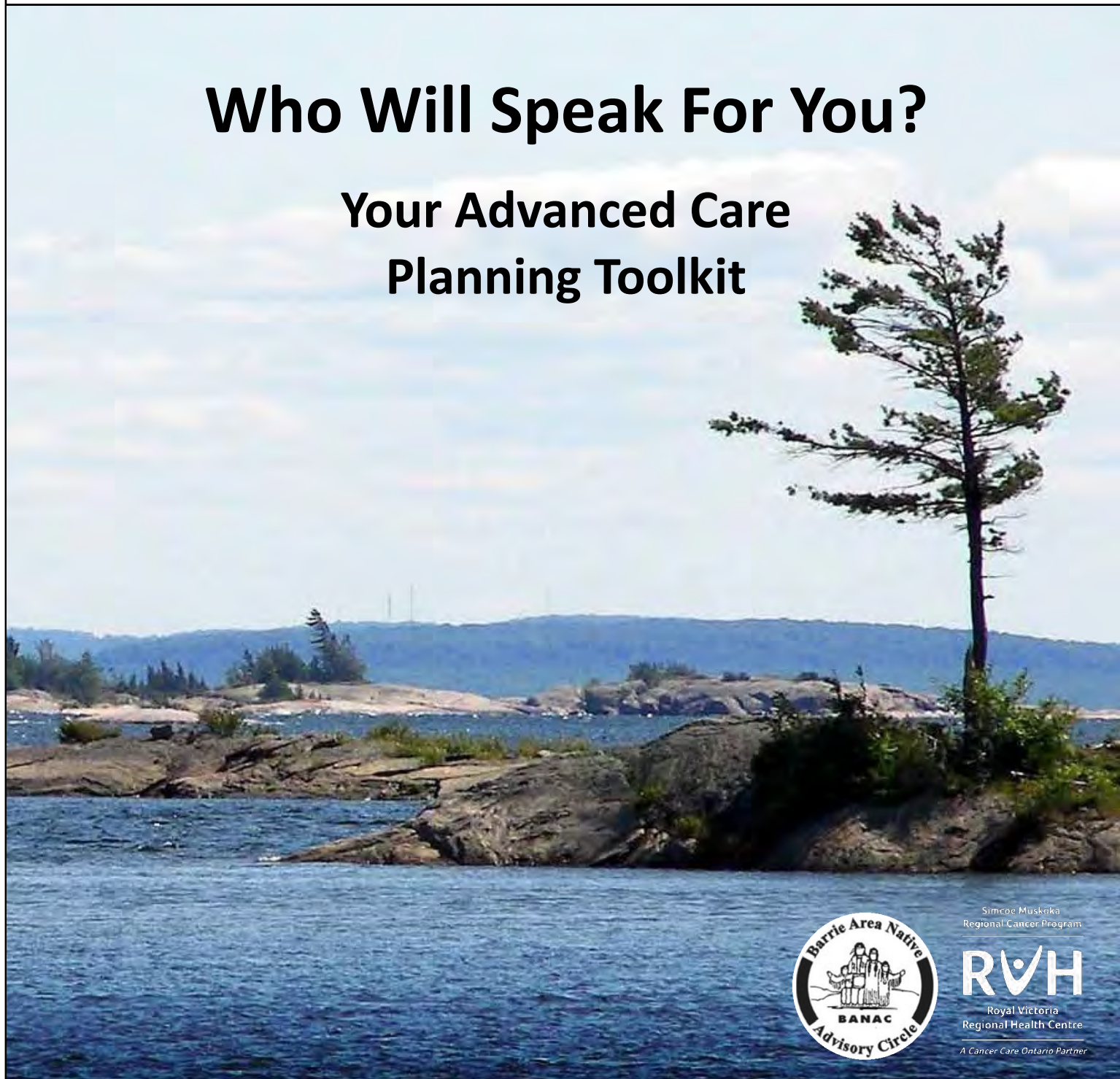




Who Will Speak For You?

Your Advanced Care Planning Toolkit



Simcoe Muskoka
Regional Cancer Program

RVH
Royal Victoria
Regional Health Centre

A Cancer Care Ontario Partner

“We understand who we are -
We know where we come from -
We accept and understand our destiny here
on Mother Earth -
We are Spirit
Having a human experience”

Ian Anderson





What is Advance Care Planning?

