

16-5588-01 16-5588-02

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

AND IN THE MATTER OF

JEP

A patient at

THE OTTAWA HOSPITAL-CIVIC CAMPUS

OTTAWA, ONTARIO

# **REASONS FOR DECISION**

## PURPOSE OF THE HEARING

A panel of the Board convened at the Ottawa Hospital-Civic Campus at the request of Dr. David Neilipovitz, a health practitioner. Dr. Neilipovitz brought a Form G Application to the Board under Section 37 (1) of the *Health Care Consent Act* for a determination as to whether or not the substitute decision maker(s) in this case complied with Section 21 of the *Health Care Consent Act*, the principles for substitute decision-making, with respect to proposed treatment for JEP. The proposed treatment was set out in Dr. Neilipovitz's Application filed as part of Exhibit 1. Dr. D'Egidio, took over carriage of the Form G Application from Dr. Neilipovitz.

An Application to the Board under Section 37 of the *Health Care Consent Act* is deemed, pursuant to subsection 37.1 of the *Health Care Consent Act* to include an application to the Board under Section 32 by JEP with respect to his 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.

# DATES OF THE HEARING, DECISIONS, AND REASONS

The hearing took place on April 25, 2017. On April 26, 2017 the panel released its Decisions finding that (i) JEP did not have the capacity to consent to the proposed treatment; and (ii) that the substitute decision makers were in compliance with the principles for substitute decision making set out in the *Health Care Consent Act*. Reasons for Decision were released on May 2, 2017.

#### LEGISLATION CONSIDERED

The Health Care Consent Act, including s. 1, 2, 4, 10, 11, 21, 32, 37 and 37.1

#### **PARTIES**

JEP's Deemed Form A – Treatment Application

JEP, patient

Dr. D'Egidio, health practitioner

Dr. D'Egidio's Form G – Treatment Application

Dr. D'Egidio, health practitioner

JEP, patient

ARE, JAE and ABE, three of JEP's children who were his substitute decision makers

JEP did not attend the Hearing. Dr. D'Egidio attended the Hearing, gave oral testimony and filed documentary evidence. All three substitute decision makers attended the hearing. They did not give oral testimony but filed documentary evidence.

#### PANEL MEMBER

Michael Newman, Vice-Chair, Presiding Lawyer Member

#### **APPEARANCES**

JEP was represented at the Hearing by counsel, Celine Dostaler.

Dr. D'Egidio was represented at the Hearing by counsel, Stephanie Pearce.

ARE, JAE and ABE, the substitute decision makers were all represented at the Hearing by counsel, Mark Handelman.

#### PRELIMINARY MATTERS

## **Jurisdiction**

The panel was advised that there had not been within the previous six months a determination by the Board of JEP's capacity to consent to treatment. The panel was also advised that JEP did not have a Guardian of the Person. JEP had a Power of Attorney for Personal Care, which it did not contain a provision waiving his right to apply for the review of the health practitioner's finding in accordance with Section 32 of the *Health Care Consent Act*. I determined that the Board had jurisdiction to continue with the Hearing.

## THE EVIDENCE

The evidence at the Hearing consisted of the oral testimony of one witness, Dr. D'Egidio, and four Exhibits:

- 1. Dr. D'Egidio's Brief (2 volumes A-L and M-Y)
- 2. SDM Documents JEP's (Power of Attorney for Personal Care) January 14, 2016, Academic Career, updated April 15, 2017 Letters (21) Dr. Jonker's typed letter, ABE's Membership in Quebec Society of Interpreters' Forms and translations, chart extract (Dr. Patel, page 1/4 March 16, 2017) various Dictionary definitions of the word "express"
- 3. Picture of JEP

# 4. Picture of JEP and Family

## **INTRODUCTION**

JEP was an 86 year old gentleman and retired pathologist. He was married for 62 years to RE until RE's death in 2013. JEP had eight children, three of whom were his substitute decision makers. He also had 16 grandchildren and 5 great grandchildren.

JEP graduated from medical school in Uruguay and held a certificate in Pathology from his medical school in Uruguay. He also earned a Ph.D. in Anatomy from Stanford University in California. What followed was a very distinguished academic career including as a researcher and educator. He was multi-lingual, in Spanish, English and French, understood and read Portuguese and had a working knowledge of Italian.

JEP authored over 150 publications related to biomedical and education issues, many written with his late wife, RE. Both JEP and RE had been tenured medical school professors at a Canadian University.

At the time of the hearing JEP had several medical conditions including renal failure, weakness/chronic respiratory failure and was at risk of suffering aspiration. He also was diagnosed with progressive advanced dementia.

Prior to Christmas of 2016, JEP was residing in independent living. He enjoyed reading books and listening to music. Other individuals took care of his finances and grocery shopping. In December 2016 JEP suffered a fall resulting in his first admission to hospital, a 10 day admission to an internal medicine unit. His mobility decreased to the point JEP required a wheelchair at times.

On January 14, 2017 JEP was readmitted to hospital with a diagnosis of heart failure and aspiration. Prior to the January, 2017 admission JEP's family physician had been concerned about possible pneumonia which resulted in JEP being started on antibiotics. Since the January 14, 2017 admission to hospital JEP received advanced and full medical therapies. However, his

respiratory status deteriorated to the stage that he required admission into the hospital Intensive Care Unit (ICU). On February 25, 2017 JEP required intubation and placement on a mechanical ventilator. JEP's condition deteriorated in spite of being in a Level 3 intensive care unit, the unit with the highest possible medical care. He was considered in multi-organ failure including kidney failure, respiratory failure, cardiac failure and hematology failure, all in a setting of advanced dementia.

On April 6, 2017 JEP was extubated and transferred out of ICU to the step-down unit called the Acute Monitoring Area or AMA unit. He was followed closely by both internal medicine and ICU staff via the Race team or Rapid Assessment of Critical Events team.

On April 9, 2017 JEP suffered a hypoxic cardiac arrest, again requiring mechanical ventilation in ICU. On April 19, 2017 JEP was again extubated and transferred out of ICU into the AMA where he remained as of the hearing.

Dr. D'Egidio an ICU and internal medicine specialist had been one of the ICU's doctors following JEP in ICU. As of the hearing Dr. D'Egidio was no longer JEP's attending or most responsible physician. However, he took the lead on behalf of the medical team concerning the Form G Application before the Board. The medical team has proposed palliative care for JEP (foregoing CPR, along with withdrawal of life sustaining therapy). JEP has been assessed incapable with respect to the proposed treatment plan. JEP's substitute decision makers, three of his children, have refused to provide consent. The medical team believed that the substitute decision makers refusal to provide consent concerning of the proposed treatment plan was inconsistent with the requirements of substitute decision making as outlined in the *Health Care Consent Act*. As such the Form G Application was made to the Board for a determination of that issue. The substitute decision makers relied on their father's wishes, as the basis of their rejection of the proposed treatment plan.

#### THE LAW

#### General

When the Board is considering Dr. D'Egidio's Form G Application and the deemed treatment capacity application by JEP, the onus is always on the health practitioner at a Board Hearing to prove his or her case. The standard of proof on any application under the *Health Care Consent Act*, 1996 is proof on a balance of probabilities. The Board must consider all evidence properly before it. Hearsay evidence may be accepted and considered, but it must be carefully weighed. In order for the Board to find in favour of the health practitioner it must hear clear, cogent and compelling evidence in support of their case. An individual who has been found incapable with respect to treatment, here JEP, did not have to prove anything to the Board.

# **Incapacity with Respect to Treatment**

The *Health Care Consent Act*, 1996 states that a health practitioner who proposes a treatment for a person shall ensure that it is not administered unless, he or she is of the opinion that the person has given consent; or he or she is of the opinion that the person is incapable with respect to the treatment, and another person has given consent in accordance with the *Health Care Consent Act*, 1996.

The test for capacity is set out in Section 4(1) of the *Health Care Consent Act, 1996* which states that a person is capable with respect to treatment if the person is able to understand the information that is relevant to making a decision about the treatment and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. The section goes on to say that a person is presumed to be capable with respect to treatment and that a person is entitled to rely on the presumption of capacity with respect to another person unless he or she has reasonable grounds to believe that the other person is incapable with respect to the treatment.

