

If not you – Who and How? Substitute decision-making

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About the presenters:

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Please note that although we are discussing legislation, we come at this as philosophers so this should not be construed in any way as “legal advice.”





Conflict of Interest Declaration

There are no conflicts of interest to declare

We start with a story

- The first snow fall of the season



Learning Objectives

- Identify the legal rules and ethical principles behind substitute-decision-making
- Identify resources and processes for advance care planning and goals of care discussions
- Explore the concept of “best interests”
- Review the function of the Consent and Capacity Board.



Foundations for consent

- Moral
- Respect for autonomy
- “Act so that you treat humanity, whether in your own person or in that of another, always as an end as never as a means only.”
- (Kant)



Autonomy and health care

- Consent guarantees (protects) freedom *from* interference
- Dynamic of health care decision-making
 - Patient presents
 - Physician diagnoses
 - Physician offers treatment(s)
 - Patient accepts(consents) refuses
- Right to *dissent* protects patient autonomy
- No corresponding “right to choose” rather a “right to refuse.”





Consent

- The Ideal (Valid) Consent
 - Voluntary
 - Capable
 - Understood

Before the Health Care Consent Act (1996)

- Annie and the bags of blood (1979)
- Malette v Schulman (Appeal 1990) [Indexed as: Malette v. Shulman et al. 72 OR \(2d\) 417](#)
- *The right to refuse treatment is an inherent component of the supremacy of the patient's right over his own body. That right to refuse treatment is not premised on an understanding of the risks of refusal*
- *Basically, any intentional nonconsensual touching which is harmful or offensive to a person's reasonable sense of dignity is actionable. (Battery)*

Health Care Consent Act (1996)

- <https://www.ontario.ca/laws/statute/96h02>
- An Act to enhance autonomy (Purpose S1c)
- No treatment without consent (S10)
 - 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...
 - Consent from capable patient
 - *Consent from SDM if patient incapable*



Treatment

- “means anything done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment, plan of treatment...” (S2 Interpretation)
- (note Rasouli)
- <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/13290/index.do>
- *Withdrawal* of life sustaining treatment is treatment



