

Let's Start the Conversation



Grande Prairie Palliative Care Society

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Let's talk about it...

Facts:

- It is one of the toughest conversations to start.
- It is one of the most important conversations to have now, not later.
- Some people call it Advanced Care Planning
- Some people call it “The Talk”
- Some people believe it is about appointing an Enduring Power of Attorney (EPOA) for Care or Substitute Decision Maker or Personal Directive
- Some believe it is about assigning a health proxy or writing a living will.

Let's address the elephant in the room

“How we die lives on in the minds of everyone that survives us”

-Peter Saul

Many people believe there is always time, or they don't know where or how to start the conversation, it can be overwhelming and confusing. It doesn't have to be. This booklet, “Starting the conversation” is a simple way to help you get started, to share your wishes.

You will learn

- 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 or speak for yourself.
- How in Alberta, if you do not assign a spokesperson, your care team will take direction from a government assigned Substitute Decision Maker as the need arises.

Let's talk about it





“It’s always too soon until it is 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 favorite?

It does not 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. We have many with our loved ones over the course of our life (school, marriage, making major purchases, birth etc.) Often “this talk” gets put off until tomorrow, then the next day, and so on, until we find ourselves in an event where we can no longer speak for ourselves.

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

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

So... Let's start “The Conversation” today, 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.

take a moment to
REFLECT

To start, reflect upon your own beliefs and values. How you choose to live your life everyday 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:

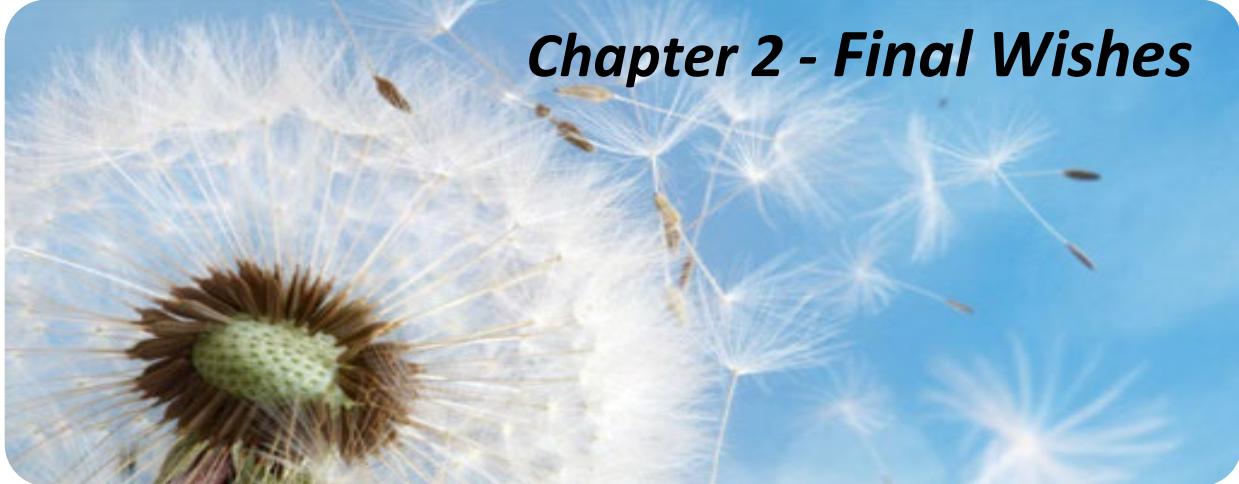
- Independence: The ability to live without help or supervision
- Communication: The ability to speak with others
- Senses: The ability to smell, taste, touch, hear and see
- Leisure: The ability to relax with favorite pastimes and hobbies
- Support: Having friends and family nearby when you need help
- 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 favorite music, movies and hobbies?
- Your personal photos, videos and memories?
- Your legacy?
- Your time in the outdoors and nature?
- Your religious or spiritual community and beliefs?
- Other things that bring your life meaning?

Chapter 2 - Final Wishes



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

For instance, 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 others in your family. That is why starting “*the conversation*” “*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?

Chapter 3 – 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.

Chapter 4 -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 compressions, 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. Please refer to our resources page where 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.

Chapter 5 - Decide



Talking about death may seem overwhelming. Thankfully, the process of deciding who to speak with and when or where to have “The Conversation” 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 starting this important “Conversation-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 Conversation or 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



WHERE

When

Important discussions are sometimes easiest to have in connection with life milestones or after significant events. You may also feel that starting “The Conversation” can happen naturally and at any time. This choice is yours.