Section 2(1) of the *Health Care Consent Act* in part reads as follows:

"plan of treatment" means a plan that,

(a) is developed by one or more health practitioners,

- (b) deals with one or more of the health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and
- (c) provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition; ("plan de traitement")

"treatment" means anything that is done for a therapeutic, preventive, 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,

- (a) the assessment for the purpose of this Act of a person's capacity with respect to a treatment, admission to a care facility or a personal assistance service, the assessment for the purpose of the *Substitute Decisions Act*, 1992 of a person's capacity to manage property or a person's capacity for personal care, or the assessment of a person's capacity for any other purpose,
- (b) the assessment or examination of a person to determine the general nature of the person's condition,
- (c) the taking of a person's health history,
- (d) the communication of an assessment or diagnosis,
- (e) the admission of a person to a hospital or other facility,
- (f) a personal assistance service,
- (g) a treatment that in the circumstances poses little or no risk of harm to the person,
- (h) anything prescribed by the regulations as not constituting treatment. ("traitement") 1996, c. 2, Sched. A, s. 2 (1); 2000, c. 9, s. 31.

Sections 10 and 11 of the *Health Care Consent Act* read as follows:

#### No treatment without consent

- **10.** (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,
  - (a) he or she is of the opinion that the person is capable with respect to the treatment, and the person has given consent; or
  - (b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this Act. 1996, c. 2, Sched. A, s. 10 (1).

# **Opinion of Board or court governs**

(2) If the health practitioner is of the opinion that the person is incapable with respect to the treatment, but the person is found to be capable with respect to the treatment by the Board on an application for review of the health practitioner's finding, or by a court on an appeal of the Board's decision, the health practitioner shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless the person has given consent. 1996, c. 2, Sched. A, s. 10 (2).

# **Elements of consent**

- **11.** (1) The following are the elements required for consent to treatment:
- 1. The consent must relate to the treatment.
- 2. The consent must be informed.
- 3. The consent must be given voluntarily.
- 4. The consent must not be obtained through misrepresentation or fraud. 1996, c. 2, Sched. A, s. 11 (1).

## Informed consent

- (2) A consent to treatment is informed if, before giving it,
- (a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
- (b) the person received responses to his or her requests for additional information about those matters. 1996, c. 2, Sched. A, s. 11 (2).

#### Same

- (3) The matters referred to in subsection (2) are:
- 1. The nature of the treatment.
- 2. The expected benefits of the treatment.
- 3. The material risks of the treatment.
- 4. The material side effects of the treatment.
- 5. Alternative courses of action.
- 6. The likely consequences of not having the treatment. 1996, c. 2, Sched. A, s. 11 (3).

# **Express or implied**

(4) Consent to treatment may be express or implied. 1996, c. 2, Sched. A, s. 11 (4).

The *Health Care Consent Act* identifies the principles that a substitute decision maker(s) must apply when making a decision about a proposed treatment. Those principles are outlined in Section 21. Section 21 of the *Health Care Consent Act* reads as follows:

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 attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.
- 2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests.
- 21.(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.

In the event that a health practitioner believes that a substitute decision maker(s) did not comply with Section 21, he or she may apply to the Board for a determination. Section 37 addresses issues related to such an application.

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 a determination as to whether the substitute decision-maker complied with section 21. 1996, c. 2, Sched. A, s. 37 (1).

#### **Parties**

- (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. 1996, c. 2, Sched. A, s. 37 (2).

#### Power of Board

(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. 1996, c. 2, Sched. A, s. 37 (3).

## **Directions**

(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. 1996, c. 2, Sched. A, s. 37 (4).

# Time for compliance

(5) The Board shall specify the time within which its directions must be complied with. 1996, c. 2, Sched. A, s. 37 (5).

#### Deemed not authorized

(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). 1996, c. 2, Sched. A, s. 37 (6).

# Subsequent substitute decision-maker

(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. 2000, c. 9, s. 35.

# **Application for directions**

(6.2) If a subsequent substitute decision-maker knows of a 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. 2000, c. 9, s. 35.

## **Inconsistent directions**

(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. 2000, c. 9, s. 35.

## P.G.T.

(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. 1996, c. 2, Sched. A, s. 37 (7).

# Deemed application concerning capacity

**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. 2000, c. 9, s. 36.

#### **ANALYSIS**

The Board carefully carried out its statutory responsibility, considered and reviewed the evidence, submissions, and the law, including the criteria set out in the applicable legislation.

Dr. D'Egidio, a health practitioner, internal medicine and intensive critical care specialist, had carriage of an application for a determination as to whether or not the substitute decision makers, three of JEP's children complied with the principles for substitute decision making as set out in the HCCA with respect to the proposed treatment for JEP. Throughout my deliberations, I imposed the onus of proof upon Dr. D'Egidio. That onus was on a balance of probabilities.

By statute this type of application triggered an application by JEP with respect to his own capacity to consent to the proposed treatment unless that capacity had been determined by the Board within the previous six months. There was no evidence of any such prior determination. I found the Board had jurisdiction in this matter.

The general law relating to capacity to consent to treatment is set out in the *Health Care Consent Act* (at times referred to as the HCCA). That legislation also sets out a scheme for identifying substitute decision makers (SDMs) for incapable persons. It also described how SDMs should make decisions and the available options should SDMs not be making proper decisions.

The Purposes of the HCCA are set out at its very beginning. These include providing rules with respect to consenting to treatment, facilitating treatment for incapable persons, enhancing the autonomy of persons for whom treatment is proposed and promoting communication and understanding between health practitioners and their patients.

Furthermore, the HCCA in Section 2 requires that a health practitioner <u>must</u> (emphasis mine) determine whether a person is capable to consent to treatment. The HCCA also provided that all health practitioners must be members of their respective professional colleges in Ontario. Physicians are included as health practitioners.

By Section 15(1) and (2) capacity can fluctuate and capacity also can vary over time and in relation to the type of treatment. The determination of capacity is therefore issue and time specific. The health practitioner must look at the specific treatment or plan and determine whether the person is capable for the particular treatment.

In the event that a person has been found incapable, a substitute decision maker may give consent to treatment on behalf of the incapable person. Section 16 of the HCCA provides that if the incapable person becomes capable, the person's own decision to give or refuse consent to treatment prevails.

## JEP'S CAPACITY TO CONSENT TO THE PROPOSED TREATMENT

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

Dr. D'Egidio's evidence, including his oral testimony and medical notes filed disclosed that JEP has had his capacity assessed several times during the admission, most recently on April 24, 2017 the day prior to the hearing. Dr. D'Egidio described JEP as not alert or oriented and as unable to follow commands. The doctor said JEP was able to open his eyes and the doctor was able to induce pain in JEP's extremities. However, when JEP was asked about his medical history and condition, he was unable to respond. On April 4, 2017 the same questions were asked of JEP in the presence of a Spanish interpreter. The same answers were obtained according to Dr. D'Egidio. The doctor noted that between April 4 and April 24, 2017 JEP's condition has changed with his level of awareness improving. However, the doctor's opinion was that JEP's state with moderate advanced dementia and his other medical conditions prevented JEP from being able to process or retain information particularly the complexities of his current medical condition. Dr. D'Egidio noted however, that JEP was able to recognize his family and interact with them.

The doctor's position was that JEP was unable to understand information and was unable to appreciate the consequences of any treatments decisions. Insofar as JEP's capacity to consent or refuse consent with respect to his own treatment decisions, the evidence of JEP's incapacity was unchallenged. According to Dr. D'Egidio JEP failed both parts of the two part legal test for treatment capacity. In Dr. D'Egidio's opinion, JEP's dementia and multiple comorbidities, significantly limited his abilities to understand relevant information and to appreciate reasonably foreseeable consequences. None of the other parties took issue with Dr. D'Egidio's opinion that JEP was incapable with respect to his own treatment.

I had to remember that there was a presumption JEP was capable unless Dr. D'Egidio had reasonable grounds to believe that JEP was incapable (S4 (3) (HCCA). Dr. D'Egidio had the onus of satisfying the Board on a balance of probabilities that JEP was incapable.

Starson v. Swayze (2003) SCC 32 is the leading case in relation to the law on consent to treatment in Ontario. As set out earlier, Section 4(1) of the HCCA provides a two part test to determine whether a person is capable with respect to a treatment.

Justice Major wrote the majority opinion for the Supreme Court in the *Starson* decision. He commented upon the onus of proof required to displace the statutory presumption of capacity at paragraph 77: "I agree with the Court of Appeal that proof is the civil standard of a balance of probabilities." Chief Justice McLachlin, who wrote the dissent, agreed on this point. At paragraph 13, she wrote, "the person is presumed to be competent and the standard of proof for a finding of incapacity is a balance of probabilities."