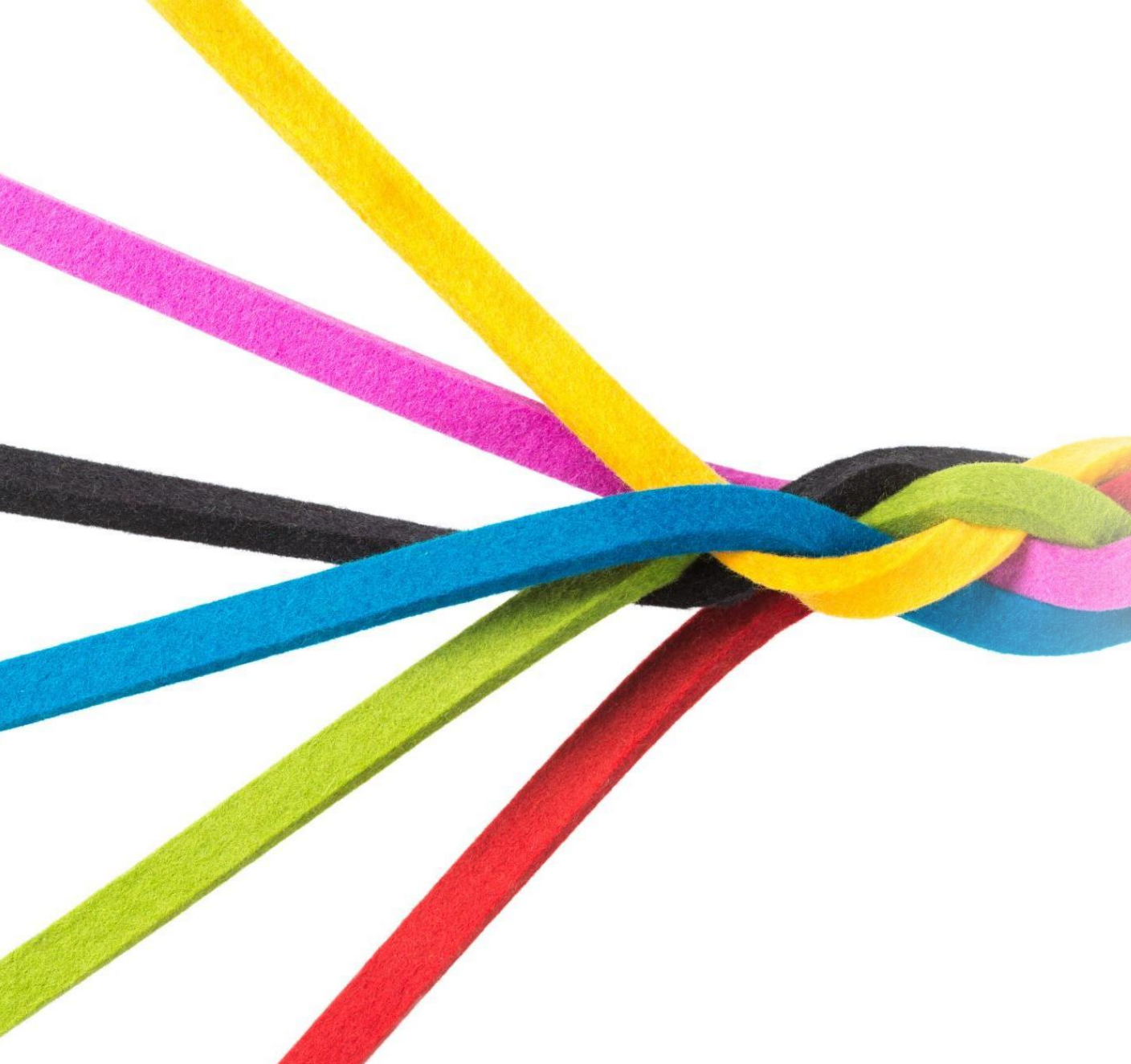
Capacity

- A person is capable ... if the person is able to ***understand*** the information that is relevant to making a decision ... and able to ***appreciate*** the reasonably foreseeable consequences of a decision or lack of decision. (S 4.1)
- **Presumption of capacity**
- A person is presumed to be capable (S 4.2).
- A person may be incapable with respect to some treatments and capable with respect to others. (S15.1)
A person may be incapable with respect to a treatment at one time and capable at another. (S15.2)
- *Principle of autonomy in action.*



Emergency exception

- Treatment can be administered without consent if: (S25)
 - Emergency
 - Delay in obtaining consent creates risk of serious bodily harm
- Exception to the emergency exception
- No treatment if there are: reasonable grounds to believe that the person, while capable and after attaining 16 years of age, expressed a wish applicable to the circumstances to refuse consent to the treatment
- *Malette v Schulman*, sharpie DNR, *expression of my autonomy now – for then*



Substitute Decision- Making (S20)

- **Only** if the patient is not capable of making their own decision in respect to the treatment concerned
- Hierarchy
 - Guardian of the person
 - Attorney for personal care
 - Board appointed representative
 - Spouse or partner
 - Child or parent (or CAS)
 - Parent who only has a right of access
 - Brother or sister
 - Any other relative
 - Public Guardian and Trustee



Conflict between equally ranked potential SDMs

- If there is disagreement between equally ranked SDMs the PGT shall make the decision (S20,6)

Power of Attorney for Personal Care

- “Power of Attorney” is a legal document which names a person (persons) the attorney(s)
- Grantor must be capable
- Attorney must be
 - Over 16
 - Capable
- *Only applies when patient is incapable*
- *Only need a substitute decision-maker when the patient is incapable*



POA

- Attorney cannot be: (unless a family member)
 - Your landlord
 - Any person who provides care where you live
 - Your social worker, counsellor, teacher
 - Your doctor, nurse, therapist or other health care provider
 - Your home maker or attendant
- Form available from Min AG website
- Must be signed and witnessed(X2) not spouse or children as witnesses)
- Ontario Ministry of the Attorney General
- <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php>

Requirements to be an SDM

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



A person wearing a white lab coat is seated at a white desk, writing in a spiral-bound notebook with a silver pen. The background is blurred, showing a clinical or office setting.

