



# **Conversation Starter Guide**

How to talk about what matters to you and have a say in your health care

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# Although we cannot plan for everything, we can talk about what is most important — in our life and in our health care — with those who matter most.

Talking with the important people in our life can bring us closer together. It also helps us create the foundation of a care plan that is right for us - a plan that will be available if and when the need arises.

The Saskatchewan Health Authority wants to help everyone talk about their wishes for your health care now and through the end of life, so those wishes can be understood and respected. This guide will help you start a conversation (and keep talking) so you can have a say in your health care even if you have lost the ability to make your own decisions.

It is also important to choose what is known as a proxy. A proxy is someone you ask to make health care decisions for you if you became unable to make those decisions yourself.

It is important to talk about what a good day looks like for you with your proxy, the people who are most important to you, and the ones who will be making your medical choices for you if you become too sick or hurt to make your own decisions.

## This guide will help you take it step by step.

It is important to take your time and not rush. There is no need to say everything that matters in one conversation. Advance care planning is an ongoing process as your health and life changes. You can start talking and then keep talking until you feel comfortable with your choices. It is all about what works best for you.

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This information has been generously shared by Ariadne Labs and The Conversation Project® https://theconversationproject.org/, an initiative of the Institute for Healthcare Improvement (IHI). This document does not seek to provide legal advice. The Conversation Project® is an American public engagement initiative with a goal to help everyone talk about their healthcare wishes so their wishes can be understood and respected.

## Step 1

#### Think About What Matters To You:

To get ready to talk about what matters to you and your wishes for health care throughout your life, it is helpful to gather your thoughts as a first step. You do not need to have the conversation just yet. Here are some helpful ways to think about what matters to you and prepare for your conversation.

What does a good day look like for you?
<b>SOME IDEAS</b> Is it time with family or friends? Enjoying favorite everyday activities? What do you need to enjoy a good life — through the end of life?
What or who supports you during difficult times?
SOME IDEAS Your faith, culture, family, friends, pets, music, comfort/sentimental items like your favorite slippers or a photograph Try finishing this sentence: What matters most to me in my life now is (This may change over time)

**SOME IDEAS** Being able to recognize/talk with my children/family/friends; being independent; being able to spend time with the ones I love; being able to communicate

# That is your "what matters to me" statement.

Sharing this statement with the people you trust could be very helpful if they need to make decisions with your health care team. They may need to share what is important to you and what you need to be able to have a good day with your health care team. They also may need to decide what type of treatment you would want or not want to receive. Completing this guide will help you clearly know what you want them to know about what matters to you and how you want to live your life.

## STEP 2

Having a say in your health care is more likely if you share how you feel about certain situations that could arise now, in the future, and toward the end of life.

For each statement below, mark the place on the line that is closest to what you think or believe about each statement now. There are no "right" or "wrong" choices — your answers are about what works for you.

As a patient, I would like to know							
□ □							
Only the basics about my condition and treatment				con	All the details ab	-	
When there is a medical d	ecision to be mad	de, I w	ould like				
□ □							
My health care team to do what they think is best				To h	nave a say in every care de		
My fears/concerns about r	nedical treatmer	nts?					
□ □							
I worry that I will not get enough				l wor	ry that I will get to	o much	
My fears/concerns about p	pain?						
<pre></pre>							
I worry that I will not get enough pain medication				l worr	ry that I will get too pain med		
My fears/concerns about your symptoms being managed?							
I worry that I will get enough medication				l worry	that I will get too medi	much cation	

If I am	diagnosed with	ı a seri	ous illness tha	t could	shorten my life	, I wou	ld prefer to	
gressin	ow how quickly it i g or my doctor's b tion for how long I	est				pro	derstand how qui gressing and my o estimation for ho hav	doctor's
Any ot	ther notes you v	vant to	add:					
	re seriously ill o		the end of you	ır life, h	ow much med	ical trea	atment would y	you
feel w	as right for you?	?				_		_
able tr	d want to try every eatment to extend en if it is uncomfor	my		Ш		ments	uld not want to to that impact my qu in order to extend	uality of
What	would you go th	rough	(endure) for t	he poss	ibility of more	time?		
able tr	d want to try every reatment to extend ven if it is uncomfo	d my				ments	ould not want to t that impact my q in order to exten	uality of
Where	e do you prefer	to be t	oward the end	of life?				
last da (hospit	gly prefer to spend ys in a health care cal, assisted living, o g facility)	facility				l str	ongly prefer to sp last days a	-

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Now, look at your previous answers. What do you notice about said is right for you?	the kind of health care you
When it comes to sharing information about my health with otl	hers
□ □	□ □
I do not want those close to me to know the details about my health	I am comfortable with those close to me knowing all the details about my health
Information about my health I am comfortable with others know	owing
Information about my health I am not comfortable with other's	knowing
When I die	
<pre></pre>	- 🗆
I want to be alone	I want to be with other people

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Recognizing things change over time, are there people you might want with you before you
die and during your last moments (if possible)? Are there people you might choose not to
see? Share some general thoughts here.
What specific information would you want (or not want) shared with certain trusted
people?
people:
What do those around you need to know about what you want or do not want when you
are nearing the end?

-	care team to		•	ngs for your fri you now and t	•

## Step 3

## **Start Talking**

How much do your decision makers and support people know about what matters most to you? There may be some things they already know and other things that you need to tell them. Sometimes we think others know how we feel, but they do not. Talking about what matters most to us helps make what we think and how we feel as clear as possible.

#### Who needs to know what matters to you in your health care? Circle all that apply:

Parents(s) Spouse/partner(s) Chosen family member(s)

Adult child/children Friend(s) Doctor(s) Nurse practitioner/nurse(s) Social worker Faith leader

Elder Neighbour Other:

# Where would you feel comfortable talking? Circle all that apply:

At home At a favourite restaurant In the car

On a walk Video chat or phone call At my place of worship

Other:

"It always seems too soon, until it is too late."

