consequences of a decision or lack of decision?

SS is six years old. It is acknowledged that he is sensate at the time of the hearing and has been throughout this hospitalization. SS cannot communicate verbally not only because he is on a mechanical ventilator but also because of a premorbid condition in the autism spectrum. According to his father and Dr. Koudys, a psychologist who supervises programs offered to SS, prior to this illness, SS was able to communicate in other ways. Dr. Koudys gave evidence that SS is diagnosed as suffering moderate to severe autism and his understanding is estimated to be that of a three year old.

The ECMO machine is a complicated piece of equipment in and of itself as are the anticipated risks and benefits of being on it. Considerable evidence as to its purpose, to give the heart and lungs a rest to recuperate and the various risks of this type of therapy and the necessary adjunct treatment medications to ensure one remains still on the machine, does not bleed and does not feel pain and discomfort, potential harm to the brain and other organs as a result of the condition from which SS suffers as well as the machine itself were explained by Dr. Cox at the hearing. It was Dr. Cox's undisputed evidence that no six year old would be able to comprehend the magnitude of the decisions being made.

SS currently recognizes his parents and at times can squeeze their hands to provide instruction on such basic wants such as watching his favourite videos or having his mother sing to him. He is heavily sedated with what are described as, "industrial levels" of muscle relaxants and pain medications, including morphine. This limited type of communication and impaired comprehension due to the drugs, further impedes SS's ability to understand the basic information about the condition he currently suffers from and the proposed treatment.

Section 4(2) of the *HCCA* provides that a person is presumed capable with respect to treatment. In *Starson v. Swayze*, [2003] SCC 32, the Supreme Court of Canada held that the standard of proof for a finding of incapacity is a balance of probabilities.

We find it has been proven on a balance of probabilities that SS is unable to appreciate the nature of the illness and the treatment proposed. It was not necessary for us to investigate the second prong of the capacity test as it relates to SS.

Did SS's parents, his substitute decision-makers comply with section 21 of the Health Care Consent Act in making the decision not to remove extracorporeal membrane oxygenation?

Is extracorporeal membrane oxygenation treatment within the meaning of the Health Care Consent Act?

We found extracorporeal membrane oxygenation (ECMO) is treatment within the meaning of the HCCA.

Ms. Jarvis submitted during the hearing and in her final submissions that she reserved her client's right to argue that withdrawal of ECMO as she described as a, "highly technical form of life support" is a treatment. She did not offer where she would argue that point. The application had however been made to this Board whose jurisdiction is limited to treatments within the meaning of the *Act*.

Treatment is defined under the *Act* section 2 (1) as:

"means anything that is done for a therapeutic, preventative, palliative, diagnostic,, cosmetic or *other health-related purpose, and includes a course of treatment, plan of treatment or community treatment plan but does not include,....".* It goes on to exclude specific acts such as taking a person's health history and assessments and examinations. It does not exclude being attached to any type of machinery.

Section 2 (2) goes on to state, "*A reference in this Act to refusal of consent includes withdrawal of consent."*

The evidence was clear that at the time ECMO was instituted, the time consent for removal was requested of the substitute decision-makers and at the time of the hearing, without the assistance of the machine, SS would likely die in a very short time, irrespective of what other palliative care was going to remain or be instituted. ECMO was keeping SS alive.

An ECMO machine is an acknowledged very complicated piece of equipment which in simple terms has the purpose of extracting blood out of the heart expressing the carbon dioxide and adding oxygen and returning the blood to the heart through two tubes (cannula) placed in a person's neck. The purpose is to give the lungs a rest so they may potentially recover. The process can be stopped by clamping parts of the tubing to the machine and does not require actually touching the patient. Ancillary to the process, the patient usually requires the administration of blood thinners to ensure a lack of clotting and a number of pain killers, sedating medications and at times anti-psychotic medication to ensure the patient remains still and the machine can work.