We make decisions and plans every day of our life. Daily decisions like what we want in our morning coffee and when to sleep, daily decisions that could include the making of some sort of plan for the day. We make monthly and yearly plans for our lives but we often overlook making a health care treatment plan in the event that we become ill. Advance Care Planning is about creating and making your own decisions about your journey's end.



This booklet is about your wishes. It allows you to reflect on your own values and beliefs that you can discuss with your family, close friends and substitute decision maker (a substitute decision maker is someone you trust who can provide consent of refusal or care if you are mentally unable to do so). By discussing your wishes it allows them to understand your personal thoughts and reasons for your decisions.



How to Begin Advance Care Planning

1. What is right for you?

Take the time to reflect on your own beliefs, values, and how you understand end-of-life care. If you have been in a situation where you've experienced someone's end-of-life journey, how did that make you feel?

Ask yourself:

- If possible would I prefer to die at home, in a hospice or in the hospital?
- What might change my mind about my choice?
- Do I want or not want certain medical interventions (e.g. resuscitation or feeding tubes) if I am unlikely to survive or live independently?
- Why would I not want these procedures?
- Do I have any fears about dying (e.g. I'll be in pain, I won't be able to breathe)?
- Is there someone that I can talk to about these fears, such as my doctor?
- What would be meaningful for me at the time of my death (e.g. family/friends nearby, music playing or pictures?)

2. Learn about end-of-life care options and procedures

Everyone has different ideas for their end-of-life journeys; some individuals want to prolong life as long as possible using medical interventions. Others would not want to be hooked up to machines at the end-of-life if there is no chance of recovery.

Take the time to talk with your health care provider to learn about different medical procedures and what they can and can't do.

3. Who do you want to make medical decisions for you if you are incapable to do so?

Think about the people in your life that you feel would understand, honour and follow your wishes. Ask yourself who would be most capable of making medical decisions for you as your Substitute Decision Maker.



How to Begin Advance Care Planning

4. Begin the conversation

When you know who you would like to be your **Substitute Decision Maker(s)**, have a conversation with them and your family to let them know what you are thinking.

This may be hard for them or may come as a relief to know what your wishes are (feel free to give them a copy of your plan, so they can understand your wishes).

Let your Doctor and other Health Care Providers know who your Substitute Decision Maker is, ask them to make a note of it, so they know who to speak with if you do become incapable to.

5. Document your wishes

The next few pages is a workbook to help you document your wishes. Be sure to include other wishes for your end of life care (e.g. dying at home, receiving hospice/palliative care, having music playing, or any specific spiritual or religious rituals).

6. Review your wishes

It is important to remember that this is your journey and you can make the decisions for your health care treatment. Reviewing your wishes allows you to reflect on your own values, and beliefs but it also allows you to make adjustments if you change your mind about a treatment.

Advance Care Planning can answer:

- Who do you want to make your health care decisions for you?
- What health care treatment(s) do you agree to, or refuse, if a health care provider recommends them?
- Would you accept or refuse life support and life-prolonging medical interventions for certain conditions?
- What are your preferences should you need residential care and not be able to be cared for at home?



The following examples may help you figure out what is important to you.

These things make my life meaningful:

- Spending time with my family and friends
- Love for my pet/music/art/garden/work/hobbies/fresh air/sports
- Practicing my faith

When I think about what my death could be like, I take comfort in:

- Knowing any pain I have will be treated
- Believing I will have good care and know that my family will continue to be with me
- Believing there is something after death, even if I don't know what

When I think about dying I worry that:

- I may struggle to breathe
- I may have uncontrolled pain
- I might be alone

When I am nearing the end of my life I want:

- My family nearby
- I want to be in the hospital, hospice or in my own home
- Someone holding my hand
- My spiritual, or religious leader to visit me
- To hear people talking gently about my life's happy memories
- To listen to the music I love
- Someone to read my favorite book to me
- A window kept open no matter what the weather

A serene lakeside scene with a canoe on the shore, surrounded by trees and foliage, with a text overlay.

My Health Care Wishes

My Health Care Wishes

— Expression of Wishes

If you decide to write a plan by another means to communicate your wishes, remember to give a copy to your Substitute Decision Maker(s). Give a copy to your family members, your doctor and any other health or legal professionals.

Most importantly — have a conversation with your Substitute Decision Maker(s) about your plan. They may have questions about your wishes.

