Your Guide for Talking with a Healthcare Team

How to talk about the care that is right for you or someone you care for

Open space in this workbook might be useful to make notes for yourself when completing your health care directive and proxy appointment.

SHA Advance Care Planning Program
Serving Saskatchewan with offices in Saskatoon & Regina
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We cannot plan for everything, and we cannot predict the future. But we can talk about what is most important — in our life, and in our health care — with those who care for us.

The Saskatchewan Health Authority wants to help you talk about your wishes for your health care throughout your life so your wishes are known and respected by those who provide your care. The Conversation Project created this guide to help you start a conversation with a health care team so you can have a say in your health care — or help someone you care for have a say — today and tomorrow.

Since anyone’s health status can change suddenly, it is a good idea to start the conversation before a medical problem happens. That way, your care plan can be built on what is important to you — and it will be available when you need it.

It is also important to talk with those close to you about what is important to you, what matters in your care, and to choose a proxy — someone who you ask to speak on your behalf if you cannot make your own health care decisions. If you haven’t had those conversations yet, read the Conversation Starter Guide and Guide to Choosing a Health Care Proxy for help.

It is important to create a health care directive — instructions you write down about the kind of care you want and what is important to you.

In this guide, we refer to the members of a health care team — doctors, nurses, nurse practitioners, social workers, health educators, and others — as “health care team.”

Since you can use this guide to advocate for yourself or someone else, when we refer to “you,” we mean you or the person you’re speaking for.

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.
How to use this guide:

You can use this guide as a workbook to make notes on WHO to talk to, HOW to set up an appointment, and WHAT to say when you get there.

It always seems too soon...until it is too late.
We will help you take it step by step.

STEP 1
Think About What Matters to You

STEP 2
Plan Your Talk

STEP 3
Start Talking

STEP 4
Keep Talking

If you have completed the SHA Conversation Starter Guide, think about what other information you may want to think about to help you feel ready to have a conversation with your health care team.
Step 1  Think About What Matters Most to You

Why is it important to talk to your health care team?
Talking with a health care team helps create a care plan that is right for you — a plan that will be available when you need it. When you share what is important to you and how you want to live your life with your health care team, you become part of the team that helps you get the care that is right for you.
The best care is possible when you and your health care team share in decision making about tests, treatments, and care plans based on good medicine and your preferences and values. Together, as one team, you can decide which treatments are right for you — especially if your health changes.

Think about what matters to you — what is important to you, and what you will say.
As you get ready to start a conversation with your health care team, there are some helpful ways you can prepare. First, if you have not already thought about what matters most, how you like to live your life, and consider quality vs quantity of life, the exercise below will guide you.

Here is a good place to start.
Try finishing this sentence:
• What matters most to me in my life is...

Answering this question can help you start thinking about what you need to have a good life, what is important to you, and what makes you happy every day. Some ideas: being able to recognize my children; being independent; being able to spend time with the ones I love.

What matters most to me........
Step 2  Plan your Talk

As you plan your talk, keep in mind:

- You can have a say in your care now. You do not need to wait for your health care team to start a conversation. You can talk with your clinician in person, by phone, or by computer.

- The goal of this conversation is not to make specific medical decisions. Instead, it is an opportunity for your health care team to listen and learn about what is important to you. For example, you may have concerns about how your care could affect your financial situation or where you live. In this conversation, you can talk with your health care team about how the treatment will allow you to work after you get better.

- If you are diagnosed with a serious illness, you could talk to your proxy or people you trust. Your proxy can join you at your next doctor’s appointment in person or by phone, so they understand your diagnosis, treatment, and decisions. You can even ask them to take notes. For example, you can tell your health care team, “I brought my partner with me today. I want to talk to you about my health care wishes, and they are my proxy. I want them to be part of this.”

- It can be helpful to have a support person or proxy with you. However, it is also OK if you are not ready to share your health information just yet. If you want to have a private conversation with your health care team, you can ask for one when you arrive.

- You can even call before your appointment to set it up. That way, the team can arrange a private conversation in a way that will not make your support person feel uncomfortable. You might say, “Could you please tell Dr. Jones that, at my visit on Friday, I’d like to talk to her alone about my future health care decisions? My proxy is coming with me, and it would help if Dr. Jones could ask them to step out for the last part of the visit.”
Next, think about who you want to talk to, when, and what you want to talk about.

You can talk to your primary care doctor or anyone else involved with your health care. It is important to choose someone you are comfortable talking to. If possible, choose someone who already knows you and your health status.

WHO do you want to talk to? Check all that apply:

- Your primary care doctor
- Your nurse practitioner
- Your nurse
- Your specialist, if you have a chronic condition (heart doctor, lung doctor, psychiatrist, etc.)
- Your therapist, social worker, or health educator
- Your case manager
- Your admitting team, if you are hospitalized
- Your staff physician or nurse at your nursing home or assisted living facility
- Your palliative care specialist

Other:

Next, plan for a good time to start the conversation. (Ideally it will be as soon as possible).