Justice Major analyzed capacity at paragraph 78 of the *Starson* decision 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.

Before turning to an analysis of the reviewing judge's decision, two important points regarding this statutory test require comment. First, a patient need not agree with the diagnosis of the attending physician in order to be able to apply the relevant information to her own circumstances. Psychiatry is not an exact science, and "capable but dissident interpretations of information" are to be expected. While a patient need not agree with a particular diagnosis, if it is demonstrated that he has a mental "condition", the patient must be able to recognize the possibility that he is affected by that condition. Professor Weisstub comments on this requirement as follows (at p. 250, note 443):

Condition refers to the broader manifestations of the illness rather than the existence of a discrete diagnosable pathology. The word condition allows the requirement for understanding to focus on the objectively discernible manifestations of the illness rather than the interpretation that is made of these manifestations.

As a result, a patient is not required to describe his mental condition as an "illness", or to otherwise characterize the condition in negative terms. Nor is a patient required to agree with the attending physician's opinion regarding the cause of that condition. Nonetheless, if the patient's condition results in him being unable to recognize that he is affected by its manifestations, he will be unable to apply the relevant information to his circumstances, and unable to appreciate the consequences of his decision.

Secondly, the Act requires a patient to have the <u>ability</u> to appreciate the consequences of a decision. It does not require <u>actual</u> appreciation of those consequences. The distinction is subtle but important... 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 courses of action available; and the expected consequences of not having the treatment. If the patient shows an appreciation of these parameters-regardless of whether he weighs or values the information differently that the attending physician and disagrees with the treatment recommendation – he has the ability to appreciate the decision he makes.

However, a patient's failure to demonstrate actual appreciation does not inexorably lead to a conclusion of incapacity. The patient's lack of appreciation may derive from causes that do not undermine his <u>ability</u> to appreciate consequences. For instance, a lack of appreciation may reflect the attending physician's failure to adequately inform the patient of the decision's consequences. Accordingly, it is imperative that the Board inquire into the reasons for the patient's failure to appreciate consequences. A finding of incapacity is justified only if those reasons demonstrate that the patient's mental disorder prevents him from having the <u>ability</u> to appreciate the foreseeable consequences of the decision."

In terms of the first branch of the test for capacity and the Supreme Court of Canada's decision in *Starson* what considerations should be utilized to determine whether or not someone is

incapable? The Supreme Court of Canada in *Starson* (paragraph 78) stated that the ability to understand relevant information required that JEP had the cognitive ability to process, retain and understand the relevant information. I found that JEP lacked that cognitive ability. The medical evidence was such that JEP's abilities to both understand relevant information and appreciate reasonably foreseeable consequences were severely compromised by his significant mental and medical conditions. In my further consideration of the first branch of the test I examined the statutory phrase "relevant information".

Starson directed (paragraph 80) that "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 proposed treatment
- The foreseeable benefits and risks of treatment
- Alternative courses of action available
- Expected consequences of not receiving treatment"

Dr. D'Egidio's evidence of JEP's incapacity with respect to treatment was clear, cogent, compelling and unchallenged. I found JEP was unable to understand or appreciate in terms of the test for capacity. He had no actual appreciation of the parameters of his treatment decisions. I agreed with Dr. D'Egidio's opinion that JEP's significant mental and physical conditions severely impaired any ability to understand information relevant to treatment decisions. I found JEP was not able to understand information that was relevant to making a decision about any treatment proposed for him. On the basis of this first part of the test, JEP was not capable with respect to any treatment proposed by Dr. D'Egidio.

*Neto v. Klukach*, [2004] O.J. No. 394, was a decision of Day, J. of the Ontario Superior Court of Justice dated February 10, 2004. In that decision, which was an appeal of a decision of this Board, the Court explained the second branch of the test for capacity (i.e. the ability to appreciate consequences) in light of *Starson*, as follows:

The second branch assesses the ability to evaluate, not just understand, information. The patient must have an ability to appreciate the relevant information as it relates to him or her.

The unchallenged evidence I received supported the conclusions of Dr. D'Egidio that JEP was also incapable with respect to his proposed treatment on the basis of the second branch of the test. JEP was unable to evaluate and therefore lacked the ability to appreciate that he was in fact suffering from manifestations of and the consequences of his significant mental and physical conditions. JEP's inability to evaluate information concerning the proposed treatment as it related to his own circumstances rendered him incapable to make a decision concern his treatment.

The evidence to support a finding of incapacity was clear, cogent and compelling. JEP had no comprehension about his need for treatment because in his mental and physical state he was unable to process, evaluate, concentrate or focus. JEP lacked insight into his conditions which rendered him unable to appreciate the information relevant to making a decision and appreciate the consequences of a decision or lack of decision. As a result of his inability to recognize he suffered from the progressively worsening dementia, his significant medical conditions and their effects on him, JEP also lacked the ability to appreciate the consequences of any treatment decisions. I found JEP was incapable with respect to the proposed treatment.

#### FORM G-TREATMENT COMPLIANCE APPLICATION

The legal consequence of JEP being incapable of making his own treatment decisions meant that consent may be given or refused on his behalf by a person described in Section 20 of the *Health Care Consent Act*. JEP as the incapable person had a Power of Attorney for Personal Care. He initially appointed his late wife RE and then three of his children jointly as his attorneys for personal care and therefore his substitute decision makers.

Where substitute decision makers (SDMs) consent to treatment on an incapable person's behalf and the health practitioner is of the opinion that the SDMs did not comply with s.21 (HCCA), the health practitioner may apply to the Board. This was the Form G application brought in this case. In determining whether the SDMs complied with s.21, the Board may substitute its opinion for that of the substitute decision makers. If the Board determines that the SDMs did not comply with s.21, it may give them directions, applying s.21 (s.37 (4)). The Board is required to specify

the time within which the direction must be complied with. If the SDMs do not comply with the Board's directions within the time specified by the Board, they shall be deemed not to meet the requirements of ss.20 (2) (s.37 (6)). If under ss.(6), the SDMs are deemed not to meet the requirements of ss.20(2), any subsequent SDM shall, subject to ss.(6.2) and (6.3), comply with the directions given by the Board on the application within the time specified by the Board (s.37(6.1)).

Conway v Jacques 2002 CanLII 41558 (ON C.A.), (2002), 59 O.R. (3d) 737, was an appeal from the Consent and Capacity Board in which the Court of Appeal discussed the principles for substitute consent to treatment. The case addressed psychiatric medication rather than end of life decision-making. Justice Sharpe's analysis is on point and binding:

"[30] Ontario's *Health Care Consent Act*, 1996 is the legislature's response to the successful *Charter* challenge in *Fleming*. The Act requires close attention to the patient's wishes by those who make treatment decisions on the patient's behalf. The wishes of the patient are to be considered by the substitute decision-maker at two stages under the Act:

1) in acting in accordance with a prior capable wish applicable to the circumstances pursuant to s. 21 (1) 1; and 2) in determining the incapable person's best interests pursuant to s. 21 (2) where there is no prior capable wish applicable to the circumstances.

[31] At the first stage, the substitute decision-maker must act in accordance with a wish expressed while capable that is applicable to the circumstances. However, I agree with the appeal judge that prior capable wishes are not to be applied mechanically or literally without regard to relevant changes in circumstances. Even wishes expressed in categorical or absolute terms must be interpreted in light of the circumstances prevailing at the time the wish was expressed. As Robins J.A. held in *Fleming* at p. 94:

In my view, no objection can be taken to procedural requirements designed to determine more accurately the intended effect or scope of an incompetent patient's prior competent wishes or instructions. As the Act now stands, the substitute consent-giver's decision must be governed by wishes which may range from an isolated or casual statement of refusal to reliable and informed instructions based on the patient's knowledge of the effect of the drug on him or her. Furthermore, there may be questions as to the clarity or currency of the wishes, their applicability to the patient's present circumstances, and whether they have been revoked or revised by subsequent wishes or a subsequently accepted treatment program.

[32] At the second stage, the substitute decision-maker must decide whether or not to consent to treatment on the basis of the best interests test under s. 21 (2). Under s. 21 (2) (b), the substitute decision-maker must take into account "any wishes expressed by the incapable person with respect to the treatment that are not required to be followed under

s. 21 (l) 1", namely any wishes that are not prior capable wishes applicable to the circumstances. It is only at the second stage that the Act allows for consideration of the decision the patient would have made in light of changed circumstances.

