IWK Health Centre Patient and Family Ethics Tool: Help with Ethical Issues

IWK Health Centre
100 YEARS OF CARE 1909-2009

Acknowledgments

This Ethics Tool was designed for, and more importantly, with patients and families at the IWK. This included working with the IWK's Family Leadership Council (FLC) and Patient and Family Centred Care. The FLC is made up of IWK patients and families from various backgrounds and experiences through the IWK, who work in partnership with staff and physicians to help improve the quality, safety and experience of care for everyone.

Members of the IWK Ethics Committee led the development of this Ethics Tool, and provided helpful feedback on earlier versions.

This Ethics Tool is loosely based on the IWK Ethics Tool, which is based on the "AVH Ethics Tool: A Guide for Addressing Ethical Issues" authored by Annapolis Valley Health (2008). The AVH document was itself influenced by "Guidelines for Ethical Decision-making" from the Sudbury Regional Hospital (2006) and "A Method for Ethical Deliberation: RICE" by A. Frolic.

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IWK Patient and Family Ethics Tool:
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Introduction

When you or someone you care about is sick or hurt, it can sometimes be hard to figure out what you should do. It may be hard to decide what treatment or care plan is right for you or your loved one. You may also feel that you are not being treated the way you should be.

Sometimes what helps is figuring out what worries you or makes you upset. Other times what helps is thinking about the choices one at a time. It can also help to talk with others about what is going on. This Ethics Tool may also help you with sorting out what is important and what to do.

What is the Ethics Tool?

The Ethics Tool has questions to help you think about what is important to you. There are suggestions about who to talk with. Resources for you are also included.

Using the Ethics Tool can help you to feel better about the decisions you have to make or the situation that you're in. It can also help you feel like you've done everything you can to make the situation better for you and/or your family and loved ones.

If you want to learn more about ethics and the Ethics Committee, please see the Frequently Asked Questions on page 31.

Other Questions about the Ethics Tool:

How do I use the Ethics Tool?

You can work through the whole Ethics Tool or you can just focus on the parts that are useful for you. There is lots of space for you to write your answers down. This Ethics Tool is for you to use as you want. You can stop using it at any time if it is not helping you.

If you are feeling stressed or upset right now, you may feel better if you have someone to help you with this workbook. Please see page 5 for some suggestions about where to get support.

If you feel that this Ethics Tool is not useful for you but you still want help, ask your health care team (see page 28 for Tips on How to Approach Your Care Team). You can also call the Ethics Committee at 902-470-8053. They will tell you about other things that might help you. To learn more about the Ethics Committee, please see the Frequently Asked Questions on page 31.

When can I use the Ethics Tool? Can I share my work with others?

You can use the Ethics Tool any time you think that you are facing an ethical issue and you could use some help dealing with the problem.

You can share it with others if you want, but you can also keep your work to yourself if you'd like.

Do I need to tell my health care team that I am using the Ethics Tool?

No. You can tell them if you want. They might be able to tell you things that could be important to you as you work through the issue, but you do not have to tell them anything if you do not want to.

What Other Supports are Available for Patients and Families?

(See page 27for phone numbers and more suggestions)

Different people need different types of support. Some people at the IWK who could give you support include members of your health care team, such as:

- Social workers – in health care, social workers help patients and families navigate the system and manage the stressors related to making important health care decisions. Social workers help patients and their families cope with a new diagnosis, injury or chronic illness by providing direct services to meet their individual needs as well as advocate for the best interests of patients and families.
- Spiritual Health Chaplains – The Spiritual Health Team is available to respond to the spiritual, religious and emotional needs of all patients, families and staff. In accordance with the IWK's "Family and Patients Centred Care Model", Spiritual Health Chaplains respond in a sensitive and respectful manner to the spiritual and

religious beliefs and practices of each person.

- Mental Health Advocate – this person addresses various types of issues patient and families may have with their care in mental health and addictions. The Mental Health Advocate can help you with the process of dealing with any ethical issues.

Within Family Centred care, we recognize that family and friends are often the most important source for strength and support.

You may also consider support from other sources as well:

- prideHealth – who provide information on transgender issues and the transitioning process, blood borne pathogen testing, free hepatitis vaccines for clients who qualify, referrals to GLBTI friendly professionals, and other information as requested.
- The IWK's Family Resource Library (main floor corridor)
- Your religious or spiritual community
- Community groups (e.g., Parents of Multiple Births Association)

- Non-profit organizations (e.g., Immigrant Settlement and Integration Services – provide crisis/outreach services)
- Organized support groups (ask your health care team for recommendations)
- Going online (ask your health care team for recommendations)
- Bilingual Services & Interpreters

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

When you talk to people, try to help them understand your problem and what's important to you. (See also the tips for approaching your care team – page 28.)