Rules of decision-making for SDM


- Ranked rules
 - First:
 - Capable patient's previously expressed wishes (prior capable wishes)
 - If the person knows of a wish applicable to the circumstances...the person shall give or refuse consent in accordance with the wish" (S21.1.1)
- *This is respect for autonomy in action*

A note on language – not really “advance directives”

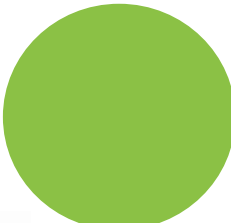
You are instructing/guiding your SDM to consent to/refuse treatments that may be offered by a health care provider at some time in the future

One cannot “consent” in advance – because the treatment has not been offered

But one can *refuse* in advance (remember *Malette v Schulman* and the emergency exception exception)



Prior capable wishes and advance care planning



Advance care planning and CPSO guidelines

- CPSO College of Physicians and Surgeons of Ontario
- <https://www.cpso.on.ca/en/Physicians/Policies-Guidance/Policies/Decision-Making-for-End-of-Life-Care>
- Identify the patient's personal, cultural, and religious/spiritual values and beliefs, as well as their wishes, including which treatment(s) they may or may not want at the end of life
- 1. physicians who provide care as part of a sustained physician-patient relationship² **must**, where possible, initiate a discussion about advance care planning, which includes: raising end-of-life care issues with the patient; and
- 2. encouraging the patient to discuss those issues with their SDM.

Advance Care Planning Resources

Advance care planning Canada

<https://www.advancecareplanning.ca/>

Resources for individuals, patients and families

Resources for health care professionals

Best Interests *if no applicable wishes (s21.2)*



Patient's values and beliefs



Any relevant wishes not required to be followed under previous section (Wishes expressed while incapable)



Whether treatment (or no treatment) improves or prevents from deteriorating the patient's condition or well being



Balance of benefit and harm



Least intrusive equally beneficial treatment

Best Interests

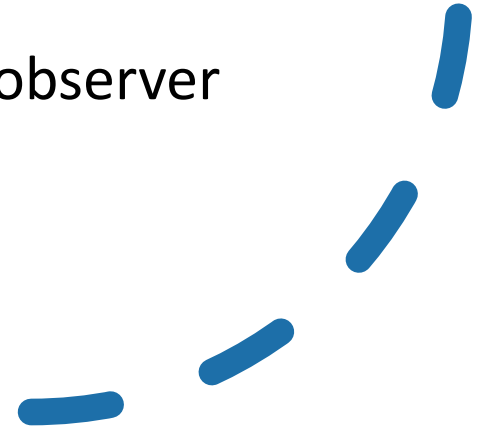
Subjective view

- Prior capable wishes
- Best interests in the light of the patient's values and beliefs

Contrast

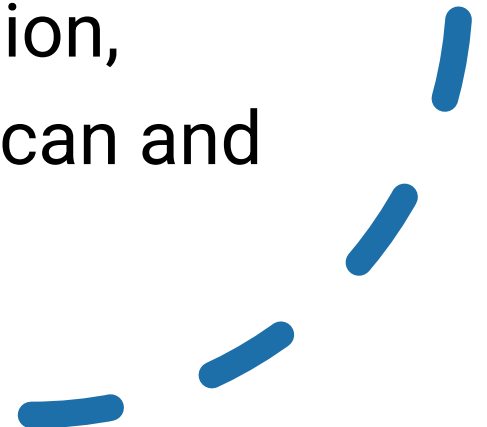
Objective view

- Where some external “objective” observer knows best



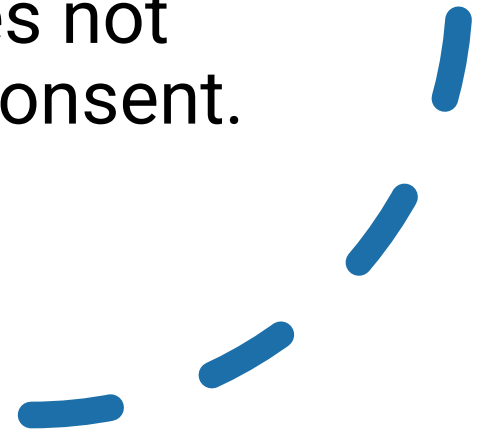
Goals of Care Discussions (CPSO)

