



What Matters to Me

A Workbook for People Making a Health Care Directive

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Table of Contents

Subject	Page
My Health	4
My Care	5
My Fears and Worries	10
My People	13
My Health Care Team	15

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.

This document is not intended to be a health care directive. It is a workbook to help you think about what is most important to you as you prepare to make your health care directive.

This Workbook is designed to help people who want to make a health care directive get ready to talk to their substitute decision maker(s) and health care team (doctor, nurse, social worker, etc.) about what is most important to them. **After completing this workbook a person will be able to complete their health care directive.**

This Workbook is NOT about making specific medical decisions. It is about thinking about what matters most to you — and sharing your goals and preferences with your health care team about how you want to live your life. Then together with your health care team you can choose the kind of care that is right for you.

FOR YOU:

- Complete the workbook by yourself or with someone else. Choose the way that works best for you.
- Take your time. You do not need to complete the workbook all in one sitting. It is okay to skip questions or come back to them later.
- Share it with your health care team. Bring the filled-in workbook to your next appointment so you can talk over your answers and questions.
- Be prepared. Even if you do not have an appointment soon, or you will not be seeing a family member soon, doing the workbook will help YOU be clear about what matters to you.

Write in all of the empty spaces as you gather your thoughts as you go through the workbook. Remember, the answers to these questions are about you and what you think is right for you.

What is your understanding of your current health situation?

FOR CAREGIVERS:

If you are helping someone else complete this workbook, here are some things to keep in mind:

- Explain why this will help. You might say, “I want to make sure we know what is most important to you so we can have a more useful conversation with your health care team.”
- Take it in small pieces. It is okay to skip a question. You can even let the person pick the questions that appeal to them. If they get tired or overwhelmed, take a break and come back to it later.
- If the person is prone to confusion, keep the number of helpers small. Having many people present can increase pressure on the seriously ill person. Have one or two people assist in completing the workbook, then share it with others.

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MY HEALTH

What is your understanding of your current health situation?

How much information about what might be ahead with your illness would you like from your health care team?

ABOUT ME

MY GOOD DAYS • What does a good day look like for you?

Here are some things I like to do on a good day:

EXAMPLES

Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee with a friend

MY HARD DAYS • What does a hard day look like for you?

These are the toughest things for me to deal with on a hard day:

EXAMPLES

Cannot get out of bed • In a lot of discomfort • No appetite • Do not feel like talking to anyone

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MY GOALS • What are your most important goals if your health situation worsens?

These are some things I would like to be able to do in the future:

EXAMPLES

Take my dog for a walk • Attend my child’s wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit

MY MEANINGFUL RECOVERY • What things in your life are so important to you that you do not want to give up at this point in your life?

EXAMPLES

Returning to my current level of function/doing the same things as I can do now • I would be okay if I needed to go to a health care facility to get stronger before going home • I would accept some help from others if it meant I could remain in my own home • I would not want any help from others to remain independent • Quality of life is important to me • Quantity of life is more important to me

MY CARE:

Everyone has their own preferences about the kind of care they do and do not want to receive. Use the scales below to think about what you want at this time.

Note: These scales on the next few pages represent a range of feelings; there are no right or wrong answers.

- **Answer where you are right now.** For each scale, think about what you want now. Revisit your answers in the future, as they may change over time as your health changes.
- **Use your answers as conversation starters.** Your answers can be a good starting point to talk with others about why you answered the way you did.
- Initial the box within the scale that best fits your answer.

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As a patient, I would like to know...

----- ----- ----- -----

Only the basics about my condition and treatment

All the details about my condition and treatment

When there is a medical decision to be made, I would like...

----- ----- ----- -----

My health care team to do what they think is best

To have a say in decisions whenever possible

My concerns about medical treatments?

----- ----- ----- -----

I worry I will not get enough care or will not get the right care

I worry I will get too many treatments or care that will not benefit me

My concerns about pain?

----- ----- ----- -----

I worry I will not receive enough medication and feel pain

I worry I will receive too much medication and not be aware of what is happening around me

My concerns about how my other symptoms will be managed?

----- ----- ----- -----

I worry that I will not get enough medication to manage symptoms other than pain or will not be heard

I worry that the side effects of treatment will be too much for me

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If I am diagnosed with a serious or terminal illness that could shorten my life, I would prefer to...

----- ----- ----- -----

I prefer not to know what to expect in terms of timelines

I prefer to know as much as possible what to expect in terms of timelines

Any other notes you want to add:

How much medical treatment would you feel was right for you?

----- ----- ----- -----

I would want every available treatment to extend my life, even if it is uncomfortable

I would not want to try any treatments that worsen my quality of life.

