**Planning for My Care**

* Ensuring Two-Spirit and LGBTQ+ people’s wishes for care are known and respected

Many of us have experienced or witnessed discrimination and ignorance in a healthcare setting. We may have received inappropriate care or, even worse, been denied care. Some healthcare workers still need to learn about the challenges our community faces. But to receive the care we need and want, we must be clear about the type of care we personally wish to receive. We are all individuals.

This document, focusing on care conversations for Two-Spirit and LGBTQ+ people, is intended to help you think about what is important to you, what concerns you might have, and who you would want to make decisions for you if a time comes when you can’t make decisions for yourself.

Take your time reading through this document. You can write your ideas down if you like. You do not have to respond to all of the questions right away or ever. Please review them at your own pace. You may want to do this alone or you could do it with a partner, relative, or friend. It could be a rich and productive discussion for both of you.

This is not a legal document and cannot be used to provide consent for treatments. It is not a Will and has nothing to do with the distribution of your property or finances. It is, instead, a guide to help you start having conversations about your care. It is a document that will help you prepare for a very important conversation. Suggestions for moving forward are contained at the end of this document.

**What’s the benefit in having this conversation?**

1. You get to think about and choose what you would like for your own care.
2. You get to state what you would not like.
3. You get to name people who may and who may not speak for you if you are unable to speak for yourself.
4. Specific health directions increase the chance your decisions will be respected and followed.

In addition to this document, you may want to review:

1. Taking Pride in My Health and Well-being, which is a personal guide for inclusive and safe care for Two-Spirit and LGBTQ+ people; and,
2. the collection of Inclusive Care web pages on the Canadian Virtual Hospice website.

**Terminology:**

When we use the word “family” we are referring to your birth family, your family through marriage, or your family of choice.

*“Sexual orientation and gender identity are not a choice. Having a care conversation about what is important to each of us is.”*

**Part 1 – What is Important to You?**

Thinking about your own values and beliefs may help you prepare to talk with your loved ones, healthcare providers, and others. Ask yourself the following questions.

**Who are the important people in your life?**

(This could include partners, family, friends, community organizers, Elders, teachers, spiritual or religious leaders, etc.)

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**What makes your life meaningful? What is important to you?**

(For example, spending time with your family and friends, working, being outside, volunteering, hobbies, music, sports, activism, gender expression, correct pronoun, sexual orientation, etc.)

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**Do you have spiritual, cultural, or religious beliefs that are important to you?**

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**What have you learned about life that you would want to share with others?**

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**What are you most afraid of or concerned about?**

(For example, being a burden on friends and family, not recognizing others, losing control of your bodily functions, not being able to do the things you loved to do or haven’t done yet, unresolved family conflicts, dying alone, etc.)

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**Part 2 – Your Wishes for Care**

What do you value the most? How would you like your physical, emotional, social, and spiritual needs to be met?

**If you were to get very sick, what would matter the most to you?**

(For example, being able to spend time with your friends and family, being in the comfort of your own home, having people around you who speak your language, being pain free, receiving excellent medical care, maintaining your dignity, preserving your culture, having your gender expression, respected, etc.)

Your response may include something like the following. *I want to have as much prepared as possible and not burden my friends or family with making decisions. I want them to just be able to come and spend time with me.*

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**If you were to get very sick, what would you be the most concerned about?**

(For example, making sure that your family and pets are taken care of, needing to leave your community to receive care, not being able to work, a lack of money, etc.)

Your response may include something like the following.  
*I follow a traditional Indigenous lifestyle and that would be part of my expectations in my care – that it would be woven into Western interventions. That might mean bringing plant medicines, teas, or even ceremonies into that context. I would want my healthcare providers’ support to do that.*

OR

*I would like to plan my care with professionals who work together to understand me and my caregivers, who allow me control, and bring together services to meet my needs.*

OR

*I am most concerned that I would lose my gender expression and have to revert to my birth gender which includes clothing and pronouns I left long ago.*

OR

*Chinese medicine, including acupuncture, is important to me, and I would like that continue.*

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**Part 3 – Writing your Wishes for Care**

This is the most comprehensive part of your care conversation. This is where you decide what you want and what you do NOT want for critical care. Some of these are very big questions.

