

Goals of Care: When You Are Very Sick and/or Dying in the Hospital

Goals of Care

This pamphlet explains what to expect when you are very sick and/or dying, and are admitted to the hospital. It lists treatments that may be used and when they may be needed.

Some words in this pamphlet may be new or confusing to you and your family – that is OK. Please ask the doctors and nurses any questions you may have. See the back of this pamphlet for more information and definitions.

What are goals of care (also called goals of therapy)?

The goal of any hospital stay is to help treat your symptoms and make you better (if possible) by providing the best treatments and interventions possible. Your health care team will always keep you informed, so we can make decisions together with you, your family (if you want them involved), and/or your **Delegate** (Statutory Substitute Decision-Maker (SSDM)).

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

This is normal. Thinking about the end of life and goals of care is not easy for most people. It is very important to talk about, and plan for, how you wish to be treated if/when you get really sick and/or at the end of your life. Your health care team wants you to be informed about these issues and to be comfortable asking any questions you may have. Understanding your goals of care helps us to make sure you get the treatment that is best for you.

Do I have to talk about my goals of care?

It may be hard, but you do need to talk about your goals of care with your health care team. The more we know about you, your values, and your goals, the better able we will be to treat you as you would want, especially if/when you are no longer able to give consent because of illness. This information is also helpful in guiding your Delegate/SSDM to help us make decisions if/when you are no longer able to.

Why do I need to know about goals of care (goals of therapy)?

“Goals of care” (“goals of therapy”) are the goals you and your health care team set for types and levels of care you may need when you come to the hospital.

Your doctors will talk with you and your family about whether or not you would like invasive interventions (such as surgery), based on your values, goals, and type of illness. They will also ask if you would like **CPR** and **defibrillation** if your heart stops. This can be a scary conversation, but it is **very** helpful in guiding us to give you the treatments you and your family want.

You and your family should read this pamphlet before you talk with your health care team, so that you are well-informed on this challenging topic.

What goals and treatment are best for me?

The goals and treatments that are best for you depend on:

- › your values and beliefs
- › your current health
- › your prognosis (how sick you are, or how sick you are expected to get because of your illness, and your chance of survival)

Your doctor will talk with you about your prognosis and answer any questions you may have. Unless you tell us otherwise, life-sustaining treatments like CPR and/or admission to the ICU may be offered if they are right for you, but these types of treatments may **not** be best for you.

For example, if you are at the end of your life, and/or there is no way to reverse/cure or treat your illness, and/or death is unavoidable, CPR, defibrillation, and ICU treatments will **not** restore your health, but prolong the dying process. At that point, keeping you comfortable may be most important. Talk with your doctor about what you would like to happen if you do not want to, or are not able to, decide yourself.

What if I want everything done to keep me alive?

If you want everything done to keep you alive, and it is medically reasonable to do so, you will be transferred to the Intensive Care Unit, have a breathing tube inserted into your lungs, and be put on a breathing machine (ventilator/life support). You will also have many lines and tubes attached to your body, things like intravenous (IV) lines for fluids and medications, arterial lines to measure your blood pressure, and other tools and monitors as well.

It is very important to talk with your doctors. They can explain which treatments they recommend for you. Often, treatments like CPR, defibrillation, and ICU admission will help you. But, sometimes, these treatments are not recommended because they will not help you, and will only make your death longer, instead of saving your life.

What other treatments are available?

There are many treatments available in the hospital, depending on why you are admitted. Even if you do not want things like CPR, defibrillation, and/or ICU treatments (such as ventilators/life support), there are other things that will be done to help you. These include giving you more oxygen (through a mask or tubes in your nose), giving you IV fluids and/or medications (such as antibiotics, pain medications, etc.), and making sure you are comfortable and do not have symptoms that bother you.

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

You can change your mind at any time about your goals of care. A member of your health care team will always be available to talk with you.

What if do not want to talk about this right now?

This is normal. Being sick and in the hospital can be very stressful and overwhelming. But, it is important to know that sometimes people can get sick very quickly and become unable to make decisions about their care, that is why we want to talk about your goals and preferences early on. For this reason, we will ask you about your decisions several times during your hospital stay: when you are admitted, when your condition changes, with any new diagnosis, and/or if/when you are moved to another unit for more monitoring and tests. This is because we want to make sure we are continuing to do what you want us to do.

I already have a Personal Directive (PD). Where do I keep it?

Your original PD should be kept with other important documents in a safe place. Your family doctor should be given a copy of your PD. If you have named a delegate in your PD, you should also give a copy to them. A copy of your current PD should be placed in your medical chart, which will become a part of your Nova Scotia Health medical record.

Definitions:

Cardiac arrest: when your heart stops beating.

CPR: cardiopulmonary resuscitation (chest compressions). CPR is used to try to restart a stopped heart (cardiac arrest) by pressing very strongly on the chest. It is usually used with defibrillation.

Defibrillation: also known as “shocking.” Defibrillation delivers electricity through the chest wall to try to restart a stopped or abnormally beating heart. It is used with CPR.

Comfort measures/symptom-based management/palliative care: medical treatments used at the end of life that focus on symptom control (such as relief of pain and suffering) and quality of life. Many diseases have uncomfortable symptoms, such as nausea (feeling sick to your stomach), pain, shortness of breath (hard to breathe), anxiety (worry), and other symptoms. These symptoms are treated so you are comfortable when the end comes. Shifting the focus to comfort changes the goals of care to treating symptoms of a disease that **cannot** be reversed/cured. Comfort measures are **as important** as any other medical treatment.

Intensive Care Unit (ICU): a special part of the hospital that treats seriously or critically ill patients. This is where interventions to support vital life functions (such as breathing, blood circulation/pumping) can be done, as needed and appropriate. Interventions such as breathing tubes (mechanical ventilation or “respirator”) and blood pressure support are called “life support.”

Personal Directive (PD): A personal directive is a legal document, under the *Personal Directives Act*, that:

- › allows you to name the person(s) you trust to make decisions on your behalf should you lose mental capacity
- › lists the areas in which the person(s) has decision-making authority (such as health care, residential issues)

See the pamphlet *Let’s Talk About Personal Directives* for information about Personal Directives:

- › www.nshealth.ca/sites/nshealth.ca/files/patientinformation/1385.pdf

Statutory Substitute Decision Maker (SSDM): A person who is given the authority to make admission, care, or treatment decisions on behalf of a patient in accordance with the *Hospitals Act*.

An SSDM is appointed when there is no delegate appointed or no court-appointed representative or guardian.

Pursuant to Section 54 of the Hospitals Act, Section 38, a patient's SDM is the person (aged 19 years or older) who is the highest ranking priority based on the order established by the Act.

See *Hospitals Act* form *Declaration of Substitute Decision Maker ("SDM")* for more details. Ask one of your health care team members to review this form with you.

Looking for more health information?

Find this pamphlet and all our patient resources here: <https://library.nshealth.ca/PatientEducation>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

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

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment.

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The information is not intended to be and does not constitute health care or medical advice.

If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.