

+ MY HEALTH CARE WISHES +

A Plain Language Health Care
Tool For People In Saskatchewan



**INCLUSION
SASKATCHEWAN**
supporting individuals with intellectual disabilities



INCLUSION SASKATCHEWAN

supporting individuals with intellectual disabilities

The Supported Decision Making Committee members, many of whom identify as Self-Advocates and people with intellectual disabilities, met with Inclusion Saskatchewan staff every week for months to create this workbook. Together we listened, learned, and thought of how we can best support people to make decisions about their health. We are excited to share this workbook with you and hope you enjoy using it as much as we enjoyed making it.

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Important Disclaimer

My Health Care Wishes Workbook and My Health Care Wishes Form are not legal documents and are not legally binding. This means that these documents cannot be used to replace legal decision making documents or processes in place by *The Power of Attorney Act, The Health Care Directives and Substitute Decision Makers Act, 2015*, and *The Adult Guardianship and Co-decision-making Act*.

My Health Care Wishes Workbook and My Health Care Wishes Form can be used to communicate your wishes to your health care team. It can also be used to communicate your health care wishes to someone who has the legal ability to make health care decisions for you. It is to be used when you are not comfortable communicating your health care wishes on your own.

The information in this document is not legal advice and is not a legal document. Instead, all the information, content and materials are for informational purposes only. If you have specific questions relating to your rights reach out to a support worker or talk with a lawyer.

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HEALTH CARE WISHES WORKBOOK

This document was created to guide your health care team, and other people who may support decisions about your medical care. This workbook will encourage you to think about who you are, what is important to you, and what type of medical care is in line with your wishes and goals. Planning for the future can be hard, but it is important to think about what you want. If you go to the hospital with a serious illness and do not have a plan in place, someone else could make decisions for you.

This document has two parts:



Part 1: Health Care Wishes Workbook

This document will guide you through the process of thinking about your health care. It features fillable worksheets and stories from Self-Advocates.



Part 2: My Health Care Wishes

Use your answers from the workbook to fill out this document. It will be a record of your health care wishes. Take this document with you to the hospital or give to first responders in an emergency.

This document can be used with our *Health Passport* and we recommend having both documents completed before you go to the hospital. If you wish to fill out the *Health Passport*, you can find it on our website: www.inclusionsk.com.

Why did we create *My Health Care Wishes*?

Our goal was to support people to be more involved in decisions about their health. We also wanted to make sure that people receive care when they need it and prevent situations where decisions are made for a person that are not in line with their goals and wishes. It is important to have a good understanding of your options so you can make the decisions that are the best for you.

How to use the *My Health Care Wishes* workbook

By reading through this workbook and filling out the worksheets, you will learn about how your choices affect your health care. The worksheets will help guide you through thinking about your health care preferences and coming up with the information you will need to fill out the *My Health Care Wishes* form.

If you want to skip the worksheets and only fill out the form, we highly recommend reading from pages 1-10 of the workbook. These pages contain information that will support you as you make choices about the care you receive.



"This document is helpful for individuals like myself. I am a person with a disability and it helps me to understand my options and what I would want if I have to go into the hospital."

- Tina, Co-Creator of *My Health Care Wishes*

What is the difference between *My Health Care Wishes* and a Health Care Directive?

My Health Care Wishes is a plain language document that can help you decide and communicate what type of care you would like to receive if you go to the hospital or any other place that you go for medical assistance and treatment.

A Health Care Directive (sometimes called an Advance Care Plan) is a legal document and is legally binding. It is used to tell your health care team what types of treatment or care you would like to receive and gives you the ability to choose someone you trust (called a proxy) to make health care decisions for you. A Health Care Directive is used when you are not able to make health care decisions on your own.

If you wish to fill out a Health Care Directive, *My Health Care Wishes* may help you decide what type of care you would be comfortable with.