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How much medical treatment are you willing to go through for the possibility of more time?

----- ----- ----- -----

Nothing: I do not want any more treatments

Everything: I want to try any medical treatment possible.

If your health conditions worsens, where do you want to be?

----- ----- ----- -----

I prefer to be in a health care facility (hospital, assisted living, or nursing facility)

I strongly prefer to spend my time at home if possible.

Now, look at your previous answers. What do you notice about the kind of health care you said is right for you?

When it comes to sharing information about my health with others...

----- ----- ----- -----

I do not want those close to me to know any/all details about my health

I am comfortable with those close to me knowing the full details about my health.

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Information about my health I am comfortable with others knowing:

When I die...

----- ----- ----- -----

I want to be alone

I want to be with other people

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?

What do those around you need to know about what you want or do not want when you are nearing the end?

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Look at your previous answers. What are the most important things for your friends, family, and health care team to understand about what matters most to you now and through the end of life?

MY FEARS AND WORRIES

What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

EXAMPLES

I do not want to be in pain; I am worried that I will not be able to get the care I want; I do not want to feel stuck someplace where no one will visit me; I worry that I might need more care than my caregivers can provide?

My Strengths: What gives you strength as you think about the future with your illness?

These are my main sources of strength in difficult times....

EXAMPLES

My family; My friends; My faith; My garden: Myself (I work through things)

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My Abilities: What abilities are so critical to your life that you cannot imagine living without them?

I want to keep going as long as I am able to....

EXAMPLES

As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I am not conscious

If you become sicker, which matters more to you: the possibility of a longer life, or the possibility of a better quality of life? Please explain.

If my health situation worsens, here is what I want to make sure DOES happen:

EXAMPLES

I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes if I say I want to switch to comfort care only

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And here is what I want to make sure DOES NOT happen :

EXAMPLES

I do not want to become a burden on my family • I do not want to be alone • I do not want to end up in the ICU on a lot of machines • I do not want to be in pain

Is there anything else you want to make sure your family, friends, and health care team know about you and your wishes and preferences for care if you get sicker?

MY QUESTIONS • What questions do you want to ask your health care team?

EXAMPLES

How will you work with me over the coming months? • What treatment options are available for me at this point — and what are the chances they will work? • What can I expect if I decide I do not want more curative treatment? • If I get sicker, what can you do to help me stay comfortable? • What are the best-case and worst-case scenarios?

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MY PEOPLE

Are there key people who will be involved in your care (family members, friends, faith leaders, others)? For each person you list include their phone number and relationship to you.

How much do they know about your wishes and preferences?

What role do you want them to have in decision making?

When might you be able to talk to them about your wishes?

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Which person would you want to make medical decisions on your behalf if you are not able to? This person is often called your health care proxy. See the Guide to [Choosing a Health Care Proxy](#) for help.

Name, phone number, relationship to me (*naming them here does not make them your proxy. You must write it down on a proxy form, sign and date it for it to be legal. There is a copy of the form at the end of this workbook.*)

Name	Phone Number	Relationship to me

Question to consider	Yes	No	Comments
I have talked with this person about what matters most to me.			
I have filled out an official proxy appointment form naming this person(s) as my health care proxy and provided a copy to them.			
I have completed a health care directive and given a copy to my proxy.			
I have checked to make sure my health care team has a copy of the official proxy form and/or health directive.			
Note: You do not need to complete both: You can complete a proxy form without a health care directive.			

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My Health Care Team

Clinicians involved	Name	Phone Number
My Family Doctor		
My Social Worker		
My Main Specialist		
Other		
Other		

Next Steps

Now that you have completed the workbook, what comes next?

- Talk it over with someone else. If you filled out the workbook on your own, make a time to share your answers and questions with a family member, a friend, or another person. You might want to give them a copy of the workbook with your answers written in. See the [Conversation Starter Guide](#) for help.
- **Talk it over with your health care team.** Make an appointment to talk over the workbook, sharing your answers and asking any questions. If your primary care doctor or main specialist works with a social worker, that person can be an excellent place to start. You might want to give your health care team a copy of the workbook with your answers written in before your appointment.
See the Guide for [Talking with a Health Care Team](#) for help.
- **Pick a proxy.** This is the person you choose to make medical decisions for you if you are not able to make them for yourself. See the [Guide to Choosing a Health Care Proxy](#) for help.
- **Keep talking.** People’s preferences often change as their health changes or as time goes by. People are often able to adapt to things they once thought were unacceptable. Revisit the workbook over time to see if your answers have changed. Be sure to keep your health care team updated so they know what is most important to you. It can be helpful to review this every year on your birthday or as life circumstances change.

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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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