

# Substitute Decision Making



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# Learning Objectives

- Critically examine the concept of autonomy and other ethics concepts in healthcare.
- Consider the tension between the duty to respect autonomy and the duty to care.
- Define substitute decision makers and their role in health care decision-making.
- Explore ethical considerations in cases involving residents who choose to live at risk.



# How Do You Define Autonomy?



**AUTONOMY**

# Autonomy

Commonly understood as: Respect for a person's right to self-governance.

- Based on the importance of freedom and choice
- Exercised through: Informed Consent, Shared Decision-Making, Disclosure.



# Defining Autonomy

Autonomy is derived from the Greek words:

- **Auto**: meaning “self”
- **Nomos**: meaning “rule” or “governance”

To be autonomous does not mean to be completely independent:

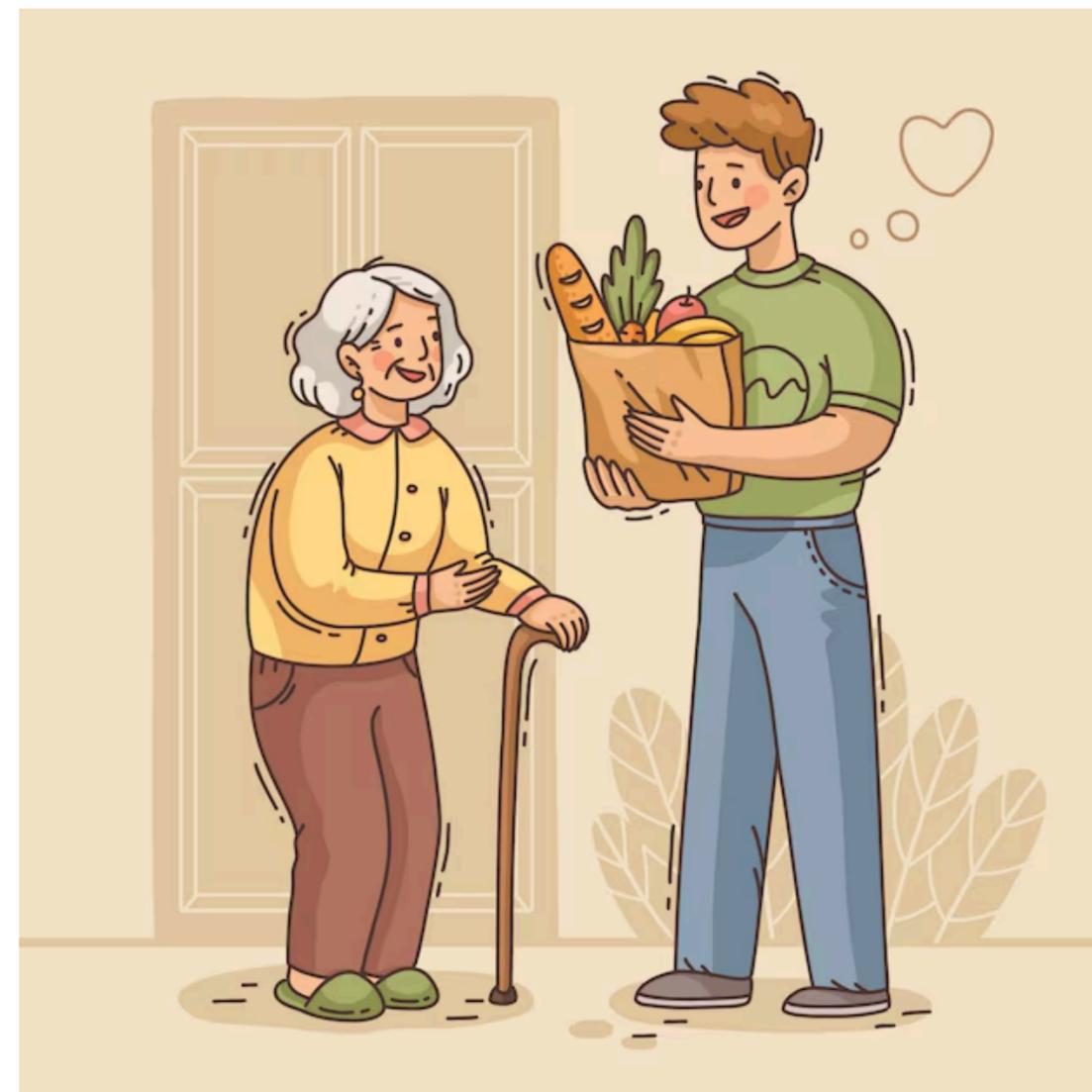
- Autonomy must fit into socialization, collaboration, and participation in society.
  - Relational autonomy: persons are socially situated and interdependent