Why you should take *My Health Care Wishes* to the hospital

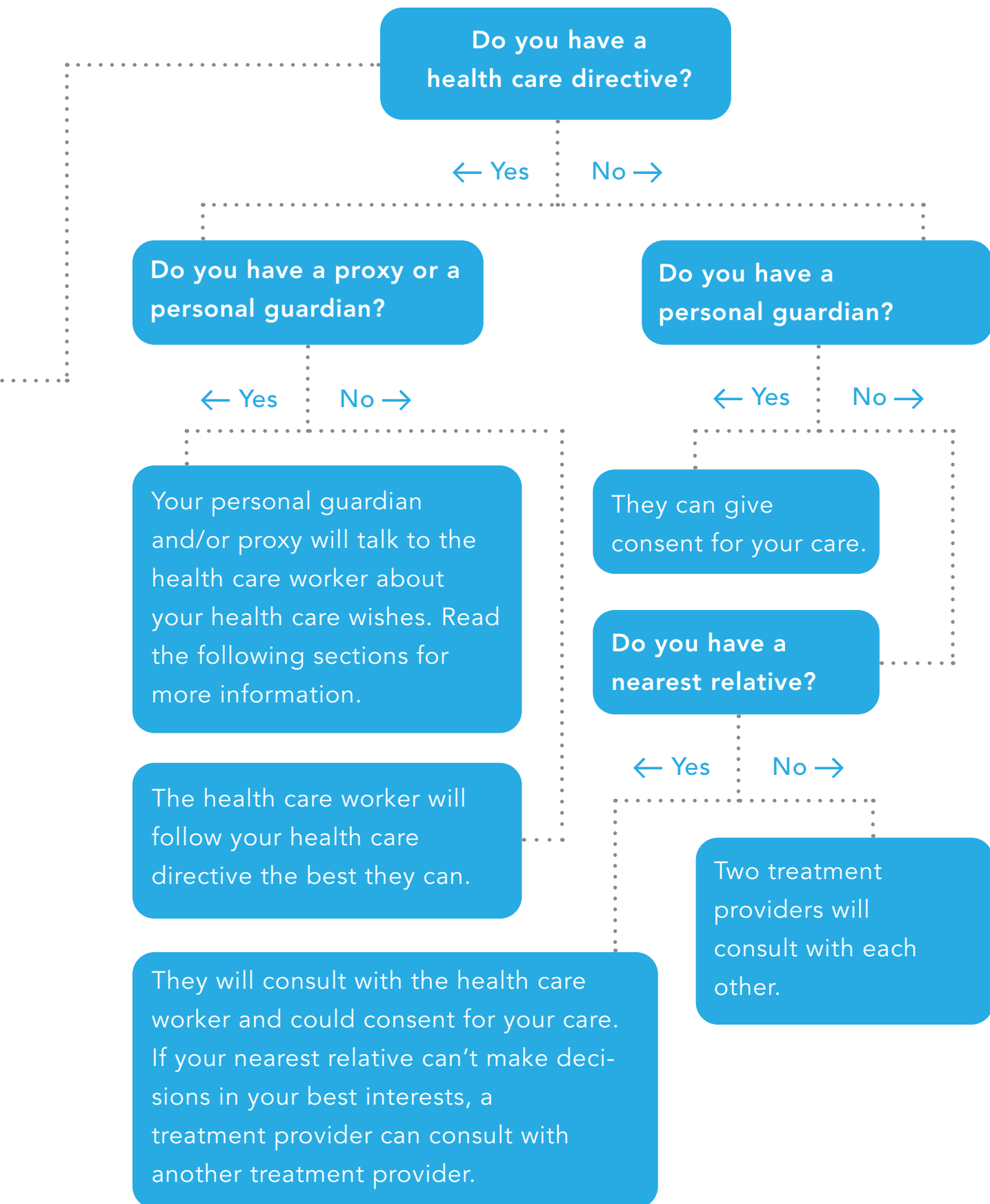
If you have to go to the hospital, one of the first things that you'll have to do is talk to hospital staff, also known as a health care team. Health care workers have to go through a series of steps to determine what type of care you need and who is involved in your health care decision making process. To see what these steps are, see the flowchart on the next page.

By taking the *My Health Care Wishes* form to the hospital, you will help health care workers better understand your needs and wishes. It will also help answer questions that your health care team ask during the admission process.

Flowchart: What Happens When You Go To The Hospital

If you have completed the My Health Care Wishes form, your supporters and health care team will follow your wishes to the best of their ability.





What is the difference between a power of attorney, a co-decision maker, or personal guardian?

A **power of attorney** cannot make medical decisions for you. If you would like to choose someone to make medical decisions on your behalf, you can choose someone as your **proxy** in a **Health Care Directive**.