[33] The appeal judge held that the Board failed to consider whether Paul Conway would have consented to the anti-psychotic medication suggested by Dr. Jacques if he had been capable of giving or refusing consent. In my respectful opinion, that is not the test mandated by the Act for determining whether a prior capable wish is applicable to the circumstances. To require the substitute decision-maker or the Board to consider what the incapable person would have decided in light of changed circumstances would replace the two-stage test mandated by the Act with a different test that is not supportable under the language of the Act. Paul Conway's prior capable wish was either applicable to the circumstances or not applicable to the circumstances. If a prior capable wish is not applicable to the circumstances, the question for the substitute decision-maker is not what the patient would have decided in light of the change, but rather what is in the best interests of the patient. I would therefore reject the analysis of the appeal judge and his conclusion that the Board erred in law and failed to make a crucial factual finding".

In Dr. D'Egidio's view both the health care team and JEP's substitute decision makers had different views of JEP's wishes, their application and his best interests.

## **JEP's MEDICAL CONDITION**

Dr. D'Egidio's evidence disclosed that JEP has required and received advanced medical therapy for months in hospital. In spite of that full medical therapy, JEP required admission to ICU on two occasions since his admission to hospital in January 2017, requiring intubation and placement on a mechanical ventilator. Dr. D'Egidio's evidence was that although JEP received Level 3 intensive care, the highest possible level of care, JEP, was as of the hearing in multiorgan failure as previously described. However, notably according to the doctor, JEP was as of the hearing no longer in ICU, but had been transferred to the AMA step down unit. Medical opinion was JEP would worsen again, at some unknown point in time.

The doctor was aware of JEP's wishes, to receive full life sustaining treatment regardless of the pain or discomfort that it would cause him. However, the doctor's opinion was that it was futile here to provide JEP with full active treatment as JEP was dying and the standard of care and what would be in JEP's best interests would be the palliative care plan proposed. The doctor testified that the proposed plan could potentially extend JEP's life and definitely could improve

the quality of his remaining life. The doctor appeared to acknowledge under questioning that JEP would have been dead by the hearing date had a palliative care plan been in place, which to be clear did not include CPR, or escalation of care, cessation of dialysis, and no ventilator support. All of these therapies have been received by JEP as part of the treatment he has continued to receive as of the hearing and I found helped keep JEP alive. The doctor noted that to the date of hearing and with full supports including CPR, JEP has not suffered physical harm from for example CPR being used on two occasions.

Dr. D'Egidio candidly testified that he was required to offer CPR according to the policy of his professional College, the College of Physicians and Surgeons, filed, and the doctor required consent to be given in order to withdraw CPR. The doctor's position was that here, CPR was not being proposed as not in JEP's best interest and was contrary to his treatment team's belief around the standard of care required in the circumstances.

The medical opinions expressed through Dr. D'Egidio and supported by reports filed were that JEP was viewed as a person who was dying but was being subjected to treatments that were not going to change the ultimate outcome and were futile. The medical opinions were that subjecting someone to treatment that caused pain, discomfort and suffering without any benefit for improving outcome was the issue. The SDM's position as I found from the evidence was that they were only trying to adhere to their father's prior capable wish, applicable to the circumstances in their view. Clinical records filed and Dr. D'Egidio's oral testimony revealed that communication between the treating team and substitute decision makers continued to disclose clearly divergent opinions on proposed treatment for JEP. However, from the evidence I found there were consistent opinions from all parties that JEP was suffering from a form of dementia that impaired his mental functioning and that would not improve. In addition, I also found the parties were in agreement that JEP was approaching the end of life.

Did the substitute decision makers apply JEP's known capable wishes about his treatment when making decisions about the proposed plan of treatment?

Dr. D'Egidio acknowledged there were prior expressed wishes by JEP. The question in the doctor's view was whether the wishes were applicable here and whether they could be followed, In the doctor's view if the wishes were not applicable or it was impossible to follow them, then the SDM's were required to act in their father's best interests.

Dr. D'Egidio and the written evidence of other health care professionals, and various statements of JEP's family and friends all noted that JEP appeared to want any form of life sustaining treatment regardless of the pain or discomfort that it would cause. That was clear.

JEP had completed a Power of Attorney for Personal Care. Three of his children were his chosen Attorneys for Personal Care. There were no specific instructions or directions in that document. However, a number of statements from family members and friends were filed at the hearing. The authors of these statements were not subjected to questioning at the hearing.

JEP's eldest daughter ARE, one of his SDM's wrote on April 16, 2017 while JEP was in ICU:

"I am the eldest of the eight children of JEP. Along with two other siblings (JEA and ABE) I was entrusted with the duty of Power of Attorney for personal care and substitute decision-making by my father.

After entering hospital with pneumonia in January, my father now finds himself in Bed#8 of the Civic Hospital ICU, where he is receiving treatment (ventilation, dialysis, NG feeding) for various serious and likely terminal medical problems. He was in a comatose state for several weeks in ICU. He recovered from the coma, and regained: ability to breathe by himself; awareness of surroundings, capacity to communicate (at first nodding or shaking head to yes-no questions, subsequently, speaking a few words at a time), and some movement in fingers and toes. He was then moved to the Advanced Monitoring Area, where, after three days, he suffered a respiratory arrest and had to return to ICU. Currently he requires ventilation, but remains aware of surroundings and able to communicate by replying to yes/no questions, moving his head and eyes. I do not know that he will be able to recover further than this. I am aware that it is likely that my father's health problems will lead to the end of his life - all of us, including my beloved father, are mortal.

When my father was in a coma, his POAs repeatedly expressed to doctors at the Civic Hospital, both verbally and in writing, our unanimous position that our father wishes to continue to receive treatment. We have repeatedly refused to consent to discontinuing treatment, removing life support, or moving to palliation or comfort care, knowing that these actions would be against our father's wishes. We also know that our position is entirely consistent with his life-long values and beliefs. Although he is no longer in a

comatose state, he still has a cognitive impairment and is unable to speak with a breathing tube in his mouth. Since he is unable to advocate on his own behalf, I am duty bound to do it for him.

These are the reasons I refuse to consent to doctors withdrawing medical treatment or life support; and insist that he be provided with CPR if his heart should fail:

- 1. He has spoken to me about his beliefs in the sacredness of life, the value that life has in and of itself, innumerable times in the 63 years I have been his daughter. From a scientific, humanist (and, in the later year of his life, from a consciously Catholic) perspective, this has been his clearly expressed and unwavering position.
  - My father's belief is that life has laughter and it has tears; it has joy and it has suffering; it has pleasure and it has pain. It also always has inherent value.
- 2. He believes strongly that it is the duty and obligation of society, and of all human beings who are worthy of their humanity, to preserve the life of others. This duty is especially strong when others are vulnerable (be it because they are weak, poor, ill, powerless, elderly, handicapped, prematurely born, or comatose). This duty to preserve life should also be what guides the actions of doctors, who are placed in a position of unique power over life and death by their fellow human beings in the 'social contract' we make with each other. The most recent conversations I had with my father on this subject were a few months ago, when debates about Canada's 'medically assisted death' legislation were in the daily news. The position he expressed was unwavering and clear, not only around 'medically assisted death', but also on the importance of preserving and extending human life on all occasions, because life in itself has value.
- 3. His beliefs are not only philosophical or ideal: he has acted upon them many times. A few examples include:
- The heroic fight he waged to extend the life of my terminally ill mother (with her full support and consent in this, as in almost every other important life subject, my parents were of one mind and one heart), against the advice and pressure from many Ottawa Hospital doctors. He chose to sell the family home to finance experimental treatments that were not offered to my mother in Canada, due to her condition and her age. Her final days were not without suffering, but they were considered by him and by her to be an ineludible part of the path of life that God had asked her to walk, and on which He also accompanied them both. I am sure details of this will be offered also by others. During my mother's illness, I kept a diary. I am attaching the text of an entry I made on March 15, 2013 in relation to a family meeting we had with Dr. Tom Forman, the ethical decisions consulting director at the cancer centre, in which end-of-life decision-making was discussed with my father. My father was adamant in insisting that my mother's autonomy her right to make her own choices about what she wanted done be respected; and also, that the hospital staff respect her wishes

- about who would be her substitute decision maker if she were to become incapable of making decisions. Appendix 1)
- The intellectual, material and moral support he provided to his friend CG, whose wife was in a coma in an intensive care unit for at least three years, to encourage and enable him to continue supporting her care and extending her life. I had several opportunities during those years to hear my father state, from a scientific perspective, that one cannot with any certainty know that a person in a coma, even in a deep coma, has no awareness; therefore, while a comatose person is alive, they must be treated with all the care and support that one would provide to any other ill human beingeven more, because they are not able to actively advocate on their own behalf. This included doing everything possible to extend their lives. I am attaching separate documents describing this in more detail. (Appendix 2)
- The unhesitating actions taken when his seventh child was born, prematurely, with what was considered a terminal cancer. Rather than agreeing with medical advice to let him die, since he 'has six other children already', my father (with my mother's complete participation and support) took that newborn to the United States and, at great financial and personal cost, obtained for him what were then experimental and extreme treatments which have extended, until today, a life that was deemed not worth saving.

