



**Advocacy Centre
for the Elderly**

2 Carlton Street, Suite 701
Toronto, Ontario M5B 1J3
Tel: (416) 598-2656
Fax: (416) 598-7924
www.ancelaw.ca

Chair, Board of Directors
Timothy M. Banks

Lawyers

Judith A. Wahl, B.A., LL.B.
Rita A. Chrolavicius, LL.B.
Graham Webb, LL.B., LL.M.
Jane E. Meadus, B.A., LL.B.
Brendan Gray, B.A., LL.B.

November 22, 2013

VIA EMAIL: EOLpolicy@cpsso.on.ca

Attention: Policy Department
College of Physicians and Surgeons of Ontario
80 College Street
Toronto, Ontario M5G 2E2

Dear Sir/Madam,

Re: Consultation on *Decision-making for the End of Life*, Policy #1-06

We write further to your online request for stakeholder feedback on the College of Physicians and Surgeons of Ontario Policy entitled *Decision-making for the End of Life* (the "Policy").

Please accept the below comments for consideration.

About the Advocacy Centre for the Elderly (ACE)

ACE is a specialty community legal clinic that was established to provide a range of legal services to low income seniors in Ontario. The legal services include individual and group client advice and representation, public legal education, community development and law reform activities. ACE has been operating since 1984 and it is the first and oldest legal clinic in Canada with a specific mandate and expertise in legal issues of the older population.

ACE staff have had extensive experience in issues related to health care consent and advance care planning and have been involved in many of the law, policy, and education initiatives related to these issues that have taken place in Ontario over the last 30 years. These have included:

- participating as a member of the Fram Committee, the work of which resulted in the passage of the *Consent to Treatment Act, 1992* and subsequently the *Health Care Consent Act, 1996*;ⁱ

- acting as one of the principal writers of the training materials for health professionals that were produced as part of two of the Alzheimer Society of Ontario Initiatives (# 2 and #7) on Physicians' Education and Advance Directives on Care Choices;
- currently participating on the Advisory Committee for the Law Commission of Ontario Project on Legal Capacity, Decision-making and Guardianship; and
- currently participating on the Ontario Medical Association Presidents Advisory Committee on Palliative Care and Advance Care Planning.

Commentary on the *Decision-making for the End of Life Policy*

While the majority of the Policy is appropriately focussed on the patient's right to consent to treatment, we believe the Policy does contain some statements that could cause physicians to misunderstand Ontario's legislative scheme for health care consent and advance care planning.

In this commentary we suggest that the CPSO:

1. amend the description of Consent (Part 1, Page 3) of the Policy;
2. change the explanation of Planning (Part 2 , pages 3 and 4) to explain its context in respect to consent;
3. correct two paragraphs in the section on Conflict Resolution (Part 4) that refer to the Role of the OPGT as these paragraphs may misstate or overstate the role of the OPGT;
4. change the definitions of Advance Care Planning and Advance Directive on the last page of the Policy; and,
5. address the recent Supreme Court of Canada decision in *Cuthbertson v. Rasouli* regarding the requirement to obtain consent for withdrawal treatment.

In providing education for health care professionals, and in particular for physicians, ACE has seen first hand the confusion and misunderstandings they have about health care consent and advance care planning. Our comments are based on that experience and from our current research on policies and practices in Ontario health facilities and services that we are doing for a paper for the Law Commission of Ontario on Health Care Consent and Advance care planning. That paper will be completed by January 2014 and we will be pleased to share that with the CPSO when it is released by the Law Commission of Ontario.

1. Part 1: Consent (page 3)

The content of this section is, in our opinion, correct. We suggest adding some content to this section for clarity to connect this section with the next section on Planning.

We realize that the College has a separate policy on Consent to Medical Treatment and that it is not necessary to repeat everything in that policy in this document. It is appropriate then for this policy to refer to the policy on Consent to Medical Treatment. We also have made comments for suggested amendments to the policy on Consent to Medical Treatment.

We suggest that Part 1 of the Policy be amended to include a statement that informed consent always comes from a person not from any advance directive document and not from previous expressed wishes of the patient. We note that in Part 2, this Policy already states that wishes in an advance directive are to be interpreted by the patient's SDM and are not directions to a health care practitioner and do not constitute a consent or refusal of consent. However, it bears repeating under the Consent section so that the reader can see the connections between the two parts.

