Patient & Family Guide

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Making Health Care Decisions for an Adult: Acting as a Substitute Decision-Maker (SDM)

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Making Health Care Decisions for an Adult: Acting as a Substitute Decision-Maker (SDM)

What is a substitute decision-maker?

- In general, adults are able to make their own decisions. This includes most people with major mental and/or physical health conditions.
- A patient may not be able to make decisions about their own health care because they are very sick or have been seriously injured. When this happens, another person is asked to make health care decisions for them. This person is called a **substitute decision-maker**.

What is the difference between power of attorney and a substitute decision-maker?

- **Power of attorney** is a power that is legally designated (given) to one person to make decisions related to **property and finances** on another person's behalf.
- A **substitute decision-maker** is a person responsible for making **personal care and/or health care** decisions on another person's behalf. This may include decisions about health care, nutrition and hydration, housing, clothing, hygiene, recreation, comfort, social activities, and support services.
- A person may have chosen one person to make both property and/or financial decisions, and personal care and/or health care decisions on their behalf, but this is not always the case. Being responsible for one area does not mean that you are responsible for both, unless the patient has designated it.

Who may be asked to be a substitute decision-maker (SDM)?

- A patient may have chosen their SDM in advance through a personal directive (PD). The person identified in a PD to make decisions on a patient's behalf is called a **delegate**. If you would like more information about personal directives, ask the patient's health care team and/or visit:
  › www.nshealth.ca/comfort-safety-and-support/your-personal-care-directives
- In other situations, a patient may have a legally appointed representative or guardian. The representation order will explain which areas of decision-making the representative and/or guardian is responsible for.
- If the patient has not named a delegate in a PD, and there is no representation order or legally appointed representative and/or guardian, the following people would be asked to make personal care and/or health care decisions in the descending order below. To fulfil the role, they must be willing and able, and have had contact with the patient within the past 12 months (1 year).
  1. Spouse (including common-law partner)
  2. Adult child
  3. Parent
  4. A person who stands *in loco parentis** to the patient
  5. Adult brother or sister
  6. Grandparent
  7. Adult grandchild
  8. Adult aunt or uncle
  9. Adult niece or nephew
  10. Any other adult relative
  11. The Public Trustee

**In loco parentis* means "to stand in place of a parent." This is an extremely rare designation and does not apply to foster parents. If you think this applies to you, please talk to the patient's health care team.

What if there is more than one person at the same level?

- If there is more than one person who meets the criteria (are able and willing and has had contact with the patient within the past 12 months), then they must decide among themselves who will have final decision-making authority and direct the patient's health care team.

Who can be involved in decision making?

- Each family approaches health care decision making in different ways. You may want to involve trusted elders in these conversations. The health care team will benefit from knowing what is important to the patient around health care decision making and who they would want involved in this conversation. Some SDMs find it helps to talk about the different options with other family members or friends.

What kind of personal care and/or health care decisions will I be asked to make?

- If you are the SDM, the decisions you will be asked to make will depend on the situation. Some decisions will be general, and others will be more specific. For example, you may be asked to decide:
  - What health care treatments and assessments the patient receives
  - Whether the patient has surgery
  - Whether the patient should get (or continue to get) artificial nutrition ("tube-feeding") and hydration ("I.V. fluids"). This involves medical treatment to deliver food and fluids to a patient who is not able to take them by mouth.
  - Where the patient will live when they leave the hospital

How do I make personal care and/or health care decisions for someone else?

- If you are asked to make personal care and/or health care decisions for someone else, you will need to follow their most recent wishes, as expressed when they were able to make their own decisions (for example, in a personal directive).
  - These wishes may have been written, spoken, or said in another way. You should consider what the person has said or done in the past.

What if I am not sure that the patient's wishes are reliable?

- You may have doubts about whether the patient understood the consequences of their wishes, or they may have changed their mind a lot. If you are not sure that the patient's wishes are reliable, it may help to talk with members of their health care team and others who knew the patient when they were doing well.
- You should also consider what the patient might be trying to express right now about their likes and dislikes.

What if the patient's wishes are not clear?