- ..in the context of a significant illness or disease when there are treatment or care decisions that need to be made in the foreseeable future. The aim of these discussions is to educate patients and/or substitute decision-makers about ***available treatment options***, and help define ***obtainable*** goals of care
- Emphasis added
- physicians **must**, where possible: initiate a timely goals of care discussion,
- explaining the outcomes that can and cannot be achieved;



Goals of care continued (CPSO)

- Physicians **must** seek to balance medical expertise and patient wishes, values, and beliefs when making decisions about end-of-life care.
- Withholding Resuscitative Measures
- A physician's decision to withhold resuscitative measures is not "treatment" and therefore does not require the patient or SDM's consent.



When things go wrong



Dispute over the facts

Patient's condition, prognosis etc.

Note CCPSO "available treatment options" and "obtainable goals"

Privileges expert assessment



Dispute over values

Patient wishes or patient best interests (not SDM or anyone else)

Privileges patient (in the context of the "facts")

When things go wrong



THE CONSENT AND CAPACITY BOARD



A QUASI-JUDICIAL TRIBUNAL CREATED BY THE
PROVINCIAL GOVERNMENT OF ONTARIO UNDER THE
HEALTH CARE CONSENT ACT (HCCA)



CONDUCTS HEARINGS ADJUDICATING CONSENT AND
CAPACITY BASED ON 6 ACTS: HEALTHCARE CONSENT
ACT, MENTAL HEALTH ACT, SUBSTITUTE DECISION
ACT, PERSONAL HEALTH INFORMATION PROTECTION
ACT, CHILD YOUTH AND FAMILY SERVICES ACT, AND
THE MANDATORY BLOOD TESTING ACT

What does the CCB do? (HCCA/SDA)

- Review of capacity to consent to treatment, admission to a care facility or personal assistance service.
- Consideration of the appointment of a representative to make decisions for an incapable person with respect to treatment, admission to a care facility or a personal assistance service.
- Consideration of a request to amend or terminate the appointment of a representative.
- Review of a decision to admit an incapable person to a hospital, psychiatric facility, nursing home or home for the aged for the purpose of treatment.
- Consideration of a request from a substitute decision maker for directions regarding wishes.
- Consideration of a request from a substitute decision maker for authority to depart from prior capable wishes.
- Review of a substitute decision maker's compliance with the rules for substitute decision making.
- Review of statutory guardianship for property.

Why make an application?



Patient: to review a health practitioner's finding that one is incapable in respect of a treatment decision



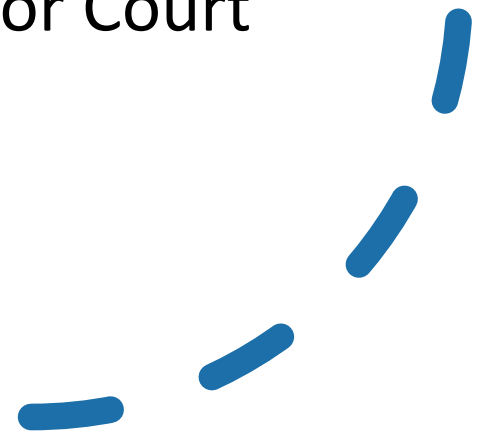
SDM: Permission to depart from a prior capable wish*



Physician: to review a SDM's consent or refusal of treatment on the grounds it does not align with a patient's prior capable wish and/or best interests

How Does it Work?

- Patients, SDM's or physicians can make an application to the CCB
- Forms can be found at:
<http://www.ccboard.on.ca/scripts/english/forms/index.asp>
- Hearings must take place within 7 calendar days of request by law
- Rulings can be appealed by any party at which point it goes to the Superior Court



Things we haven't spoken about

- Substitute decision-making
 - Children
 - Those who have never been capable
 - Research
- The limits of autonomy
 - What are the limits of the things I can agree to?
 - Implicating others in my autonomous decisions
- Autonomy, vulnerability, assisted/supported autonomy
- Autonomy and compassion

Comments,
questions,
feedback

