

The Talk

Sharing Your Health Care Wishes



Let's Talk About It

Some people call *The Talk* Advance Care Planning. Others believe it is about appointing a Power of Attorney for Care or a Substitute Decision Maker. Some believe it is about assigning a health proxy or writing a living will.

Many people don't know any of these terms. It can be overwhelming and confusing. It doesn't have to be. *The Talk* is simply a way to share your wishes.

In this pamphlet you will learn about:

- Why sharing your care wishes helps those you love better understand what is important to you.
- How to make your wishes for care known and how to choose someone to speak for you, your care, and what that means when you are no longer able to communicate.
- How in Ontario, if you do not assign a spokesperson, your care team will take direction from a government assigned Substitute Decision Maker as the need arises.



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“It’s always too soon until it’s too late.”

Everyone has a story about losing someone close. Many people know what it was like to have to guess; wondering whether or not their loved one’s wishes were carried out. Did they want to be on life support? Was pain to be managed even though medication made them sleepy? Was that song and photo their favourite? It doesn’t have to be this way.

One simple talk can make all the difference.

Talks are the many natural, monumental discussions that take place in your life. Usually, these conversations involve your loved ones. They are about you, your loved ones, and personal wishes:

- Choosing your future career or school
- Deciding on your life partner or marriage
- Making major purchases, like vehicles or homes
- Adding to your family
- Explaining the birds and the bees

A talk about care wishes and end-of-life is also significant.

Talking offers your loved ones the comfort of knowing what you value most when the time comes.

Let’s have *The Talk*.

The Talk is about sharing your future health decisions. Now is the best time to act, while you can communicate. Understanding your end-of-life wishes can bring you closer to the people you love.

Let’s plan ahead to prevent your loved ones from having to guess.



I. Reflect

To start, reflect upon your own beliefs and values. How you choose to live your life every day will help guide you through what is important to you at end-of-life.

Personal Values

What matters most to you in life? You may value:

- **Independence:** The ability to live without help or supervision.
- **Communication:** The ability to speak with others.
- **Senses:** The ability to smell, taste, touch, hear and see.
- **Leisure:** The ability to relax with favourite pastimes and hobbies.
- **Support:** Having friends and family nearby when you need help.
- **Recognition:** Knowing who your loved ones are and being aware of their presence when they visit.
- **Privacy:** Limiting information to select individuals.

Life Goals

Often what brings us joy at the end are those things that brought us meaning during life. What makes your life meaningful?

- Your friends and family?
- Your pets?
- Your favourite music, movies and hobbies?
- Your personal photos, videos and memories?
- Your legacy?
- Your time in the outdoors and nature?
- Your religious community or spirituality?
- Other things that bring your life meaning?

Final Wishes

Thinking about the end of your life can be difficult. Sometimes it helps to recall or imagine a situation with someone else:

Your friend's dad is dying and unable to communicate. Your friend is now responsible for their parent's health choices. Speaking on their behalf, they must make difficult decisions impacting their dad's care and comfort. Would their father want to be pain-free, but miss out on being awake enough to visit with friends? Would their parent want to listen to specific music, or be out in nature? Would they want to have extra days, but rely on life support?

Everyone has different beliefs and values. Your end-of-life decisions may not be the same as your loved one's. That's why having *The Talk* is so important.

Deciding on what matters most at the end-of-life may be difficult to identify. It helps to reflect upon what comfort means to you.

If given the chance to extend your life, what would you consider to be an unbearable sacrifice?

- Being in a coma with no chance of waking?
- Losing control of your bodily functions?
- Not being able to eat, wash or get dressed?
- Suffering through unmanageable pain?
- Losing one or more senses?
- Being unable to communicate?
- Forgetting loved ones?
- Relying on life support to be kept alive?



Finding Balance

Knowing what matters most to you is essential in order to make end-of-life decisions. What would you prefer?

- Living as long as possible or the quality of your final days?
- Respecting the wishes of your family or ending life on your own terms?
- Knowing only basic information about your condition or detailed information?
- Having friends and family nearby or experiencing quiet and solitude?
- Dying in the comfort of your home, hospice, or hospital?
- Having comfort care or seeking medical solutions until the very end?

You've now reflected on what matters most to you. It may help to take the time to learn about specific medical opportunities. What each option can and cannot provide during end-of-life may help determine your choices.