What if I want to give feedback to the IWK about good or bad things that happened to me or my family member or loved one but I don't have an ethics issue?

Quality Resources is always happy to get feedback and ensures it goes where it needs to for follow-up. You can go to the IWK website to do a feedback survey or call or write them at:

Quality Resources
IWK Health Centre
5850/5980 University Ave.
PO Box 9700, Halifax, NS B3K 6R8
902-470-7536

A survey about your experience at the IWK is on the IWK's website at www.iwk.nshealth.ca. Click on "Patient/Family Survey".

Some Ethics Stories:

These stories are about making hard choices and wondering what the right thing to do is. That is the same as saying that all of these stories are about ethics.

None of these exact stories are from the IWK, but things like them happen all the time. You might want help if you find yourself in a story like these ones. The Ethics Tool may be helpful.

Story #1:

Lin is 25 weeks pregnant and learns that she has a very serious kind of cancer. If she does not start treatment right away her chance of dying is much greater. The medicine for her cancer would probably hurt her baby. Lin has to choose between waiting until the baby is born normally to start treatment for her cancer or having the baby very early by Cesarean section. Her doctor and the nurses want her to have the Cesarean section but Lin and her partner want to wait.[1]

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[1] Loosely based on Paul, Pamela, "With Child, With Cancer", *The New York Times* online, August 29, 2008

Story #2:
Ivan is 15 years old and has schizophrenia. His parents want him to stop taking the drugs he is on and to try an alternative treatment using herbs. Ivan's doctor, Anne, does not want Ivan to stop taking his medicine because she does not think that the herbs will work.[2]

Story #3:
Marie-Eve is an 85 year old woman with breast cancer. She is Deaf and talks using 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.[3]

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http://www.nytimes.com/2008/08/31/magazine/31cancer-t.html.

[2] Loosely based on Black, Lee, "Limiting Parents' Rights in Medical Decision Making", *Virtual Mentor* 8.10 (Oct. 2006): 676-680. Online http://virtualmentor.ama-assn.org/2006/10/hlaw1-0610.html)

[3] Loosely based on Moore, Thomas J. et al., "Informed Consent in Emergent Surgery and Unplanned Surgery", *Journal of*

Story #4:
Sam is 7 years old and has to have blood taken to find out why he has strange bruises all over his body. He is scared of the needle and so he is crying and yelling and will not hold his arm still for the nurse. The nurses ask Matt, Sam's dad, to hold Sam down so that they can get the blood.

Note: If you would like to see how the family in Story #2 used the Ethics Tool, please see page 35.

Orthopedics 6.2 (2009). Online
http://www.jortho.org/2009/6/2/e8/index.htm)

The Ethics Tool

Getting Started:

It is important to remember when dealing with ethical issues that:

- There may be more than one answer or approach to the issue
- The best possible outcome may not feel totally right, and
- Sometimes ethical decision-making is a matter of doing the least bad thing.

Using this Ethics Tool, however, may help lead to better decision-making. It may also help you feel better about decisions you make.

Notes:

- You do not have to share this workbook if you do not want to. It is for your own use.
- These questions are only a guide to help you talk and think about an ethics issue.
- You may want to move back and forth between questions.
- 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 these questions.
- You can work with this Ethics Tool when and where you would like. If you are looking for a quiet spot at the IWK, you might want to consider the Ronald McDonald Family Room (see page 34 for more information).

First Steps: Exploring the Issue

1. What are you worried about? What is the problem you're having?

2. What are your gut feelings about this issue or 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 this issue to you?

5. What do you already know about what's going on?

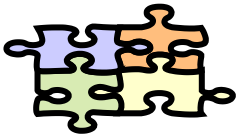
6. What do you need to know?

7. Who else might be able to help you with this? (See page 5 for some ideas.)

8. What do you want to do now? 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 if you feel ready
   - ☐ Wait for a bit and see what happens

Next Steps: Going Further



1. Who else do you want to talk to? You could:
   - Talk to a member of your health care team
   - Talk to friends or family members
   - Ask for a team meeting
   - Ask to talk to someone else at the IWK
   - Talk to someone else in the community who might provide support for you
   - Contact the Ethics Line or the other supports at the IWK listed on page 5.

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

2. Has hearing other people's points of view changed how you feel?

3. What are the possible ways to change what is happening? It can help to make a list. The list can be as long or as short as you like.

