

## Patient and Family Ethics Tool

### Help with Ethical Issues

**Find Ethics Nova Scotia Health contact information at:**

**> [www.nshealth.ca/content/ethics-nsha](http://www.nshealth.ca/content/ethics-nsha)**

Aussi disponible en français : *Outil d'éthique pour les patients et les familles - Aide pour les enjeux d'éthique* (FF85-2142)

Also available in Arabic: (AR85-1478)

لعمريئة مغللابة ابعضا منوفر

Also available in Simplified Chinese: (CH85-2168)

同时提供简体中文版



# Patient and Family Ethics Tool - Help with Ethical Issues

Ethics questions ask how we should treat each other. We answer ethics questions by thinking about our values, or what is important to us.

When you or someone you care about is sick or hurt, it can be hard to figure out what to do. You may feel that you are not being treated the way you should be.

It may help to figure out what is worrying you or making you upset. It may also help to think about your choices and talk with others about what is going on.

This ethics tool can help you decide what is important and what to do.

## How do I get started?

When dealing with ethical issues, it is important to remember that:

- There may be more than one answer or approach to the issue.
- The best possible outcome may not feel totally right.
- Sometimes ethical decision-making means doing the **least bad** thing.

Using this ethics tool may help you to make better decisions. It may also help you feel better about decisions you make.

## As you use the tool, remember:

- The questions are only a guide to help you think and talk about an ethics issue.
- You do not have to do the questions in order.
- You do not have to answer all of the questions.
- You might find that you need more information to answer some of the questions.

## Explore the issue

You can think about the following questions, or it may help to make some notes. There is space at the end for notes.

1. What are you worried about? What is the problem you're having?
2. What are your gut feelings about the problem?
3. What sorts of things are making you feel this way?
4. Why does this issue have to be dealt with now? How important is the issue to you?
5. What do you already know about what's going on?
6. What do you need to find out?
7. Who else might be able to help you with this? (See Ethics Resources and Supports for Patients and Families section on page 4 for ideas.)
8. What do you want to do next? For example, you could:
  - › think some more about the issue on your own.
  - › talk to more people about the issue.
  - › make a decision, if you need to and feel that you are ready.
  - › wait a bit and see what happens.

## Go further

1. Who else do you want to talk to? You could:
  - › talk with a member of your health care team.
  - › talk with friends and/or family members.
  - › ask for a team meeting.
  - › ask to talk with someone else at Nova Scotia Health.
  - › talk with someone else in the community who might be able to provide support.
  - › contact Ethics Nova Scotia Health or the other supports listed in this tool.

When you talk with people who may not agree with you, try to understand where they're coming from. It is not always easy to be open to other people's points of view when you are dealing with an ethics issue.

2. Has hearing other people's points of view changed how you feel?
3. What are the choices you could make? (Remember that you can always leave things as they are.) It can help to make a list and think about why someone might or might not choose each option.
4. All things considered, the best possible choice is \_\_\_\_\_  
\_\_\_\_\_  
Why do you think this is the best way to solve the problem?
5. When you explain the option you think is best to someone else, does it make sense? Check if it still feels good when you say it out loud to someone else.
6. Are you OK with the option you've chosen? Are others OK with it? Do you need to think more about what you want to do?
7. What will you do now? Who do you need to tell about your choice?

### **Followup questions**

After you have faced an ethics issue, it can help to look back later. Looking back can help you feel better about what happened. It can also help you to prepare if you have to deal with an ethics issue again.

1. How do you feel now?
2. Are you still OK with your choice?
3. Do you think that others are still OK with your choice?
4. Do you still have any feelings about the issue that you need to talk about?

# Ethics Resources and Supports for Patients and Families

## Health Care Team

Health care team members may be able to give you support. Members of your health care team include:

- **Direct care providers** – Talking with the health care providers who are directly involved in your care is the first step to getting extra support. They can tell you about supports and services that other patients and families in your situation have found useful.
- **Social workers** – Social workers help patients and families figure out the health care system and handle stress related to making important health care decisions. Social workers can help patients and families cope with a new diagnosis, an injury, or a chronic (ongoing) illness, as well as speak up for their best interests.
- **Spiritual care providers** – The spiritual health team is available to respond to the spiritual, religious, and emotional needs of all patients, families, and staff. Nova Scotia Health provides patient and family-centred care. Spiritual health chaplains are sensitive and respectful to the spiritual and religious beliefs and practices of each person.