Throughout the medical exhibits filed, ECMO has been described as, "treatment" and "therapy". Examples include:

a) (exhibit 1, tab 2 E) Dr. Parshuram, April 29, 2015, stating to SS's father that if there is little chance of recovery we should, "then stop the treatment".

b) (exhibit 1, tab 2 G) Dr. Mohseni-Bod, May 5th, 2015, stating, "Unfortunately the disease process in the lungs has not responded favourably to our treatments."
c) (exhibit 1, tab 2 H) Dr. Cox, May 6, 2015, stating, "there are processes in the hospital, which we may need to invoke to ensure that we do not continue with a treatment that is not helping".
d) (exhibit 1, tab 2 H) Dr. DeLama, May 6, 2015, 'She understands (referencing SS's mother) that ECMO is supporting his son 100% and not being a treatment at this point". She later stated, "Dr Cox in agreement with the PICU team- recommendation is discontinuation of the therapy".

Dr. Cox, in his oral evidence described ECMO as an, "invasive treatment". Exhibit 12, an Article in the ASIAO journal, although acknowledged as American, also describes ECMO as a treatment.

In *Cuthbertson and Rubenfield v. Rasouli,* 2013 SCC 53, the Supreme Court of Canada addressed the issue of removal of life support. The Court determined that withdrawal of life support is treatment within the meaning of the HCCA.

Paragraph 40 of the judgement states, "The words of the HCCA on their face cover provision of life support that is effective in keeping the patient alive and forestalling death. Life support arguably falls within "therapeutic" and "preventive" purposes, listed in the definition of "treatment" in s. 2(1). At paragraph 45, the majority stated, "[W]ithdrawal of life support involves – indeed may be viewed as consisting of – a series of acts that serve health-related purposes, and because of the critical interests at stake where withdrawal of life support is concerned go to the heart of the purposes of the HCCA.

We found ECMO and its related protocol is a treatment. Dr. Cox's plan of treatment is to discontinue the ECMO, administer palliative care only, while leaving SS on a mechanical respirator, and not resuscitate SS when he is off the ECMO machine.

ECMO fits into many of the purposes defined in the *Act*, it is a therapy for oxygenating blood and providing a way for the lungs to rest. That is clearly a health related purpose. It does not fit under any of the exclusions set out in the definition and is quite the contrary.

Withdrawal of life support, in this case disconnecting the ECMO machine, is clearly treatment for which consent to remove is required.

Is consent being sought from the appropriate decision-maker within the meaning of section 20(1) of the Act?

This is not in dispute. SS is six years old and found incapable of making his own treatment decisions. Due to his age, he is not able by law to complete a Power of Attorney, there is no Court Order naming a Guardian of the person under the *Substitute Decisions Act* and his parents the parties to this application, who are not separated from one another, are the highest ranking persons to give consent under section 20(1) of the *Act*.

Was sufficient information given to the substitute decision-makers about the treatment proposed prior to the decision to apply to the Board, to satisfy the conditions for informed consent under section 22 of the Act?

The panel was split on this issue.

The presiding member and Mr. Warr were satisfied that although there was not well documented evidence, that both parents received the information about the risks and benefits of the treatment including having their questions answered and the provision of a second opinion.

It was acknowledged that information about the discontinuance of the machine was not given to the substitute decision-makers in a formal fashion. It appears to be given over a period of two days immediately prior to Dr. Cox completing the application to the Board on May 7th, 2015.

Information about the process was given to mother and father separately at the bed side by the most responsible physician and other health professionals, when they asked questions. Most discussions took from five to fifteen minutes.

Consent for starting the treatment was given in verbal form. We accept RF's evidence that it was not their, (the parents) decision to transfer SS to Sick Kids. It was what the majority of the panel would call emergency treatment within section 18(4) of the Act. RF did acknowledge at the hearing that although the details of the treatment or nature of the procedure were not explained in detail, they were told the procedure was highly risky and complications can arise from the operation. That was about 1:00 am and by 2:30 they were informed the operation (to attach SS to ECMO) was successful and SS was stable. Exhibit 1 tab 2 contains Dr. Guerguerian's April 14th, 2015 note as to the explanation given to the parents and their consent to the procedure. It is understood the transfer process and decision took just a few hours in total to complete. In these circumstances, although a written consent to treatment with reference to when it would be expected to discontinue the treatment if not successful would have been preferable, the majority of the panel found this was sufficient consent to commence ECMO treatment.

