Consent and Capacity Board	**Commission du Consentement de la Capacitie**

File No. LO-10-3745
File No. LO-10-3746

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

AND IN THE MATTER OF
" S S "
A PATIENT OF
GRAND-RIVER HOSPITAL-KITCHENER-WATERLOO HEALTH CENTRE
KITCHENER, ONTARIO

REASONS FOR DECISION

PURPOSE OF HEARING

The onus is always on the attending physician at a Board Hearing to prove his or her case. The case must be proved on the preponderance of evidence. In order for the Board to find in favour of the attending physician, it must hear cogent and compelling evidence in support of the physician's case.

The Applicant appearing before the Board does not have to prove anything, the onus being entirely on the attending physician.

In this matter, the Applicant was the attending physician on behalf of the treatment team attending to Ms. SS who had been a patient of Intensive Care Unit of the Hospital for several months.

The team was of the opinion that to keep Ms. SS on life support, by continuing the use of the ventilator, was medically futile. The team took its instructions from the patient's only child, her daughter, Ms. XA, who refused to follow the team's advice to end life support after first ensuring, by outside expert opinions, that the patient's condition's would not improve.

Because the daughter would not consent to the withdrawal of life support, the team applied under section 37 of The *Health Care Consent Act* (*HCCA)* for a decision by the Board as to whether the substitute decision maker complied with the provisions of section 21 of the same Act in deciding, as she did, against the advice of the treatment team.

However, because the right of a substitute decision maker to act on behalf of a particular person does not arise until there has been a finding that that person is incapable of consenting to his or her own medical treatment, a "deemed hearing" was first required to be conducted and the Board provided with sufficient evidence to decide, on the balance of probabilities, that the patient was incapable. If the Board agreed with the physician that Ms. SS was incapable to consent to her own medical treatment after hearing the evidence, it could then move on to decide the health care practitioner's application under section 37; i.e. whether the daughter was acting in accordance with the principles set out in section 21 of the *HCCA.*

DATES OF HEARINGS, DECISIONS AND REASONS

The deemed capacity hearing was held on Friday, January 7, 2011 and used up most of the day. The Board adjourned the remaining matter until 6 pm on the evening of Wednesday, January 12, 2011.

The decision, finding the patient incapable was served on the parties on January 11, 2011 and the remaining decisions as to the section 37 matters were served on January 13, 2011, being the day following the decision.

At the conclusion of the hearings, Counsel for the substitute decision maker, asked for reasons for the decisions.

LEGISLATION CONSIDERED

1. *The Health Care Consent*, sections 4, 37 and 21

PARTIES

1. The Applicant, the Health Care Practitioner, Dr. William Paxton
2. The Patient, Ms. SS
3. The Substitute Decision Maker, Ms. XA

Dr. Paxton and Ms. XA both attended the hearing. The patient was not able to attend.

PANEL MEMBERS

1. Mr. David J. Ramsbottom, Presiding Member and Senior Lawyer Member;
2. Dr. Gerald Shugar, Psychiatrist Member ; and
3. Mr. David Simpson; Public Member

APPEARANCES

1. Dr. Paxton represented himself and the treatment team;
2. Ms. Willa V0roney appeared for the patient; and
3. Mr. Clarke Melville appeared for the substitute decision maker.

WITNESSES

1. Dr. William Paxton, the Applicant;
2. Dr. Paul Hosek;
3. Dr. Natalie Needham-Nethercott;

LIST OF EXHIBITS

A. DEEMED CAPACITY HEARING

1. Ethics Committee Consultation Note.

B. COMPLIANCE WITH PRINICIPLES FOR SUBSTITUTE DECISION MAKING

1. Plan of treatment, dated January 7, 2011;
2. Medical Imaging Report, dated October 7, 2010; and
3. Medical Imaging Report, dated December 13, 2010

PRELIMINARY MATTERS

There were none.

Grounds for Finding of Incapacity Consent to or refuse treatment

Dr. Paxton, Dr. Paul Hosek and Dr. Natalie Needham-Nethercott gave evidence. All are part of the treatment team. Each was of the opinion that, since the patient was in an almost "persistent vegetative state" save for a few grimaces and the occasional nodding response to simple questions, the patient was unable to understand the facts necessary to make a decision and was unable to appreciate the reasonable foreseeable consequences of her decisions, thereby meeting the definitions of incapacity set out in the *HCCA.*

None of the other parties objected to that evidence and in fact agreed with it. On that basis, the Board agreed that Ms. SS was incapable of consenting to her own medical treatment.

