



PennState Health

WITH THANKS TO



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the conversation project



What Matters to Me

A Workbook for People With Serious Illness



PennState Health

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Name:

Date:

This workbook is designed to help people with a serious illness get ready to talk to their health care team, including doctors, nurses, social workers, etc., about what is most important to them.

This workbook is NOT about making specific medical decisions. It's for 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.

How to use this workbook

- 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 OK to skip questions or come back to them later.
- Share it with your health care team. Bring the completed 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 COMPLETE

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 to share with others.

Adapted by Penn State Health from:

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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 OK 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 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: *Can’t get out of bed* • *In a lot of discomfort* • *No appetite* • *Don’t feel like talking to anyone*

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 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...



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



What are your concerns about medical treatments?



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



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



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



My fear 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 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 with your illness, 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 abilities are so critical to your life that you can't imagine living without them?

As long as I can, I want to...

Examples: *At least sit up in bed and occasionally talk to my grandchildren • Eat ice cream and watch the football game on TV • Recognize my loved ones • Have a heartbeat, even though I'm 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:

My wishes and preferences • What wishes and preferences do you have for your care?

If my health situation worsens, 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 intensive care unit 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 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'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 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?

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.

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?

My primary care provider	<input type="text"/> <i>Name</i>	<input type="text"/> <i>Phone Number</i>
My social worker	<input type="text"/> <i>Name</i>	<input type="text"/> <i>Phone Number</i>
My main specialist	<input type="text"/> <i>Name</i>	<input type="text"/> <i>Phone Number</i>
Other	<input type="text"/> <i>Name</i>	<input type="text"/> <i>Phone Number</i>

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 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 it.
- **Talk it over with your health care team.** Make an appointment to talk about 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.
- **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.
- **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.

