Patient & Family Guide

2024

Talking About Your Goals of Care and Choosing a Level of Intervention

Aussi disponible en français : FF85-2505

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www.nshealth.ca

Talking About Your Goals of Care and Choosing a Level of Intervention

This pamphlet is written for patients and substitute decision-makers. If a patient is not able to make decisions about their own health care, another person (called a substitute decision-maker) will be asked to make health care decisions for them.

During a conversation about your goals of care, you will be asked to talk about your:

- values and the most important priorities for your health.
- treatment preferences if your health were to become worse.

Talking about your goals of care and levels of intervention (treatments) may feel overwhelming – this is normal.

Having these conversations helps to make sure that your health care team understands your values and preferences related to your health and quality of life.

This pamphlet will help you get ready to talk about your goals of care. Talking about your goals of care will help you decide on a level of intervention. Your health care team will always keep the level of intervention you choose in mind when reviewing your care plan.

What are goals of care?

- Goals of care are your priorities (what you feel is most important) for your health care. They are based on:
  - Your values
  - Your beliefs
  - What quality of life means to you

What are levels of intervention?

- Levels of intervention describe:
  - The general goals for your health care
  - The kinds of treatments that might help you reach those goals
  - Where you would prefer to receive care

Your level of intervention decision will be documented and be available to health care providers involved with your care.

Levels of intervention include several options, including:

- **Comfort Care**: Treatments to control your symptoms. **Comfort care does not mean giving up or not providing care**. It means providing care that prioritizes your quality of life. There are 2 levels of Comfort Care:
  - C2: Accept treatments to address (relieve) your suffering, but not treatments that could prolong life (keep you alive longer).
  - C1: Accept treatments to address your suffering, and painless treatments that could prolong life.
- **Selective Care (S)**: Treatments that try to make your life longer, but do not include CPR (see page 7).
  - S2: The choice to not receive intubation.
  - S1: The choice to receive intubation if it is medically necessary.

If you choose 1 of the selective care options, this treatment can be provided on a hospital unit.

- **Full Code (F)**: Treatments that try to make your life longer or to keep you alive using any way possible (like CPR and intensive care). Treatments are chosen based on whether they may help you survive, instead of on your quality of life or comfort.

Why do I need to talk about my goals of care and level of intervention?

- Talking about this helps you and your health care team develop a care plan that matches your priorities.
- Your health care team may ask you about your goals of care and level of intervention:
    - any time you are admitted to the hospital.
    - if your health changes.
    - if you are moved to another unit.

What will my health care team ask me?

How has your health been in the last year?

Your health care team will ask how you have been managing with your health (what has been happening with your health, if you had or are having any challenges). They will also ask about your current health.

Who is your Substitute Decision-Maker?

- If you get sick very quickly, you may not be able to choose your goals of care or communicate them to your health care team. If this happens, your health care team will work with your substitute decision-maker.

- Your substitute decision-maker will interpret and carry out the decisions written in your *Patient-Centered Priorities and Goals of Care (GOC)* form (see page 13). This form is used to keep track of your goals of care.
- You may choose your substitute decision-maker in advance through a Personal Directive (see page 6). If you do not already have a substitute decision-maker named in a Personal Directive, the next step depends on your ability to choose a substitute decision-maker:
  - If you cannot speak for yourself at the time to choose a substitute decision-maker, a family member will be asked to be your substitute decision-maker based on an ordered list set out within Nova Scotian legislation (for example, your spouse, followed by any children over the age of majority).
- We recommend having your substitute decision-maker with you when talking about your goals of care. This will help them to become familiar with your health and your decisions.

What are your priorities as they relate to your quality of life?

For example, your priorities may include comfort, living a longer life, staying at home instead of in the hospital, privacy, safety, and anything else that is important to you. Your priorities can change over time, as can your goals of care and the treatments you are willing to accept.

Do you have a Personal Directive?