- If the patient did not tell you their wishes, you can make decisions based on what you know about their **values and beliefs**. Try to choose what you think the patient would have chosen, if they were able to. You may wish to consider:
  - What would they care about most?
  - What kinds of sacrifices would they be willing to make?
  - What kinds of things would they want to avoid?

What if I do not know the patient's wishes, values, or beliefs?

- If you do not know the patient's wishes, values, or beliefs, you should make decisions based on their **best interests**. Think about what would be best for them physically, mentally, socially, and spiritually. The patient's health care team will give you information about possible harms and benefits of the options available. You should consider:
  - Whether their condition is expected to improve with the recommended treatment(s)
  - Whether their condition is expected to improve without the recommended treatment(s)
  - Whether the anticipated (possible) benefit of a treatment outweighs the likely harm.
- Please ask the patient's family, friends, and health care team any questions you may have. The patient's health care team can reserve a room at the hospital for a family meeting. A team member can be present at the meeting to give information and help answer questions.

What if I do not agree with the patient's wishes?

- One of the hardest parts about being an SDM is making decisions for someone else based on what they would want. **This is not the same as making decisions based on what you would want or what you believe is right.** If you do not feel comfortable, talk with members of the patient's health care team.

What if the patient wants tests and/or treatments that the health care team does not offer?

- Respecting patient preferences is important, and health care providers will do their best to honour patient wishes. However, what tests and/or treatments can be offered is limited by professional standards and guidelines (see glossary), current best evidence (see glossary), and the patient's health circumstances.
  - For example, the patient and/or their family may want treatments that are not usually provided in a hospital. Sometimes, but not always, these preferences can be worked into a care plan that is in line with professional standards and guidelines.

What if the patient's wishes cannot be met in their chosen location?

- A patient may have expressed a wish to receive care in a certain location (for example, at home), but their wishes and needs cannot be met in that location. Sometimes the health care team can come up with ways to meet the patient's needs and wishes, but there are some practical limits.
  - For example, a patient may need specialized care that involves a particular kind of expertise (like care from a chemo nurse) or specialized equipment (like an MRI machine) that is only available in certain locations, or 24-hour support from a health care provider is not possible in their home.
- In these situations, health care providers and SDMs work together to decide how to best meet the patient's needs, using the options available.

What if there is conflict about the SDM's decisions within a patient's family?

- A patient's family should decide how to manage the conflict. It often helps to share information and try to explain your point of view. The SDM does have ultimate decision-making authority. The patient's health care team is here to help. We can connect you with other resources like Spiritual Care, Social Work, Continuing Care, or Ethics, as needed and where available.

What if there is conflict between the SDM and the patient's health care team?

- The SDM and the patient's health care team may disagree about what is best for the patient. If this disagreement continues, the SDM may lose trust in the health care team. Respectful, informed, honest, and open-minded conversation with the patient's health care team is important. The goal is for the SDM and the patient's health care team to work together.

Are there some health care decisions that an SDM cannot make?

- Yes. Legislation prevents an SDM from making certain kinds of decisions. For example, an SDM cannot make a new request for medical assistance in dying (MAiD) on behalf of someone who can no longer make this decision for themselves. SDMs generally have authority for health care decisions, but not decisions that go beyond this. Please ask the patient's health care team if you have any questions.

What if the decisions I make affect other people?

- Some decisions, like going home from the hospital, may impact you or other family members. It is important to talk with the people who may be affected.

What should I do if the patient's expressed wishes are not being respected by the patient's health care team?

- An SDM should be an advocate for the patient, especially if it seems like the patient's wishes are not being respected. If you need help with this, consider asking Ethics or Patient Relations for help (see page 9).

What if I am struggling with being an SDM?

- You may find that you are struggling with your role as an SDM. For example:
  - The instructions the patient left may no longer make sense because something has changed (like their health or where they live).
  - The patient may have imagined a very different situation when they expressed their wishes.
- This may make you feel uncertain or upset — this is common. All health care decisions involve some risk and even the best decision can involve some negative consequences. It can be stressful when there are no options that are completely good. If you are struggling, talk with the patient's health care team about your concerns.

Where can I get help with making decisions?