The following is a list for you to think about. There are no wrong answers. You may want to choose “Yes”, “No”, “Maybe”, “Some”, “None”, or expand on your choice. Some of the questions may not be applicable to you or you may not be prepared to answer them now. You may also want to add other items after reviewing the next page.

If you were to get very sick…

|  |  |  |
| --- | --- | --- |
| 1 | How much information do you want shared about your sexual orientation or gender identity with the medical team? |  |
| 2 | How much detail would you like to know about your illness? |  |
| 3 | How much say would you like to have about your treatment and care? |  |
| 4 | Would you like your doctor to give you their best estimate of how long you have to live? |  |
| 5 | Would you like to stop medical treatments if they impact your ability to enjoy your life? |  |
| 6 | Would you want natural or alternative medicine as part of your treatment? (For example, traditional Indigenous medicine, holistic medicine, homeopathy, acupuncture, herbalism, etc.) |  |
| 7 | Would you prefer to spend your last days at home, in a hospice, in a hospital, in a nursing home, or a special place in your community? |  |
| 8 | Would you want to live as long as possible, even if it means leaving your community? |  |
| 9 | If you have to leave your community for care, who would you like to accompany you? What items would you like to take to remind you of home and family? What spiritual or religious items would you wish to have? |  |
| 10 | Would you want your loved ones to follow your wishes exactly, even if they do not agree with them? |  |
| 11 | Do you wish to be left alone or have loved ones around? |  |
| 12 | Do you wish to be kept alive by machines if you won’t recover? |  |
| 13 | Would you want to live as long as possible, even if it means leaving your community? |  |
| 14 | Who do you want or not want providing your care? |  |
| 15 | Do any of your loved ones disagree with your wishes? |  |
| 16 | Are there things that you still need to talk to your loved ones about?  (For example, organizing your finances, deciding who is going to take care of your children, grandchildren, pets, preparing for ceremonies, legal documents, etc.) |  |

**Part 4 – Sharing Your Wishes**

Share your answers from this document with the important people in your life (partner, family, friends – all the people you identified in Part 1) to ensure that everyone is aware of your wishes. If you and your loved ones disagree, it is helpful to know this now and to talk about it before a crisis happens.

Here are some ways to start the conversation:

* “I’ve just filled out this document called ‘Planning for My Care’ and I want to share it with you.”
* “My health is good right now, but I want to talk to you about what I’d want if I got sick.”
* “I was talking with Home Care and they encouraged me to think about my future and make a plan in case I got sick. Can you help me?”
* “One of my biggest fears is that if I got sick, the important people in my life might argue with each other about what is best for me. I want to share with you what I want so that everyone understands.”
* “I was thinking about what happened to \_\_\_\_\_\_ when they got sick, and it made me realize that I would never want those things to happen to me or my partner.”

**Part 5 – Making Sure Your Wishes are Heard and Honoured**

Now that you have shared your wishes with the important people in your life, you may want to choose one or two people you feel would honour your wishes and be able to make future health and life decisions on your behalf. This person(s) would speak for you and may be asked to give consent for treatments if you are not able to speak for yourself.

For example, depending on where you live, the person(s) you identify to speak on your behalf may be called a Delegate, Substitute Decision Maker, Proxy, Agent, or Mandatary. In this document, we’ll use the terms “Delegate”

When choosing who will speak for you, think about the following:

* Do you trust the Delegate(s) to make decisions for you?
* Do you think the Delegate(s) would be willing to speak for you if you can not speak for yourself?
* Does the Delegate(s) meet the legal requirements to speak for you (varies across provinces/territories)?
* Can the Delegate(s) talk clearly with your healthcare team?
* Can the Delegate(s) make difficult decisions in stressful times?
* If you have more than one person speaking for you, have you included each person in the decision-making conversations?

**I have discussed my wishes for future health and treatment with the person(s) named below. The person(s) who will speak for me if I am not able to speak for myself is:**

Name:

Relationship to me:

Phone number or email:

Name:

Relationship to me:

Phone number or email:

**I have also discussed my wishes with the following people (For example, healthcare providers, spiritual leaders, etc.):**

Name:

Relationship to me:

Phone number or email:

Name:

Relationship to me:

Phone number or email:

Note: Some provinces and territories require you to complete certain legal forms to identify your Delegate. Find out more about resources in your province or territory by visiting www.advancecareplanning.ca and clicking on “Your Province/Territory.”