- A Personal Directive is a legal document, under the *Personal Directives Act*, that:
    - allows you to name a substitute decision-maker.
    - lists the areas in which the substitute decision-maker has decision-making authority (like health care, care arrangements at home).
    - lets you outline your health care wishes and preferences (for example, treatment you would want or not want), and more.
- For more information on Personal Directives, see the pamphlet *Advance Care Planning – Making Your Personal and Medical Wishes Known*:
    - www.nshealth.ca/patient-education-resources/1942

Words you might hear while talking about your goals of care and choosing a level of intervention:

Cardiac arrest: When your heart stops beating. This is considered natural death.

CPR (cardiopulmonary resuscitation): CPR is used to try to restart your heart if it stops. This is done by pressing very strongly on your chest (chest compressions). CPR is often used with defibrillation (see below).

Although CPR could help your heart to start beating again, there are risks. CPR can cause:

- Broken ribs
- Collapsed lungs
- Worse health and ability to do things (if your health was very poor before you had CPR). This is because of stress from:
  - › the illness that caused you to need CPR.
  - › receiving CPR and other treatments.

Defibrillation: This is also called “shocks.” Defibrillation delivers electricity through your chest wall. It is used to try to reset an abnormal heart rhythm. It is used with CPR for some types of cardiac arrest.

Intubation: Intubation means having a tube inserted (put in) through your mouth and then down into your windpipe (trachea). The tube is connected to a ventilator (breathing machine) that helps you breathe. You will likely also need medication so you are able to tolerate the tube and ventilator.

Although intubation can help you breathe while your lungs heal, or while your body recovers from illness, there are risks:

- Intubation is uncomfortable and hard to tolerate.
- The tube can irritate your airway and increase your risk of getting a lung infection (pneumonia).
- When you are intubated, you cannot talk or eat food by mouth. Most people who are intubated need to be fed by a feeding tube or an intravenous (I.V.) line.
- If you have lung problems, neurological problems (you have had a stroke, you have multiple sclerosis [MS], or a spinal cord injury) or an illness where you need to be intubated for a long time, it may be hard to breathe on your own again without the ventilator.
- Being intubated for more than a few days usually causes trouble walking and psychological distress (like fear, worry).

  - If you have serious, chronic (long-term) health issues, intubation will not fix these problems. It may just delay your death.

Intensive Care: This involves getting intensive treatments (“life support”) to keep your vital organs (heart, lungs, kidneys) working while your body recovers from an acute (short-term) illness.

If you are frail (vulnerable), your memory, function, and/or walking may be worse after intensive care.

What questions should I ask my health care team?

To help you understand your current medical condition and how it is expected to change in the future, ask your health care team:

- How far along is my illness?
- What should I expect to happen in the future?
- How will my illness affect my life in the future?
- What treatments will help me live the way I want to?
- Are there treatments that would not support my goals?
- What are the risks of these treatments to my quality of life?

What else should I consider?

- What are your main goals or priorities related to your health?
- Is not being admitted to the hospital important to you?
- What functions or activities are important to your quality of life?
- What brings you joy?
- Do you want a treatment that might make your life longer if it may make your quality of life worse?

What if I change my mind about my goals of care?

Goals of care can change over time. If you or your substitute decision-maker wants to change your goals of care, let your health care team know so they can review this with you and document these changes.

What if I am not sure what treatments I want to receive?

This is normal. If you have questions, make sure you ask your health care team. We want you to be comfortable with your decisions.

What if I do not agree with what my health care team recommends?

Talk with a member of your health care team if:

- you do not understand the information you receive.
- you feel the treatments recommended by your health care team are not right for you.

The health care team will work with you to find a level of intervention that is right for you.

Who needs to know about my goals of care and level of intervention choices?

- You should give a copy of your *Patient-Centered Priorities and Goals of Care (GOC)* form to:
    - Your primary health care provider (family doctor or nurse practitioner)
    - Your substitute decision-maker (if you have named one)

- A copy of your *Patient-Centered Priorities and Goals of Care (GOC)* form will be placed in your medical record.
- It can help to share your thoughts with someone you trust who knows about your health issues, such as your substitute decision-maker. **That way your substitute decision-maker will be prepared if they are called upon to make decisions**.

I already have a *Patient-Centered Priorities and Goals of Care (GOC)* form. Where should I keep it?