# Autonomy vs. Duty Of Care

The duty of care means substitute decision-makers must make thoughtful, informed decisions that prioritize the person's values, well-being, and legal rights.

- It is rooted in the principle of **beneficence**.
- It can conflict with autonomy
  - How do we navigate this?



# Autonomy Versus Outcomes

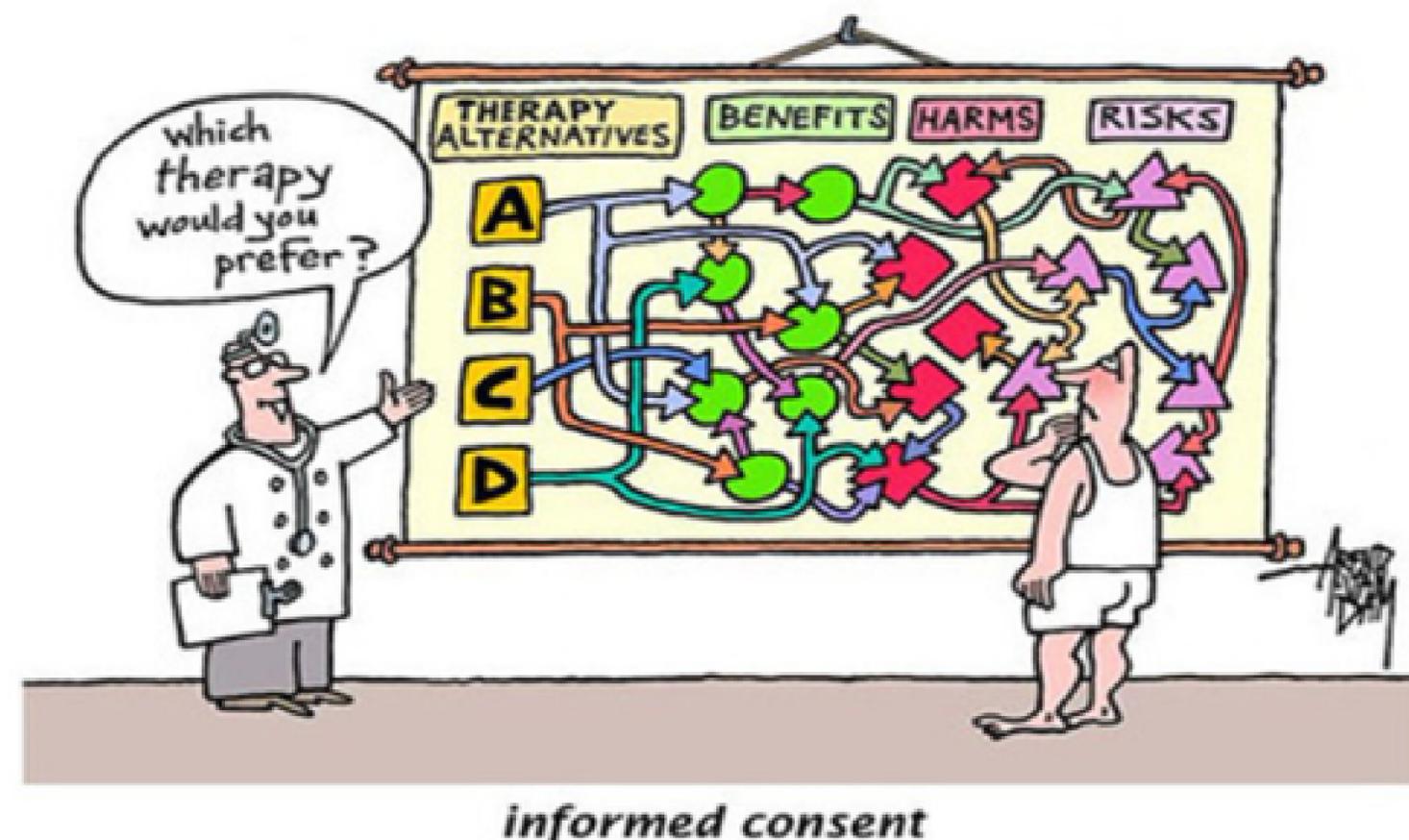
Respecting choice  $\neq$  endorsing outcomes.