When will you start this conversation?	
You have gathered your thoughts, written down your ideas, and picked trusted people. Now, how do you begin a conversation?	your
This list does not cover everything but here are some things you can say to start t	alking.
"I need your help with something."	
"Can you and I talk about	?"
"I was thinking about what happened to and it may	ade me
realize"	
"Even though I am OK right now, I am worried that	<u></u>
and I want to be prepared. Can we talk about some things that matter to me?"	
"Will you help me think about my future?"	
"I heard about the SHA Conversation Starter Guide and answered some of the questions about t	hings that
matter to me when it comes to my care through the end of life. I would like to talk to you about	it."
"When died, do you think their wishes	and priorities
were respected toward the end of their life?"	

#### Here is a list of some other things you may want to cover when you talk.

- Do you have any worries about your health?
- What do you need to address to feel more prepared (Examples: finances, property, legal documents, relationships, health care situations)?
- Do you have any fears, concerns, or mistrust about where or how you receive health care?
- 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 able to be there for?
- Are there kinds of treatments you would want or not want (Examples: resuscitation attempts, 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?

#### Tips for your talk

Imagine the conversation in your mind first. You can even write a letter that explains your values about the kind of care that works for you to figure out words that feel comfortable for you to use.

You can make a video of yourself sharing what is important to you, your values, goals, experiences, and beliefs. (This is not a replacement for a health care directive)

You can have a practice conversation, so you feel as prepared as possible to have a "real" conversation.

You do not have to talk about everything or talk to everyone in the first conversation. In fact, we suggest you keep talking over time, especially when there are major changes in your life circumstances.

Be patient. Some people might be nervous or may need time to get ready to talk. Every time you start a conversation, it helps you come closer to making your wishes fully known. Keep trying.

You do not have to lead the whole conversation; it is important to also listen to what the other person says so you can build trust.

Nothing you say is permanent. You can always change your mind as things change in the future as your life circumstances change.

You may find out during these conversations that you and your trusted people disagree. That is OK (no judgment). The important thing is that you are talking now and to keep talking — so you are prepared in case your health changes.

You can share this guide, with or without your thoughts included, with your trusted people.

#### STEP 4

## **Keep Talking**

Now that you have started the conversation, keep going! Talk to more people who may have a say in your health care. The more you talk, the more people you are close to will know what matters to you. And that makes it more likely that you'll get the kind of health care you want — now and through the end of life. Here are some things you can think about to keep the conversation going.

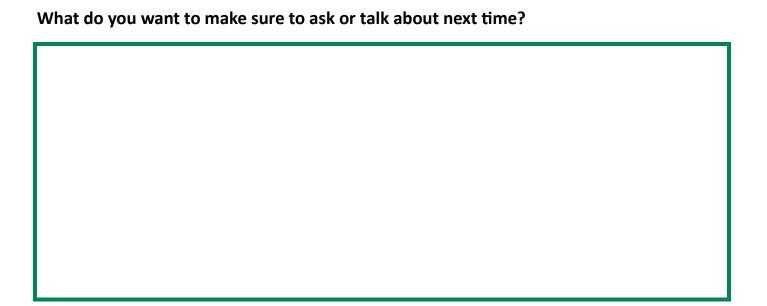
The more you talk the more they will know: Love is not Enough: A video

https://www.youtube.com/watch?v=hsZ287okl8c

When would be a good time to talk again?						

**SOME IDEAS** It is a good idea to have another conversation when life changes happen, such as the birth of a baby, when family and friends are together for a holiday or visit, before a trip, or when a health issue is getting harder to manage.

What do you want to repeat or explain again, so you are sure your trusted people understand what is important to you?
Who do you want to talk to next time? Are there people (such as family members who may disagree) who should hear things from you at the same time?
When do you want to talk with your care team (doctor, nurse practitioner, social worker, or others) next?
Remember that your care team is available to talk with you about the health care situation now the diagnosis might impact your life, the treatment options, the treatment outcomes, now these will impact your quality of life, and how you want to live.



#### What to do next

Now, it is a good idea to record your conversation with an important legal document to be sure your choices are followed. This is called advance care planning. It has two parts.

#### 1. Your Health Care Proxy

This is the part of a health care directive where you name the person you have chosen to make health care choices for you if you are too sick or hurt. You can have just one proxy or more. They can make decisions jointly or in the order you have listed them. As explained in this guide, be sure to have a conversation — and keep talking — with these people to be sure they understand what matters to you. You can find more information and suggestions in <a href="Your Guide to Choosing a Health Care Proxy">Your Guide to Choosing a Health Care Proxy</a>.

#### 2. Your Health Care Directive

This is the part of advance care planning where you talk about what is important to you or state what you want or do not want for your health care if you cannot speak for yourself and if you know there are medical treatments you may face in the future. These are many of the same things that you have thought about and discussed throughout this guide. Your <a href="Health Care Directive">Health Care Directive</a> can be general or specific. A plan is specific if you say you want or do not want specific treatments under specific circumstances. Your plan will be general if you do not say anything about specific treatments.

It is important to share your Health Care Directive with more than your proxy. For example, if you pick an adult child to be your proxy and have other children, they should all be aware of what matters to you in your health care and know who you have chosen as your proxy. Talk to anyone who can help you have a say in your care through the end of life and provide copies of your health care directive to anyone who may need them. If you want tips on talking about what matters to you with your health care team, call the SHA Advance Care Planning Program team at 306-766-5922.



Notes	

# For More Information:

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## 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

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