

Being A Healthcare Substitute Decision Maker (SDM) in Saskatchewan:

What you need to know to support someone receiving health care in Saskatchewan at a time when they are unable to make healthcare decisions for themselves.

Open space in this workbook might be useful to make notes for yourself.

SHA Advance Care Planning Program

Serving Saskatchewan with offices in Saskatoon & Regina Phone 1-833-544-2255 or Email:

advancecareplanningprgm@saskhealthauthority.ca





A Proxy: A Health Care Advocate

We cannot plan for everything. But we can talk about what is most important to us — in our life, and in our health care — with those who matter most to us. Knowing the content of the health care directive of the person you are speaking for makes sure they continue to participate in their health care decisions when they cannot speak for themselves.

Discussing what matters most can bring us closer with the people who matter most to us. Knowing what is important to the person we are speaking for helps you make sure they receive the type of health care that is right for them.

The Saskatchewan Health Authority, with the support of the Conversation Project*, wants to help everyone talk about their health care wishes so those wishes can be understood and respected when they cannot speak for themselves. An important step in that conversation is to choose a health care proxy (also known as a substitute decision maker). You may be reading this information because someone has asked you to speak for them, as their proxy, if they become too sick or hurt to make their own health care decisions. It is an honour to be asked to fill this role for someone. It shows they trust you to make important decisions for them and it can deepen your relationship.

You may need to speak for this person if they have a serious accident or illness and cannot speak for themselves. That is why it is really important to understand your role now before that happens.

This guide was created to help you be an effective and helpful health care substitute decision maker (SDM). It is a good idea to read this along with our Conversation Starter Guide. For more information see our Guide to Choosing a Health Care Proxy. You can call the Advance Care Planning team at 1-833-544-2255 if you have questions or want more information.

Use this guide to help you be a Substitute Decision Maker:

STEP 1	
Learn About It	Page 3
STEP 2	
Think About It	Page 4
STEP 3	
Talk About It	Page 5
Appendix A	
Definitions of Medical Terms	Page 8
Appendix B	
Treatments in Serious Illness	Page 9
Quick Links and QR Codes	Page 10

CS-PIER-0025

^{*} The Conversation Project is a public engagement initiative with a goal to have every person's wishes for end-of-life care expressed and respected

STEP 1

LFARN ABOUT IT

Let us review what it means to be someone's substitute decision maker:

When a person is unable to speak for themselves, as a proxy, you can talk with doctors, nurses, and other members of the care team to review medical information related to the person's current medical care. By talking about the kind of health care they want now and in the future, you will be prepared if you have to make decisions about tests, procedures, and treatments if they became too sick to make those decisions themselves.

It is important to know your rights and responsibilities as a proxy as well. The pamphlet, Being a Substitute Decision Maker and the My Voice Planning in Advance for Health Care Choices have information about being a proxy too.

> A health care proxy may also be called a substitute decision maker (SDM). The SDM becomes the voice of the person at times when that person does not have capacity to make those decisions for themselves.

Proxy appointment form: A legal document that is signed and dated by the person that allows them to appoint a proxy (SDM) of their choosing. You will have been given this document by the person who has asked you to speak for them at times they are not. You will be asked to bring a copy of this form to show you are the legal proxy. Health Care Directive: This document is the written instructions about medical treatments a person would or would not want, now and in the future. In Saskatchewan, the person making the directive must be 16 years or older and have capacity. When they sign and date the directive, it becomes a legal document.

These documents are only used when the person cannot speak for themselves.

STEP 2

THINK ABOUT IT:

Someone has asked you to be their health care proxy. It is an honour to be asked to take this step for someone. It is a good idea to be prepared to act as their proxy.

Things to consider:

As you think about whether you would be comfortable acting as a proxy, it is helpful to understand the role of a proxy.

Being an effective and helpful proxy.

As a proxy, you only need to try your best. The person you are speaking for trusts you to speak for them when they are not able to.

In any situation your goal will be to be the person's voice to say what you know the person's values are, what is important to them, and how they want to live their life.

You will need to speak for the person if they are unable to speak for themselves.

That means putting aside your own priorities and preferences while thinking about what the person you are speaking for would want.

You would need to be able to answer the question, "If they could speak and make their own decision, what would they say?"

As a proxy, you have certain legal responsibilities.

As a proxy, you have the legal authority to make medical decisions for that person if they can no longer make them for themselves.

- In order to do that, you will have access to the person's medical information related to the current medical care they are receiving, under Saskatchewan's The Health Information Protection Act known as HIPA.
- You talk to the person's doctors and health care team to gather information about their current condition so you make an informed decision about tests, procedures, and other treatments for them.

Shared decision making

Shared decision making is a collaborative process that includes the patient/SDM and physician and also may include other members of the health care team, family and support people, and other people of the person's choosing.

This process involves working together to make decisions and select tests, treatments and care plans based on clinical evidence that balances potential benefits and risks with patient preferences, goals and values. It is okay to talk about the health care team's recommendations and how those align with the person's values and known wishes. Remember the person's health care directive or previously stated or known health care wishes are to be followed as closely possible.

Preferences aren't always possible.

Sometimes it is not possible to follow every one of someone's health care preferences, and that is okay.

• In that case, you would make the best decision based on the current information, options available, and what you know matters most to them.

It is okay to say no.

Being a proxy may not be right for you. In that case, it is best to be honest, kind, and decline.

It is okay to change your mind about being a proxy if it becomes too much for you. If there is another proxy listed on the proxy form they can take over for you. You cannot ask someone else to take your place as the proxy or substitute someone else to take your place as a proxy. If there is not a legal guardian, the health care team will ask the person's family about being a SDM. If a nearest relative cannot be found two health care members will become the SDM.