- Major life decisions can be challenging to make for another person. You may feel under pressure to make a decision quickly. The situation may be very emotional. **It is OK to be sad or upset**. It can be hard to know what choice to make.
- **If you need support, please tell the patient's health care team.** They may be able to help answer clinical questions and provide information. They can connect you with other supports, like:
  - Spiritual Care
  - Social Work
  - Ethics, where available, to help talk through complex decisions
- You may also find it helps to seek support in the community from clergy, friends, or counsellors.
- Mi'kmaq Indigenous Patient Navigators are available to Indigenous patients and families to help ensure access to culturally safe care, bridge cultural gaps and advocate for cultural and spiritual needs.

What if I no longer want to act as the patient's SDM?

- If you are no longer available, willing, or able to act as the patient's SDM, talk with the patient's health care team. You may be asked to sign a form confirming that you are giving up your decision-making role. The patient's health care team may also initiate contact with you about your continuing in the SDM role if they have concerns about your availability or ability.
- Decision-making authority would then be passed to someone at the same level or the next level in the list of substitute decision-makers.

For more information:

- Visit:
  - › www.nshealth.ca/comfort-safety-and-support/your-personal-care-directives
- Ask a member of your health care team for pamphlet 1942, *Advance Care Planning: Making Your Personal and Medical Wishes Known*, scan the QR code below, or visit:
  - › www.nshealth.ca/patient-education-resources/1942

Scan the QR code on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears)

Glossary

- **Adult**: A person who is 19 years or older.
- **Current best evidence**: Health information can vary in quality and accuracy. Health care providers make recommendations based on the most up-to-date and reliable sources available.
- **Delegate**: A person 19 years of age or older who is authorized in a Personal Directive (PD) to make personal care decisions on another person's behalf when that person is not able to make these decisions on their own. The person(s) they name is usually a family member or friend.
- **Ethics support**: Available to help patients and families look at a care situation and think about fairness and other values that are important to the patient and their family. For more information, visit:
  › www.nshealth.ca/clinics-programs-and-services/ethics-nova-scotia-health
- **Family:** In this pamphlet, the word "family" means a person(s) the patient identifies as being within their immediate support network. This is understood broadly to include people who may or may not be related legally or by blood.
- **Health care team**: Includes all health care providers who contribute to looking after a patient. This may include doctors and nurses, respiratory or occupational therapists, physiotherapists, social workers, personal support workers, and more.
- **Next of kin**: Next of kin is not a legal word, but it has been used in health care and continues to be used informally. Typically, this refers to a person (not necessarily a family member) identified by the patient as someone who is their support person and who should be called, for example, if the patient requires supplies brought in or transportation after a procedure. Note that this may not be their legal substitute decision-maker should the patient lose decision-making capacity.
- **Patient Relations**: This team listens to your concerns about your health care experience. For more information, visit:
  › www.nshealth.ca/contact/patient-relations

- **Personal care**: This includes a person's health care and treatment, where they live, what they eat and drink, their clothing, hygiene, safety and comfort, recreational and social activities, and services in the community to support them. The SDM who has authority over personal care decisions may or may not be the same person named under a power of attorney.
- **Power of attorney**: A legal document giving someone else authority to act on property or financial matters under certain circumstances. The person who gives this legal authority is called the donor or grantor, and the person receiving authority is called the attorney. For example, the person who has been given power of attorney may be asked to arrange payment of hospital bills or fees for a long-term care facility.
- **Professional standards and guidelines**: Regulated health care professionals must act within the rules, standards, and guidelines of their profession. This is often called best practice. Within best practice, a test and/or treatment may be recommended on a case-by-case basis, depending on a patient's health. There may be other treatments that are not recommended for **any** patient because it is not best practice.
- **Social worker**: A social worker will work with you and your family, offering emotional support and help to find available community programs and services.
- **Spiritual care**: Spiritual care is non-denominational (all faiths are welcome). Staff are available 24 hours a day for patients, family, and friends. If you would like to talk with spiritual care staff, please ask a member of your health care team.
- **Substitute decision-maker (SDM)**: Someone who is asked to make personal care and/or health care decisions on behalf of someone else who, because of illness, disease, or injury, is not able to make these decisions on their own.

Notes:

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Find all patient education resources here:
www.nshealth.ca/patient-education-resources

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: https://811.novascotia.ca

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Learn more: https://library.nshealth.ca/patient-education-resources