The Board therefore proceeded, on Wednesday, January 12, 2011 to hear the evidence dealing with the treatment team's application to determine if Ms. XA complied with the provisions for make such decision, under section 21, on behalf of her mother.

INTRODUCTION

The patient, Ms. SS, was born in what is now Kosovo and speaks the Albanian language. Her daughter, Ms. XA, told the Board that her mother was unable to read or write. She was uncertain whether her mother had received any formal schooling. Except for the period between 1991 and 1996, when she accompanied her husband to Germany for his work, the patient lived her life in Kosovo. On the death of her husband, she returned to Kosovo to reside with her only child, Ms. XA, and husband and four children.

The patient is presently 58 years of age.

The family, including Ms. SS, immigrated to Canada in 1999 and continued, until this hospitalization, to reside together.

They are of the Muslim faith. Ms. XA, when asked how she knew her mother was also of that faith, indicated that in growing up and throughout the daughter's life, she observed her mother to celebrate the Muslim holidays such as Ramadan, to pray as required by the faith and in effect to show all of the outward signs of belonging to that religion. In addition, there had been the verbal communication over a lifetime among the family including Ms. SS, to convince the substitute decision maker that her mother was guided throughout her life by the principles and beliefs of Islam.

The patient was admitted to hospital and subsequently to the ICU on October 5, 2010 with intermittent apnea spells and sustained multiple vascular injuries surrounding certain areas of the brain, including the medulla of the brain stem. There is occlusion with no blood flow in the right vertebral artery resulting in partial central respiratory drive syndrome so that she is unable to breathe adequately, on her own, to sustain life. The brain injuries are so severe and so permanent that in the present situation, there is no possibility of any meaningful recovery.

She has had a full tracheotomy and has been on full life support since that time. The patient has a history of diabetes, severe neuropathy, renal failure, hypertension, glaucoma, and is wheel chair bound. She recently suffered a multivascular stroke involving the neurocortex as well as ischemic brain lesion. A tube feeds her.

The medical team is of the opinion that this patient will not recover from her medical difficulties and that acute interventions such as ventilation, resuscitation, life support sustaining measures and future admission to an ICU are futile and therefore not medically indicated.

The team seeks to provide a caring, supportive, understanding and comforting environment for both Ms. SS and her daughter. No one is aware of a written power of attorney. No application has been made to this Board for anyone to be appointed as substitute decision maker. While Ms. SS has siblings, all reside in Kosovo except for a younger sister now living in Switzerland. Thus, Ms. XA is her closest relative, both in terms of geography and lineage. The treatment team and the Board accepted Ms. XA as the substitute decision maker.

Ms. XA told the Board that she spends four to five hours daily with her mother, often attending three times daily. During those times, she has seen her mother shed a tear, move her head, squeeze a finger, and other such responses when spoken to, albeit very infrequently.

The team describes the patient as being in an almost “persistent vegetative state” although it agrees that there have been a very few times when Ms. SS has appeared to show some response to external stimuli. Much was made of an incident that occurred on December 26, 2010 in the patient’s room when a physician, in the presence of a nurse proficient in the Serbian language, asked the patient to respond by nodding or shaking her head to some simple, yet profound, questions. According the testimony, the patient responded to some questions, put to her in Serbian, including whether she wanted to go on living. She shook her head to indicate she did not.

Dr. Paxton, however, stated that he did not accept this answer as a capable wish and was not relying on it in his treatment decisions since he stated that the team would want to have some consistency in such an answer made to them over several days. In addition, Ms. XA told the panel that her mother spoke only Albanian and she could not explain nor believe her mother responded to or understood the Serbian language.

Dr. Paxton and his team are of the opinion that the patient has frequent intermittent periods of awareness but clearly is unable to neither understand nor process the information given to her.

Ms. XA believes that her mother is “alive inside her body.” She believes her mother is still able to think and can smile when asked by her daughter. She agrees that her mother is unable to speak, even if the ventilator is turned down to allow for such. She told the panel that she believes that if her mother’s heart were to stop, the team should attempt to restart it. She disagrees that her mother should be taken off the ventilator, in effect, that life support should not be withdrawn. She believes, and believes that her mother would want all stops to be taken to preserve her mother’s life.

