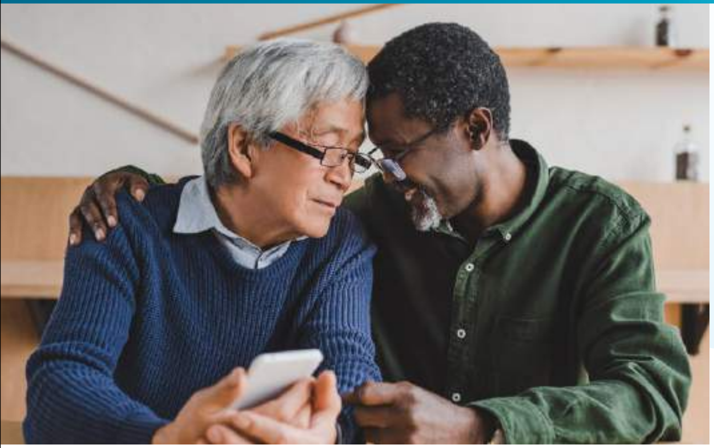
Planning for My Care

For people who identify as Two-Spirit and LGBTQ+

CANADIAN
VirtualHospice

Safer Space



Planning for My Care is part of ***Proud, Prepared and Protected*** – a series of resources to support 2SLGBTQ+ inclusive palliative care. These products were developed by people who identify as Two-Spirit & LGBTQ+ and the Canadian Virtual Hospice.

Many who are 2SLGBTQ+ have experienced or witnessed discrimination and ignorance in a healthcare setting. You may have received inappropriate care or, even worse, been denied care. Some healthcare workers are not aware of the challenges the 2SLGBTQ+ communities face. This booklet will help to ensure your needs and wishes are respected.

This document, focusing on care conversations for Two-Spirit and Lesbian, Gay, Bisexual, Trans, Queer, and all sexual and gender-diverse 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.

Consider giving a copy of this document to the important people in your life, and sharing this information with healthcare providers. Take it with you when you attend appointments, call 911, visit the emergency department, or access other healthcare services. If your province has a process for documenting your wishes for care, ensure this information is included on those documents and kept in the same place.

Ensuring your wishes for care are known and respected.

Please 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.

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

What's the benefit of having this conversation?

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

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

- *My Choices for Safe and Inclusive Healthcare,* which is a personal guide for inclusive and safe care for Two-Spirit and LGBTQ+ people;
- The *2SLGBTQ+ Canadian Healthcare Bill of Rights;* and,
- 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.

Part 1 – What is important to you

Thinking about your own values and beliefs may help you prepare to talk with the people in your life, 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.)

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(s), sexual orientation, etc.)

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

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

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, feeling like you need to hide your authentic self (sexuality or gender expression), etc.)

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.

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 including plant medicines, teas, or including certain ceremonies. I would want my healthcare providers' support to do that."

"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."

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

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

Part 3 – Your wishes for care

This is where you decide what you want and what you do NOT want. Some of these are very big questions.

The following is a list for you to think about. There are no wrong answers. Some of the questions may not be applicable.

If you were to get very sick…

How much information would you want shared about your sexual orientation or gender identity with the medical team?

☐ Everything ☐ Some ☐ None

How much detail would you like to know about your illness?

☐ All ☐ Some ☐ None

How much say would you like to have about your treatment and care?

☐ All ☐ Some ☐ None

Would you like your healthcare provider to give you their best estimate of how long you have to live?

☐ Yes ☐ No ☐ Maybe

Would you like to stop medical treatments if they impact your ability to live the rest of your life the way you want?

☐ Yes ☐ No ☐ Maybe

Would you want natural or alternative medicine as part of your treatment?

(For example, traditional Indigenous medicine, holistic medicine, homeopathy, acupuncture, herbalism, etc.)

☐ Yes ☐ No ☐ Maybe

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?

Would you want to live as long as possible, even if it means leaving your community?

☐ Yes ☐ No ☐ Maybe

If you have to leave your community for care, who would you like to accompany you? What items would you like to take with you?

Would you want the people in your life to follow your wishes exactly, even if they do not agree with them?

☐ Yes ☐ No ☐ Maybe

Do you wish to be left alone or have people in your life around?

Do you wish to be kept alive by life support if you won't recover?

☐ Yes ☐ No ☐ Maybe

What type of clothing would you like to wear? (This may include cultural, religious, or gender-specific clothing and jewelry).