Ongoing information was given to RF such as when the decision was made to transfer from VV to VA as indicated in Dr. Parshuram's April 25th, note (exhibit 1 tab 2 E).

Exhibit 1 Tab G indicates the information given to RF about the possible removal on May 5, 2015. Dr. Mohseni-Bod's note is very clear. It is corroborated by Dr. Cox in his 14:48 note that day as well as Katherine Reise RRT, 20; 13 note of that day. Exhibit 1 tab 2 H contains the note of the notes of Kathleen Camya RN, Dr. Cox and Dr. De Lama May 6th, 2015 about the benefits and risks of the treatment.

Information continued to be given as requested as indicated on May 9th, 2015 the second time the machine had to be discontinued and SS's mother inquired as to the possibility of a lung transplant. The transplant team negative response is set out in Exhibit 1 tab 4 and the second opinion after reviewing the medical chart was given by Dr. Ferguson as set out in Tab 5.

Much emphasis was placed by Ms. Perez on the fact the parents were told that the x-rays indicated there has evidence of failure of another organ, being an enlarged heart, prior to the hearing. Despite Dr. Cox's oral evidence that it is always their goal to keep the family informed as to what we are doing with our therapies, it was acknowledged they were not told about the significance of the x-rays until they heard it at the hearing. Exhibit 1 tabs 3 - A, B and C contain the radiologist reports. April 15th, 2015, indicated mild cardiomegaly, May 6th, the radiologist suspected severe cardiomegaly. It remained unchanged May 8, 2015. Dr. Cox in his evidence stated this indicated progressive organ damage. Dr. Cox commented that RF has asked to see the actual x-rays May 6, 2015, then declined (exhibit 1 tab j). We find it was the actual x-rays not the reports of Dr. Yoo that were offered on May 6th, 2015. May 20th, the respiratory therapist indicated to RF that their appeared to be some improvement in the heart based on their colour. May 22nd, Dr. Mema, in response to questions regarding a change in the positive direction on a May 20th, 2015 x-ray, commented, "not a lot of emphasis" was being placed on the results of the x-rays. Also exhibit 4 the email from Dr. Kleinman, dated May 14, 2015 notes, "he has mildly elevated LFTs but no other major organ system failure,…".

Although the possibility of multi organ failure concerned the majority of the panel, their decision on best interest was not affected by the possible multi organ shut down issue and it did not find, not informing the parents of this finding, would lead to dismissing the application for lack of informed consent.

Again although it would be preferable to have had a full extensive family meeting with all the PICU intensivists , the parents together, an independent Spanish interpreter, representatives from the ethics services at the hospital, to explain the plan and guidelines regarding best interests under the HCCA, with written documentation of the recommendations and why they were being made, before the application to the Board was made, the majority of the panel were satisfied the benefits and risks of discontinuing ECMO at that time were explained to the substitute decision-makers to the extent it could be considered informed consent within the meaning of the HCCA. This meeting may have happened in the May 12, 2015 meeting between various parties and lawyers but the panel was prevented by the parties from knowing any content of that meeting.

Minority Dissent

Ms. Maraj disagreed and would have dismissed the application following the reasoning in the Board decision in *CN* reported at 2014 CanlII 53714 (ON CCB). Had she not dismissed it for lack of informed consent, she would have agreed with the majority on the application of the best interest test.

She found there was no evidence produced that there were any formal or informal discussions with the team of eight doctors with respect to the treatment plan proposed and its details with the substitute decision-makers. She is of the opinion that the 5 to 10 minute bedside discussions with RF, when the Doctor was examining SS were not sufficient to be considered meeting the requirements of informed consent.

She noted that the cases EJG at Tab 3 in the Applicants Brief of Authorities and Tab 2 CA were distinguishable from this case, in that in EJL page 5 there were extensive discussions with the family and Ethics services and in CA at page 11& 12, at least two family meetings with respect to the treatment were held. This did not happen in SS's case.