- In health care, respect for autonomy upholds an individual's ability to direct their own care.
- Respect for autonomy focuses on freedom, not on assessing the values that underly an individual's choice, nor the outcomes produced.



# Informed Consent

- In health care, we exercise a person's right to autonomy through informed consent
- This requires a person to agree or disagree to a particular treatment or intervention or other health care decision that is proposed by a health care provider



# What Makes Consent Informed?

1. Provided with information about nature of treatment
2. Expected benefits of treatment
3. Expected side effects or relevant material risks
4. Alternative options
  - a. there can be no alternatives in some cases
5. Likely consequences of not engaging with treatment
6. Free of coercion or misrepresentation of information

# Beneficence

Requires that individuals caring for others act in such a way that will promote the good of others.

- Emphasizes acting in a way that will provide benefit to the resident.
  - This objective **can** conflict with autonomy.



“What’s the next best medicine?”

# Paternalism

Paternalism: a restriction on a person's conduct which is justified out of a concern for the best interests of that person.

- “Doctor/Family knows best” model of care.
- Rooted in beneficence.
  - But, extended beyond limits.
  - Discounts patient autonomy.
  - Can lead to overprotection of residents against their will.



# Examples Of Paternalism

- A physician does not tell a capable patient about a non-surgical option because they believe surgery is “clearly the best choice” and don’t want to “confuse” them
- A family member answers all questions on behalf of a capable resident, and staff direct communication to the family member instead of the resident
- A nurse refuses to administer pain medication to a capable patient because they think the patient is “asking too often” and might become dependent
- A capable resident is told they must bathe in the morning because that is “how the unit runs,” despite repeatedly asking to bathe in the evening

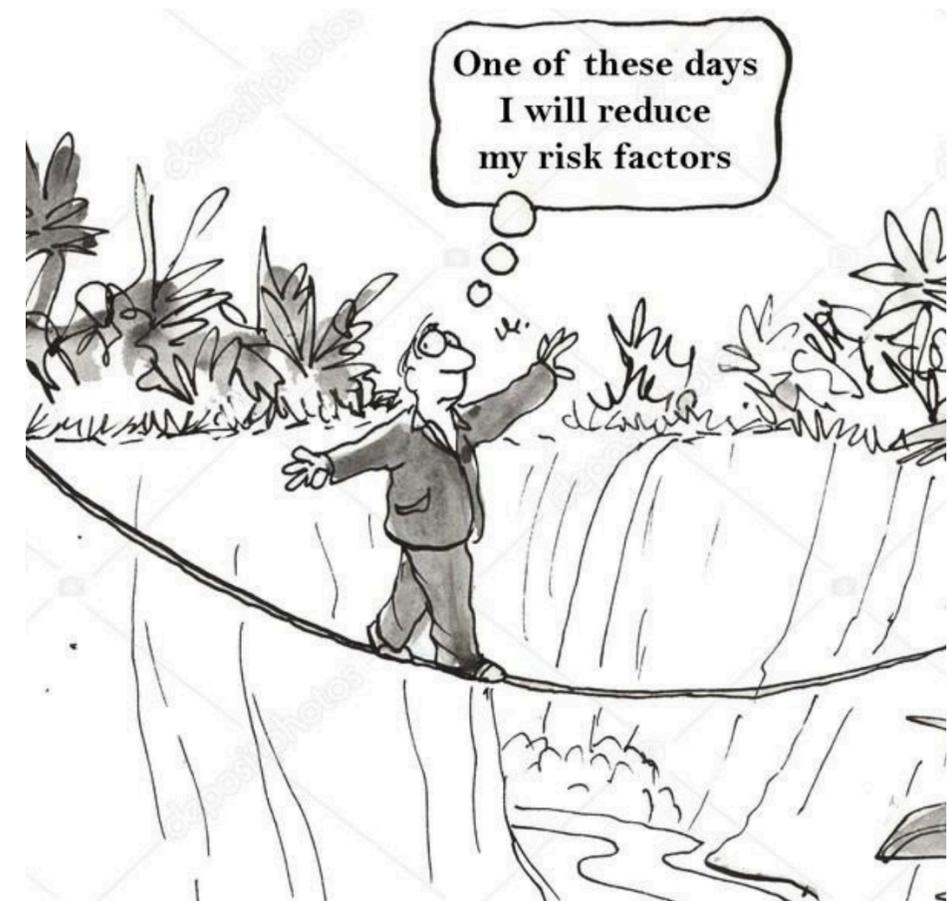
# Are we allowed to make bad decisions for ourselves?