These are some of the more dramatic instances, but my father has assisted and supported the preservation of life in many similar situations over the years.

My father has never signed a 'Living Will'; neither did he make any specific requests in the Power of Attorney document in which he asks me and two siblings to act on his behalf in terms of personal care. To write down those detailed instructions would be foreign to both his culture and his character: He has complete and total faith that his children know what he wants done, not only because he brought us up to understand his beliefs and values, but also because he expressed what he wants on many occasions: he wants to have all medical interventions possible to extend his life for as long as possible. The last time he communicated something about this wish to me was a few days after his hospitalization. I had been approached by staff, in his presence, to ask what my father's instructions were regarding resuscitation- they appeared to be surprised when I stated that he wanted to be resuscitated. I asked them to put that note in the chart, and confirmed with my father that that was what he still wanted- he said yes, of course. To make sure that this was clear, I wrote a note with red marker on a sheet of paper, showed it to my dad (who gave it a 'thumbs-up'), and taped it to the wall above his bed. That note accompanied him when he moved to different rooms in the hospital, but was removed when he was transferred to the ICU. I believe there is a photo of him in a hospital room which shows that note. The note says "YES, RESUSCITATE".

To summarize: I am fully and entirely convinced that I know and am acting upon my father's wishes, which are consistent with his values and beliefs. On my father's behalf, I

refuse consent to the doctors' request to remove treatment or life support. On my father's behalf, I refuse consent to him being placed only on 'comfort' or palliative care."

# ABE, another of JEP's children and an SDM wrote:

"My understanding of Father's wishes, values and beliefs I am the third-born child, 60 years old. I believe I know my father well. Not only did I live the first 19 years of my life in the family home, but also I lived most of my adult life in the same city (Quebec), where I raised my children and spent a lot of time with both my parents, who I saw nearly every week-end, generally at our home or theirs.

After Father and Mother's retirement, they sold their home and lived with my husband, myself and our younger child for about 9 years, from 2001 to 2010. We saw each other on practically a daily basis (except when travelling). Father named three of his eight children, including myself, as substitute powers of attorney for personal care should his wife predecease him and he be unable to take decisions, including consent to treatment. The Power of Attorney for Personal Care document contains no specific conditions or restrictions, no specific instructions and no special provisions. I conclude from this that he saw no need to do so and that he has complete and absolute trust in the persons he named to take decisions for him as his substitute decision makers according to his wishes, beliefs and values, as well as his best interests. Throughout his life, Father has made great efforts to seek treatment and prolong the life of family members, including his seventh child, Antonio, born prematurely with cancer, his nephew El Pibe (nickname) who lived in our home for many months while Father investigated possible cures for his growth hormone deficiency, his sister Isabel, who he brought to Canada for cancer treatment when other options had been exhausted (all of these at a time when there was no public health plan, therefore assuming the burden personally). He also made multiple trips back to the home country to actively seek medical treatment for ailing or dying family members; including his own parents (his father had dementia at the end of his life). Father has always said "Donde hay vida, hay esperanza" (Where there is life, there is hope). This exemplifies his attitude of respect for life and the struggle to protect and prolong life as a value in itself, even in the most adverse of situations where others may have given up all hope.

Another expression which he has used regularly over the years upon waking up is "Otro difta mas", celebrating the dawn of a new day, one more day of life. He often has reminded me, and others, that life is not just happiness, but that pain, sorrow and suffering are an integral part of living. A video message to family members which he recorded on the day of his 85th birthday, with technical assistance from some of his children, amply illustrates this. As a research scientist in the field of medicine, he has always valued knowledge and has never been afraid of novel medical treatments or procedures, once the traditional options have been exhausted. Both in the case of my brother Antonio, when he was a baby, and in the case of mother, ill with cancer, he availed himself of all resources available, seeking various medical opinions, weighing the options, traveling to other countries where treatments not available in Canada were being offered. He has been a fighter when it comes to medical treatment, seeking to prolong the

life of loved ones not only with ordinary medical measures, but extraordinary ones. Where there is life there is hope and it is worth struggling even if to live just one more day. There is no reason for me to think that his beliefs or values have changed in recent weeks or that they do not apply to his present situation. I have the profound conviction that his wishes for himself and for others are exactly the same and that he has always done unto others as he would have them do unto him. Father is Roman Catholic. He took the decision to convert when he was about 40 years old, was baptized, received Confirmation and celebrated a religious wedding to his wife of many years (to whom he had been married since the age of 21 following a civil ceremony). His faith, a source of strength, has never interfered with his career as a scientist nor in his search as an individual for knowledge, truth, and justice. In recent years, during mother's illness and since her passing, he has become more devout. For example, he has been going to Church at Iglesia de la Sagrada Familia (when transportation can be arranged with a family member or caregiver), reading every morning the story of the "Saint of the Day" in a book, in Spanish, that he greatly treasures, taking communion once a week at home (an arrangement made by his Parrish priest (Father Lopez) who noticed last year that he was unable to go to Church as frequently as before and called him to find out how he was). He has also been greatly interested in the words and actions of the Head of the Church, Pope Francis, who has shown deep concern for the plight of the most fragile members of society, those who cannot speak for or defend themselves, including children, the poor, the sick and the elderly. He has systematically expressed indignation at the idea that medical treatment, including life support, should be denied to or withdrawn from any individual, whatever his or her age or condition, or their death expedited by any means. A few years ago, he was very troubled that the life of a friend who had been fighting cancer had been prematurely ended, possibly against her wishes. He decided to discontinue his friendship with the husband of the deceased, unable to reconcile their differences of opinion on such a fundamental issue. In another instance, he and mother provided continued support to the wife and family of another friend who continued to struggle against all odds against cancer and survived several years more than anticipated by the medical team that was treating him. As a practicing Catholic, father believes that life is a gift given by God and it is a duty to do everything to preserve it. For these reasons, he has always been firmly opposed to the death penalty, abortion, euthanasia and, more recently, "medically assisted death", which is abhorrent to him. In addition to what his faith dictates, Father is a proponent of aggressive medical treatment and has always sought all treatments available, including experimental procedures, when other avenues have been exhausted."

## Another child, JAE, wrote on March 20, 2017:

"Both my father and mother have stated in many different settings that they would want to live and maintain life with any means possible. This is espoused not only by the values and beliefs and wishes they expressed but also by their own actions through their lives together.

In regards to my father, one can witness his words and wishes directly transferred to action by the constant application of these beliefs, values and actions upon many challenging health issues that have crossed his path.

One of the most recent is my mother's diagnosis of terminal cancer where they agreed and spend much personal resources to ensure that all options where explored and acted on. This included surgical procedures in Baltimore (given the refusal of treatment due to the age of the patient by the Canadian healthcare system) as well as experimental treatment in Germany. Unfortunately she passed away at the Ottawa hospital in 2013. But not without a very difficult and painful battle to life to the last possible breath and pulse. On a personal note, I was born in 1967 with neuroblastoma (including mets in the liver) at a premature 7 months. Being the 7th child (today of eight siblings), the doctors questioned the validity of attempting to prolong my life given my parents already had six children. As a testament to their values and beliefs and actions I write to you today in the privileged position to express to you that I have been with, seen and discussed with both of my parents their own desires and wishes. They reflect, in no uncertain circumstances, their wish to ensure life at any cost is worth maintaining, including their own."

