









What Matters to Me

A Workbook for Better Health Care

NAME

DATE

ARIADNE LABS

the **conversation** project

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This Workbook is designed to help people get ready to talk to their health care team (doctor, nurse, social worker, etc.) about what is most important to them.

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

DO THIS

- Do the Workbook by yourself or with someone else. Choose the way that works best for you.
- Take your time. You don't need to complete the Workbook all in one sitting. It's 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 don't have an appointment soon, or you won't be seeing a family member soon, doing the Workbook will help YOU be clear about what matters to you.

TWO WAYS TO SHARE

1. If you are doing the Workbook on your computer, be sure to save it to your computer before typing in your answers. Otherwise, what you type will not be saved.
2. Many people find it easier to write their answers in the printed document, then make copies of the filled-in document to share with others.

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's most important to you, so we can have a more useful conversation with your health care team."
- Take it in small pieces. It's always 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.

My Health

What is your understanding of what's happening with your health now?

How much information about what might be ahead with your health 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

Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

MY GOALS • If your health gets worse, what are your most important goals?

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 Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.
Note: These scales represent a range of feelings; there are no right or wrong answers.

- Answer where you are right now. For each scale below, think about what you want now. Revisit your answers in the future, as they may change over time.
- 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.

As a patient, I'd like to know...

Only the basics about my condition and my treatment — All the details about my condition and my treatment

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

My health care team to make all the decisions — To have a say in decisions whenever possible

What are your concerns about medical treatments?

I worry that I won't get enough care — I worry that I'll get too much care

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

Nothing: I don't want any more medical treatments — Everything: I want to try any medical treatments possible

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

I strongly prefer to be in a health care facility — I strongly prefer to be at home, if possible

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

I don't want those close to me to know all the details — I do want those close to me to know all the details

ABOUT ME • What would you like your health care team to know about you?

Something basic or practical:

EXAMPLES

My faith is very important to me • I live alone and need to be able to care for myself • I remember things better when they are written down

MY FEARS AND WORRIES • What are your biggest worries?

These are the main things I worry about:

EXAMPLES

I don't want to be in pain • I'm worried that I won't be able to get the care I want • I don't want to feel stuck someplace where no one will visit me • I worry about the cost of my care • What if I need more care than my caregivers can provide?

MY STRENGTHS • As you think about the future, what gives you strength?

These are my main sources of strength in difficult times:

EXAMPLES

My friends • My family • My faith • My garden • Myself ("I just do it")

MY ABILITIES • What activities bring joy and meaning to your life?

I want to keep going as long as I can…

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 football on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious

MY HOPES • What are your hopes for your health?

Here's 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

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

EXAMPLES

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

Is there anything else you want to make sure your family, friends, and health care team know about your hopes for care?

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'll work? • What can I expect if I decide I don't 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?

My People

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

- How much do they know about your hopes 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?

- Which person would you want to make medical decisions on your behalf if you're not able to? This person is often called your health care proxy, agent, or surrogate. See the Guide to Choosing a Health Care Proxy for help.

Name, phone number, relationship to me

I have talked with this person about what matters most to me.	◯ Yes	◯ No
I have filled out an official form naming this person as my health care proxy.	◯ Yes	◯ No
I have checked to make sure my health care team has a copy of the official proxy form.	◯ Yes	◯ No

My Health Care Team

Who are the key clinicians involved in your care?

	Name	Phone
My primary care provider		
My social worker		
My main specialist		
Other		

Next Steps

Now that you have completed the Workbook, what's 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. Revisit the Workbook over time to see if your answers have changed. And be sure to keep your health care team updated so they know what is most important to you.

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