Ms. Maraj also had concerns that important medical information was not given to the substitute decision-makers at the time that the Form G application was made. These include the parents not receiving information as to the enlarged heart, not receiving information that the saturation levels had at one point reached 0% as Ms. Jarvis submitted, not receiving information that there were concerns that fluid was coming out of the test tubes and not receiving information as to the cause and/or possible treatments for the enlarged heart as commented on by Dr. Mema on the second day of the hearing. The physicians had not quantified the amount of medication given to SS to be 8-10 times the usual amount to keep, "pain" away or information about the possible metabolic genetic disease that may have caused the enlarged heart.

For these reasons, she would have decided following the reasoning in CN that not enough was done to provide information available as to the illnesses and proposed treatment for the parents to make an informed decision to remove or not remove the ECMO machine. She found the application was premature and should not have been made until section 11 of the HCCA had been complied with. Ms. Maraj would have dismissed the application.

Mr. Warr and Ms. Jones went on to consider section 21 of the HCCA.

Were the substitute decision-makers required to follow any prior capable wishes regarding treatment?

As SS is not sixteen years of age, his wish if any is not applicable under section 21(1) of the HCCA.

In applying the best interest test:

Did SS have any prior values and beliefs that he would still act on if capable?

There was no evidence that SS ever had any values or beliefs that he would act on if capable. The treatment was unknown to him and prior to this medical crisis SS was a non-verbal six year old child according to an expert in the field of autism and assessed to have the understanding of a three year old.

Did SS express any wishes with respect to the treatment that are not prior capable wishes?

The statements immediately above apply to this question.

The decision as to compliance with the *HCCA* in this case depends totally on whether SS's parents applied considered and applied the principals set out for determining SS's best interest.

Is the treatment likely to:

Improve SS condition or well- being, prevent SS's condition or well-being from deteriorating, or reduce the extent to which, or rate at which, SS's condition or well-being is likely to deteriorate?

Without the treatment is SS's condition or well-being likely to improve, remain the same or deteriorate?

Mr. Warr and Ms. Jones had to consider this question in the context of SS being off or on ECMO treatment.

Well-being involves a subjective assessment including a person's dignity and level of pain as set out by Rady J. in the oral reasons for appeal released February 17, 2011 in *JM*, an appeal of a Consent and Capacity Board decision reported at 2011 Canlii 7955 (ON CCB). Justice Atkin in *Janzen v. Jansen*, [2002] 44 E.T.R. 217 (S.C.J.), described the concept of well-being as "a very broad concept which encompasses many considerations, including quality of life".

In *Re Conry*, (1985) NJ 321, the court held that:

> "the medical and nursing treatment of individuals in extremis and suffering from these conditions (persistent vegetative) state entails 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 arouse 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".

Airedale NHS Trust v. Bland, [1993] 1 All ER 821 is a House of Lords decision, the highest court in Great Britain. It has been considered in many cases involving end of life in Ontario. It must be noted however, it dealt with person in a vegetative state. In that case reference is made to *Re: J (a minor)*, [1990] All ER 930: where Lord Donaldson stated:

> "what doctors and the court have to decide is whether, in the best interest of the child patient, a particular decision as to medical treatment should be taken which as a side effect will render death more or less likely. This is not a matter of semantics. It is fundamental.
>
> … This brings me face to face with the problem of formulating the critical equation. In truth it cannot be done by mathematical or any precision. There is without a doubt a very strong presumption in favour of a course of action that will prolong life, but, even excepting the "cabbage" case to which special consideration may well apply, it is not rebuttable."

In *Bland* the courts rejected that against life the only consideration on the other side was that of the pain the incapable patient was likely to suffer. Lord Sloss stated," To limit the quality of life to extreme pain is to take a 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".

In SS's case, we have the guidance of section 21(2) of the HCCA to assist us in determining whether SS's parents followed the principles for giving or refusing consent to removal of ECMO, that is whether they took into account all of those factors.

In SS's case we are dealing with an acknowledged sensate person. For the most part, when awake he recognizes his parents. He grimaces and reacts both metabolically and physically when routine and other procedures such as suctioning or the removal of his blankets is undergone. Dr. Cox acknowledged in his testimony, SS demonstrates some purposeful movements. His parents both believe he squeezes their hand to indicate simple directions such as to play his favourite videos or stop them, he indicates whether he wants his mother to sing or stop.