We further suggest that this section be amended to include a statement that the process of informed consent includes planning about care (discussing immediate care options but also setting goals for care and preparing plans of care" related to the patients' present health condition). In the course of our other work we have identified that many physicians think that any "care planning" – any talking with patients about goals of care even if it is in the context of the patient's present condition – is "advance care planning" rather than part of the consent process. This may be the result of the recent flurry of attention on "advance care planning" in the press and in the health system (which is usually explained to physicians without any reference to how it connects with informed consent). That is why we always explicitly connect health care consent and advance care planning in our education programme.

Physicians may think that all end-of-life treatment discussions are done through "advance care planning," when in fact physicians should be obtaining informed consent from the patient, when capable (for example, to a DNR). Similarly, physicians may get informed consent to end-of-life care from the SDM for an incapable patient as part of a plan of treatment.

The Policy should also note that SDMs cannot "advance care plan" and express wishes for a patient, but must always make decisions (give informed consent) for a patient in the context of the patient's present health condition. If a patient is at end of life, much if not all of what an SDM is doing is giving or refusing informed consent to treatments (for example, such as refusing consent resuscitation).

We recommend that the Policy be amended to include a statement that

informed consent always comes from a person not from any advance directive document and not from the previous expressed wishes of the patient.

We also recommend that the Policy be amended to include a statement that the process of obtaining informed consent includes planning about future care (i.e. consent includes immediate care options but also setting goals for care and consenting to plans of treatmentⁱⁱⁱ related to the patients' present health condition).

2. Part 2: Planning

We recommend that the description of Advance Care Planning be amended to better clarify what it is. The description that is cited is a good generalized description about the fact that it is a communication process. We would consider this to be a type of generic description of advance care planning. However, this description does not help physicians understand how advance care planning fits into the legal structure as set out in the *Health Care Consent Act* and therefore does not guide physicians to think about how to implement a process of advance care planning with patients, the patients future SDMs, and their families, and where to obtain consent to treatment.

Below is the explanation of Advance Care Planning that ACE has been using in education programmes. We include with this commentary the complete Tip Sheet Handout that we have been providing to health care professionals when we do education on these issues from which the below description is an excerpt:

What is ADVANCE CARE PLANNING^{iv}?

Advance Care Planning has TWO PARTS

FIRST – A Decision about Future SDM

DECISION about who would be the Patient's future SDM which is done either by:

Patient confirming he or she knows who is his or her automatic future Substitute Decision Maker in the hierarchy list^v that is in the Health Care Consent Act and that he or she is satisfied that that person should so act as SDM when the Patient is incapable OR

Patient choosing someone else to act as SDM by preparing a Power of Attorney for Personal Care^{vi}.

SECOND – Patient communicating WISHES^{vii}

Making statements about wishes for future care, if the Patient has any, as well as the Patient expressing his/her own values, beliefs and anything else that he/she thinks will help the Patient's SDM understand what he/she may want or not want in terms of health

care when the Patient is not mentally capable and is not able to provide his/her own consent or refusal of consent to treatments and health care at the time such decisions need to be made.

Just as the CPSO policy on Consent to Medical Treatment and this Policy on Decision Making at End of Life states, we explain consent as decision-making (see description of Health Care Consent on Page 1 of the Tip Sheet 1). Advance care planning first involves helping the patient make a decision about who will be their future SDM if they should become incapable. This is done by either confirming their SDM on the hierarchy or by preparing a POAPC to name a specific person or persons as their attorney for personal care. Second, advance care planning involves talking with patients about wishes, values, and beliefs.

Making this distinction between decisions (made in context of the patient's present condition) and wishes (which are speculative, without full knowledge of what the patient's condition will be at some future time), helps health care practitioners understand that:

- wishes are not consents;
- any advance care planning document or oral directive is not a consent; and,
- that they still must obtain informed consent from the patient if capable or the incapable patient's SDM, even if there is some advance care plan in existence in any form, except in an emergency.

This distinction also helps health care practitioners understand the point that is clearly stated in this Policy (page 4) that advance directives are to be interpreted by the patient's SDM and not the health care practitioner, and do not constitute consent or refusal of consent.

Our description of advance care planning also seems to help physicians understand how to operationalize advance care planning by addressing specifically who would be the patient's future SDM, should the patient become incapable. We then encourage physicians to talk with the patient and, if the patient consents, with the patient's future SDM and family, about the patient's wishes, values, beliefs.

We recommend that the description of advance care planning be amended to clarify that advance care planning involves a decision as to who the patient's SDM would be if they should become incapable, and that advance care planning further involves patient's communicating any wishes they have about future treatment and care as well as their values and beliefs and anything else that would assist their SDMs when their SDMs must make decisions on their behalf.