Your Information

First Name:

Middle Initial:

Last Name:

Date of Birth:

Do you Identify as: ☐ First Nation ☐ Métis ☐ Inuit ☐ Other

From Which Nation:

Address:

Telephone:

Cell Phone:

Email Address:

What makes life meaningful to me:

My Health Care Wishes

— Expression of Wishes

Consider the following questions to help guide the conversation(s) and expression of your wishes:

1. What do I value most in terms of mental or physical health?

- | | | |
|-----------------------------------------------------------|------------------------------------------------------------|----------------------------------------------------|
| <input type="checkbox"/> Being able to live independently | <input type="checkbox"/> Being able to recognize others | <input type="checkbox"/> Being able to communicate |
| <input type="checkbox"/> Having my privacy | <input type="checkbox"/> Being able to still do my hobbies | <input type="checkbox"/> Keeping my dignity |
| <input type="checkbox"/> Having friends and family nearby | <input type="checkbox"/> Other: _____ | |

2. What would make prolonging life unacceptable to me?

- | | | |
|-------------------------------------------------------------------------------------|--------------------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Being in a coma with little or no possibility of waking up | <input type="checkbox"/> Not being able to communicate with others | <input type="checkbox"/> Being a burden to family members |
| <input type="checkbox"/> A loss of privacy | <input type="checkbox"/> Losing control of my bodily functions | <input type="checkbox"/> Being in pain |
| <input type="checkbox"/> Being kept alive by machines | <input type="checkbox"/> Other: _____ | |

3. What are my concerns about death?

- | | | |
|------------------------------------------|----------------------------------------------|-----------------------------------|
| <input type="checkbox"/> Be in pain | <input type="checkbox"/> Struggle to breathe | <input type="checkbox"/> Be alone |
| <input type="checkbox"/> Lose my dignity | <input type="checkbox"/> Other: _____ | |

4. If I were near death, what would I want to make the end more peaceful for me?

- | | | |
|-------------------------------------------------------|-------------------------------------------------|----------------------------------------------------------------|
| <input type="checkbox"/> Family and friends nearby | <input type="checkbox"/> Be able to die at home | <input type="checkbox"/> Have spiritual or traditional support |
| <input type="checkbox"/> Having specific music played | <input type="checkbox"/> Other: _____ | |

My Health Care Wishes

— Expression of Wishes

5. Do I have any spiritual or religious beliefs that would affect my care at the end of life?

6. What other thoughts and wishes might help others understand and support me at the end of life?

7. Do I want to request the services of a Traditional Healer?

8. If I were ill, what would be important for others to know?

These questions can help you think a bit more about what interventions you would or would not want:

How important is it that I be comfortable and suffer as little as possible?

☐ Not important ☐ Somewhat important ☐ Very important ☐ No opinion

How important is it that I live as long as possible?

☐ Not important ☐ Somewhat important ☐ Very important ☐ No opinion

How important is it that I respect the wishes of other family members regarding my care?

☐ Not important ☐ Somewhat important ☐ Very important ☐ No opinion

My Health Care Wishes

— Substitute Decision Maker(s) (SDMs)

I have discussed my wishes/plans with the following people and/ or they have copies. List all the people who have copies, their relationship to you and their contact information.

Name	Relationship to me	Contact Information
1.		
2.		
3.		

I have discussed my wishes for health care with the person(s) named below.

My Primary Substitute Decision Maker (SDM):

(see next page for a listing of other SDMs)

Name: _____

This person was appointed through a Power of Attorney for Personal Care Document: ☐ Yes ☐ No

Location of the current Power of Attorney for Personal Care (original document): _____

☐ My Substitute Decision Maker has a copy of the document.

OR if no Power of Attorney for Personal Care document: the Substitute Decision Maker who is the highest ranked person in the Hierarchy of Substitute Decision Maker(s):

Name: _____

Relationship of this Substitute Decision Maker to me: _____

Phone Number: _____

Mobile Number: _____

Address: _____

Email Address: _____

My Health Care Wishes

— Substitute Decision Maker(s) (SDMs)

My Second Substitute Decision Maker is:

Name: _____

This person was appointed through a Power of Attorney for Personal Care Document: ☐ Yes ☐ No

Location of the current Power of Attorney for Personal Care (original document): _____

☐ This person has a copy of the document.

