Caring Conversations® in a time of COVID-19

Advance Care Planning - Always important…and suddenly urgent

Americans have always believed in the importance of advance care planning, but we also have been skillful at putting it off. “We'll do it,” we tell ourselves, “…when the time comes.” We also know that doing anything in a time of crisis makes it even more challenging. So, in this time of crisis, when advance care planning is more important than ever, we encourage you to follow these suggestions, and hopefully, you can make the best of a crisis situation. Suggestions are designed for all adults, particularly those living with serious illness or considered at higher risk for COVID-19.

Follow these 6 steps and connect to the tools.

1. Gather your thoughts. Remember to start with the most important – the things that matter most.
   - This is not (yet) about treatments; it is about values, meaning and purpose.
   - What do those around you need to know about life and love, what gives joy, meaning and purpose to your life? This is about legacy and living and dying… from your heart, your mind and your soul.

2. Share with those who matter.
   - Now, gather your people – those who need to hear what you have to say. You don't need a healthcare professional to help with this step unless you are confined to a setting that limits your contact with others.
   - Start wherever it makes sense – stories of the past, hopes and dreams for the future, thoughts, prayers, messages for those far away, treasured memories. Trust it will come. Tools exist to help (see links).
   - Allow those you are sharing with to ask questions.
   - Get clear about the three, four or five things that matter most.
   - Write them down if you can or record them in audio or video format to be shared with others.
   - Do this before answering questions about treatments or medical things that you do or don’t want.

3. Decide who the person is who will do the best job of speaking for you, honoring your values.
   - Name this person as your “agent” if you haven’t already – the person who will speak for you when you can’t.
   - Share as much as you can about these matters. It may be the first time you have had this kind of talk.
   - This may be hard. You might cry. It can be scary – but you will be scared with people you love, and it’s always better to be scared together. No one likes to think about these things, but we must.

4. Now, you are ready to act. You will likely be asked by others to name your agent using a form.
   - Fill out and sign the form(s) or record your agent appointment using a video or audio recording. Advance Care Planning documents allow you to do this and to have them witnessed. If you can’t get all that done, record your wishes and instructions using whatever tools you have available.
   - Tell everyone you can who that special person is who you have named and why you’ve chosen him/her.
   - It is recommended that you only appoint one person. You can also name an alternate, but it is easier for everyone if someone is listed first. That’s who medical people will turn to first when you can’t speak.

5. Next, talk with healthcare providers or clinicians about treatments and your goals.
   - They will need to ask you questions about your values and goals and wishes in order to help you decide what kinds of treatments or medicines or medical things that could happen based on your medical condition.
   - If you already know what kinds of things you do and don’t want, tell them. But don't assume that you know what all the options are. Ask them about your concerns and fears. Make sure they speak to you in language you understand.
   - They will have things like “decision aids” or other tools they might call “paths or algorithms” that will help you decide what kinds of things would be important. They should ask questions to make sure that you/your agent and they are clear about how your values match your goals. Make sure you agree
They should let you know that the goals they confirm with you/your agent should become part of your record.

o You/your agent should ask about your medical conditions and how they might impact the kinds of treatment options that could help or hurt your chances for survival and recovery.

o If you do not want to go to the hospital or intensive care, you should tell them. Make sure you understand what that means and how your care needs will be met if you don’t go.

6. If you are sure you know what kinds of treatments you want and don’t want, you may need to sign another form called a healthcare directive, which is another Advance Care Planning form.

   o If, for any reason, you can’t sign that form, you can just say that your agent makes all decisions for you. You may need to write that statement on your agent appointment form, so there is no question about your agent’s authority. Tell the clinician and the agent both what you are thinking.

   o If you don’t have the chance to meet with a clinician, you can still complete this directive and write down your thoughts about what you want. This form can be included with the agent form. To make it “legal,” you may need to have it witnessed or notarized. There are tools and resources to help with this.

You can use a variety of paper forms produced by numerous organizations to appoint your agent and record your treatment preferences. Links are provided below. Electronic Caring Conversations® Workbooks are available online for free. If you want to record what is important to you in a video or audio recording, you can use MyDirectives® to upload and share them. They partner with the Center to provide that service to you at no charge. You can also scan and upload any written record you have as well to MyDirectives® so it will be available from anywhere you need it. Remember, your agent speaks for you only when you can’t speak for yourself.

Use MyDirectives® to create a new record using that application (Option 1) or use an existing record and store it in the cloud for sharing and retrieval (Option 2)

Option 1

   Easy to create
   • Tailor it to your specific values, beliefs and treatment goals.
   • Answer questions in your own words or pick from a selection of the most common answers.
   • Add your thoughts with as much detail as you wish, including video response.

   Easy to share
   • Access your plan 24/7 online—nothing to search for during a crisis.
   • Share it with anyone at any time, including family, healthcare providers and hospitals.
   • Hospitals that link to MyDirectives® can access your care plan when you have to go.

   Easy to update
   • Change an answer, add to your plan or consider other options whenever you wish.
   • Doctors can only access your most recently signed version.

Option 2 – I already have an advance directive or want to record and upload my statement.

With MyDirectives®, you can upload a previously existing document, such as a paper advance directive or portable medical order like POLST/TPOPP. Once added, it becomes part of your online record with MyDirectives® that can be shared with providers and family.

Other COVID-19 Resources referred to above

Below are some tools and resources you can use to help you complete the above steps.

• Consumer tools for advance care planning and making healthcare decisions. GoWish online, the conversation project,
• Patient Decision Aids Ventilator (U of CO), Respecting Choices Decision Aids: CPR, RC Decision Aid: Help with Breathing
• Guides for clinicians and providers - Scripts and facilitation - VITALtalk, CAPC, NHPCO, User Guide for Decision Aids,
• Medical Orders – POLST/TPOPP Guidance

CLICK HERE TO SEE ALL ABOVE RESOURCES IN ONE LOCATION.