We considered what the treatment would do for SS's condition.

We found it had been proven that the treatment will not likely improve SS's condition as he will likely die quickly.

The ECMO machine is designed in the case of Acute Respiratory Distress Syndrome (ARDS) to act for the lungs in exchanging the gases brought into the heart, giving the lungs an opportunity to rest and repair themselves. In the interim, the machine keeps the patient alive. Statistics vary on how likely there will be success and for how long. It depends on the nature, cause and extent of the damage and the person.

It is a last resort approach to improve lung function due to the associated high incidents of complications associated with the equipment and procedure. Given past experience with ECMO, Dr. Cox hoped there would be signs of improvement within one week of SS being on the machine and there were not.

On April 29th, day 15, the VV line was converted to VA to try to increase the blood flow with less negative pressure and improved oxygenation (Exhibit 1 tab 1 C). SS tolerated this event. May 5th, air got into the circuit and the ECMO circuit was repaired. Once disconnected, monitoring indicated he had a very low concentration of oxygen and that his lungs were unable to add oxygen to his blood. SS also went into cardiac arrest and had to be resuscitated by manual chest compressions for ten minutes. His heart beat came back quickly and remained beating until May 9th, when a similar event with the machine occurred. As again air was found in the machine, it was temporarily disconnected and SS suffered another cardiac arrest, and under-went eleven minutes of Cardio Pulmonary Resuscitation, followed by resumption of the heart function, while the repair was made. These events are outlined in detail in the numerous health professionals reports set out in exhibit 1 tab 2, G and O. Dr. Cox sees these events as proof the lungs have not improved and SS cannot survive without ECMO. There has been no evidence of heart failure since these two events. RF is of the opinion, the fact SS survived many events and the fact SS was again alert shortly after the arrests, demonstrates SS's strength and ability to pull through. SS has been stable during the last week.

Many professional articles and reports as to the recovery and lack of recovery of those who have undergone ECMO were filed as exhibits. RF, in his oral evidence, indicated he has found a group of survivors on Facebook, who indicated having survived having had ECMO for greater than two months.

Dr. Cox indicated in his evidence that you cannot in advance know if a particular patient will recover. He stated in mid-April it was known 100% that SS would die without ECMO and that with it he had a 30 to 50% chance of recovery. Reference was made to Exhibit 11, the article, "prolonged extracorporeal oxygenation for children with respiratory failure", a report on a study of children who have survived a period in excess of twenty-one days. Dr. Cox's interpretation of the paper was that it is difficult to tell when to stop as you cannot say with 100% certainty if the lungs will recover. There is no scan to determine for sure if the lungs will recover. Dr. Cox indicated studies have changed from looking at days on ECMO, to recovery by a certain day, as they cannot prove or disprove a person will survive to be successfully removed from ECMO by any certain day. He also acknowledged nature has surprised us.

There were references in the documents filed as to persons surviving after 46 days (Exhibit 15) and 66 days (Exhibit 16) on ECMO. We found those reports were not helpful in coming to a conclusion about SS's likelihood of improvement, as there was insufficient information and specific health information about those individuals to make comparisons with SS.

A team of eight doctors at this hospital all believe that at this time there is no benefit to continuing with ECMO as SS will not likely recover lung function.

SS's mother reported a relative was given a similar prognosis on life support and defied the odds and did recover from a different event.

The panel accepts that nature can surprise us and that SS is a strong boy who has survived many crises in his life both before and during this medical crisis. Given the retrospective review of the cases and SS lack of recovery of any lung function as of May 9th, 2015, the majority found it had been proven it is unlikely as opposed to impossible SS's lungs at this point will recover.

With the removal of the treatment, SS's condition will deteriorate. He will not be able to oxygenate his blood even with the continuation of a mechanical respirator and will likely die hooked up to machines in the intensive care unit. That is the current plan of care presented by Dr. Cox. Removal of ECMO will in fact hasten this process.

We then looked at whether SS's well-being would deteriorate, or remain the same and the rate of same.