Do you have preferences when it comes to your personal care?

(For example, shaving, make-up, hair, etc.)

Are there prosthetics, or other equipment you would like to continue to use?

Are you interested in receiving emotional or spiritual support? If so, please specify:

☐ Yes ☐ No

Who do you want or not want providing your care?

Does anyone disagree with your wishes?

☐ Yes ☐ No ☐ Maybe

Are there things that you still need to talk to the people in your life about?

(For example: your finances and legal documents; who will care for your dependants, pets; ceremonies and memorials, etc.)

☐ Yes ☐ No ☐ Maybe

Additional items.

Part 4 – Sharing your wishes

We encourage you to share your answers from this document with the important people in your life (partner, family, friends - all the people you identified in Part 1). This will ensure that everyone is aware of your wishes. If you and the people in your life 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 term “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) communicate clearly with your healthcare team?
- Can the Delegate(s) echo your wishes 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 or willing to speak for myself is:

Name: ______________________________

Pronoun(s): ______________________________

Relationship to me: ______________________________

Contact Info: ______________________________

Name: ______________________________

Pronoun(s): ______________________________

Relationship to me: ______________________________

Contact Info: ______________________________

I have also discussed my wishes with the following people:

(For example, healthcare providers, spiritual leaders, etc.)

Name: ______________________________

Pronoun(s): ______________________________

Relationship to me: ______________________________

Contact Info: ______________________________

Name: ______________________________

Pronoun(s): ______________________________

Relationship to me: ______________________________

Contact Info: ______________________________

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 people in your life 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. You can also decide to choose a different person(s) at any time. It is important to talk about any changes with the people in your life.

> *I'm really glad I thought about my future care. It took a bit of time and some thinking, but now I know my wishes are understood by those closest to me and my healthcare team. I'm trying to get into the habit of reviewing it every year – just to ensure it's kept current.*

Part 6 – Quick facts

People who identify as Two-Spirit and LGBTQ+ may experience difficulties accessing healthcare. Here are some quick facts that highlight the importance of planning for your care.

Compared to the general population, people who are 2SLGBTQ+ are:

1. Three times more likely to be single;
2. Less likely to have children who will care for them when they are unwell or frail;
3. Less likely to be in contact with or on good terms with their family of origin;
4. Are more susceptible to circumstances of social isolation.
5. Are more reluctant to seek care for fear of stigma or discrimination which can cause a delay in diagnosis, care and treatment.
6. Likely to have a higher incidence of life-limiting and life-threatening disease; and,
7. Significantly more likely to experience mental health problems.

Five factors that negatively impact healthcare, including palliative care:

1. Expecting discrimination or stigma may prevent people from accessing care;
2. Assumptions by healthcare providers about identity and family structure may result in discrimination;
3. Chosen family may not be respected and recognized as next of kin;
4. There may be increased pressure on 2SLGBTQ+ caregivers due to accessing care late or not at all; and,
5. Loss and grief is often unrecognized and poorly supported, increasing a sense of isolation.

Considering your future healthcare and starting conversations with family, friends and healthcare providers can help you access and receive care that respects your wishes and preferences.

ADDITIONAL RESOURCES

1. **Marie Curie (2013) Hiding who I am:** The reality of end of life care for LGBT people.
2. **de Vries, B., et al (2020) Advance care planning among older LGBT Canadians:** Heteronormative influences.
3. **Kcomt, L., Gorey, K. (2019) Advance care planning among LGBT people:** An integrative review and analysis.
4. **de Vries, B. (2015) End-of-life care discussions foster community in the families we create.**
5. **Canadian Virtual Hospice (2019) A Literature Review & Environmental Scan of the 2SLGBTQ+ Population and Palliative and End of Life Care.**

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The Conversation Project for providing us with permission to extract, adapt, and use material located in the following document:
The Conversation Project: An initiative of the Institute for Healthcare Improvement, *theconversationproject.org*.

Visit www.virtualhospice.ca/2SLGBTQ for more inclusive care resources including:

- My Choices for Safe and Inclusive Healthcare
- 2SLGBTQ+ Canadian Healthcare Bill of Rights for Advanced Illness, Frailty and End of Life

We are grateful to all the individuals and organizations who contributed to making this a safe and inclusive document.

Aussi disponible en français.

virtualhospice.ca

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