STEP 3

TALK ABOUT IT

If you have said yes to being someone's proxy, you can feel proud of the role you will play in reassuring the person that someone they trust will be there for them to make health care decisions when they cannot. The goal of this information is to help you feel prepared in your role as a proxy. When you have agreed to be someone's proxy, it is important for you to understand the preferences of the person you are speaking for. That way, if you need to represent them, you can help them get the kind of health care that works for them.

It is a good idea to set up a time right away to talk with this person about what matters to them and how you can best advocate for them. Allow for plenty of time to talk — it is important not to rush these conversations, and it may take multiple sittings to discuss and understand the person's wishes.

Understand what matters.

Our Conversation Starter Guide is a helpful resource to use when talking with the person you have agreed to be a proxy for. It can help you understand what matters most to them in their life, in their health care, and how they want to live their life.

You can go through the guide with them and talk over their answers to questions that would help you make informed choices for them.

It is also a good idea to talk to the person you would be speaking for about their health care directive specific instructions for their care preferences in certain situations.

It is important to have these conversations before a medical crisis — so you can be ready to make decisions for the person if the time comes.

Here are some things you can say to start a conversation and get the information you need to fulfill your important role as a proxy. You can see our Conversation Starter Guide for more ideas.

- Do you have any worries or fears about your health?
- What do you need to talk about to feel more prepared? (Examples: finances, property, legal documents, relationships, health care situations)?
- Do you have any fears or concerns about where or how you receive health care? Do you have any thoughts or memories about the health care system that could influence your decisions (good or bad)? Are there things that you have seen that you would want or not want based on your experience?
- Who do you want (or not want) to be involved in your health care?
- When you look ahead to the future, are there important events or dates you hope you are there for?
- Are there treatment and procedures you would want or not want? (Examples: resuscitation attempts, CPR, mechanical ventilation, feeding tube)?
- If your health condition changed, when would it be okay with you to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?

Speak up if you need to.

If there is something you do not know about that matters to the person you will advocate for, have another conversation with them and ask questions.

If the time comes when you need to speak for the person as their proxy, it is important to speak with doctors, nurses, and other members of the care team. That way, you can make sure you understand the situation and can make the best possible decisions for the person.

You can ask the care team to repeat information, explain things that are not clear, and help you understand the details of a certain test or treatment. For example, you could say:

- I would like to speak to you about (person you represent's) wishes.
- I don't understand what you just said.
- I have some questions I would like to ask you. When would be a good time for you?

You may want to write down questions in advance, so you remember them.

NOTES:		

Your role as substitute decision maker is important. It is important to have all the information you need to answer the question, "What would they want?"

Appendix A: Definitions of Medical Terms

Here are some common medical terms that might come up during your conversations with your health care team.

Advance Care Planning

Advance care planning is the process of making plans now for the care a person wants in case of a serious illness or health care emergency. It includes instructions stating choices around the health care throughout the person's life and choosing a proxy or proxies — to make decisions for the person if the person becomes unable to express them.

Health Care Directive

A health care directive is written instructions stating what a person wants for medical care. It is an important legal document that helps make sure a person's choices are followed.

Palliative Care

The goal of palliative care is to help people get relief from pain, emotional distress, spiritual distress, and other symptoms that can occur during an illness. A person can receive palliative care at any stage of a serious illness, including during potentially life-extending treatments.

Proxy

Appointing a proxy can be part of the advance care planning process where a person or persons are chosen and asked to make health care decisions on behalf of another person.

Saskatchewan Medical Order for Scope of Treatment or SMOST

The medical order used in Saskatchewan is called the Saskatchewan Medical Order for Scope of Treatment or SMOST and is used if you are admitted to a hospital. A form is completed by a practitioner after a conversation between patients, people they care about, their proxy, and their health care team. It is designed to help patients choose the treatments they want or do not want, and make sure that their wishes are documented and honored. These treatment wishes are documented on the SMOST for the care team to follow.

Appendix B: Treatments

Here are brief explanations of some of the treatments your care team might mention in a conversation about a serious illness.

Artificial Nutrition and Hydration

If a person cannot eat or drink on their own, fluid and nutrients can be delivered into a vein or through a tube in their nose or stomach. This tube is sometimes called a "PEG tube," which stands for percutaneous endoscopic gastrostomy. This approach can be used short-term or long-term, depending on the person's needs and preferences.

CPR (Cardiopulmonary Resuscitation)

If a person's heart stops, attempts are made to restart their heart with chest compressions or an electrical charge that is applied across their chest (electricity).

Comfort Focused Care

Comfort focused care is the use of medication or other aspects of care to help with quality of life and keeping patients comfortable through the end of life.

In comfort care, our goals switch from prolonging life, to ensuring that each hour and each day provides optimal quality of life, regardless of life expectancy.

Intubation/Mechanical Ventilation

If a person cannot breathe on their own, a breathing tube might be placed in their throat and into their lungs. The tube connects to a machine that can breathe for them. Mechanical ventilation can be used short-term or long-term, depending on the person's needs and preferences.

Appendix C: Quick Links and QR Codes

SHA Advance Care Planning Webpage



Conversation Starter Guide



Advance Care Planning—Appointing a Proxy



Being a Substitute Decision Maker



My Voice—Planning in Advance for Health Care Choices



The Conversation Project



Notes	



For More Information:

Phone: 1-833-544-2255

Email: advancecarerplanning prgm@saskhealthauthority.ca

Note: this number and email can be used for anyone in the province.

September 2023

Healthy People, Healthy Saskatchewan

The Saskatchewan Health Authority works in the spirit of truth and reconciliation, acknowledging Saskatchewan as the traditional territory of First Nations and Métis People.

PIER—Patient Information and Education Resource



