Talking About Your Illness With Loved Ones and Caregivers

Advance Care Planning and Serious Illness Conversations



This booklet is meant to help you talk with your loved ones and caregivers about your illness and the future. Pick a time when you feel comfortable and have time to talk.



Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones:

- Think about when and where you want to talk.
- Choose a time and place when you feel relaxed.
- Be sure you have time to talk for a while.

You can use the words in this guide, or use your own words – whatever is easier for you.

Start the conversation

I am doing OK right now, and even though there is no rush, my doctors think we need to begin talking about my future care.

They believe in being prepared and want to know my goals and wishes for medical care.

Since you are important to me, I'd also like you to be part of the conversation.

If there came a time when I can't make decisions for myself, I want you to be prepared to make decisions for me, ones I would make for myself, respecting who I am and my wishes

Check in with your loved one

Understanding

What is your understanding now of where I am with my illness?

Information

I know that it may not be easy, but I would like to share information about my illness with you. Is that okay?

How much information about what is likely to be ahead would you like from me?

My doctor/clinician and I talked about the outlook for my illness. Can I share that with you?

Share what is important to you

If my health gets worse, these main topics describe my thoughts and feelings about the care I'd want.

Goals and wishes

The goals that are most important to me are..

Examples: Meeting my new grandchild, celebrating my next birthday, finishing up a project, getting in touch with friends and family, etc.

Fears and worries

My biggest fears and worries about my future with this illness are:

Examples: Not being able to make decisions for myself, having to ask others for help with basic needs, not being able to breathe, needing to live in care, etc.

Abilities

I can't imagine not being able to do certain things...these are:

Examples: Not being able to recognize or interact with people, not being able to care for myself, not being able to get outside or travel, etc.

Tough choices

If my health continues to get worse, I know that we may have to choose between treatments that are hard to go through but may give me more time - quality of life vs prolonging life.

Examples: having a feeding tube, being on a breathing machine, more chemotherapy; Some treatments may mean I'm in the hospital a long time when I want to be home, others that I may need to live in a care home, etc.

Here's what I think about those choices...

Plan to talk again

Do you have any questions about what we have discussed?

I know this was probably not an easy conversation. How do you feel now that we have talked?

Are there other people we should talk with?

I would like to talk with you more about my illness and medical care as my health changes. Is that okay?

For more information

To learn more about Advance Care Planning and decision making, visit:

- Montgomery Hospice www.montgomeryhospice.org/acp
- <u>Maryland Advance Directive</u> <u>www.marylandattorneygeneral.gov/Pages/HealthPolicy/advance-directives.aspx</u>
- NHPCO Advance Directives www.nhpco.org/patients-and-caregivers/advance-care-planning/ advance-directives

Talk often with your loved ones and caregivers as your health and wishes change.



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