

## Consent, Capacity, and Substitute Decision-Making – Lecture guide

### Informed Consent

- What is it?
  - Legal process: In Ontario the Health Care Consent Act.
  - Consent must be obtained before treatment begins, possible exception in emergency case.
  - Consent may be refused or withdrawn by a capable patient at any time.
- Why do we need informed consent?
  - Ethically: Respect for persons and their informed choices as far as is reasonable.
  - Legally: To have a clear process in place to protect the rights of individuals. (e.g. Health Care Consent Act [HCCA])
- What type of choices must we respect?
  - Can patients demand treatments? +/-

### What does informed consent require?

- There are differing models, but the Ontario Health Care Consent Act (HCCA) views consent to require:
  - Decision-making capacity
  - Disclosure of relevant information (Informed)
  - Voluntariness
  - Consent

### Decision-Making Capacity

- To have decision-making capacity, one must be able to:

#### **Understand:**

- The facts around the decision about treatment
- What the different options are
- The risks/benefits
- The expected outcomes
- The consequences - What happens with or without the treatment? And,

#### **Appreciate:**

- How their life and health will be affected by the different treatment options

- How the side effects, risks and benefits may change their life or function
- Capacity is also:
  - Presumed
  - Task specific
  - Varies over time, and
  - Is not associated with a specific age

#### When is consent informed?

Consent is **informed** when:

- The patient received the information...that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and
- The person received responses to his or her requests for additional information about those matters. (HCCA 1996, c. 2, Sched. A, s. 11 (2)).

Specifically, for consent to be informed, the following information must be communicated:

- The nature of the treatment or intervention being proposed
- Expected **benefits** of the treatment or intervention
- Possible **risks**
- Potential **side effects**
- **Alternative** courses of action
- Likely consequences of not having the treatment or intervention (HCCA 1996, c. 2, Sched. A, s.11 (3)).

#### Voluntariness

- Consent should be provided voluntarily to ensure legitimacy, and to support the patient's autonomy.
- Voluntariness requires that a decision is free from coercion, and undue influence, and can serve to protect the interests of patients.

#### Patient lacking capacity

- If the patient lacks the capacity to make a specific health care decision, a substitute decision-maker shall be designated to do so on their behalf.
- Hierarchical list in HCCA:
  - Guardian of the incapable person
  - POA for personal care
  - A representative as appointed by the CCB

- The spouse or partner of the incapable person
- A child or parent of the incapable person
- A parent with only right of access
- A brother or sister of the incapable person

Any other relative of the incapable person

#### Substitute decision-maker requirements

- Must be capable
- Must be 16 years old – unless they are the incapable person’s parent
- Must not be prohibited by court order
- Must be willing and able to give or refuse consent
- Must first act in accordance with previously expressed wishes. If such wishes are not known or not applicable, best interests are to guide decision making.

What if more than one person is eligible? All eligible substitute decision-makers will have equal right to make a decision.

#### Best Interests

- “... a person who gives or refuses consent on an incapable person’s behalf shall do so in accordance with their best interests.” (HCCA, 1996) Taking into consideration:
  1. The values and beliefs that the Substitute Decision Maker knows the incapable person held when capable, and believes he or she would still act on if capable.
  2. As well we must assess whether the treatment is likely to:
    - a) Improve the incapable person’s condition or well-being,
    - b) Prevent the incapable person’s condition or well-being from deteriorating, or
    - c) Reduce the extent to which, or the rate at which, the incapable person’s condition or well-being is likely to deteriorate.
  3. Whether the incapable person’s condition or well-being is likely to improve, remain the same or deteriorate without the treatment.
  4. Whether the benefit the incapable person is expected to obtain from the treatment outweighs the risk of harm to him or her. And finally,
  5. Whether a less restrictive or less intrusive treatment would be as beneficial as the treatment that is proposed.