On the same topic, we would also suggest that the CPSO not use words like “instructions” when referring to advance care planning. In particular we refer to this section on page 3 of the Policy:

*When patients become ill and as illness progresses, physicians should ensure that the patients’ advance care **instructions** and wishes are reassessed with the patients or substitute decision-makers, and family if there is consent, on an ongoing basis.*

There is another issue with this paragraph that we should raise. We do understand that the point of this statement is that physicians are being reminded to continue the communications with a patient or their SDMs and family if there is consent as the patient’s condition changes. This is to ensure, we assume, that physicians are not incorrectly believing that just because a patient or an SDM has given an informed consent to treatment or a plan of treatment that the physician is ‘locked-in’ to that decision when the patient’s condition has been changing. However as this paragraph is under the section on “Advance Care Planning” and refers to re-assessing advance care plan “wishes”, this may lead physicians to confuse advance care plan wishes with consent by a SDM, and appears to suggest that SDMs can advance care plan on behalf of incapable patients by expressing new wishes or altering previously expressed wishes, values and beliefs.

We recommend that if this paragraph remains in the Policy the word “instructions” be removed and only the word “wishes” remain. This also reflects the language in the Health Care Consent Act which references “wishes”.

We recommend that this paragraph be amended to refer to consent (i.e. remove the words “advance care instructions and wishes” and replace with “plan of treatment”) and that the paragraph be included under section 1.1 on Capacity and Informed Consent

The Policy contains the following paragraph on Page 4 under the section on Advance directives:

Physicians should be aware that the Health Care Consent Act allows a capable person to create an advance directive. Through an advance directive, a person can indicate the kinds of treatment that he or she would accept or reject should he or she become incapable. Advance care wishes need not be written and can be changed at any time. These wishes are to be interpreted by the person’s substitute decision-maker; they are not directions to a health care practitioner and do not constitute a consent or refusal of consent to treatment.

We agree that this paragraph does reflect the provisions of the *Health Care Consent Act*. Based on our experience educating physicians and other health care practitioners, we recommend that the Policy be amended to expand this explanation to further clarify

advance care directives. Below are examples of possible rewordings that we offer for consideration.

Physicians should be aware that the Health Care Consent Act allows a capable person to create an advance directive. The term “advance directive” is not used in the Health Care Consent Act. That legislation refers to the terms “wishes” and “Power of Attorney for Personal Care”.

Advance care wishes need not be written. Advance care wishes may be expressed orally, in writing, or communicated by any alternative means the patient uses (i.e. communication board, etc)

Advance care wishes can be changed at any time. Even if wishes were previously expressed in writing, a patient may change their wishes orally and any oral wishes expressed when capable override the previously written wishes.

Through an advance directive, a person can indicate the kinds of treatment that he or she would accept or reject should he or she become incapable. These wishes are to be interpreted by the person’s substitute decision-maker; they are not directions to a health care practitioner and do not constitute a consent or refusal of consent to treatment.

3. Part 4: Conflict Management – References to Role of OPGT

There are two paragraphs in this section that we believe may misstate or overstates the role and authority of the OPGT. We suggest that the CPSO consult with the OPGT office to determine whether they wish to be described in this way in the Policy.

Both paragraphs appear on Page 7 of the Policy. The first paragraph that we have concerns about is the following:

Conflicts between health care providers and authorized substitute decision-makers arising from questions of whether the substitute decision-maker has followed the principles set out in the Health Care Consent Act can be addressed to the Office of the Public Guardian and Trustee (see Consent to Medical Treatment policy).

It is unclear what role the OPGT would play when contacted by a physician pursuant to the above paragraph. We are not aware of any provisions in the legislation that gives the OPGT any required role or particular authority when contacted by a physician in the above circumstances. Presumably, this paragraph envisages that the OPGT will either educate SDMs on what the law states they need to consider when making decisions for patients, or direct SDMs to make decisions in a particular way. If the OPGT is indeed acting in such a role, we are not aware of it. We suggest that you speak with the OPGT

to determine whether they offer any services in this respect that would assist physicians.

According to the *HCCA*, the OPGT is the SDM of last resort if the patient has no other SDM that is higher ranking on the SDM hierarchy (as correctly stated on page 5 of the Consent policy). As well, the OPGT must act as SDM for the patient if equal ranking SDMs disagree and that disagreement cannot be resolved (see *HCCA* s. 20(6)). However, this is different from the OPGT being contacted where the physician believes an SDM is not acting in accordance with the *HCCA*.