There are medical risks and likely repercussions of being on ECMO. ECMO requires that SS remain still so as to not disturb the tubing and ensure the blood flows appropriately in and out of the body. Medications are required in order to ensure this including at times muscle relaxants, high levels of pain medication and blood thinners to avoid clotting. There is a risk of bleeding into body cavities including the brain as well as infection at the cannula sites.

SS was observed as being restless and tests were conducted to see if blood was going to his brain, to date CT Scans of the brain have been negative. EEG's were performed to see if SS was experiencing seizures. To date there is no evidence of same and for the time being this testing has been discontinued.

The equipment has malfunctioned on May 5th and 9th as was anticipated, and SS suffered two cardiac arrests when the equipment was disconnected. He was heavily sedated during the repairs and on both occasions he has returned to what is believed the same state as it relates to his vital signs and cognition as he was in before the arrests. The return was within hours or overnight and there has been no such event since May 9th, 2015.

X-rays indicate ongoing persistent lung deterioration as shown in the x-ray reports but Dr. Mema acknowledged there has not been a negative change in the last two weeks and commented they (the paediatric ICU doctors) do not put much emphasis on the x-rays. She also provided a remote but possible other explanation for SS's enlarged heart and offered the heart might improve with time if the lungs improve. Dr. Kleinman, (exhibit 4) stated, "He has mildly elevated LFTs but no other major organ system failure". .Dr. Mema also reported that SS's liver is enlarged but the cause, treatment or current implications of same were not elaborated on. Given the evidence of Dr. Mema and Dr. Cox's lack of emphasis on the heart until the first day of the hearing, the panel, did not find clear and cogent evidence that multi organ shut down had occurred and even if it had, their decision regarding compliance with the HCCA would remain the same. We did not find that Dr. Cox has provided clear, cogent and compelling evidence of organ failure.

Much time was spent at the hearing in efforts to establish what pain and/or discomfort SS was suffering.

Exhibit 3 was a document Dr. Cox provided as an addendum to his clinical summary in these proceedings, setting out what he believes are issues regarding the discomfort and pain SS suffers. SS suffers shortness of breath even when using the ECMO machine. He requires suctioning of his trachea and lungs, mouth and nose. He requires a bronchoscopic exam of his lungs and has some eleven tubes attached to his body for such things as connecting the ECMO machine, his ventilator, feeding, bowel and bladder elimination, measuring temperature and catheters for medication. These at times need replaced. He also is noted to have abdominal distension and is likely frightened by the abnormal and foreign situation he finds himself.

The ability of assessing pain and discomfort is limited given the fact SS suffers autism and was and is not verbally communicative. Dr. Cox indicated that RF had told him, this could explain his son's reaction to being touched. When questioned by the Board, RF indicated if his son hurt himself, he would not voluntarily register the complaint and cry. He was teaching SS to indicate a response to him if he hurt himself. At the hearing, RF indicated, that his son likes to be touched and cuddled. He stated SS did respond by crying, pre-hospitalization when he was required to do things he did not want to do such as being required to continue with his therapy when he wanted to play with his favourite toy. We accepted these observations and in particular noted the fact that in the past, although able to cry when dissatisfied, SS did not cry in response to pain. Dr. Koubys noted there was no note in SS's file to indicate he was sensitive to touch which would lead her to believe he was neither hyper or hypo sensitive to touch and she would therefore assume he experienced pain the same way as any other children. The matter is further complicated by the fact SS receives what are described as, "industrial doses' of medications designed to keep him still, not agitated and hopefully without significant pain and discomfort. We found these drugs assist in diminishing SS's pain and discomfort.

Little reference to actual pain or discomfort is mentioned in the extensive medical records filed as exhibits at the hearing. Dr. Cox commented when asked, that the parents never asked about pain. There was a notation that the Pastor's wife on one occasion asked that question. (exhibit 1 tab 2 I). The answer given was, "We would like to keep him as comfortable as possible". Dr. Cox made it clear, he wanted to discontinue the treatment because of lack of recovery not pain. He would not have recommended discontinuance, despite pain, if the lungs had shown improvement.