The daughter told the Board that before her mother had her strokes in September, they did not discuss specifically what Ms. SS would want to occur with respect to her health care decisions if she were unable to make her own decisions. She stated that “death or sickness does not ask so we pursue our religion. That faith, according to the substitute decision maker, requires life to be sustained at all costs, even if there is pain to the patient. Only God can decide when it is time to end a life.

Ms. XA could not, she said, be involved in any decision that would remove life support from her mother, both as a personal matter and based on the family’s religious beliefs.

No evidence was given to contradict that of Ms. XA. Her testimony stood alone as to the beliefs and values of her mother.

THE LAW

Incapacity to Consent to Treatment

The test to be applied is set out section 4 of the *Health Care Consent Act*, which states

> s. 4 (1) A person is capable with respect to a treatment, admission to a care facility or a personal assistances 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.
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> s. 4 (2) A person is presumed to be capable with respect to treatment, admission to a care facility and personal assistance services.
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> Justice D. M. Brown, in the case of Conway. V. Darby, (court file no. 03-53/07) provided written reasons in a matter dealing with capacity and relied on a recent case of the Supreme Court. In the judgment on the Ontario case,, the Honourable Justice made the following comments:
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> > The Supreme Court of Canada in the case of Starson v. Swayze, 2003 SCC 32 interpreted these statutory definitions. As the Court noted in that case, the *Health Care Consent Act* requires a Board to adjudicate solely

upon a patient's capacity; the Board's conception of the patient's best interest is irrelevant to that determination.

Further, since the Act presumes a person is capable to decide to accept or reject medical treatment, at a capacity hearing the onus is on the attending physician to prove, on a balance of probabilities, that the patient is incapable. In Starson, the Court, at paragraph 78, described the two branches of the statutory test of capacity as follows:

> Capacity involves two criteria. First, a person must be able to understand the information that is relevant to making a treatment decision. This requires the cognitive ability to process, retain and understand the relevant information… Second, a person must be able to appreciate the reasonably foreseeable consequences of the decision or lack of one. This requires the patient to be able to apply the relevant information to his or her circumstances, and to be able to weigh the foreseeable risks and benefits of a decision or lack thereof.

The Court went on to deal with the second requirement of the test for capacity to demonstrate how the Supreme Court treated the element of the ability to appreciate the reasonable foreseeable consequences of a decision.

First, the court distinguished the *ability* of a patient to appreciate the consequences from his *actual* appreciation of those consequences. The statutory test is concerned with the former, not the latter. A Board must determine whether the reasons for a patient's failure to appreciate consequences demonstrates that the patient is unable, as result of his condition, to appreciate those consequences.

The Court went on to offer a step-by-step process as to how a Board should go about this inquiry.

In practice, the determination of capacity should begin with an inquiry into the patient's actual appreciation of the parameters of the decision being made: the nature and purpose of the proposed treatment; the foreseeable benefits and risks of treatment; the alternative course of action available; and the expected consequences of not having the treatment. If the patient shows an appreciation of those parameters - regardless of whether he weighs or values the information differently than the attending physician and disagrees with the treatment recommendation – he has the ability to appreciate the decision that he makes…

The second observation that the Court made about the second branch of the capacity test was that a patient need not agree with the attending physician's diagnosis in order to be able to apply the relevant information to his own circumstances. Here the Court distinguished between a "condition" and an "illness."

The court held that;

(i) A condition refers to the broader, objectively discernible manifestations of an illness rather than the existence of a discrete diagnosable pathology – i.e. the clinical interpretation that is made of those manifestations;

(ii) A patient's failure to describe his mental condition as an illness or to agree with the physician's diagnosis of the cause of that condition does not mean that the patient lacks capacity;

(iii) However, if the patient is unable to recognize that he is affected by manifestations of the condition, then he will be unable to apply the relevant information to his circumstances and therefore unable to appreciate the consequences of his decision.

Put another way, where it is demonstrated that a patient displays objectively discernible manifestations of an illness, a Board should ask: does the patient recognize that he is affected by such manifestations or that his mental functioning was not normal? If he does not, then the patient may be unable to apply the relevant information to his circumstances and may be unable to appreciate the consequences of his decision.

Compliance with the Principles of Substitute Decision Making

Section 37 deals with the Application to determine compliance with section 21.

It states

(1) " if consent to treatment is given or refuses on an incapable person's behalf by his or her substitute decision make, 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 care practitioner may apply to the Board for a determination as to whether the substitute decision maker complied with section 21.