When is the time that you would feel most comfortable starting “The Conversation?”

- When your child goes to school?
- Before your next trip?
- 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 starting “The Conversation-The Talk”. Imagine a location that puts you at ease for this sort of discussion.

Where do you imagine being the most comfortable starting “The Conversation-The Talk?”

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

Choose your Spokesperson



Your spokesperson is someone who will speak on our 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, 18 years of age or older and mentally capable of making decisions. Your spokesperson will likely be one of the people with whom you start “The Conversation-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
7. 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 Alberta to be **your “Guardian of the Person”** with authority for treatment (ranked highest on the list) to make all care decisions.

Enduring Power of Attorney (EPOA) for Personal Care

If you do not want to 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 Enduring 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 & Trustee

Website: <https://www.alberta.ca/office-public-guardian-trustee.aspx>

Edmonton

Adult guardianship services
4th Floor, 108 Street Building
9942 108 Street NW
Edmonton, AB T5K 2J5
Phone: 780-427-0017
Fax: 780-422-9138

Trusteeship Services
4th Floor, John E. Brownlee Building
10365 97 Street NW
Edmonton, AB T5J 3Z8
Phone: 780-427-2744
Fax: 780-422-9136

Service Alberta Publications

Website: <http://www.servicealberta.ca/644.cfm>
Phone: 310-0000 (toll-free anywhere in Alberta)
780-427-2711 (outside of Alberta)

Consent to Treatment/Procedure(s) - Alberta Health Services

Website: <https://www.albertahealthservices.ca/info/page3064.aspx>
Alberta Health Services Corporate Office
Seventh Street Plaza
14th Floor, North Tower
10030 – 107 Street NW
Edmonton, Alberta T5J 3E4

Phone: 780-342-2000
Toll free: 1-888-342-2471

Chapter 8 - 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 start
"The Conversation-The Talk"

It's time to start "The Conversation-The Talk"

Get comfortable with thinking about and discussing death. You can write a letter to yourself, your loved ones, or a friend. Another idea is to practice "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?"



When you have started “The Conversation-The Talk”, keep in mind the following:

- **Be patient.** You've had time to reflect on your “Conversation”. 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-The Talk”.** Let it 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 “Conversation, 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 the remainder of your time. Quality vs Quantity



Chapter 9- Record

After your “Conversation-Talk”, record your wishes.

There are many ways you can do this:

- **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 (Personal Directive), 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.

Community Resources

Grande Prairie Palliative Care Society

GPPCS's team can direct you to appropriate resources to help you start "The Conversation", discussing care, making plans for the future, and linking you with other community resources.

Phone: 780-897-0066
Email: admin@gpcare.ca
Website: www.gpcare.ca

Suite #204 10134-97ave
Grande Prairie, AB
T8W 7X6

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 start
“The Conversation-The Talk”**

Speak Up

Online interactive and printable workbook to make your wishes known
Website: www.advancedcareplanning.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 – Alberta Health Services

A website to discuss options and how to share your wishes by Alberta Health Services
Website: www.albertahealthservices.ca/info/page12585.aspx

Review

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

Your “Conversation-Talk” can make all the difference, and may inspire others to “Start the Conversation-The Talk” of their own.

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

Decide

- Determine who, when and where you’re going to start “The Conversation”
- Choose the spokesperson who will make care decisions for you when you no longer can

Talk

- Share your wishes with your loved ones

Record

- Write down, video or audio your wishes and have them available
- If you change your mind, revise your wishes and speak to your loved ones or doctor
- If you prefer, seek legal advice
- Complete the Power of Attorney for Personal Care



Glossary

- **Advance Care Planning:** Planning care wishes, also known as The Talk
- **Advance Care Plan:** A written document of your “Conversation” or The Talk
- **Agent:** Also known as a spokesperson
- **Cardiopulmonary Resuscitation (CPR):** Restarting a heart: mouth-to-mouth, chest compressions or shock
- **Comfort Measures:** Means used to keep you comfortable, but not used to prolong your 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 Limiting Illness:** Illness without a cure that leads to death
- **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
- **Proxy:** Also known as a spokesperson
- **Public Guardian & 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 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

thank you



A Special Thank you to ARCH Hospice for sharing your amazing resources and knowledge.