## Nova Scotia Health Resources

- **Ethics Nova Scotia Health** – Ethics Nova Scotia Health provides support to all patients, families, volunteers, staff, and health care providers at Nova Scotia Health when they need help making difficult choices or when there is disagreement about what is most important. For more information or to talk with the Ethics Resource Coordinator, contact:
  - › Phone: 902-473-1564
  - › Email: [czethics@nshealth.ca](mailto:czethics@nshealth.ca)
  - › [www.nshealth.ca/content/ethics-nsha](http://www.nshealth.ca/content/ethics-nsha)
- **prideHealth** – prideHealth works to improve access to health services which are safe, coordinated, comprehensive, and culturally appropriate for people who are gay, lesbian, bisexual, transgender, Two-Spirited, intersex, queer, and questioning (members of the LGBTIQ+ community).
  - › Phone: 902-487-0470
  - › Email: [prideHealth@nshealth.ca](mailto:prideHealth@nshealth.ca)

- **Nova Scotia Health’s Diversity and Inclusion Coordinator**
  - › Email: DiversityandInclusion@nshealth.ca
- **Nova Scotia Health Patient Relations**
  - › Phone (toll-free): 1-844-884-4177
- **Bilingual services and interpreters**
  - › Phone: 902-470-8572

## Other Resources

- **Nova Scotia Department of Health and Wellness Mental Health Services: Patient Rights Advisor Services** – “Rights advice is a standard form of information provided to patients in Nova Scotia who experience a change in legal status, for example upon being made involuntary, incapable of consenting to treatment etc.  
Rights advice provides protection to individuals who are experiencing a loss of freedom to make their own decisions. This protection takes the form of explaining the loss, the options available to the affected individual with respect to having the decision reviewed and obtaining legal representation if requested.”
  - › <https://novascotia.ca/dhw/mental-health/patient-rights-advisor-services.asp>
  - › Phone: 902-470-7302
- **Family and friends** – NSHA’s family-centred care focus recognizes that family and friends are often the most important source of strength and support for patients.
- **Your religious or spiritual community**
- **Community groups** (e.g., The Alzheimer Society of Canada)
- **Non-profit organizations** (e.g., Immigrant Services Association of Nova Scotia (ISANS), groups that provide crisis/outreach services)
- **Organized support groups** – ask your health care team for recommendations
- **Public and hospital libraries**
- **Online resources** – ask your health care team to suggest reliable sources

**The most important thing is to get the support you need.  
 You are the best judge of what kind of support is right for you.**

# Patient and Family Rights and Responsibilities

How you and your family are treated at Nova Scotia Health is an important ethical issue. The following description of how you should be treated is from Nova Scotia Health's *Your Rights and Responsibilities* pamphlet:

“You are an important member of your health care team. It is important that you understand your rights and responsibilities as a patient or client at Nova Scotia Health. Your rights explain how you should expect to be treated as a patient or client. Your responsibilities explain how you can be a more active member of your health care team and help us provide you with the best and safest care possible. We encourage you and your caregivers to talk openly about your health care. If you have any questions or want to talk more about your rights and responsibilities, please speak with a member of your health care team or the Patient Relations team. They can help you with any concerns about your health care experience.”

# Tips for Talking About Concerns with Your Health Care Team

More patients and families are talking about care decisions with their health care team. Most times the health care team is able to work the patient and family's concerns into the care plan.

It might be harder to talk about your concerns if it is a difficult situation or if this is your first time raising an issue.

Here are things to keep in mind when having this conversation:

- **Consider where, when, and who.** If the staff member is rushed, ask for a better time to talk. If you can, meet in a neutral space away from the hospital room, such as a quiet office. If the patient can take part, they should be included.
- **Be honest, polite, and direct.** For example, "I know that you are working very hard to help me/my loved one, and I sincerely appreciate everything you are doing. I do, however, have an important concern I want to talk with you about."
- **Be open and flexible.** Let's say your loved one gets upset before a medical procedure (like a needle poke). You have done some research online and found another method to try. The team says this method does not meet safety standards. You ask if there are other options that do meet safety standards, even if they aren't usually used. If you work with the health care team to solve the problem together, even if the solution is not the one you found, you will have a better chance of feeling comfortable with the outcome.
- If a health care provider hears what you say as criticism about their work, they may get defensive. To help them hear what you have to say, tell them that:
  - › You know you are both on the same team. You are not trying to prove them wrong. You both care deeply about you/your loved one getting better. You are both working hard to see that this happens.
  - › You know that they are the medical experts. You are the expert on your/the patient's life. You understand that each of you is looking at the situation differently.