Relationship of this Substitute Decision Maker is: _____

Phone Number: _____

Mobile Number: _____

Address: _____

Email Address: _____

My Third Substitute Decision Maker is:

Name: _____

This person was appointed through a Power of Attorney for Personal Care Document: ☐ Yes ☐ No

Location of the current Power of Attorney for Personal Care (original document): _____

☐ This person has a copy of the document.

Relationship of this Substitute Decision Maker is: _____

Phone Number: _____

Mobile Number: _____

Address: _____

Email Address: _____

My Health Care Wishes

— Expression of Wishes

It's time to talk to your Substitute Decision Maker, your family and your health care provider about your wishes. These conversations may not be easy— but they will help your loved ones know what's Important to you.

Who do you want to talk to?

When is a good time to talk to them? Think about when you might approach your loved ones—for example, at a family gathering, over a meal, before the next big trip, etc.

Where is a good place to talk? Think about where you might have the conversation—for example at the kitchen table, at a restaurant, during a walk or drive, at the cottage, etc.

What do I want to be sure to say? List the most important things you want to make sure you'll talk about during your conversation:

My Health Care Wishes

- Summary of Information

This is a good time to put all your personal planning information together where they can be found. This will help those you have put in charge of your affairs to find them if needed (check all that apply, and note the location of each document):

☐ Written statement of my wishes about health care (e.g. hand written notes) Location: _____

☐ Power of Attorney for Personal Care Document Location: _____

☐ Substitute Decision Makers: Phone: _____
1. _____
2. _____
3. _____

☐ Lawyer Name: _____ Location: _____

☐ Will: Location: _____
Yes ☐ No ☐

☐ Insurance Policy Location: _____
Company Name: _____

☐ Funeral and burial/ceremonial arrangements Location: _____
Company Name: _____

☐ Other (e.g. organ donors, specific bequests) Location: _____
Name of Document: _____

☐ Name of Document: Location: _____

Signature

Date:



Community Resources

**Simcoe Muskoka Regional
Cancer Centre**

**Phone: 705-728-9090 ext. 4333
Website: www.rvh.on.ca**

**Aboriginal Patient Navigator
Leah Bergstrom**

**Phone: 705-728-9090 ext. 43133
Email: bergstromel@rvh.on.ca**

Rotary Place Lodge

**Phone: 705-739-5662
Website: www.rvh.on.ca**

**Barrie Area Native Advisory Circle
(BANAC)**

**Phone: 705-734-1818 ext. 235
Email: admin@banac.on.ca
Website: www.banac.on.ca**

Traditional Healer

Cell: 705-937-1206

Barrie Native Friendship Centre

**Phone: 705-721-7689
Website:
www.barrienativefriendshipcentre.com**

**Enahtig Healing Lodge and
Learning Centre**

**Phone: 705-534-3724 ext. 210
Email: enahtig@enahtig.ca**



Community Resources

Georgian Bay Métis Council	Phone: 705-526-6335 Website: www.georgianbaymetisCouncil.com
Chigamik Community Health Centre	Phone: 705-527-4154 1-877-527-4154 Website: www.chigamik.ca
Traditional Healing	Phone: 705-527-4154 ext. 204
Georgian Bay Native Friendship Centre	Phone: 705-526-5589 Website: www.gbnfc.com
Hospice Simcoe	Phone: 705-722-5995 ext. 222 Email: doris@hospicesimcoe.ca
Métis Nation of Ontario	Phone: 705-526-6335 Website: www.metisnation.org
Muskoka Community Health Hub—Wahta	Phone: 705-762-1274 Website: www.ccfht.ca



Community Resources

North Simcoe Muskoka Hospice Palliative Care Network	Phone: 1-877-235-2224 Website: www.nsmhpcn.ca
Orillia Native Women's Group	Phone: 705-329-7755 Email: donnafinance@outlook.com Website: www.onwg.ca
Rising Sun Native Women's Support Group	Phone: 705-737-3532 Email: admin@sunhousing.ca
Georgian Bay Native Women's Association	Phone: 705-527-7043 Email: gbnwa@rogers.com Website: www.gbnwa.ca
<u>Other Resources:</u> — Speak Up: Advance Care Planning Workbook— Ontario Edition	Website: www.advancecareplanning.ca
— Lakehead University: End of Life Care In First Nation Communities	Website: www.eolfn.lakeheadu.ca

Word List

Allow Natural Death:

The decision NOT to have any treatment or procedures that will delay the moment of death. It applies only when death is about to happen from natural causes.