A **co-decision maker** is someone approved by the court to help a person make decisions. A co-decision maker can be assigned to help someone with personal matters (such as medical decision making) and property matters (such as helping with your finances). A co-decision maker has a responsibility to make decisions with you, not make decisions for you. If you have a personal co-decision maker, you may want to have them involved in your plan. You may also wish to choose your co-decision maker as your proxy if you are comfortable with them making health care decisions for you.

A **guardian** is someone approved by the court to make decisions for someone. An adult guardianship order can be approved to help someone with personal matters (such as medical decision making) and property matters (such as helping with your finances). If you have a personal guardian, your guardian can give permission for your medical treatment when you go to the hospital if the court has given them power to do so.

Be aware that even if you have a personal guardian, you have the right to fill out *My Health Cares Wishes* as well as a health care directive to express your wishes. Both your guardian and the health care team have a responsibility to listen to your wishes.

What is a proxy?

A **proxy** is someone you choose to make health care decisions for you in a **Health Care Directive** when you are not able to make the decision on your own. A **proxy** will try to make sure that your health care goals and wishes are carried out. *Saskatchewan's Health Care Directives and Substitute Decision Makers Act* tells us how to include supporters to make decisions about our health.

If you choose to have a proxy, it is very important that they are someone you trust and who knows you well, is available when you need them to be, and is comfortable communicating your health care wishes. You do not have to choose someone who shares all your beliefs but you should choose someone who will respect your wishes and tell others about the type of health care treatment you want.

It's important to know that if a treatment provider has signed a certificate of incapacity, they may not be able to honor your chosen proxy.

As Self-Advocate Dan explains: "As a transgender man, I find the health care system to be a bit tricky to navigate, because most medical professionals go by a person's physical sex when giving care, which I understand in some cases but not others. I haven't shared my health care wishes with anyone yet because I am still trying to figure out who I feel would best follow through with my wishes."

What is a substitute decision maker?

A **substitute decision maker** is someone who can make health care decisions on your behalf if you are not able. If you have not chosen someone as your proxy, and you do not have a personal guardian, the health care team may reach out to your closest living relative. The health care team follows a prioritized list of who should be contacted first. The order of this list is the same for everyone. This family member could be your substitute decision maker and would tell the health care team which type of care you would receive.

If your health care team asks your nearest relative to make decisions for you, your nearest relative can say no. They may not feel comfortable making decisions for you or may not know your wishes. Sometimes people are not close to their families and yet, family members are called upon to make decisions. If you have concerns about a family member making decisions for you, speak with a supporter you trust.



"There are times when my family has been asked to be a part of my health care planning and it is very hard for me because I have a challenging relationship with my family. It feels like trying to rebuild a bridge that has already burnt down. When I have to include them, it feels like they are undoing the work that I have done for myself. The parent's opinion shouldn't be more important than the individual's. The individual should be allowed to be the driver of their own life."

- Aiden, Co-Creator of My Health Care Wishes

What if I don't have a power of attorney, a co-decision maker, guardian, or health care directive?

If a doctor determines that a person does not have capacity to consent for their care, and there is no legal decision making document in place (such as guardianship, co-decision-maker, health care directive, or a proxy), they will contact that person's nearest relatives. Your nearest relative is your closest living relative or relatives. This person may also be called your substitute decision maker. The health care team follows a list of who should be contacted first which is as follows:

1. A spouse
2. An adult child
3. A parent
4. An adult sibling
5. A grandparent
6. An adult grandchild
7. An adult aunt or uncle
8. An adult nephew or niece

Some people do not have a nearest relative, or their nearest relative may not be available. If you do not have a nearest relative, you can contact Inclusion Saskatchewan for more information.



"I think *My Health Care Wishes* is important because my brother was in the hospital and I went to see him before he passed away. He didn't have a plan in place so they had to guess the type of care he wanted to receive. I want to have a plan in place so it's easier for my family and the doctors to know what I want."

- Darren, Co-Creator of My Health Care Wishes

Talking about getting sick, death, and dying

Talking about getting sick, death and dying can make some people feel uncomfortable, while it might make others feel better. It may bring up feelings or thoughts that make you sad or worried, or it may make you think about people you know who have gotten sick or died. Death is a natural process and every living thing dies. The more you talk about it with those you are close with, the better you can plan. If you have an idea of how you would like to be remembered and what you can do to plan, it can help you and your loved ones prepare.

Questions you may want to ask your supporters include: What happens to our bodies as they get older? What happens if our heart or our brain stops working?