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

Section 21 sets out those principles for giving or refusing consent

It states:

(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 incapable person knows of a wish applicable to the circumstance that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with that wish.

2. If the incapable person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining sixteen years of age, or 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 that 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 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 wellbeing 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.

ANALYSIS

Capacity to Consent to Treatment

As set out above, there is no question that Ms. SS is incapable of consenting to her treatment. She is in an almost persistent vegetative state and does very infrequently respond to very simple questions put to her by her family and medical treatment team members.

Even Dr. Paxton when hearing of her responses on December 26, 2010, did not accept the same as capable or informed responses.

Since the patient was unable to understand the facts necessary to make the decision about withdrawing the ventilator and certainly was unable to weigh the consequences of doing

so, the Board agreed with all of the parties that Ms. SS was incapable of consenting or refusing the proposed treatment.

Was the Substitute Decision Maker in Compliance with the Principles set out section 21?

Barring a miracle, there is virtually no chance for Ms. SS to recover to any point where she would have a quality of life that would take her out of her persistent vegetative state. To use the medical term, any ongoing life support will or would be " medically futile" and the treatment team, seeing the grief and continued agony of the substitute decision maker, the ongoing state of her mother, and the possibility that Ms. SS would be in pain with no hope of relief, Dr. Paxton and his colleagues proposed withdrawing life support after obtaining various independent but confirming assessments by specialists in those fields of illnesses affecting the patient. If the specialists found there were some hope, the team would continue to provide life support.

Ms. XA, despite her earlier decisions, did not agree to the withdrawal of life support and in fact stated that such action would amount to the murder of her mother.

The Board, in the Application before it, may agree with one or the other of the positions taken or may substitute its own. However, it is not a matter of the personal choices of each Member. Rather, the panel must have regard only to the legislation and what the law requires in such circumstances.

No written and valid Power of Attorney was produced for the Board. The daughter stated that she has lived with her mother for most of her life, certainly for all of her life since coming to Canada. She was not aware of a written Power or Attorney nor did she and her mother, or any one else of whom she is aware, discuss what her mother would want in these circumstances.

The question then is: In the absence of any verbal or oral wishes, what would the patient want to happen to her? Would Ms. SS want, in the present circumstances, to be allowed to pass away, thus ending her ordeal?

Section 21 (1) 2 directs the person, Ms. XA, to act in the *best interests* (emphasis added) of the patient where there is no prior expressed wish.

Fortunately, section 21(2) provides the guidance needed to determine " best interests".

The panel heard from the daughter that her mother was of the Muslim faith, a faith that, she stated, believes that only God can take a life. She believes therefore that her mother, Ms. SS would want to endure the pain, to suffer whatever the consequences may be, to maintain and sustain her life. Ms. XA on those bases and for those reasons demands that the ventilator be maintained, that all steps necessary and advisable be taken by the team to protect and prolong the life of her mother must be undertaken.

Section 21(2) ((c)) is of some, but little assistance, since it deals with whether a treatment is likely to improve or worsen the condition or well-being of a patient. The team admits that death would likely result at some point in the near future if the ventilator were to be withdrawn, since it is medically futile to go on, without hope of improvement. The SDM acknowledges that fact death is likely in that situation and insists that her mother's life be prolonged until God determines when she will die.

Whether death worsens or improves a person's condition is a philosophical discussion that depends on the direction from which the issue is approached. The physicians approach it from one of care, concern, their oath to do no harm, and the medical futility of prolonging this life. Without specific direction from the patient, the daughter resorts to her religious beliefs and those of her mother insisting that life be prolonged, no matter what the suffering. Death or continuing life, notwithstanding the consequences, as an improvement or worsening of a condition is the result, not the choice. That section is therefore of little or no help in life-ending matters.

CONCLUSIONS

Thus, the decision this Board was asked to make is to choose between what the treatment teams feels is in the best interests of the patient and what the patient herself would want. The only evidence provided is that the patient's faith mandates that life be sustained, no matter the circumstances. This is not a situation where the Board has the option to impose its own order. The choice was plain and well presented to the Board by the parties.

Since no other evidence was provided concerning the patient's beliefs and values, the Board felt compelled to accept the submissions and position taken by the substitute decision maker.

It therefore dismissed the physician's Application that the Substitute Decision Maker failed to comply with the principles set out in the legislation when she refused to agree to end life support for her mother.

Dated at Hamilton, Ontario this 18th day of January, 2011

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David J. Ramsbottom, Presiding Member and Senior Lawyer Member