## On March 20, 2017 another child JE wrote:

"I agree completely with the decision to oppose any application to the consent and capacity board purporting to withdraw life supporting measures for Father. Father had profound and unequivocal moral convictions with respect to the value of life. I do not doubt for a second that in furtherance of that conviction he would vigorously oppose withdrawing such measures for any person he loved. I have listened to Father speak at length and with clarity and passion why he felt it was vitally important to weigh the cruel finality of death against what he perceived was the far greater moral imperative to preserve life. Father was particularly critical with respect to end of life decisions regarding the elderly. He felt that greater vulnerability at the end of life required even higher vigilance for the protection and preservation of life. Our Father unfortunately had to deal with the harsh reality of our Mother's ordeal with cancer only a few years ago. All efforts to preserve her life were pursued including experimental surgery in Germany despite advice from medical professionals who repeatedly urged palliative care. Father's beliefs and values were not merely philosophical musings or abstractions divorced from the reality of life but tested in the intense crucible of his most intimate relationship. "

# AEP a daughter wrote on March 21, 2017:

"To whom it may concern, My name is AEP, I am one of JEP's daughters. Over the past 53 years I have not only lived with him as a child and young teenager but also more recently as an adult, for a couple of years, with my spouse and child when my mother passed away in 2013.

My father is a Neuropathologist with a PHD from Stanford University who worked at NASA, and then taught medicine and did research at Laval University alongside my

mother. It was only later in his life, in his 30's, that he discovered his spiritual faith. Both my parent's medical knowledge, determination and faith is what saved my younger brother's life as a child. Had my parents followed what the medical team at the time wanted to do, essentially let him die, my little brother would not be here. They instead drove down to Boston where his life was saved. He has always believed and said that "where there is life, there is hope".

I have personally had discussions with my father in which he has expressed his wish for life preservation, no matter what. Not only have we talked about it, but I have also witnessed this with regards to the continued medical treatment my mother received up to her passing in 2013. My father doesn't believe in palliative care, he believes life is precious and all efforts that could be made to preserve it must be taken.

It is my deepest belief that my father's POAs are unequivocally acting as my father has asked them to. I would find any other cessation of treatment would be against my father's wishes. "Where there is life, there is hope." "

A son, LE wrote on March 20, 2017:

"To whom it may concern, I have direct knowledge of my Father, JEP's, values and beliefs.

His fundamental value and belief is that he should not be allowed to die under any circumstance and that life should be prolonged with aggressive medical treatment, even if the resulting quality of life is poor, and even if there is no reasonable expectation of recovery. What is more, he holds this belief for all persons, not only himself.

I know of this because of the numerous conversations I have had with him over the course of my life on this subject, most notably during the more than 27 years that I lived with him from 1970 to 1998, and more recently in relation to the medical treatment and subsequent passing of my mother, RE. He expressed many times that both her and his values and beliefs were essentially as I have outlined above.

More specifically, on numerous occasions, he very clearly stated that in his view, any doctor that, either by action or inaction, causes the death of a person is violating a fundamental principle of the hypocratic oath: noxamvero et maleficium pro pulsabo (I will utterly reject harm and mischief), or as is it is often paraphrased prim urn non nocere (First do no harm).

Thus his values and beliefs are so deeply rooted that they not only apply to his own life, to his spouse, but to all human life.

Given the fact that my Father taught medicine and did fundamental research in the field of neurpathology, and helped form medical doctors for decades, the mere possibility that anyone should question my Father's values and beliefs, as stated by those who he designated with power of attorney for such matters, precisely when he is at his most vulnerable, is quite disturbing, to say the least."

JS, JEP's son-in-law wrote on March 20, 2017:

"To Whom it May Concern, I have known JEP, for close to 40 years. He has been my Father-in-law for over 37 years. In the conversations that I have had with him about the progress and passage of life, the provision of medical services to support life by all means has been core to his beliefs and discussions on medical ethics.

These values were held by him and his wife REF, who passed away in 2013. Both REF and JEP held as sacrosanct the belief that as medical doctors they had a moral, professional, and spiritual obligation to maintain and continue life as long as medically possible, for others and for themselves.

His attachment and belief to continuation-of-life principals were first and foremost when it came to prolonging REF's life. He supported every possible medical intervention available in helping REF in her struggle with cancer, and in the conversations he has had with family over the last year, he has made it abundantly clear that he wished that same approach to be taken with his own life: he insisted that every medical option available to be used in keeping him alive, regardless of his medical condition; and that those medical options be exercised until the moment of his death.

Those were his wishes and that was his attitude regarding the progress of his life as I remember and recall.

JT, JEP's daughter-in-law wrote on March 20, 2017:

"To whom it may concern, JEP never spoke to me about his end of life personal wishes but I can attest that he has made everything he could to keep his wife alive as long as he could, even when she was in a coma following a fight with cancer. He asked that she be revived after she went into cardiac arrest after this very long fight. She was revived and lived for a few days after that. I am sure he would have wanted the same standard of care for himself. "

MEP, JEP's daughter-in-law wrote on March 20, 2017:

"To whom it concerns, my name is MEP, and I am writing in support of the expressed wishes my kind-hearted father-in-law JEP. Since 2005 I have been a part of the family, and AP is my spouse. During those years I have been close with my in-laws, including living with AP's dad (with AP and our son) for approximately two years very recently.

I can say, without a doubt that my father-in-law's expressed wishes at this crucial time in his life would be to do all that was necessary to keep him alive. He has said this numerous times over the years, directly to me (and I have overheard him say it to Ana) with him indicating a wish for preservation of life. His life. For his children.

For his grandchildren, including our son MP whom JEP is very close with, and for his great grandchildren.

On a personal note I am not fond of lying, so please know that these words are written with great respect about a remarkable man, my father-in-law.

NS, JEP's granddaughter-in-law wrote on March 20, 2017:

"To whom it may concern, I am writing this today to attest that my grandfather on numerous occasions throughout his life indicated to me that in the event of a coma or other event where he was unable to advocate on his own behalf, he strongly wanted to be kept alive as long as possible. Both of my grandparents on my mother's side believed that human life of any kind was precious, and I distinctly remember having these conversations with him and with my grandmother from a very early age. It was a deeply held, philosophically rooted belief for both of them."

There were other statements filed as Exhibits.

In Dr. D'Egidio's opinion the proposed palliative plan would improve JEP's condition and well-being which did not mean life itself. Dr. D'Egidio's further opinion was that the current plan merely prolonged JEP's dying process and suffering.

Dr. D'Egidio acknowledged that JEP's family were not praying for miracles. He noted they recognized that JEP was dying. He testified that they were insisting on Full Code status because they were respecting JEP's wishes, values and beliefs. However, he said, these were now impossible to respect because they violated physician ethical principles. The doctor agreed the wishes were still possible to follow, they should however, not be followed as wishes, because he believed they were causing JEP harm. Dr. D'Egidio acknowledged that CPR and dialysis provided in hospital have both been instrumental in saving JEP's life, though he argued they also provided harms to him. In the doctor's view, there were less intrusive interventions that could help keep JEP alive. The doctor said the goal of palliative care would be to extend JEP's life as much as possible with minimal suffering and let JEP pass naturally. The doctor acknowledged that JEP wanted to continue his life. In the doctor's view, patients could not dictate treatment,

that full treatment here was medically futile, not medically effective that JEP would die regardless. In Dr. D'Egidio's view he could not be required to act outside of the standard of care for JEP. The doctor believed that what he was being asked to provide, by following JEP's wishes was morally and ethically at odds with his physician's oath to do no harm.

Counsel referred me to case law including the Ontario Superior Court decision in Scardoni v. Hawryluck 69 O.R. (3d) 700, Board decisions in DW (HA-10-4434, 4435) and SL (16-0402)) and the Supreme Court of Canada decision in Cuthbertson v. Rasouli 2013 SCC 53. I reviewed all case law carefully.

What bears repeating at this point was the Purposes of the *Health Care Consent Act* ("HCCA"). These included providing rules with respect to consenting to treatment, facilitating treatment for incapable persons, enhancing the autonomy of persons for whom treatment is proposed and promoting communication and understanding between health practitioners and their patients. The Board took this to include substitute decision makers who make decisions on behalf of incapable persons.

The HCCA provided that subject to an emergency situation arising in limited circumstances treatment cannot be given without the requisite consent having been obtained. That consent can only be obtained by the health practitioner from either a patient, if capable or if incapable, from the patient's substitute decision maker(s) (S10, HCCA)

The HCCA codified the common law principle of requiring that consent be informed (S11 HCCA). In that regard, consent must relate to the treatment, be informed and given voluntarily without being obtained through misrepresentation or fraud (S11 (1) HCCA). As well as the information about the treatment which must be given whenever treatment is proposed (S11 (2) HCCA), where consent of an SDM is sought on behalf of an incapable person, as here, the health practitioner is also required to provide certain information about the law. The Ontario Court of Appeal has interpreted the requirement to obtain consent "in accordance with this Act" as imposing a statutory obligation on health practitioners to ensure that SDM's understand the criteria specified in Section 21 of the HCCA when deciding whether consent for a proposed

treatment should be given or refused (M. (A). v. Benes 46 O.R. (3d), 271 (Ont C.A) at paras 18, 19, 20 and 21).