"At one point I was in the hospital and was given a health care directive to fill out. It was not in plain language and was very hard for me to understand. If I had a supporter who I was comfortable with and who could explain it in plain language, I may have understood but I didn't and many people don't when they go to the hospital. I would like to see all of these types of documents be in plain language to allow more people to understand. It's so important for people of all abilities to be included in their own medical decision making as much as they would like to be."

- Char, Co-Creator of My Health Care Wishes

Who I want to help me with *My Health Care Wishes*

There is a process called **Supported Decision Making** that can help you make decisions about your life with the support that you choose. The people you choose to help you fill out your health care wishes are called your **supporters**. You get to choose which supporters will help you. You may wish to include family members but you do not have to include them. It is helpful to choose supporters who know you well and you can include anyone that you trust and feel safe with.

There may be times when you are not sure about how to answer something so your supporters can help you to think about what you may want. The most important thing about supported decision making is that you feel supported.

Who I want to support me	How I want to be supported

Who I will share *My Health Care Wishes* with

My Health Care Wishes is a personal document that includes a lot of information about you. A copy of your wishes should only be given to people who need it and who you trust. This may include certain family members, your doctor, and supporters who may need a copy. Your health care team will not share information about you with others unless you give them permission to do so, or if you have a substitute decision maker.

Who I want to receive a copy	Relationship and contact info

Worksheet: All About Me

The things that are important to us are called our **values** and these things help make us who we are. Our values can also help us decide what type of medical care we would like to receive if we get sick and have to go to the hospital. The questions below can help you think about who you are and what's important to you.

People who are important to me and why:

Places I love to go and why:

Activities I enjoy:

My current goals:

Some things I am good at:

Some things that make me feel happy:

Some things I still want to do or places I still want to see:

Things I worry about:

Worksheet: My Health Care Experiences

Our health care experiences can sometimes help us to know what works or does not. We may learn about different types of care that we would be okay with receiving or that we would not like to receive. The following questions can help you think about your personal experiences.

What have your experiences with doctors or other health care professionals been like?

What have you experienced at a hospital? For example, did you have a good experience or did anything make you feel scared? Are you comfortable going to the hospital?

Have you had to go to the hospital for a serious illness? If yes, was there care that you received that you were glad you received? Was there care that you received that you did not want or would not want to receive again?

Do you have a loved one who has experienced a serious illness and/or spent time in the hospital? Think about if you were in a similar situation. What did you like about the care that they received that you would also want yourself? Was there anything that you did not like and would not want to experience yourself?

Are there any other experiences that you would like to share?

Worksheet: Communication and Consent

We all have different communication needs, and it is important to tell others how to best communicate with us. For example, we may communicate with words, our body (shaking or nodding our head), or by using technology. If you go into the hospital, it is helpful if the health care team has a good understanding of how you communicate, which includes how they should communicate with you.

This is especially important because understanding how someone communicates is the most important part of being able to give consent. Giving consent means that you are giving permission for something. For example, we may consent to receiving a certain type of care or treatment. If you do not wish to receive a certain type of care or treatment, you can say no and that means you are not consenting.



"I asked my mom to take me to a medical appointment. I was in a lot of pain and had to get an x-ray done. When the doctor was explaining my x-ray, I was having a hard time focusing on what she was saying because I was in so much pain. I asked if my mom could come into the room with me so she could help explain things when I was feeling better. The doctor was very understanding and went and got my mom. I was very glad that the doctor was so understanding of what I wanted and needed."

- Leanne, Co-Creator of My Health Care Wishes

For you to consent to medical care, a doctor will want to know that you understand information about your health. This includes understanding the possible impact of whether or not you receive the treatment or care. For example, if you have a heart condition and decide not to have a surgery, your doctor will want to make sure you understand that if you do not have the surgery, your heart could stop.

I communicate by/with (check or circle all that apply):

- ☐ Talking
- ☐ Writing or typing
- ☐ Pictures
- ☐ Sign Language
- ☐ Pointing to words
- ☐ Assistive technologies, using a device or using a voice app
- ☐ Lip reading
- ☐ Hearing aid
- ☐ Facial expressions or other gestures
- ☐ Other _____
- ☐ I may not communicate in a way you will understand, please contact:

_____ at _____
(name) (phone)

How do you communicate your wishes? For example, how do you say yes or no?