   When you write your list, think about why someone might or might not choose that option.

   Remember that you can always leave things as they are.

Option 1.

Option 2.

Option 3.

4. All things considered, the best possible option is _____.

5. Why do you think this is the best way to solve the problem?

6. When you explain the option you think is best to someone else, does it still make sense? See if it still feels good when you say it out loud to someone else.

7. Are you okay with the option you've chosen? Are others okay with it? Do you want to think some more about what you want to do?

8. What will you do now?

9. Who do you need to tell about your choice?

Wrap-up Questions

After you have faced an ethics issue, it can help to look back later and make sure that you did the best you could.

Looking back can help you feel better about what happened. It can also help you prepare if you have to deal with an ethics issue again in the future.

1. How do you feel now?

2. Are you still okay with the choice?

3. Do you think that others are also still okay with the choice?

4. Are there any leftover feelings from the issue that you need to talk about?

Resources and Information

Partners in Care:

How you and your family are treated at the IWK is an important ethical issue. This description of how you should be treated is taken from the IWK's "Partners in Care" booklet:

The IWK Health Centre practices patient and family centred care. This means we value and support you and your family as partners in care. We will work together so that you receive the information and attention you need. The IWK is committed to our vision: "Healthy Families. The Best Care." We show this by conducting research and teaching people who will work in health care.

You and your family can expect that we will...
• treat you with dignity and courtesy
• respect your cultural, spiritual and religious beliefs
• show respect for you in the course of care, teaching and research

As well, you and your family can expect to...
• Receive the safest health care possible.

• Be involved in planning your ongoing care.
• Make informed choices about your care, including refusing treatment(s).
• Make an informed choice about whether you wish to take part in research, if the opportunity is available.
• Know when students and trainees are involved in your care.
• Have your privacy respected.

• *We want you to speak up if you have concerns about your care.*

Speaking up will not harm your care. If you have a concern please talk to your health care team. If your concern has not been addressed or you would rather talk to someone else, please contact Quality Resources. See page 8 for contact information.

"The word "family" refers to two or more persons who are related in any way-biologically, legally, or emotionally. Patients and families define their families" (Institute of Patient and Family Centered Care, 2007)[4]"

[4] All of the above comes from the "Partners in Care" document produced by Quality Resources.

Contact Information for Patient and Family Supports at the IWK

Bilingual Services & Interpreters
902-470-8572

Mental Health Advocate
902-470-7302

prideHealth
902-220-0643

Social Work
902-470-8076

Spiritual Health
902-470-7722

Tips for Approaching your Care Team

As health care information becomes readily available (i.e. internet), more patients and families are feeling empowered and more comfortable engaging in discussions about the course of their or their loved one's care with their Health Care Team. Most times this is going to go well and the patient and family will be listened to and their points/concerns worked into the care plan. Other times, particularly around difficult scenarios, or if this is your first time raising an issue or concern with a staff member or team, this may be a more difficult conversation to approach.

So, let's consider how you would handle this conversation. The following tips will help these types of discussions stay in a respectful and productive place:

- **Consider the where and when.** If the staff member is rushed, best to ask for a better time to talk. And if possible, arrange to meet in a neutral space away from the patient if needed. If the patient is old enough to participate, consider including

them as this could be a great opportunity to help teach them how to advocate for their own health and/or to actively participate in the discussion.

- **Frame what you would like to talk about in a positive way, and be sincere.** For example, "I know that you are working very hard to help 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 in what you are looking for.** Let's say your loved one is becoming distressed by a medical procedure (i.e. IV poke). You have done some research online and found another method to try. The problem is, you will discover this method is not a safe practice standard within the IWK. This conversation will have a better chance of a good outcome for everyone involved if you stay open to work with the Health Care Team to figure out a solution that might not be the one you originally brought forward.

- If a staff/physician interprets what you say as criticism about the quality or safety of care they provide, **they may become defensive**. To help neutralize this circumstance, and help get your message to a place where they can more openly hear what you have to say, it can be helpful to weave these points in as reminders:
    - You recognize you are both on the same team. No one is out to prove the other wrong. Rather, you both care deeply about this patient getting better. You are both working hard to see that this happens.
    - You appreciate that they are the medical experts in this situation – this is why they are the ones providing care. You, on the other hand, are the expert on the patient, and you are coming at this with a completely different set of eyes. Hopefully the Health Care Team will find this opportunity helpful to see an even bigger picture and make decisions from there.

Frequently Asked Questions about Ethics and the Ethics Committee:

1. Am I facing an ethical issue?

A gut feeling that something is wrong or that someone is being treated unfairly is often the first sign of an ethical issue.