References were made to SS demonstrating pain and discomfort when certain acts were done to him such as suctioning. There is a noted increase in blood pressure and decease in saturation levels as well as a physical response such as pushing away at the instrument or arm of the person doing the suctioning. Decisions have been made to try and reduce this distress by clustering several cares at one time. The same happens when the blanket is removed for diaper changes and physical exams. Dr. Mema stated in her evidence there was no noted difference in reaction whether she administered soft pressure such as stethoscope or deep touch, when she tried to feel his organs, suggesting to us SS, at minimum, is unable to differentiate between light and severe pain. RF indicates, when he talks to SS and explains the suctioning is about to start, SS's reaction to the procedure is lessened.

SS has been noted to be more responsive, as reported by his mother and has required less PNR medication to carry out nursing care and physical monitoring during the past week, which indicates either they have found a more stabilizing balance of medications, or SS is more accepting of his circumstances or both. Nursing notes in exhibit 18 make comments such as, "tolerating handling tonight, sedation improved tonight". The skin integrity strategies put in place are working. He is moved every two hours. SS is receiving exceptional medical and nursing care and responding to it.

It is also of note that none of the external opinions given by Dr. Ferguson, Dr. Kleinman and Dr. Shernie noted the issue of pain and/or discomfort. Ms. Jarvis suggested in her submissions, we should read into Dr. Ferguson's comment, "heavily sedated" equates to experiencing pain. We did not agree.

We found there was no direct conclusive medical evidence that the agitation and discomfort described were not in part or in whole related to his underlying autism and just exacerbated by the procedures required to be administered to him during his hospitalization.

Dr. Cox made note of reported tears. We did not place much weight on this fact. Tears and crying are two different things. The tears could be related to something as simple as response to eye drops or dryness. RF said they would discontinue ECMA if they believed their son was suffering pain as that would be undignified. Dr. Mema indicated, they would not allow for SS to cry for an extended period of time. They would use medication. The doctors are preventing SS from suffering pain and discomfort.

We did not find it was established that the reason for removal of ECMO was due to pain as opposed to the fact the procedure had not worked in improving lung function. More importantly we did not find that there was clear, cogent and compelling evidence that SS was in fact suffering pain to the extent that discontinuation of life would be considered as of the hearing date.

The panel members also considered SS's dignity, lying in a hospital bed hooked up to many machines with tubes. They envisioned a very unpleasant sight. They also considered the alternative which was a quicker death. There was no other difference to SS in the parents and Doctor's proposed treatment plans as all tubes and other treatments with the exception of perhaps increases in medication, which are constantly adjusted and increased as needed now, would remain in place. The palliative care plan was the same as the current plan except for the switching off of the ECMO machine. The likely cause of death we were told would be organ failure on or off the machine. The timing was the only difference.

Reference was made to SS's parents making a decisions based on religious beliefs. Both parents acknowledged at the hearing that they were raised in a religious family and were members of the Pentecostal Church. Their pastor once enquired as to whether SS was brain dead as he believed the parents had misunderstood that he was and that was clarified. It was the pastor's wife who in fact made the inquiry as to pain.

It is natural for those of faith to pray and to ask others to. In times of stress and trouble those who are not usually religious resort to their God. It was of note that there was a large chapel outside the Board Room at the hospital where the hearing was held, allowing for prayer to loved ones. On at least three occasions May 6th (exhibit 1 tabs 2 G, H, I and M). SS's parents made references to a miracle and God will determine when SS will die. At the hearing his mother stated, "If God was going to save my child through a miracle it would have happened a long time ago". They both indicated they believed in Science. It would have been that belief that led to them consenting to SS being placed on a Ventilator and the ECMO machine in the first place. We found that SS's parents decision-making was not made on a belief of divine intervention as was found in EJG set out the Applicants Book of Authorities, tab 3. There was no evidence their religious beliefs were the driving force behind their decisions. We found the parent's own religious beliefs and faith had little bearing on their decision-making.

The majority of the panel found that at this time, it had not been proven by clear and cogent evidence that SS's condition and well-being would not remain the same as it currently is without treatment. This may change, should there be later evidence of pain and discomfort. His condition and well-being have not either improved or deteriorated over the course of the treatment with ECMO to date.

Does the benefit SS is expected to obtain from the treatment outweigh the risk of harm to SS?