What ways work best for people to share information with you? For example, what ways work best for you to learn? How do you need information presented to you?

Are there people who know you very well who you would like to help describe how you communicate and give consent? Please list their name and contact information here:

Is there anything else that would be helpful for the health care team to know about how you communicate or how to communicate with you? For example, some people find nodding or facial expressions to be helpful when someone is talking to them.

Worksheet: Cultural Considerations

Everyone has different beliefs, and it is important that the health care team considers this as part of your care. Your beliefs or wishes should be communicated to your substitute decision maker so that they can uphold your wishes in the event you are not able to communicate your wishes yourself.

Is there a culture, religion or belief system that is important to you?

Are there certain beliefs or aspects of your culture that you feel are important for the health care team to be aware of?

If your belief system is different from that of your substitute decision maker or any of your nearest relatives, do you have any concerns that they will not respect your wishes?

Are there any dietary restrictions, or things that you cannot eat, that you would like the health care team to be aware of? For example, in some cultures people do not eat pork.

Are there any considerations around clothing or modesty that you want the health care team to be aware of? For example, making sure that there are as few people in the room as possible before removing a piece of clothing.

Are there any other cultural beliefs that the health care team should be aware of before providing you with treatment or care? For example, some people value their independence above all else. If that is the most important thing to you, please explain what you value the most.

Worksheet: My Current Care Needs and Future Preferences

If you go into the hospital with a serious illness, you may need to receive intensive care. Receiving certain types of treatment or care may mean that your needs will change if you recover. However, if you choose not to receive treatment that may mean that you could die.

If staying alive is the most important thing to you, write that decision in this document. You should also make it clear to your Substitute Decision Maker or nearest relatives that you are okay with receiving any types of treatment that will allow you to live. If there are certain things that you would not be okay with living with if you recover, you can write that in this document. It is important to think about the risks of receiving treatment versus the risks of not receiving treatment.

The following questions will help you think about any concerns you may have with your needs changing due to receiving treatment for a serious illness in the hospital.



"I used to be more comfortable with my mom making decisions for me but I know she won't be here forever. Now that I live on my own, I have realized that I don't need to hold her hand for everything but there are times when I do need help so I just text or call her. Sometimes you need supports to help you make a decision and it's okay to ask for help when you need it."

- Sydney, Co-Creator of My Health Care Wishes

Mobility: Do you currently use any mobility aids such as a wheelchair or walker? Would you be okay with these needs changing? For example, would you be okay with not being able to move parts of your body?

Hygiene: Do you currently need any support with your hygiene? Would you be okay with these needs changing? For example, would you be okay with using a catheter or underwear that you use and throw away?

Sleep: Do you currently have any needs to help you go to sleep or to stay awake? Would you be okay with these needs changing? For example, would you be okay with having a CPAP machine to help you breathe while you are asleep? CPAP machines have a breathing mask.

Energy: What is your current energy level like? Would you be okay with these needs changing? For example, would you be okay with not having very much energy and feeling tired easily?

Communication: How do you communicate? Do you need support to communicate? Would you be okay with these needs changing? For example, would you be okay if your ability to speak, or to hear, changed?

Eating & Drinking: How do you eat or drink? Do you need support to eat or drink? Would you be okay with your needs changing? For example, if you needed to be fed by a tube inserted in your stomach?

Vision: Do you currently need any support to help you see? Would you be okay with these needs changing? For example, would you be okay with no longer being able to see as well or not at all?

Breathing: Do you currently need any support to breathe? Would you be okay with these needs changing? For example, would you be okay with needing a machine to breathe? Would you be willing to stay in a hospital if you needed support to breathe for the rest of your life?

Inclusion: Do you currently receive support to do activities in the community? Would you be okay with these needs changing? For example, would you be okay with not doing activities in the community?

Independence: What does your current living arrangement look like? Would you be okay with these needs changing? For example, if your care needs change, would you be okay with moving?

Pain: Do you currently experience any pain or discomfort in your body? Would you be okay with these needs changing? For example, would you be okay with living with regular pain or discomfort?

Treatment: Would you be okay with needing regular treatments for your illness? This may include treatments that will change your daily schedule, or may be challenging for you physically or mentally. For example, having daily renal dialysis or chemotherapy, or regular physiotherapy.