# Living At Risk

The term **Living at risk** is used when individuals choose to engage in activities and behaviours that put themselves at risk of harm.

- Whether an activity or behaviour constitutes living at risk depends on:
  - The probability of the risk materializing into harm.
  - The severity of the potential harm.



# Living At Risk: Examples

Some examples of behaviours that carry risks include:

- Eating when choking is possible.
- Living at home without adequate support.
- Going on unsupervised outings.
- Smoking around oxygen supplies.
- Refusing to use a walker needed to prevent falls.



# Dignity Of Risk

There is dignity in an individual's ability to tolerate risks in their own life.

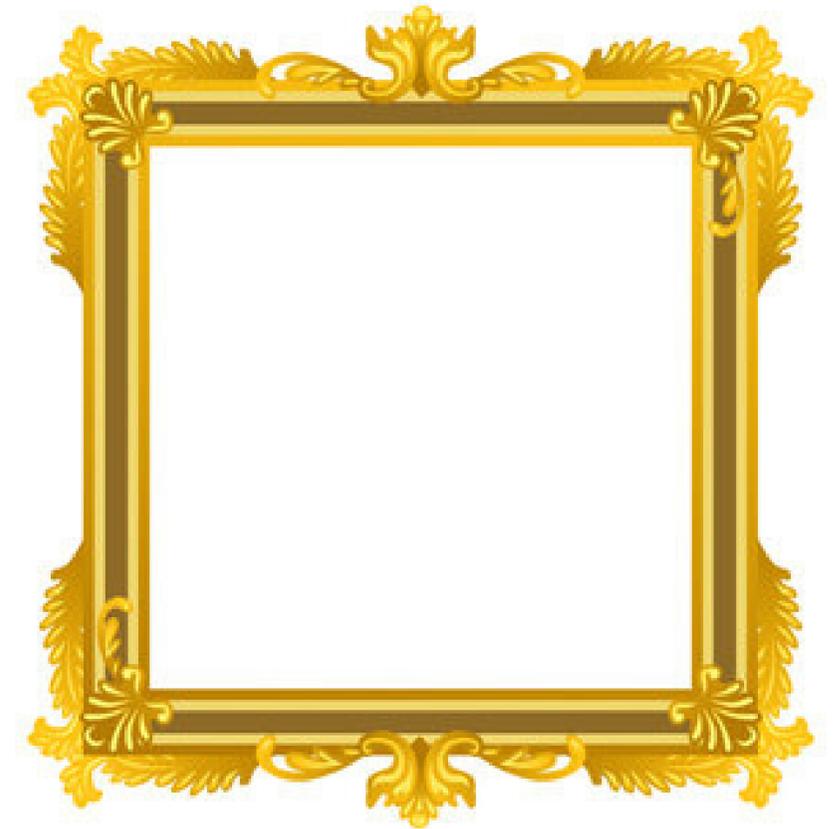
- Persons cannot be treated as entities that are separate from risk.
  - Sometimes, there are benefits to tolerating risk.
- This view suggests that the overprotection of individuals from risk may undermine aspects of their dignity.