Cardiopulmonary Resuscitation (CPR):

A medical procedure used to restart your heart and breathing when the heart and/or lungs stop working unexpectedly. CPR can range from mouth-to-mouth breathing and pumping of the chest to electric shocks that may restart the heart and machines that breathe for the individual.

Comfort Measures:

Treatments that keep you comfortable (e.g. pain relievers, psychological support, physical care and oxygen).

Dialysis:

A medical procedure that cleans your blood when your kidneys can no longer do so.

End-of-Life Care:

Health care provided at the end of a person's life. This type of care focuses on you living the way you choose during your last days or weeks and providing comfort measures until the time of death.

Feeding Tube:

A way to feed someone who can no longer swallow food.

Health Care Professional:

A person licensed, certified or registered in their province or territory to provide health care (e.g. a doctor, nurse, or social worker).

Informed Consent:

Is the permission you give to health care providers that allows medical investigations and/or treatments. Health care providers are required to offer you, and you are entitled to receive, detailed explanations of the investigation/treatments and their risks, benefits and side

Word List



effects alternatives to these options; and what would likely happen if you refuse the options. Health care providers must also answer any questions you have about the treatments and the information must be provided before you give verbal consent or sign a consent form.

Intravenous (IV):

Is a way to give you fluids or medicine through a vein in your hand or another part of your body.

Life support with Medical Interventions:

Medical or surgical procedures such as tube feeding, breathing machines, kidney dialysis, some medications and CPR. All of these use artificial means to restore and/or continue life. Without them you would die.

Life Limiting Illness:

An incurable medical condition caused by injury or disease.

Palliative Care:

Is the way we care for people who have a life limiting illness. It focuses on providing good quality of life. In other words, keeping you as comfortable and free of pain or other symptoms as possible. Palliative care may involve medicines, treatments, physical care, psychological/social services and spiritual support, both for you and for those who are helping to care for you. Palliative care can be provided anywhere, at any stage of any illness along with care and treatment aimed at cure or prolonging life.

Power of Attorney for Personal Care (PoA):

A document in Ontario that you prepare when you are mentally capable to name a person or persons to be your Substitute Decision Maker for health and other personal care decisions. That person or persons would make decisions about treatment and health care on your behalf if you become mentally incapable.

Substitute Decision Maker (SDM):

A person(s) who provides consent or refusal of consent for treatment or withdrawal of treatment on behalf of another person when that person is mentally incapable to make

Word List

decisions about treatment. The Substitute Decision Maker(s) is required to make decisions for you following any wishes you expressed about your care when you were mentally capable. If your Substitute Decision Maker does not know your wishes applicable to the treatment decision to be made, he or she is required to act in your best interest.

Symptoms:

Signs that you are unwell (e.g. pain, vomiting, loss of appetite or high fever).

Terminal Illness:

An incurable medical condition caused by injury or disease. These are conditions that, even with life support, would end in death within weeks or months. If life support is used, the dying process takes longer.

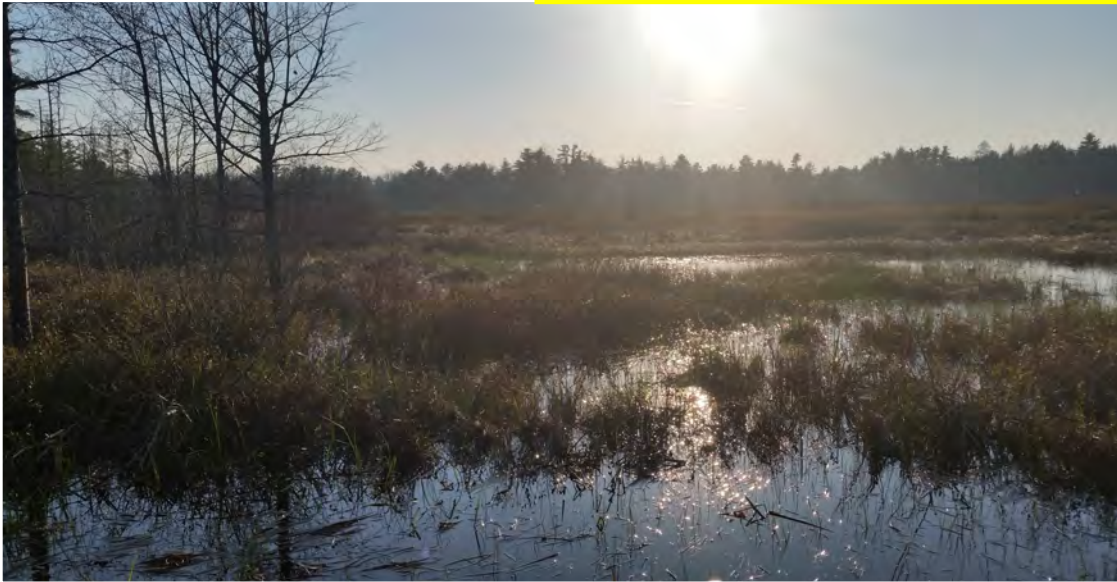
A Ventilator:

A machine that helps people breathe when they cannot breathe on their own.



Preparing For the Journey

Mohawk Perspective



When humans are born they come from the Sky World. When they are nearing their end-of-life stage they begin planning their quest back to the Sky World; to the House of Souls through ceremonies and other cultural practices.

When humans die, each soul has their own path of destiny they must follow. Souls that are at peace travel through the Great Sky Road which is the good sky path that leads to the House of Souls. Here the souls will be greeted with an eternal home with other souls, pleasant smells, refreshing spring waters and sweet strawberries.

The living take comfort in ceremonies before and after death to assist the soul of their loved one to make its journey through the Great Sky Road to the House of Souls.

Traditional support is available [see community resources]

<http://www.cpd.utoronto.ca/endoflife/Modules/Indigenous%20Perspectives%20on%20Death%20and%20Dying.pdf>

Thanksgiving Address

Ohén:ton Karihwatéhkwen Words Before All Else

Sewatahonhsí:iost ken`nikarihwésha sewakwé:kon. Ne
kati`tentshitewanonhwerá:ton ne
Shonkwaia`tíson, ne wáhi rohsa`ánion akwé:kon tsi nahó :ten
teiotawénrie ne tsi iohontsá:te.

*Let us all listen for a moment. We will give thanks to the
Creator, for it is he who has made everything that is in this universe.*

Akwé:kon énska entsitewahwe`nón:ni nonkwa`nikón:ra tánon...
Let our minds come together as one mind and...

Teiethinonhwerá:ton ne Onkwehshón:`a
Let us give thanks to all people

Teiethinonhwerá:ton ne lethi`nisténha Ohóntsá
Let us give thanks to our Mother Earth

Teiethinonhwerá:ton tsi Kahnekarónnion
Let us give thanks to all waters

Teiethinonhwerá:ton ne Kentson`shón:`a
Let us give thanks to all fish

Teiethinonhwerá:ton ne Ohtera`shón:`a
Let us give thanks to all roots

Teiethinonhwerá:ton ne Ohonte`shón:`a
Let us give thanks to all plants

Teiethinonhwerá:ton ne Ononhkwa`shón:`a
Let us give thanks to all medicines

Teiethinonhwerá:ton ne Otsinonwa`shón:`a
Let us give thanks to all insects

Teiethinonhwerá:ton ne Tionhéhkwen, ne ne áhsen nikon-
tate`kén:`a – Ónenhste, Onon`ónsera, Osahé :ta
*Let us give thanks to the sustainers of life, the three sisters –
corn, beans and squash*

Teiethinonhwerá:ton ne Kahihshón:`a, tánon kwah
tkonwakowá:nen – Niiohontésa
*Let us give thanks to the fruits, and the leader, the
strawberry*

Teiethinonhwerá:ton ne Kontírio, tánon kwah
tkonwakowá:nen – Oskénón:ton
Let us give thanks to the animals, and the leader, the deer

Teiethinonhwerá:ton ne Otsi`ten`okón:`a, tánon kwah
tkonwakowá:nen – Á:kweks
Let us give thanks to the birds, and the leader, the eagle

Teiethinonhwerá:ton ne Karonta`shón:`a tánon
Okwire`shón:`a tánon kwah tkonwakowá:nen – Wáhta
*Let us give thanks to the trees, the shrubs, and the leader,
the maple*

Teiethinonhwerá:ton ne Kaié:ri Nikawerá:ke – Othoré:ke,
Ná:kon, Entié:ne, É:neken
Let us give thanks to the four winds – North, East, South and West