There are several medical care opportunities you may want to be aware of or learn more about:

- **Palliative Care:** Care focusing on a person's emotional, spiritual, medical, and physical comfort. It is compassionate care that respects a person's wishes through end-of-life.
 - **Hospice Care:** Palliative care that does not hasten nor prolong end-of-life, provided by professionals in a home-like setting.
 - **Comfort Measures:** Care to keep you comfortable, but not used to prolong life. Examples include pain medication and oxygen.
- **Life Support:** Medical procedures that artificially prolong life.
 - **Resuscitation:** Restarting a heart, including mouth-to-mouth, chest pumps, or shock.
 - **Dialysis:** Substituting the kidneys by regulating fluids through tubes in the veins.
 - **Feeding Tube:** A tube inserted through the stomach and abdomen to supply food.
 - **Hydration:** A process to provide fluid by mouth, tube, or veins.
 - **Intubation:** A long plastic tube placed into the windpipe to keep an airway open.
 - **Ventilator:** A tube inserted into the mouth or throat that connects to a breathing machine.
- **Medical Aid in Dying (MAiD):** A care professional administering or prescribing a substance to a person, at their request, that causes death.

There are many resources that can help you. On page 17 we've provided several helpful options in your search for end-of-life care. Reaching out to your local health care community is the best way to find answers.



2. Decide

Talking about death may seem daunting. Thankfully, the process of deciding who to speak with and when or where to have *The Talk* may provide you with peace of mind. There is never a perfect person to choose or a perfect place to talk about end-of-life. Weighing your options will make you more comfortable with having *The Talk*.

Who

When you imagine discussing your final wishes, who are you speaking with?

- Parent
- Child
- Spouse
- Sibling
- Friend
- Clergy
- Doctor
- Other

You may feel most comfortable talking with your family. Your death will likely impact them the most. It's important to understand not all of your loved ones may agree with your decisions. Speaking with them first sometimes can cause more stress. Sometimes it's easier to have *The Talk* with others first, then speak to family.

Talking with a close friend may provide a less stressful route. Your friend may disagree with your wishes, but they may also be less impacted by your decisions.

Reaching out to your religious community may bring you some spiritual comfort. Your clergy may give answers to any lingering questions about your faith.

Talking with your doctor is another option to let you freely speak your mind. Your doctor can also answer any medical questions you have about the end-of-life journey.

When

Important discussions are sometimes easiest to have in connection with life milestones or after significant events. You may also feel that *The Talk* can happen naturally and have a conversation at any time. The choice is yours.

When is the time that you would feel most comfortable having *The Talk*?

- When your child goes to school?
- Before your next trip?
- The next time family visits?
- At the next family dinner?
- Before your health is affected?
- Before the baby arrives?

Where

Think about an environment that would make you feel safe and comfortable having *The Talk*. Imagine a location that puts you at ease for this sort of discussion.

Where do you imagine being the most comfortable having *The Talk*?

- At the kitchen table
- At a restaurant
- At a place of worship
- At a medical facility
- Sitting in the park
- Lying at the beach
- In a car on a trip
- During a walk



Choosing Your Spokesperson

Your spokesperson is someone who will speak on your behalf if you are unable to communicate. They will express your end-of-life wishes. A spokesperson is able and willing to speak for you, 16 years of age or older and mentally capable of making decisions. Your spokesperson will likely be one of the people with whom you have *The Talk*.

If you have not appointed a Power of Attorney for Personal Care (see below), the government automatically assigns a spokesperson(s) in order from the list below:

1. Spouse/common-law/partner
2. Parent/children (16+)
3. Parent/guardian with right of access only
4. Sibling(s)
5. Relative (by blood/marriage/adoption)
6. Office of the Public Guardian & Trustee

There may be two or more people in the same category on the above list, for example, multiple children. If so, they share responsibility and everyone qualified must agree to care decisions or they must designate a representative. If you have not appointed a spokesperson, anyone, including family and friends, can apply to become your **board-appointed representative** (ranked higher than spouse) to the *Consent & Capacity Board* for medical treatment, admission to long-term care facility, and personal assistance services. They can also apply to the *Superior Court of Ontario* to be your “**Guardian of the Person**” **with authority for treatment** (ranked highest on the list) to make all care decisions.

Power of Attorney for Personal Care

If you do not want the person(s) on this list to be your spokesperson, you must make your preference known and fill out the appropriate forms. These forms are called Power of Attorney for Personal Care. You may wish to have legal counsel to assist or you can obtain the documents directly from the Office of the Public Guardian and Trustee. **Completing the Power of Attorney for Personal Care ensures your spokesperson is the person you want.**

Information on Selecting a Spokesperson

Office of the Public Guardian and Trustee

Part of the Ontario Ministry of the Attorney General. Contact them for information about Powers of Attorney for Personal Care, Continuing Powers of Attorney for Property, the Substitute Decisions Act, and guardianship.