CPR

As you make decisions about your care, you may be asked if you want CPR or resuscitation. CPR is also called Cardiopulmonary resuscitation and is a technique that could save your life if you stop breathing. You should talk with a health care provider so you understand the risks of having CPR, which can include broken ribs or brain injury. If someone performs CPR on your body, you could end up in the hospital, or in intensive care. The main benefit to receiving CPR may mean that you will stay alive. Only you can decide what you want, but you should have information so you can make the right choice for yourself.

Have you ever seen an example of someone receiving CPR? Do you need more information about this before you decide?

Organ and Tissue Donor Information

Everyone has organs that support their body to live. If a person's organ becomes damaged or injured, and does not recover, it could mean that they could become very sick or die. Organ and tissue donation could help save a person's life or help them become healthier because they will receive a healthy organ from another person's body. It involves removing an organ, or tissue, from one person's body and giving it to a person who needs it. Most people make the decision to donate their organs if they die, but you could donate a certain organ, like a kidney, and still live. In Saskatchewan, there is a program that you can sign up for if you are interested in being an organ donor.

Reflecting on My Wishes & Responses

Thinking about change can be scary. People are often comfortable with what they know so it is hard to think about the unknown. It is impossible to know if you will become seriously ill or get into an accident. It is also impossible to know what type of treatment you may need to receive and what the possible outcomes of that treatment may be. For this reason, it can be helpful to think about anything that you would **absolutely not** be okay with.

If you say no to receiving certain types of treatment or care, you may die sooner. For example, you need enough oxygen to live so, if you are not okay with living with an oxygen tank when you need one, your life will end more quickly. Another example would be if you need more care than what your current home can provide, you may need to move. If you are not okay with moving, you will not have proper support which means you could get seriously hurt.



“One time, I was at an appointment and my mom came into the room with me. The doctor was asking me questions and my mom was trying to help me understand, but I did understand. I wasn’t answering the questions because they were very personal and I didn’t feel comfortable answering them in front of my mom. Everyone seemed upset with me and I left the appointment upset and in tears. I would like people to ask me who I would like in the room. ”

- Jamie, Co-Creator of My Health Care Wishes

I understand that not being okay with certain changes to my life or my care may mean that I will die sooner. With that in mind, are there any changes I am NOT okay with?

Do I need more information from my team so that I can understand my options?

Your choices and experiences change throughout your life. Your plan should be reviewed at least once a year, or as soon as your medical needs or preferences change. You may want to think about the things that have changed in your life or your feelings about recent hospital stays or serious illnesses.

It's important that your wishes always reflect you! You have the right to review your wishes as often as you like.

+ HEALTH CARE WISHES +

I AM A PERSON WITH DIVERSE NEEDS PLEASE READ

Your health care team has a process to get to know you. This form will help you communicate with your health care team so they can understand your goals and wishes.

My Name: _____

Birthdate: _____

Health Card: _____

Who supported me to fill this out	Relationship and contact info

All About Me

People who are important to me and why:

Places I love to go and why:

Activities I enjoy:

My current goals:

Some things I am good at:

Some things that make me feel happy:

Some things I still want to do or places I still want to see:

Things I worry about:

My Health Care Experiences

What have your experiences with doctors, health care professionals, and hospitals been like?

Have you had to go to the hospital for a serious illness? What did you like about the care you received? Was there something about the care you received that you did not like?

Are there any other experiences that you want to share?

Communication

I communicate by/with (check or circle all that apply):

- ☐ Talking
- ☐ Writing or typing
- ☐ Pictures
- ☐ Sign Language
- ☐ Pointing to words
- ☐ Assistive technologies, using a device or using a voice app
- ☐ Lip reading
- ☐ Hearing aid
- ☐ Facial expressions or other gestures
- ☐ Other _____
- ☐ I may not communicate in a way you will understand, please contact:

_____ at _____
(name) (phone)

How people should share information with me:

	Current care needs	Changes to my care needs that I am not okay with
Mobility		
Hygiene		
Sleep		
Energy		
Communication		
Eating & Drinking		

	Current care needs	Changes to my care needs that I am not okay with
Vision		
Breathing		
Inclusion		
Independence		
Pain		
Treatment or Other Care Needs		

CPR Considerations

Do you understand the risks and benefits of receiving CPR?

☐ Yes ☐ No

Do you need information from your health care provider before you make a decision about having CPR performed on your body?

Cultural Considerations

Please include anything that would be helpful for the health care team to be aware of:
