Care Planning Is Challenging but Important: Your Practitioner Can Help

Wayne Saltsman, MD, PhD, CMD, talks about how and why family members should be involved in their loved one’s care planning.

Getting the care we want when we’re ill or injured isn’t something most people want to think about or discuss. But these conversations can offer much comfort down the road. In fact, it’s important for anyone over the age of 18 — even if they are very healthy — to begin to ask about their treatment goals and other issues to ensure their care is managed the way they want.

It is important to realize that advance care planning isn’t just about end-of-life care. A person doesn’t need to be seriously ill to make plans and express wishes or goals. In fact, these conversations are all about life and how we want to live even if we are sick or hurt. These plans should be made and wishes documented before an illness or injury.

When you participate in care planning for your loved one, you are helping to make sure they get the care they need and would want. It may be hard for you to talk about these things, but remember that you are touching your loved one’s life in a very positive way, often at a difficult time. For instance, you know how much mom loves strawberry ice cream or Tony Bennett music. Or you know that mom doesn’t want to go to the hospital, but you’re worried that she won’t get any care if she doesn’t. The physician and other clinicians can explain to you what your care your mom will get on-site and how this will help her and keep her comfortable.

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Setting realistic goals is an important part of care planning. Remember that your practitioner and other team members care for your loved one and want the best for them. It’s important not to get angry or upset if they tell you something you don’t want to hear. At the same time, if you don’t feel like they’re being sensitive or helpful, it’s okay to tell them this. You very likely will find that the practitioner cares very much about your loved one but is trying to stay detached and professional or simply doesn’t know what to say. Although their work is based in empathy and compassion, some have a harder time expressing those feelings.

Without a doubt COVID-19 has made care planning more challenging. It is possible to have these conversations via telemedicine visits, but it is challenging to complete a health care proxy or any document that requires witnesses and signatures. If you haven’t participated in your loved one’s care planning during the pandemic, it’s time to start again. Talk to your practitioner about your loved one’s conditions and any changes to their health or care in recent months. Review any appropriate documents with your loved one to make sure they are up to date and still applicable.

Care planning isn’t one and done. Changes in your loved one’s condition and other developments may impact how they feel about their care or their wishes. At the same time, throughout your loved one’s illness you can play a key role in their care and in keeping them comfortable. You can help identify any subtle changes in your loved one’s condition, mood, or behaviors. At the same time, you know what will bring them joy and comfort — whether it’s visiting with a pet, playing favorite music, or holding a virtual tea party with grandchildren.

If a care planning conversation becomes too difficult or stressful, it’s okay to take a deep breath and take a step back. But don’t let the fact that this is hard keep you from helping to ensure that your loved one is comfortable, content, and get the care and treatments they want. If you need help or support, there are many organizations with useful resources, or you can engage a member of the clergy or other trusted person to help.

Questions to Ask Your Practitioner
• How often should we have care planning conversations?
• Can I or should I participate in care planning meetings with the interdisciplinary team?
• Whom do I contact if I am concerned that my loved one’s wishes aren’t being followed?
• What can I do if my loved one refuses or is unable to complete an advance directive or other document and/or won’t talk about their wishes?
• How can I best help with care planning? What information or insights will be most helpful for me to provide?

What You Can Do
• Ask your loved one if they are getting the care they want and if they would wish for anything different, particularly if they have been sick or their condition has changed in some way.
• Work with your loved one (and your practitioner) to make sure they have an up-to-date advance directive or similar document. Review these from time to time with your loved one.

For More Information