Website: www.attorneygeneral.jus.gov.on.ca

Phone: 1-800-366-0335

ServiceOntario Publications

Information about Ontario's Health Care Consent Act and the Substitute Decisions Act.

Website: www.ontario.ca/publications

Phone: 1-800-668-9938

Consent and Capacity Board

Conducts hearings related to capacity, wishes, and substitute decision-making with application forms.

Website: www.ccboard.on.ca

Phone: 416-327-4142

Lawyer Referral Service (LRS)

Process to help you determine your rights and options. First 30 minutes are free.

Website: www.legalaid.on.ca

Phone: 1-800-668-8258



3. Talk

You've reflected on your wishes. You've decided who you would prefer to share your end-of-life goals with. You've chosen when and where you want to have the conversation.

It's time to have *The Talk*.

Get comfortable with thinking about and discussing death. You can write a letter to yourself, your loved one, or a friend. Another idea is to practise the conversation with someone you trust.

If you've chosen a loved one to speak with, the beginning may be painful. Starting a conversation about death is never easy. We've provided some strategies below to break the ice.

Breaking the Ice

- "I need your help with something."
- "I was thinking about what happened to _____, and it made me realize..."
- "Even though I'm okay right now, I'm worried that _____, and I want to be prepared."
- "Will you help me think about my future?"



Your Talk

When you have *Your Talk*, keep in mind the following:

- **Be patient.** You've had time to reflect on *Your Talk*. Your loved one may be caught off guard. Give them time to absorb what you're saying.
- **You don't have to direct the conversation.** Let *Your Talk* happen and see where the discussion goes. Questions you've never considered may come up.
- **Reserve your judgment.** There are no right or wrong answers about death. Everyone will have a different opinion.
- **Any progress is progress.** Death is an emotional, heavy subject. Understand the conversation may take more than a single sitting to complete. Take pride in your progress.
- **Nothing is final.** Life is not linear. At any given moment your values and beliefs may change. It's okay to change your mind.

Remember, this is *Your Talk*. It will be focused on what you want to discuss, and may be a series of discussions, including:

- Your values, beliefs, and wishes reflecting end-of-life
- Any health concerns
- Deciding who you want involved with your care
- Opinions on medical treatments
- Dealing with personal finances
- Managing family problems or disagreements
- Being there for an important milestone
- Where you want to receive end-of-life care
- Shifting the focus from curing an illness to comfortable living

4. Record

After having *The Talk*, record your wishes. There are many ways you can do this:

- **Fill out the included *My Wishes Card* wallet insert.** This is a simple way to record your wishes and have it handy in case of emergency. It can be filled out before, during or after *The Talk*. Fold it and keep it in your wallet.
- **Write on paper.** This is an easy choice for those who are uncomfortable with technology. Be sure your writing is readable to prevent any miscommunication.
- **Type on a computer.** Sometimes writing can be difficult to read. Some people prefer to type. Be sure to print your document signed and dated for clarity.
- **Record yourself.** If you can't write or type, then you may choose to use a camera, smartphone, or webcam to record your voice. Be sure to leave the video or audio recording in a location where it isn't locked behind a password or key.
- **Ask your care professional.** Your doctor can add your wishes to your medical record. This ensures your care preferences are in a safe, easy to find location.
- **Ask your lawyer.** Your lawyer can place your wishes into an official document, such as a living will or health care proxy. These documents can help guide your spokesperson, but do not specifically direct care.

Remember to keep your wishes somewhere easy to find.

More *My Wishes Cards* are available at archhospice.ca/talk, as well as by contacting ARCH Hospice at info@archhospice.ca or by calling 705-942-1556 ext. 202.





Community Resources

ARCH Connect

ARCH Hospice's team can help you with having *The Talk*, discussing care, making plans for the future, and linking you with community resources.

Phone: 705-942-1556 ext. 236

Email: info@archhospice.ca

Website: www.archhospice.ca

229 Fourth Line West

Sault Ste. Marie, Ontario

Clergy/Churches

Please reach out to your clergy or church if you have any spiritual questions or concerns about your end-of-life wishes.

Additional Guides and Help

There are many guides and workbooks to help you have *The Talk*.

Speak Up

Online interactive and printable workbook to make your wishes known.

Website: www.advancecareplanning.ca

The Conversation Project

Downloadable workbook and guide to sharing your wishes and care plans.