Remember: Once you have selected the person who will speak for you, let them know if your wishes, values, and beliefs change over time. Continue to talk with other loved ones and your healthcare providers to ensure everyone understands your wishes. They will then be better able to support the person speaking for you when decisions about your care need to be made.

You can always change your mind about your wishes for care as things change. You can also decide to choose a different spokesperson(s) at any time. It is important to talk about any changes with your loved ones.

*“I’m really glad I completed my advance care plan. It took a bit of time and some thinking, but now I know my wishes are understood by those closest to me and my doctor. I’m trying to get into the habit of reviewing it every year – just to ensure it’s kept current.”***Part 6 – Additional Discussion Items**

The following are additional considerations regarding your care. Indicate what you would like and what you don’t want. It is recommended that you specify what you want. Please recognize that everything may not be available, but it is important that your care team, including your Delegate(s) if named, knows what you would like. You may want to add why you want or not want these items.

|  |  |  |
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| 1 | CPR (Cardiopulmonary Resuscitation). This combines chest compressions with artificial ventilation. If people do not want this, then a DNR (Do Not Resuscitate) order is signed which may also be referred to as an AND (Allow Natural Death) or a No CPR form. |  |
| 2 | Medications for pain, sleep, Hormonal Replacement Therapy, medical marijuana, etc. |  |
| 3 | Oxygen to assist with shortness of breath. |  |
| 4 | Clothing. What type of clothing would you like to wear? This may include cultural, religious, or gender-specific clothing including your favourite jewelry. |  |
| 5 | Personal care. Perhaps it is important for you to have your face, legs, and armpits shaved, wear make-up or a wig whenever possible. Or you may NOT want shaving and other types of personal care. If you have any prosthetics or other equipment, you may want to state your desire to keep wearing them whenever possible. |  |
| 6 | Fluids for dehydration. This may include ice chips. |  |
| 7 | Oral nutrition. If you choose to continue with food, you may want to specify vegetarian, vegan, kosher, halal, or other dietary requirements. Would you like a feeding tube if required? |  |
| 8 | Mouth care. Brushing the teeth, rinsing the mouth, and using mouth swabs. If you have dentures or other removable dental work, you may want to have them taken out for part of the time. |  |
| 10 | Emotional support. |  |
| 11 | Spiritual support. |  |
| 12 |  |  |

**Part 7 – Quick Facts**

Research on certain health aspects of Two-Spirit and LGBTQ+ people is limited. Here are, however, some quick facts from Marie Curie, King’s College London, and the University of Nottingham that highlight the importance of starting a discussion about Advance Care Planning.

Members of our community are:

1. Three times more likely to be single;
2. Less likely to have children;
3. Far more likely to be estranged from their birth families; and,
4. Significantly more likely to experience damaging mental health problems.

Six factors impact our health care, especially palliative care:

1. Anticipating stigma or discrimination may prevent people from accessing care;
2. Healthcare services may not always ensure that our spiritual needs are met;
3. Assumptions about identity and family structure by healthcare professionals may result in discrimination;
4. Chosen family may not be respected and recognized as next of kin;
5. There may be increased pressure on Two-Spirit and LGBTQ+ caregivers due to accessing care late or not at all; and,
6. Unsupported grief and bereavement because of sexuality may lead to partners feeling isolated.

By thinking about our own Advance Care Plan and starting the conversation, we may be closer to achieving the two most important results desired by our community:

1. We receive patient-centred care which is care centred around us as individuals; and,
2. Our partners are accepted as such.

**Additional Resources:**

1. Marie Curie (2013) Hiding who I am: The reality of end of life care for LGBT people.  
   <https://lgbtsand.files.wordpress.com/2013/12/reality-end-of-life-care-lgbt-people.pdf>
2. de Vries, B., et al (2020) Advance care planning among older LGBT Canadians: Heteronormative influences.  
   <https://journals.sagepub.com/doi/abs/10.1177/1363460719896968?journalCode=sexa>
3. Kcomt, L., Gorey, K. (2019) Advance care planning among LGBT people: An integrative review and analysis.  
   <https://academic.oup.com/innovateage/article/3/Supplement_1/S181/5618075>
4. de Vries, B. (2015) End-of-life care discussions foster community in the families we create.  
   <https://coalitionccc.org/2015/06/advance-care-planning-and-the-lgbt-community/>