WHEN would be a good time to talk? Check all that apply:

- At your next annual physical, in-person or virtually
- At your next routine follow-up appointment, in-person or virtually
- After a visit to the emergency room
- Before surgery
- When you’re admitted to the hospital
- If you have a new diagnosis (for example, heart or lung disease, cancer)

Other:

Would you like an interpreter to translate for you? Yes/No
Step 3  Start Talking

When you are ready to talk to your health care team, here are some ways to start a conversation.

Call or email your health care team’s office before your appointment, if possible. You can plan to have this talk at an in-person or virtual visit. It helps your health care team if they know in advance that you want to take time during your visit to discuss your care preferences, now and through end of life. That way, they can make sure to set aside time for this important conversation.

You might say: “Could you please tell Dr. Jones that, at my visit on Friday, I would like to talk to her alone about my future health care decisions?”

Prepare your opening line. When you meet with your clinician, start simply.

You might say:
“| I want to talk about my goals for care and living with my serious illness.”
| “I want to have a conversation about my wishes for end-of-life care.”
| “I am making my health care directive and want to talk about what would be best for me.”

Share what matters. Here are some things you can talk about:

You might say, “Have you heard about the Saskatchewan Health Authority’s advance care planning program? They have information and workbooks to help people talk about what they want for health care throughout their life. Here is what I have thought about so far.” You can share the information from Step 1 (“Think about what matters to you”) and Step 2 (“Plan your talk”).

You can complete our Conversation Starter Guide and bring it with you to your appointment. Our What Matters to Me Workbook is another resource to help prepare you for the conversation. Call or email the Advance Care Planning program team if you have questions or want this information mailed to you.

Bring any information you think is important to share with your clinician.
You may want to share your thoughts about illnesses, treatments, and health care experiences of people close to you. There are no “right” or “wrong” choices when it comes to your care. The important thing is to share what matters to you.

Here are some examples to get you started:
“| My cousin was diagnosed with a serious illness, and did not want to know how quickly it would progress — but I would want you to tell me how quickly it could progress.”
| “My nephew recently died in the hospital after weeks of aggressive care. That is what he wanted, but I do not want that. I think I might prefer to die at home. How can we make a plan for that when the time comes?”
| “I want you to know what is important to me and how I like to live so I get care that is best for me.”
You can also tell your health care team about important personal events you want to be a part of. You might say:
“My best friend is getting married later this year and I would really like to be there. Can you help me understand what I might need to do to make it to the wedding?”

**What to do in case of a health emergency.**
Sometimes, it is not possible to plan ahead for a conversation. When a health emergency occurs, it is just as important to say what matters to you in your care. It is helpful if you or your proxy talks with your health care team about your care right away and share the above points about your choices. That way, your health care team can have them in mind when planning your care.

**Ask questions.**
To make sure you have all the information you need, ask a lot of questions. It is OK to ask questions of your health care team, even if it feels uncomfortable or scary. Having a say in your care is only possible when you have all the information you need. Having a say will also help your health care team make the best possible decisions in your care.

If you want to know about numbers and statistics, ask if they are available. If you do not understand something, ask your health care team to explain it in a different way. You can even ask your health care team to write things down for you.

**If you learn you have a medical problem, here are some questions you can ask to help you understand the condition and plans for your care.**

- “Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?”
- “What can I expect about my ability to function independently?”
- “What are some possible big changes in my health that I should be prepared for?”
- “What can I expect to get better if I choose this treatment? What are my other choices?”
- “What can I expect if I decide to do nothing? What will my quality of life be like?”

Ask your health care team to write down your discussion, and your wishes, in your medical record. When you choose a proxy, let your health care team know who that person is right away.

If you have started to create a health care directive, bring that with you to the appointment. If not, you can ask the Advance Care Planning program to mail a package to you or ask your care team for the forms. A health care directive is an important legal document that helps make sure your choices are known by everyone in your care.
Plan to talk again in the future.

If you need to make a decision, take the time you need. You might say:
“"I would like to talk this over with my siblings. Can we have another conversation in a couple of weeks?""

Write some of your ideas here:

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**Step 4  Keep Talking**

It is important to have many conversations with your health care team over time. The conversation will change as your health changes. To get the best care possible, keep your health care team updated so they understand what is most important to you.

Here are some of the reasons you may need to start conversations more often.

- My clinician does not want to talk or does not agree with my choices.
- It is your right to talk about the kind of care that is right for you. You can and should advocate for yourself. Here are some things you can say or do.

**Mention that your condition can change over time.** “Yes, I am doing well now, but things can change at any moment and I want us both to be prepared.”
If there is not enough time, suggest scheduling another appointment specifically to focus on the conversation.
If you continue to feel resistance, or your practitioner asks you to make choices you do no agree with, you may need to consider seeking a new practitioner.

**You know yourself — and what you want from your health care — best.** It is important for you to have a say in your care.

**I got two different opinions from two of my health care team.**
If this happens, it is a good idea to arrange a meeting or call with both health care teams to talk at the same time. We do this in other areas of life when people have different opinions. It is extra important when it comes to your health care.
If you are not comfortable bringing together two health care teams at the same time, you can ask them each separately about the disagreement. Tell them you have received a different opinion and you would like help understanding the difference.
Notes
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.

For More Information:
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