Website: www.theconversationproject.org

A Guide to Advance Care Planning

A workbook to share your wishes published by the province of Ontario

Website: www.ontario.ca/seniors

Phone: 1-888-910-1999



Glossary

- **Advance Care Planning:** Planning care wishes, also known as *The Talk*.
- **Advance Care Plan:** A written document of *The Talk* or your completed *My Wishes Card*.
- **Agent:** Also known as a spokesperson.
- **Cardiopulmonary Resuscitation (CPR):** Restarting a heart: mouth-to-mouth, chest pumps, or shock.
- **Comfort Measures:** Means used to keep you comfortable, but not used to prolong life.
- **Dialysis:** A medical procedure that cleans the blood when the kidneys are unable to do so.
- **Do Not Resuscitate (DNR):** An order requesting emergency personnel to not perform CPR.
- **Feeding Tube:** A way to feed someone unable to swallow.
- **Health Care Proxy:** Also known as a Power of Attorney for Personal Care.
- **Hydration:** A process to provide fluid by mouth, tube, or veins.
- **Intravenous (IV):** A tube that delivers fluid and medicine through a vein.
- **Intubation:** The placement of a long plastic tube into the windpipe to keep an airway open.

- **Life Support:** Medical procedures that artificially prolong or restore life.
- **Living Will:** Also known as a Power of Attorney for Personal Care.
- **Natural Death:** When someone dies without medical treatments prolonging life.
- **Palliate:** To relieve, but not cure symptoms of a disease.
- **Palliative Care:** Care focusing on a patient's emotional, spiritual, medical, and physical comfort.
- **Power of Attorney for Personal Care:** A written, legal document that assigns a specific person as your spokesperson (in Ontario Law).
- **Proxy:** Also known as a spokesperson.
- **Public Guardian and Trustee:** A provincial or territorial spokesperson in case one cannot be found for you.
- **Spokesperson:** Someone who will make care choices for someone who is unable to communicate.
- **Substitute Decision-Maker (SDM):** A spokesperson assigned by the government by a specific hierarchy.
- **Terminal Illness:** Sickness without a cure that leads to death.
- **Ventilator:** A tube inserted into the mouth or throat that connects to a breathing machine.



Next Steps

Having *Your Talk* will help those you love, and those who love you. It may even bring you closer. Your decision to have this important conversation is a statement that you are thinking about your future, and your loved one's future. It shows you care.

Your Talk can make all the difference, and may inspire others to have *The Talk* with you.

1. Reflect

- Consider your own values and beliefs
- Review your preferences and care wishes for your end-of-life journey
- Think about different care options for you

2. Decide

- Determine who, when and where you're going to have *The Talk*
- Choose the spokesperson who will make care decisions for you when you no longer can

3. Talk

- Share your wishes with your loved ones

4. Record

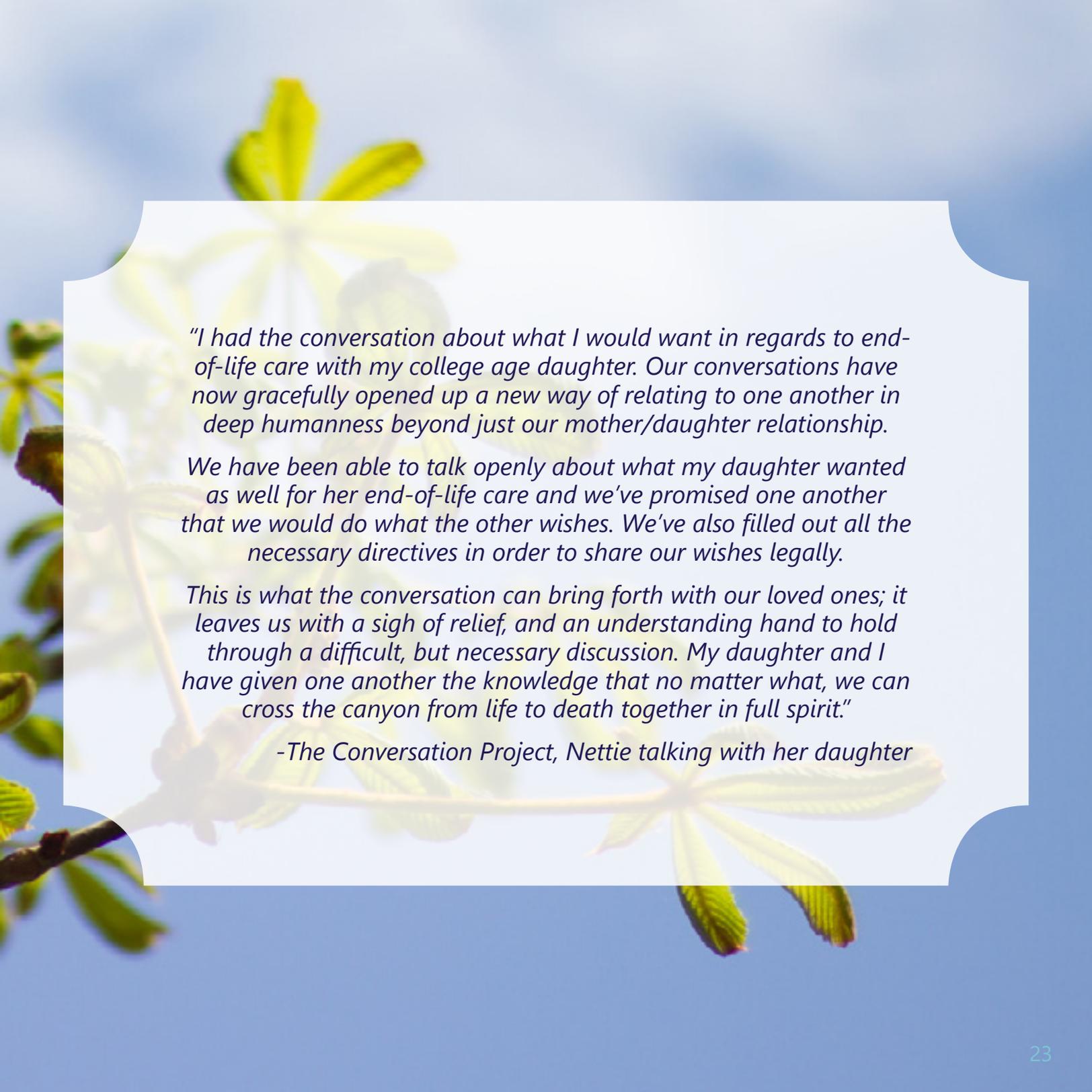
- Fill out and carry your *My Wishes Card* in your wallet
- If you change your mind, revise your wishes and speak to your loved one or doctor
- If you prefer, seek legal advice
- If necessary, complete the Power of Attorney for Personal Care