We found it had not been proven.

We would comment that we believe that SS has and continues to receive the best medical care and that the doctors, nurses and other health practitioners involved in his care should be commended for their tireless, compassionate and expert care. We also acknowledge their opinion to discontinue ECMO because they believe it is futile and SS is in fact suffering pain and discomfort.

The benefit of their proposed removal of treatment is an almost immediate death likely from one of the causes SS will eventually succumb to. There will be limited time for him to feel discomfort or experience a lack of dignity due to his living with his condition.

We found the benefits of living with the discomfort are very significant. SS will likely not go home and again enjoy playing with his favourite toy that RF mentioned when he showed us the photograph of SS. It is acknowledged he suffers some undefined pain and discomfort particularly when health practitioners need to touch him but he also experiences pleasure. That pleasure comes from his contact with his parents just as it did before this hospitalization. One of his parents is with him practically every hour of every day. Both physicians who testified agreed that SS responded to his parents. SS is clearly not in a persistent vegetative state, the situation when dignity has been considered in most of the case law presented.

We considered the parents evidence regarding their responses with their son carefully to determine whether it was SS who obtained pleasure or just them. We were satisfied it was both. It must be stressful watching their son in this condition, but they see him experiencing some pleasure. Not removing ECMO allows that for some likely limited time, that SS can spend some time with likely the only persons he has ever had a positive relationship with.

On ECMO he will continue to enjoy his favourite videos, which he has loved since he was very young and enjoy his mother's singing. His mother indicated SS loves the music and the rhythm. His father stated they, "bring happiness to him". We accept this is true.

This last week, SS has been very stable. According to his father he raises his right hand to touch his parent's left hand. LMS described her son as very serene in the week before the completion of the hearing and indicated he would consciously hold her hand tight and looks for her eyes so she can see him. Both parents indicate, SS is not as sedated and is experiencing more positive awake time with them. They note he is less restless. This interaction with the parents was not disputed by Dr. Cox or Dr. Mema.

RF indicated the doctors feel we (the parents) are undermining SS's dignity and being disrespectful. He disagrees. He stated, keeping SS alive when is able to recognize his parents, enjoys our singing and presence is more dignified than allowing removal until he [RF] knows SS is suffering and in some level of pain.

This case is quite distinguishable from the case of *S.R.* tab 6 in the Applicant's Book of Authorities. S.R. did not have any meaningful response to any commands. Furthermore he had been in ICU 112 days, had suffered aspiration pneumonia, his fingers and toes were necrotic, and he had many fevers due to infection and ulcers over his body. His skin oozed to the point of tearing away. His facial grimaces were interpreted as expressions of pain. His state of deterioration was far greater than SS's. There was no evidence of S.R. experiencing any pleasure.

SS's parents were well aware, his lungs have not improved, and there are risks of death on or off ECMO. RF is well researched on the matter and LMS right after witnessing a second arrest, after this application was made, asked about transplant. They were well aware of signs of deterioration and suffering such as skin integrity. The difference between them and the medical team is that they do not find it has be proven that SS currently is in sufficient pain or discomfort to take away his simple pleasures. As RF put it, "he [RF] has a different way to balance".

We found that as SS presented irrespective of the time he had been on ECMO without improvement, at the hearing 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.

We found it had not been proven that these benefits outweighed the risks, being some degree of pain and discomfort.

Whether a less restrictive or less intrusive treatment would be as beneficial as a treatment than the treatment proposed?

There are no alternatives for SS. He is not a candidate for a lung transplant and the only treatment is continuation of ECMO.

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. It is acknowledged that SS is undergoing an invasion of his personal privacy and suffered certain exacerbated difficulties due to EMCO, and is in some discomfort, but 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".

We find that has not been proven that they have not complied with the principles contained in section 21 of the HCCA.

RESULT

For the above reasons, we determined SS was incapable of making his own decisions with respect to removal of extracorporeal membrane oxygenation and found his substitute decision-makers RF and LMS complied with the principles for substitute decision-making set out in the *Act*.

Dated at Midhurst, Ontario, May 29th, 2015

Carolyn Jones - Presiding Member