M. (A). v. Benes was a Court of Appeal decision on appeal from the Consent and Capacity Board. The case involved psychiatric treatment but also contains general principles applicable to any review by the Board of treatment decisions made by substitute decision-makers.

"[18] Assuming, however, that Sutherland J. had jurisdiction to consider the notice issue, counsel for the Attorney General submits, correctly in our view, that properly construed, s. 10(1) (b) of the <u>Act</u> imposes a statutory obligation on health practitioners to ensure that S.D.M.'s understand the criteria specified in <u>s. 21</u> of the <u>Act</u> when deciding whether consent to a proposed treatment should be given or refused. That provision reads:

10. (1) A health practitioner who proposes a treatment for a person shall not administer the treatment, and shall take reasonable steps to ensure that it is not administered, unless,

. . .

(b) he or she is of the opinion that the person is incapable with respect to the treatment, and the person's substitute decision-maker has given consent on the person's behalf in accordance with this <u>Act</u>.

# [Emphasis added.]

[19] For reasons which need not be detailed, Sutherland J. refused to interpret <u>s. 10(1)(b)</u> in the manner suggested by the Attorney General. In short, he construed the words "in accordance with this <u>Act</u>" narrowly and restrictively and found that they did not impose a statutory obligation on health practitioners to ensure that S.D.M.'s understand the requirements of s. 21 of the Act.

[20] With respect, we are of the view that Sutherland J. erred in his approach to the interpretation of <u>s. 10(1)</u> (b). In particular, he incorrectly applied the principles of statutory interpretation to the words "in accordance with this Act."

[21] The first of those principles is found in Rizzo v. Rizzo Shoes Limited (R.E.), <u>1998</u> CanLII 837 (SCC), [1998] 1 S.C.R. 27, where, at paragraph 21, Iacobucci J. adopted the following passage from Driedger's Construction of Statutes (2 ed.1983):

Today there is only one principle or approach, namely, the words of an <u>Act</u> are to be read in their entire context and in their grammatical and ordinary sense harmoniously with the scheme of the <u>Act</u>, the object of the <u>Act</u>, and the intention of Parliament.

At paragraph 22 of the same decision, Iacobucci J. went on to state that every <u>Act</u> shall receive "such fair, large and liberal construction and interpretation" as will best attain the objects of the <u>Act</u>.

In *Benes* the Court of Appeal held that the Board did not have to defer to a decision of an SDM just because it was made in "good faith and was reasonable." The Board had the right to review a decision by the SDM in the absence of prior expressed wishes by the incapable person. The SDM refused treatment against the recommendation of the incapable person's physician and the physician then applied pursuant to s.37 for a review of the decision. The Board found that the SDM had not complied with s.21 of the HCCA and ordered that she consent to the recommended treatment. The SDM appealed arguing that s.37 was unconstitutional because it violated the incapable person's rights under s.7 of the *Charter*. For other reasons, the court held that the section was unconstitutional. The finding was appealed to the Court of Appeal by the Attorney General of Ontario.

The evidence of JEP's expressed wishes described in Exhibits filed were unchallenged and confirmed in health practitioner reports filed based on discussions with family. This evidence was clear. The wishes disclosed that JEP, who as a highly educated and trained health practitioner spoke about his wishes with respect to end of life care. By the time of the Hearing, JEP had been discharged from ICU and was a patient in the hospital step-down or AMA Unit. He was conscious, based on the evidence and my own visit to his hospital room. The evidence disclosed he interacted with family and his care providers and recognized them. This evidence was clear.

Dr. D'Egidio testified that JEP was aware and could answer questions around pain and "simple things". Without CPR and dialysis which he has received and required twice as of the hearing. Dr. D'Egidio testified JEP would have passed away. However, according to the doctor these interventions provided more harm than benefit to JEP. There was no denying they have helped keep him alive, even if he was going through a dying process. I was not satisfied the evidence of the doctor that JEP's current treatment harmed him was clear, cogent or compelling.

I found there was a prior capable wish (Section 21(1), HCCA) expressed by JEP while capable applicable to the circumstances. There was no evidence that any wishes expressed by JEP were made when he was incapable. There was no evidence JEP had changed his wishes. I also read the Dictionary extracts for the word "express" and found that JEP expressed his wishes clearly.

If I am wrong in regard to the prior wishes, I would still find that the SDMs complied with the principles for substitute decision making on the basis of consideration of Section 21 (1) and Section 21 (2) of the HCCA. I say that because (i) there were wishes expressed by JEP, his values and beliefs were clear and considering the other factors in Section 21 (2) related to best interests, it was not clear, cogent or compelling to me on a balance of probabilities based on the evidence before me that the proposed palliative treatment plan would improve JEP condition or well-being, or prevent his condition or well-being from deteriorating, reduce the extent to which or the rate at which the incapable person's condition or well-being was likely to deteriorate. I also considered the balance of the principles set out in section 21 (2), 2, 3 and 4 in making my findings and conveying my conclusions here. I noted JEP was not in a vegetative state, unaware of his surroundings. To the contrary the evidence was that JEP was more aware and interacting with those around him. Dr. D'Egidio spoke of JEP being able to respond to simple questions.

I considered the case law referred to, particularly the Supreme Court of Canada decision in Rasouli. I noted the discussion of well-being in Scardoni. The other cases did not consider prior capable wishes.

I again noted parts of the Purposes provisions in the HCCA. These were referred to by McLachlin, C.J in writing for the majority in Cuthbertson v Rasouli 2013 SSC 53:

"[24] The purposes of the [Health Care Consent] Act are:

(c) to enhance the autonomy of persons for whom treatment is proposed, persons for whom admission to a care facility is proposed and persons who are to receive personal assistance services by,

3. (iii) requiring that wishes with respect to treatment, admission to a care facility or personal assistance services, expressed by persons while capable and after attaining 16 years of age, be adhered to;"

Chief Justice McLachlin went on to write in Rasouli as follows:

"[26] The substitute decision-maker does not have a free hand to grant or refuse consent at will. She must respect prior applicable wishes of the patient expressed while the patient was capable: s. 21(1). If there are no such wishes, the substitute decision- maker must decide based on the best interests of the patient, taking into consideration a series of mandatory factors relating to the medical condition, well-being, values, and wishes of the patient: s. 21(2).

[27] The HCCA does not neglect the role of health practitioners in the treatment of incapable patients. First, where there is a prior wish by the patient, the attending physician may ask the Board to find that the wish is not applicable to the patient's current circumstances (s. 35), or to permit a departure from the wish because the likely result of treatment has significantly improved since the wish was made: s. 36.

Second, if the physician feels that a substitute decision-maker has not complied with the HCCA's rules for giving or refusing consent to treatment, he may challenge the consent decision by application to the Board: s. 37. Such a challenge will generally focus on medical considerations within the s. 21(2) best interests' analysis. The physician's views of what will medically benefit the patient are obviously critical to the Board's determination of the patient's best interests. However, the HCCA gives the Board final responsibility to decide disputes over consent to treatment for incapable patients, based on an objective assessment of whether the substitute decision-maker complied with the requirements of the HCCA.``

Dr. D'Egidio had carriage of the type of application the Chief Justice wrote about.

The Chief Justice continued at paragraphs 36, 37, 39, 40, 41 in Rasouli:

"[36] The concept of "medical benefit" is a clinical term used by physicians to determine whether a given procedure should be offered to a patient. This clinical term has legal implications for the physician's standard of care. If a treatment would be of medical benefit to the patient in this sense, the physician may be required to offer that treatment in order to comply with his standard of care. Whether a given treatment offers a medical benefit requires a contextual assessment of the patient's circumstances, including the patient's condition and prognosis, the expected result of treatment for that patient, and any risks of treatment for that patient: A.F., at para. 44.