Nature photography of the Algoma District generously donated by Bo Lu



"I had the conversation about what I would want in regards to end-of-life care with my college age daughter. Our conversations have now gracefully opened up a new way of relating to one another in deep humanness beyond just our mother/daughter relationship.

We have been able to talk openly about what my daughter wanted as well for her end-of-life care and we've promised one another that we would do what the other wishes. We've also filled out all the necessary directives in order to share our wishes legally.

This is what the conversation can bring forth with our loved ones; it leaves us with a sigh of relief, and an understanding hand to hold through a difficult, but necessary discussion. My daughter and I have given one another the knowledge that no matter what, we can cross the canyon from life to death together in full spirit."

-The Conversation Project, Nettie talking with her daughter



ARCH
hospice

Comfortable End-of-Life Journeys

229 Fourth Line West
Sault Ste. Marie, Ontario P6A 0B5
info@archhospice.ca | 705-942-1556

My Wishes Card

Name: _____

Date: _____

What makes my life meaningful?

What matters most to me at end-of-life is:

What I would value if nearing death is:

- My friends & family
 - Enjoying peace, quiet & reflection
 - My pets
 - My favourite music, movies & hobbies
 - My personal photos, videos & memories
 - Leaving my legacy
 - Enjoying the outdoors & nature
 - My religious community or spirituality
 - Other things that bring my life meaning
-

What I would consider unacceptable is:

- Being in a coma with no chance of waking
 - Losing control of my bodily functions
 - Not being able to eat, wash or get dressed
 - Suffering through unmanageable pain
 - Losing one or more of my senses
 - Becoming unable to communicate
 - Forgetting my loved ones
 - Relying on machines to keep me alive
 - Other sacrifices that would be unbearable
-

I would prefer to die in:

- A hospital or medicalized setting
- A hospice or palliative care setting
- My home or current setting

Finding balance in what matters most to you is essential – what would you prefer?

- | | | |
|--|---|---|
| Living as long as possible | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | Living as fully as possible |
| Ending life on my own terms | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | Respecting the wishes of my family |
| Knowing basic information about my condition | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | Knowing detailed information about my condition |
| Having friends and family nearby | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | Having quiet and solitude |
| Dying in the comfort of my home | <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> | Seeking medical solutions until the end |

I have had *The Talk* with: _____

Other thoughts & wishes:

Location of important documents:

- Will: _____
- Organ Donation: _____
- PoA for Property: _____
- PoA for Care: _____

Spiritual or religious preferences:

Funeral or memorial preferences:

Spokesperson contact information:

Name: _____

Relationship: _____ Phone: _____

Email: _____

Address: _____