We Recommend: Unless the OPGT advises the CPSO that they are willing to act in the role as described in the existing Policy, we would suggest that this statement as it is worded now be removed from the Consent Policy .

The second paragraph that we have concerns about is the following:

If more than one person is authorized under the Health Care Consent Act to consent to treatment on behalf of an incapable patient and no other individual ranks ahead of them, and they disagree about whether to give or refuse consent, the Public Guardian and Trustee must make the decision in their stead. If a dispute arises between joint guardians or joint attorneys under a Power of Attorney in the performance of their duties, the Public Guardian and Trustee may mediate the dispute if the parties are prepared to pay the mediation fees set by the Public Guardian and Trustee, and enter into a mediation agreement as part of the process.

We do agree that the first sentence of this paragraph is correct. It is the second sentence that may be an overstatement of what the OPGT does in practice. In our experience, we know that OPGT staff talk with equal ranking SDMs that disagree, whether they are the court ordered guardians or joint attorneys or other family members on the hierarchy. These discussions normally occur informally before the OPGT acts as SDM. In the ordinary course of events, we understand that the OPGT does not charge a mediation fee to everyone when these discussions take place. While we understand that the OPGT does have the ability to charge for mediations, we further understand that these charges are made only in limited circumstances.

We recommend that the CPSO consult with the OPGT and confirm whether this paragraph accurately states their practices and policies.

4. Appendix: Definitions of Advance Care Planning and Advance Directive

We recommend making changes to the definitions of Advance Care Planning and Advance Directives in the Appendix.

Referring back to our comments under Part 2: Planning, we recommend changing the appendix definition of Advance Care Planning to reflect any changes that the CPSO may make to that section.

We also recommend making changes to the definition of Advance directive and refer back to our comments on Part 2: Planning.

In keeping in line with those comments, we recommend changing that definition to read as follows:

Advance directive: Referred to in the Health Care Consent Act as “wishes” and as a “power of attorney for personal care”. “Wishes” are any communications about the kinds of treatment or care that would be accepted or rejected by that person in the event he or she becomes incapable at some time in the future. An advance directive that expresses wishes may be communicated orally, in writing or by alternative means. An advance directive that designates a substitute decision-maker must be in writing and must be in the form of a power of attorney for personal care.

5. Address *Cuthbertson v. Rasouli*

In the very recent case of *Cuthbertson v. Rasouli*, the treating physicians for a patient who underwent brain surgery and who was initially in a persistent vegetative state (later upgraded to minimally conscious) took the position that the withdrawal of life support that was of no medical benefit to the patient was not “treatment” under the HCCA – and as such they were not required to obtain consent to withdraw life support.^{viii} This case hinged on the definition of “treatment” under the HCCA:

“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.^{ix}

Ultimately, the majority of the Supreme Court of Canada decided that the removal of life-support constitutes treatment as it would be done for a “health-related purpose.” The majority explained its ruling as follows:

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.^x

We Recommend that the Policy be amended to reference the decision in *Cuthbertson v. Rasouli* that consent is required for withdrawal of treatment.

Conclusion

We would like to thank the CPSO for this opportunity to provide feedback on the Policy, and would be pleased to clarify or discuss any aspect of this commentary going forward.

Yours very truly,
Advocacy Centre for the Elderly

Judith A. Wahl
Executive Director
Barrister and Solicitor

Brendan Gray
Staff Lawyer
Barrister and Solicitor

ENDNOTES

ⁱ *Health Care Consent Act*, 1996, S.O. 1996, c. 2, Sched. A

ⁱⁱ *Health Care Consent Act*, s. 13. Definition of Plan of Treatment

ⁱⁱⁱ *Health Care Consent Act*, s13. Definition of Plan of Treatment

^{iv} *Health Care Consent Act*, s 5 The HCCA does not refer to “Advance Care Plans” or “Advance Directives” but refers to Wishes. Wishes may be expressed orally, in writing or be communicated by any other means.

^v *Health Care Consent Act* s.20 Hierarchy of SDMs

^{vi} *Substitute Decision Act*, s.46 and HCCA, s20 Definition of POAPC and ranking of attorney in POAPC on HCCA Hierarchy

^{vii} *Health Care Consent Act*, s. 5 Wishes and How Wishes may be expressed

^{viii} *Cuthbertson v. Rasouli*, 2013 SCC 53

^{ix} *Health Care Consent Act*, 1996, s. 2(1)

^x *Cuthbertson v. Rasouli*, 2013 SCC 53 at para. 68