But feeling that something is not right might also be because of a lack of communication, personal conflict, or misunderstanding.

These are some of the signs that your problem is probably an ethical issue:

a. There seems to be a conflict of important values or beliefs.
b. Important values or beliefs are being ignored.
c. There seems to have been needless suffering or harm for you or a loved one.
d. You are not sure what the right thing to do is.

2. Why have the Ethics Committee and others at the IWK created the Ethics Tool?

Ethics issues are often hard to deal with. They can make a very difficult time worse if you don't feel like you can share your feelings about them.

It can also be hard to keep your thinking straight. This Ethics Tool can help you organize your thoughts.

Using this Ethics Tool can help you to feel better about the decisions you have to make or the situation that you're in. It can also help you feel like you've done everything you can to make the situation better for you and/or your family and loved ones.

3. If I have questions about the Ethics Tool, is there someone who can help me?

The Ethics Committee is available to provide support and guidance. You can contact the Ethics Committee by calling the Ethics Line at 902-470-8053. All calls are confidential.

4. What happens if I call the Ethics Line?

Someone will return your call within 24 hours, Monday to Friday.

Everything you say will be confidential. They will talk to you to find out what sort of help you need. They will tell you what they can do to help. They will also tell you 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 you find that what the Ethics Committee is doing is not helping you, you can ask them to stop at any time.

Ronald McDonald Family Room

The Ronald McDonald Family Room is a 'home away from home' designed for and by IWK patients and families as a space where they can step away from the hospital setting and settle into a warm, relaxing atmosphere. Here IWK families can take a breath, cook a meal and eat together like at home, find some needed personal space, bake cookies with staff, play with siblings, entertain visitors, have coffee and a snack, sit in front of the fire, do some work or banking or emails on the internet, do laundry, and much more.

The Room is open to all IWK patients and families, including inpatient families and those waiting for loved ones in day treatment or in between clinic visits. It is located on the 3rd floor, in between PICU and the IWK Heart Centre – just left, then right off the green elevators.

Example: Ethics Story #2

The story told below is an example of how someone might use this Ethics Tool. It is based on Ethics Story #2 which is on page 9.

Ivan's parents – Tyrone and Ingrid – are very upset about what is happening to their son. They are not sure what the best decision for Ivan is. Should he take the medicine that the doctor wants him to? Would an alternative treatment work? Would it help? Ivan is not able to help with this decision because he is having problems telling what is real from what is not.

While they are leaving the IWK, Tyrone and Ingrid see the Ethics Tool. Ingrid picks up a copy and they take it home. At home, Ingrid starts to read the Ethics Tool. She likes knowing that other parents may find it hard to make decisions for their child too.

Ingrid and Tyrone decide that they would like to use the Ethics Tool to talk about what is going on with Ivan. In the *First Steps: Exploring the Issue* section (see page 14), Ingrid talks about how worried she is about Ivan. Tyrone

talks about whether Ivan will be able to finish high school. Both Ingrid and Ivan agree that this decision about treatment is important. What they choose will make a difference to Ivan's life.

Ingrid and Tyrone also talk about how much they trust their alternative care provider. This person has helped before with Ivan's allergies. It made a big difference.

Tyrone says that he is having a hard time talking with Anne, the doctor at the IWK. He finds that she uses a lot of big words. When Tyrone is upset, he knows that he has a hard time listening to what Anne is saying. Ingrid says that it is clear to her that Anne cares about Ivan like they do.

As Tyrone and Ingrid discuss what they should do next, they realize that they need more information. What are the side effects of the medication that Anne wants Ivan to take? Can Ivan take the medication and the alternative treatment at the same time?

Other members of the health care team have also said that they would be happy to talk more with Tyrone and Ingrid. The social

worker and the Mental Health advocate have both made contact.

Tyrone decides that he would like to read the "Tips for Approaching Your Care Team" section in the Ethics Tool (see page 28). Ingrid reads the list of other resources and supports (see page 5).

At the end of the evening, Ingrid and Tyrone feel better about what they need to do next. In the morning, they will go to the IWK and ask to meet with Anne and the social worker. They know that if they need some more support, they can ask for it.

They feel that they will be able to make a good decision for Ivan. If they are unsure, Ingrid and Tyrone will use the Ethics Tool to decide what to do next.

The Ethics Committee is happy to get feedback on this Ethics Tool or about any support that they have provided for you. Call 902-470-8053 to provide feedback to the Ethics Committee directly or call 902-470-7536 to give feedback to Quality Resources.

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