Teiethinonhwerá:ton ne lethihsothó:kon Ratiwé:ras
Let us give thanks to our Grandfathers, the Thunderers

Teiethinonhwerá:ton ne lethihsótha Ahshonthénkhkha Karáhkwa
Let us give thanks to our Grandmother, the Moon

Teiethinonhwerá:ton ne Ehtshitewahtsí:`a Tiehkehnékhkha
Karáhkwa
Let us give thanks to our older brother, the Sun

Teiethinonhwerá:ton ne tsi lotsistohkwarónnion Tsitkaronhiá:te
Let us give thanks to the stars in the heavens

Teiethinonhwerá:ton ne Shonkwais`tíson (Ka`satsstenhserakó:wa
Sa`oié:ra)
Let us give thanks to the Creator (all natural force/power)

Ó:nen tho niió:re wa`kkwé:ni. Toká' thé:nen sonke`nikónhrhen
í:se ne'é ia'sewatahsónteren tánon ska`nikón:ra' kénhak tánon
tsonhniióhak.
*This is as far as I am capable of. If I have forgotten anything, then
you continue and be of one mind and keep healthy.*



Preparing For the Journey

Ojibway Perspective



The journey of life begins and ends with The Creator in The Spirit World. Everyone has a spirit and when we are born into this life we are given a temporary body. The human spirit has four stages to their journey; birth, life, death and afterlife.

As we are born our spirit leaves the spirit world and we begin life. Throughout life we enter different stages; childhood, youth, adulthood and elder years. During these times our purpose is to find and understand who the Creator is and help those around us to do the same.

At the point of dying we take comfort in returning to the spirit world. Our family and friends help us get there by their support and prayers. When our spirit leaves our body it travels westward across the land, until it reaches the high clouds where a bright light guides it to a place where loved ones wait to embrace it—in the spirit world.

Traditional support is available [see community resources]

The Great Spirit Prayer

Oh Great Spirit

Whose voice I hear in the winds,
and whose breath gives life to all the world
Hear me! I am small and weak
I need your strength and wisdom
Let me walk in beauty,
And make my eyes ever behold the red and purple sunset.
Make my hands respect the things you have made
And my ears sharp to hear your voice.
Make me wise so that I may understand
The things you have taught my people
Let me learn the lessons you have hidden in every
leaf and rock
I need strength, not to be greater than my brother, but to
fight my greatest enemy— myself
Make me always ready to come to you with clean hands
and straight eyes
So when life fades, as the fading sunset, my spirit may
come to you without shame
Miigwech



Gzhe Mnidoo

Giin e-noondoonaan e-bganaanmag,

Miinwaa giin e-nesedman maanda aki.

Noondwishin! Aapchi ndi gaashiin'iw miinwaa ndi niinmis.

Niin ndanwendaan mshkawziiwin miinwaa nbwaakaawin

Begish pane ji bmooseyaan mampii akiing ezhi-gnaajwang.

Begish gaye pane ji waabmag Giizis ni-bngishmod.

Begish gaye ji mnaandenmaan kina gaa wzhitooyin.

Pane gaye ji noondoonaan bi-gnoozhyin.

Ndi bgosendaan nbwaakaawin wii nsitomaan kina gaa

kinoomodwaa nwiji-bemaadzijig. Miiwaa Kina

kinoomaadwinan gaa gaadooyin niibiishing miinwas siniing.

Ndi bgosendaan mshkawziiwin gaawiin washme wii

pitendaagoziyaan, ni'ii eta wii gshkitoonyaana wii miigaanag

pane myaananmag 'niin'.

Ndi bgosendmin pane ji aabji-zhiitaayaan bi-zhaamnaana, ji

biinaagog nninjiin miinwaa gwayak ji gnawaabminaana.

Pii dash ni-shkwaasek ndi bmaadzinwin ga mno-gnawaabmaa

maaba n'jichaakim.

Miigwech





Simcoe Muskoka
Regional Cancer Program



Royal Victoria
Regional Health Centre

A Cancer Care Ontario Partner

My Name is: _____	
Incase of Emergency Call:	
Name: _____	Phone: _____
My Health Care Provider is: _____	
I am an Organ Donor: Yes <input type="checkbox"/> No <input type="checkbox"/>	
My Important papers are located in: _____	