- [37] The concept of "health-related purpose", by contrast, is a legal term used in the HCCA to set limits on when actions taken by health practitioners will require consent under the statute. "Treatment" is "anything that is done" for one of the enumerated purposes (therapeutic, preventive, palliative, diagnostic and cosmetic) or "other health-related purpose". Under the HCCA, only acts undertaken for a health-related purpose constitute treatment, and therefore require consent. The concept of health- related purpose in the HCCA does not interfere with a physician's professional assessment of whether a procedure offers a medical benefit. Its only function is to determine when the actions of health care practitioners require patient consent.
- [39] The wording of the HCCA does not limit "health-related purpose" to what the attending physician considers to medically benefit the patient. The HCCA does not use the terms "medical benefit" or "medically indicated". The legislature could easily have taken this approach but instead chose to define "treatment" more broadly with a wideranging and non-exhaustive list of health-related purposes.
- [40] 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).
- [41] The New Oxford Dictionary of English (1998) defines "therapeutic" as "relating to the healing of disease", but also as "having a good effect on the body or mind" (p.1922). Maintaining life support for Mr. Rasouli does not serve the purpose of "healing of disease". However, it can be argued that maintaining life support has a "good effect on the body", in the sense of keeping it alive."

As the Chief Justice noted in paragraph 41 "maintaining life support for Mr. Rasouli does not serve the purpose of "healing of disease". However, it can be argued that maintaining life support has a "good effect on the body", in the sense of keeping it alive". This was a particularly powerful statement.

The Chief Justice continued in paragraph [42], [43], [51] and [68] of Rasouli.

- "[42] The same dictionary defines "preventive" as describing a medicine or other treatment "designed to stop disease or ill health from occurring" or "designed to keep something undesirable such as illness, harm, or accidents from occurring" (p.1469). If death is considered harmful or a manifestation of ill health, then life support serves a preventive purpose so long as it is effective in preventing death.
- [43] Inclusion of life support in "treatment" is also generally supported by the objects of the HCCA. It provides consistency with respect to consent, protects autonomy through

the requirement of con-sent, and provides a meaningful role in the consent process for family members. An interpretation of "treatment" that is confined to what the medical caregiver considers to be of medical benefit to the patient would give these statutory purposes short shrift. The legislature cannot have intended such a crabbed interpretation of "treatment".

- [51] The objects of the HCCA also support the view that "treatment" may include withdrawal of treatment. The values of autonomy-critical where life is at stake-and providing a meaningful role for family members support regarding withdrawal of life support as "treatment" requiring consent. These values must be balanced against that of ensuring appropriate care for incapable patients. The HCCA aims to strike the right balance among these values. Its purposes would be ill served by an interpretation that holds withdrawal of life support cannot constitute "treatment" under the Act.
- [68] In summary, withdrawal of life support aims at the health-related purpose of preventing suffering and indignity at the end of life, often entails physical interference with the patient's body, and is closely associated with the provision of palliative care. Withdrawal of life support is inextricably bound up with care that serves health-related purposes and is tied to the objects of the Act. By removing medical services that are keeping a patient alive, withdrawal of life support impacts patient autonomy in the most fundamental way. The physicians' attempt to exclude withdrawal of life support from the definition of "treatment" under s. 2(1) of the HCCA cannot succeed."

In paragraphs [71], [72], [73], [76], [78] and [80] of Rasouli the Chief Justice spoke about the ethical dilemma physicians such as Dr. D'Egidio may find themselves in at times. She wrote:

- "[71] A final argument raised by the physicians is that they may be placed in an untenable ethical situation if consent is required for withdrawal of life support. They could effectively be compelled to continue providing life support, even where they consider it to provide no medical benefit to, or even to harm, the patient. This could place physicians in breach of their legal and professional obligations to act in the best interests of the patient.
- [72] Legally, a physician cannot be faulted for following the direction of the Board, any more than he could be faulted for abiding by a judge's direction at common law not to withdraw life support. Implicit in the physicians' request that a judge resolve the present dispute is acceptance that if a judge orders that life support cannot be withdrawn, they must comply. Their legal position under the HCCA is no different.
- [73] However, a physician may feel that his legal obligation not to withdraw life support is in tension with his professional or personal ethics. Such tensions are inherent to medical practice. Indeed, the law of consent to medical treatment evolved through cases in which the patient did not wish to be treated, but the physician felt a professional obligation to treat: see Malette, at p. 420; Fleming, at pp. 85-86. The law is now clear that

treatment cannot be administered without consent, irrespective of the ethical imperative that physicians may feel. Similarly, a physician's duty of care may require that treatment not be withdrawn despite the physician's ethical objections to its administration: see R (Burke) v. General Medical Council, [2005] EWCA Civ 1003, [2005] 3 W.L.R. 1132, at para. 34. If the present case were resolved as my colleague Justice Karakatsanis proposes, the physicians may still be required not to withdraw life support based on their common law or fiduciary duties. Their ethical position under the HCCA is no different.

[76] While the end-of-life context poses difficult ethical dilemmas for physicians, this does not alter the conclusion that withdrawal of life support constitutes treatment requiring consent under the HCCA.

[78] To recap, the HCCA is a carefully tailored statute. It deals with patients capable of consent and patients who no longer have the power to consent. It seeks to maintain the value of patient autonomy-the right to decide for oneself-insofar as this is possible. This is reflected in the consent-based structure of the Act. If the patient is capable, she has the right to consent or refuse consent to medical treatment: s. 10(1) (a). If the patient is incapable, the HCCA transfers the right of consent to a substitute decision-maker, often next of kin (s. 10(1)(b)), who is required to act in accordance with the patient's declared applicable wishes or, failing that, the patient's best interests: s. 21. Finally, it provides that a physician may challenge a substitute decision-maker's consent decision by application to the Board: ss. 35 to 37. The physician may make submissions to the Board regarding the medical condition and interests of the patient. If the Board finds that the substitute decision-maker did not comply with the HCCA, it may overrule the substitute decision-maker and substitute its own opinion in accordance with the statute: s. 37(3). To be clear, this means that, even in life-ending situations, the Board may require that consent to withdrawal of life support be granted.

[80] If the substitute decision-maker knows of a prior wish regarding treatment that the patient expressed when capable and over 16 years old, and that is applicable in the circumstances, the wish must be followed: s. 21(1). This reflects the patient's autonomy interest, insofar as it is possible."

I found the Chief Justice's comments particularly applicable here. I was satisfied that JEP expressed a prior capable wish applicable to his current circumstances. The opinions of Dr. D'Egidio and the medical team spoke about the ethical dilemma they faced and as discussed by the Chief Justice above.

Dr. D'Egidio testified that given the progressively deteriorating, irreversible medical conditions JEP faced, it was in his best interests not to be put through CPR, dialysis and other full code treatments, none of which could reverse any of his underlying conditions. The doctor's opinion that full code treatments could cause more harm than good, and did not improve the status of

JEP's life. In Dr. D'Egidio's view full active treatment only prolonged JEP's dying process. In the doctor's view continuing to pursue JEP's wishes was impossible, because it violated his oath as a physician and went against all the other expert medical evidence.

However, I remained satisfied based on the evidence I received and the law that JEP had a prior capable applicable wish. JEP was dying. There was no evidence as to when that would occur. However, his applicable wishes remained binding on his SDMs and they are in compliance with the principles for substitute decision making.

I found that without the life sustaining treatment currently consented to, including CPR and dialysis, JEP would not be alive. He was alive, somewhat improved, awake, recognizing and interacting with family, hospital staff and Dr. D'Egidio. I found that JEP expressed clear wishes were to do everything to prolong his life which included here CPR and dialysis without regard to pain and suffering or enduring indignities according to the clear and unchallenged evidence. I found that as a result of receiving CPR to the date of the hearing JEP received no significant injuries.

The Ontario Court of Appeal in Fleming v. Reid (1991), 4 O.R. (3d) 74 has reminded us that the HCCA required close attention to a patient's wishes by those who make treatments decisions on a patient's behalf. At the same time, the Court also noted that wishes were not to be applied mechanically or literally without regard to relevant changes in circumstances. I have closely considered these matters here in coming to my Decision. In Fleming, the Court of Appeal noted wishes may range from an isolated or casual statement to reliable and informed instructions based on the patient's knowledge of the effect of the drug (in that case) on him or her.

I noted in particular that ARE wrote in her note about her father's wishes "YES, RESUSCITATE".

JEP was a medical doctor for many years. I found the wishes expressed by him, according to the evidence were clear and would be applicable to his current circumstances.

#### RESULT

I confirmed the health practitioner's finding that JEP was incapable with respect foregoing CPR along with withdrawal of life sustaining therapy and instead provide palliative care. I also determined that the substitute decision makers have complied with the principles for substitute decision making set out in the *Health Care Consent Act*.

Dated: May 2, 2017

Michael D. Newman

Presiding Member