# Framing Matters!

When navigating residents choosing to live at risk, the language that is used to frame the situation can shape how we act.

- Frame decisions in terms of resident choice, rather than solely in terms of risk
  - “You’re on a puréed diet now – it’s safer.”
  - vs
  - “A puréed diet reduces choking risk, but it can affect enjoyment of food. Why don't we discuss texture options and what level of risk you’re comfortable with?”



# What is Capacity

The **ability to understand** relevant information and the **ability to appreciate** the foreseeable consequences of action *or* inaction

- Capacity is time dependent
- Capacity is **decision specific**
  - resident can be capable with respect to some decisions while incapable with respect to others
- It is the responsibility of the most responsible care provider proposing the treatment to determine capacity



# Incapable Person's Rights

- They must be informed they have been determined to lack capacity at this time
- Reserve the right to file an appeal with the Consent and Capacity Board
- Have a Substitute Decision Maker (SDM) appointed



# What is a Substitute Decision Maker (SDM)

- An individual who makes medical decisions and provides consent on behalf of an incapable person
  - So that we can respect the principle of autonomy even if the person cannot act of their own accord
- Must abide by guidelines set in the Health Care Consent Act (HCCA)
  - Respecting previous expressed wishes
  - Acting in the best interest of the incapable person
- Being an SDM is **not** mandatory

# SDM Requirements

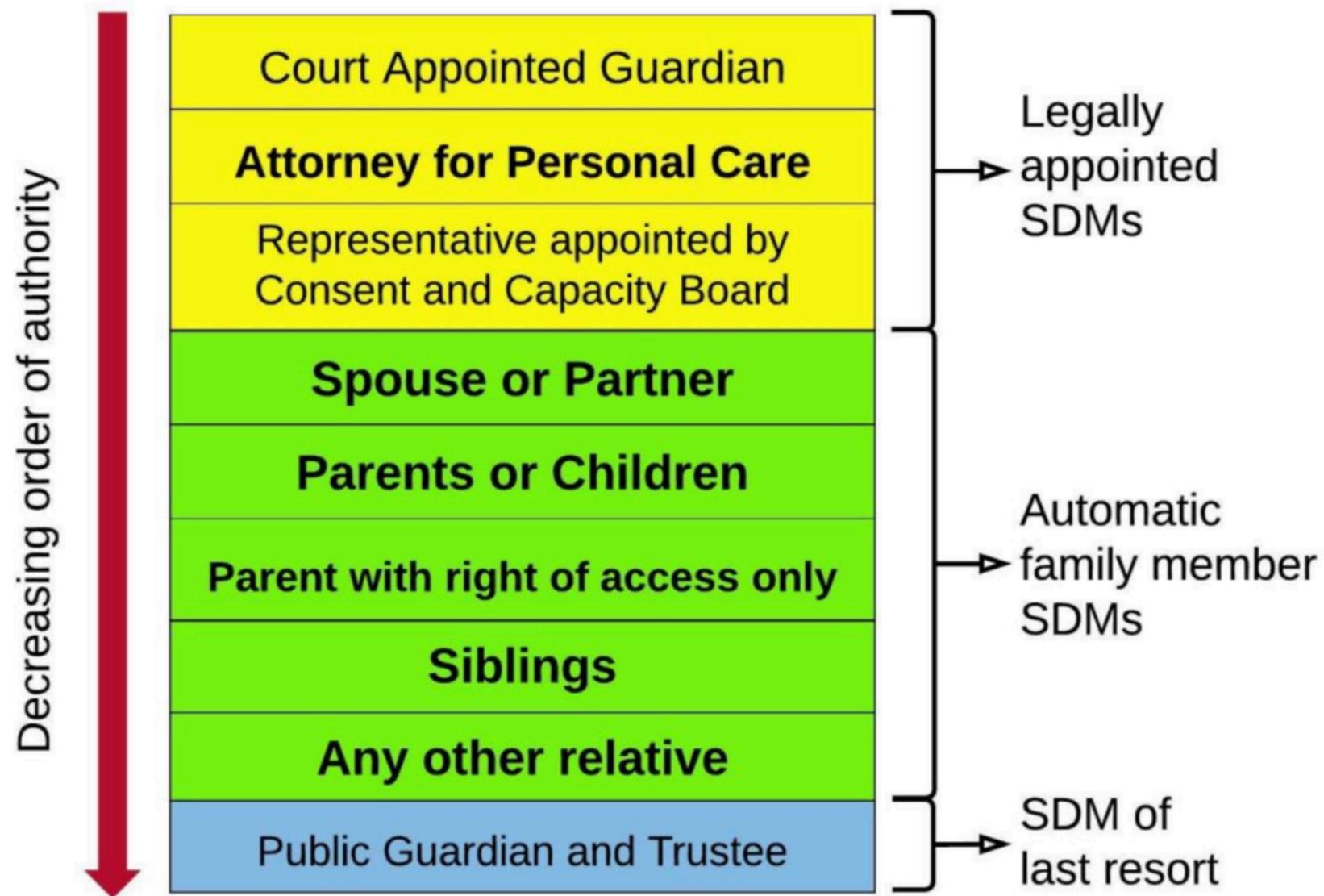
- Capable of making decisions
- 16 years of age or older
- Must not be prohibited by court order
- Reasonably available to give consent
- Must act as the incapable person would have
- Must act in accordance with patient's previously expressed wishes or according to the Best Interests Standard (if wishes are unknown)
- SDMs are legally required to represent the person's voice, not replace it with their own.