# Frequently Asked Questions

## **1. Who do I ask if I have questions about the ethics tool?**

Ethics Nova Scotia Health is available to provide support and guidance. You can contact Ethics Nova Scotia Health at [www.nshealth.ca/content/ethics-nsha](http://www.nshealth.ca/content/ethics-nsha) or by searching for “Ethics Nova Scotia Health” online. Members of your health care team may also be able to answer some of your questions.

## **2. What will happen if I contact Ethics Nova Scotia Health?**

Someone will get back to you within 2 business days, Monday to Friday.

Everything you say will be kept confidential. Staff will talk with you to find out what sort of help you need. They will tell you what they can do to help and let you know if someone else can do a better job of helping you.

Their goal is to help you deal with ethics issues in a way that works for you.

If at any time you find that Ethics Nova Scotia Health is not helping you, you can ask them to stop.

# Ethics Stories

These stories are about making hard choices and wondering about doing the right thing.

None of these stories are from Nova Scotia Health, but things like these happen all the time. You might want help if you find yourself in a situation like the ones in these stories. It might also help you to think about what you might want in situations like these.

## Story #1:

Lin is 25 weeks pregnant and learns that she has a very serious kind of cancer. If she starts treatment right away, her chance of dying is much lower than if she waits. The medicine for her cancer will probably hurt her baby. Lin has to choose between waiting until the baby is born naturally to start treatment for her cancer, or having the baby very early by Cesarean section (C-section). Her doctor and the nurses want her to have a Cesarean section, but Lin and her partner want to wait.

## Story #2:

Marie-Eve is an 85 year-old woman with breast cancer. She has just started her first round of treatment. She is Deaf and uses sign language. She can read lips, but only if the person is speaking French. The hospital's sign language interpreter is on vacation so Marie-Eve has been communicating using gestures and simple written words in English. Her two adult children have just arrived from Quebec. They are worried that Marie-Eve does not understand her treatment and they think she would not have said yes to it if she did understand.

## Story #3:

Sam is 47 years old and has cancer. His health care team says that he has weeks to months to live. Sam asks his nurse about Medical Assistance in Dying (MAiD). Sam's brother overhears them talking and takes the nurse aside afterward to say, "I don't think you should listen to him when he talks like that. He doesn't know what he wants."

# Ivan's Story: Using the Ethics Tool

Ivan is 25 years old and has schizophrenia, a mental illness. He wants to stop taking the medicine he is on and try an alternative treatment using herbs. Ivan's doctor does not want him to stop taking his medicine because she does not think that the herbs will work.

## How might Ivan use the ethics tool?

Ivan's health care team is upset about Ivan's decision to stop taking his medicine and try herbs instead.

Ivan understands that he's making a big decision. A social worker suggests using the Ethics Tool to help explain what's important to him.

Ivan answers the questions in the tool. They help him think about why he wants to use herbs instead of his medicine. The questions also help him to figure out what has been bothering him about his situation.

As Ivan uses the tool and describes his options, he realizes that he needs more information. Some of his questions are:

- What are the side effects of the medicine that the doctor wants me to keep taking?
- Can I take the medicine and the alternative treatment (herbs) at the same time?

After using the tool, Ivan decides to look for more information and also asks for a meeting with his health care team.

In the team meeting, Ivan talks about how much he trusts his herbalist. This person has helped Ivan before with his allergies. This made a big difference in his life. Ivan also talks about how he doesn't like the way his medicine makes him feel.

Ivan says that he is having a hard time talking with his doctor. He finds that she uses a lot of big words. When Ivan is upset, he knows that he has a hard time listening to what his doctor is saying. Ivan says he understands that his doctor cares about him and wants what's best for him.

Other members of the health care team have also said that they would be happy to talk more with Ivan to help him with his decision.

At the end of the meeting, Ivan and the health care team feel better about what they need to do next. Ivan knows that if he needs more support, he can ask for it.

# Feedback

**How can I give feedback to Nova Scotia Health about good or bad things that happened to me, my family member, or my loved one if I don't have an ethics issue?**

Nova Scotia Health has a Patient Relations team that takes feedback. Information can be found at:

- › [www.nshealth.ca/contact-us/patient-feedbackcommentaires-des-patients](http://www.nshealth.ca/contact-us/patient-feedbackcommentaires-des-patients)

Feedback includes compliments, suggestions, and concerns. It tells us what we do well and what needs to be improved for better patient care. Feedback is important to the work we do and we welcome all calls and e-mails.

# Acknowledgments

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This ethics tool is adapted with permission from the IWK Patient and Family Ethics Tool.



**Looking for more health information?**

Find this pamphlet and all our patient resources here: <http://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>

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[www.nshealth.ca](http://www.nshealth.ca)

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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.