- You should keep it with your other important documents in a safe place.
- You may choose to keep it with your Green Sleeve (if you have one). For more information about Green Sleeves, see the pamphlet *The Nova Scotia Green Sleeve – Information for Patients, Families, and Substitute Decision Makers*:
  - › www.nshealth.ca/patient-education-resources/1833
- Tell your substitute decision-maker where these forms are.

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PATIENT-CENTERED PRIORITIES AND GOALS OF CARE (GOC)

☐ NO KNOWN PREVIOUS GOC/LEVEL OF INTERVENTION (LOI) DECISION

☐ REPLACES GOC/LOI COMPLETED (YYYY/MON/DD): ____________________

PURPOSE: ☐ Future planning ☐ Current or new medical condition ☐ Admission ☐ Other: ______________________________

CAPACITY FOR MAKING THIS LOI DECISION (at cognitive baseline; no delirium; understands medical situation)

Patient demonstrates capacity for this LOI decision: ☐ Yes ☐ No	☐ Delegate named in Personal Directive ☐ SDM as per patient ☐ SDM as per hierarchy Name: ________________________________ Relationship: ____________________

PRESENT DURING GOC DISCUSSION: ☐ Patient ☐ SDM ☐ Other(s): ______________________________

☐ SEE PAGE 2 for additional information

PATIENT PRIORITIES (e.g. REMAIN AT HOME, SYMPTOM CONTROL) **OR OTHER DETAILS INFORMING LOI:**

LOI DECISION MADE AFTER CONVERSATION BETWEEN PATIENT AND/OR SDM AND AUTHORIZED HEALTH CARE PROVIDER (AHCP) AND/OR MOST RESPONSIBLE HEALTH CARE PROVIDER/AUTHORIZED PRESCRIBER (MRHCP/AP)

Focus of Care	Supportive care, symptom management and comfort measures within current location of care if possible. Allow for natural death.		Medical treatment to cure or control symptoms and prolong life, excluding CPR. Allow for natural death.		Preserve/prolong life by all medically effective means.
Type of Care and Level of Intervention:	**COMFORT CARE**		**SELECTIVE CARE**		**FULL CODE**
	☐ C2	**☐ C1**	**☐ S2**	**☐ S1**	**☐ F**
Patient's perspective	"Keep me comfortable and do not delay my death"	"I accept treatments but not at the expense of my immediate comfort"	"Do as much as possible but I do not want life support"	"Do everything until the point of my natural death"	"Do everything possible to save my life, even if it causes discomfort"
Care and treatment targeted to symptoms	✓	✓	✓	If possible	If possible
Treatment which may prolong life	X	Decided in real time based on context and priorities	✓	✓	✓
Transfer to acute care facility	Decided in real time based on context and priorities	Decided in real time based on context and priorities	✓	✓	✓
Non-invasive positive pressure ventilation and/or vasopressors	X	X	Decided in real time based on context and priorities	✓	✓
Intubation (outside surgery)	X	X	X	✓	✓
Full Resuscitation (CPR)	X	X	X	X	✓

Copy to: ☐ Primary Care Provider ☐ LTC Facility ☐ Continuing Care ☐ Patient/SDM ☐ Other: ____________________

AHCP conducting discussion (Print Name)	AHCP conducting discussion (Signature)	Date (YYYY/MON/DD)	Time (HH:MM)
MRHCP/AP (Print Name)	MRHCP/AP (Signature)	Date (YYYY/MON/DD)	Time (HH:MM)

*****FAX BOTH SIDES OF COMPLETED FORM to Health Information Services' centralized office for processing. FAX NUMBER: 902-473-4999*****

Advanced Directives
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NSPPGOC

Pamphlet survey:

- Your feedback is very important to us.
- To fill out a short survey (3 questions) about this pamphlet:
  - Scan the QR code on your smartphone (open your camera on your smartphone, point the camera at the code, and tap the banner or border that appears) or use the link below:
  - https://surveys.novascotia.ca/TakeSurvey.aspx?SurveyID=omKMm640H

Prepared by: Goals of Care Working Group; led by Episodic and Integrated Acute Care Network and Palliative Care Network
Reviewed by: Legal Services
Designed and Managed by: Nova Scotia Health Library Services

To be reviewed June 2027 or sooner, if needed.
Learn more: https://library.nshealth.ca/patient-education-resources