# SDM Limitations

- Cannot **demand a particular treatment option** that is not clinically indicated
  - SDMs cannot insist on treatments that clinicians determine are not medically appropriate or offered.
- Cannot make decisions based **on their own values** or convenience
  - Decisions must reflect the person's wishes, values, and beliefs not the SDM's preferences

# SDM Hierarchy

## Substitute Decision Maker Hierarchy



Ontario's *Health Care Consent Act*, 1996

## True or False:

A POA has more power than other SDMs **FALSE**

The eldest SDM is the primary SDM **FALSE**

An SDM must always have physical access to the resident **FALSE**

# SDM Myths and Misconceptions

Myth	Legal Reality (HCCA)
“I’m the SDM, so I always make the final decision.”	SDMs decide <b>only if the person is incapable</b> for a specific decision.
“I decide based on what I want or think is best.”	SDMs must act according to the person’s <b>prior capable wishes</b> and <b>best interests</b> .
“Once my parent has dementia, they can’t make any decisions.”	A dementia <b>diagnosis does not equal incapacity</b> for all decisions.
“I can demand any treatment I want.”	SDMs <b>cannot demand</b> or expect specific <b>treatment</b> , an <b>SDM’s role is to provide consent</b> when asked
“Once I’m SDM, I always am.”	Capacity is <b>decision-specific and can change</b> over time.
“If staff disagree with me, they must still follow my decision.”	<b>Staff must follow the law and professional standards</b> , even if that means challenging an SDM
“If my parent is upset, I can consent to medication to calm them.”	SDMs cannot consent to medication solely for convenience or behaviour control.

# Questions?



*"I think we just have time for one more quick question."*

# Ask An Ethicist



**Ethicists can walk you through difficult situations and the use of the relevant framework.**

- Clinical ethicists are specially trained in thinking about moral issues in healthcare. They are able to listen to problems in a non-judgmental way, and can help make complex problems easier to understand.
- There is never a wrong reason for reaching out to ethics.
- Ethics can help identify the relevant features & principles of a decision and support decision making.

# Contact Us!

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