

PREPARE FAQs

General Questions about Advance Care Planning and the PREPARE Website

Question: Does it cost money to use PREPARE?

Answer: No. PREPARE is free as long as its use follows our terms of use.

PREPARE is not a company, but a program within the University of California. It is OK to go through the PREPARE website, watch the videos, download any of the PREPARE materials, or put on PREPARE movie events – as long as these materials and events are provided for free.

Under our copyright and license agreement, it is OK to provide a PREPARE link as a list of resources to individual patients or people. Please use the complete program name, Prepare for Your Care, and this web link: https://www.prepareforyourcare.org.

For companies, organizations, clinics, hospitals, insurers, employers, researchers or other institutions who want to brand our materials with their own logos, put our PDF materials on their own websites, use PREPARE materials in research, or use part of PREPARE in their own work, they must have a license agreement with the University of California. Please go here for more information: https://prepareforyourcare.org/partner

Question: Do I have to create an account and sign in to use PREPARE?

Answer: No. You can use PREPARE as a guest. But, if you want PREPARE to save your answers, you have to sign in. You may want PREPARE to save your answers if:

- You want to complete one step of PREPARE at a time and come back later.
- You want PREPARE to put your answers into an easy-to-read advance directive.
- If you have already filled out the advance directive for one state on PREPARE to put your answer on another state's form.

Question: Do I have to watch or go through all 5 steps of PREPARE?

Answer: No. You can pick which step or steps are the right ones for you.

Each step below takes about 10 minutes to go through and answer questions about:

- 1. Choose a Medical Decision Maker
- 2. Decide What Matters Most to You
- Choose Flexibility for Your Decision Maker
- 4. Learn How to Tell Others About Your Medical Wishes
- 5. Learn How to Ask Doctors the Right Questions

If you create a PREPARE account and sign in, PREPARE can save your answers. That way, if you want to go one step at time, PREPARE will save your answers and your place.

Question: Is PREPARE in more than one language?

Answer: Yes. PREPARE is in Spanish and English. We are attempting to get additional funding to provide PREPARE in Chinese. Many of our printed advance directive forms may also be in several languages depending upon the state.

Question: How can I get the PREPARE newsletter?

Answer: Getting the PREPARE newsletter is a great way to stay up to date on PREPARE innovations, research, events, and coming attractions.

You can also follow us on Twitter: @prepareforcare and Facebook:

www.facebook.com/prepareforcare

You can also sign up for our quarterly newsletter: https://prepareforyourcare.org/newsletter

Question: What are all the different PREPARE materials?

Answer: PREPARE has several different types of materials that can be helpful for different purposes:

- The Website: Going through the PREPARE website and the 5 steps is a great way for someone to learn about what is important in their life and their health care. The website walks people step-by-step through important information, video stories, and questions tailored just for them.
- Summary of My Wishes: As people go through PREPARE, the website automatically creates a "Summary of My Wishes." This summary can be printed and saved as a PDF file.
- PREPARE Printed Materials and Movie materials:
 - The PREPARE Advance Directive in English and Spanish. This form can be printed or people can complete this on PREPARE in what is called an editable PDF. It allows you to type in your answers before you print the form.
 - The PREPARE Pamphlet: This can be helpful to print and hand out in clinics, at health fairs, PREPARE movie events, or just to learn more about the PREPARE basics.
 - The PREPARE Question Guide: Some people prefer to answer questions about what is most important for their healthcare in a printed workbook form and not on a website.
 - The PREPARE Movie: All of the information, video stories and values questions have been combined into 5 separate PREPARE step movies.
 These movies are best for group events or group medical visits.
 - The PREPARE Toolkit for Group Movie Events: This is a step-by-step guide with all the materials needed to put on a group event and to show the PREPARE movies

Question: How can I donate and help support PREPARE program?

Answer: Thank you for thinking of us. PREPARE is not a business, but a small program run out of the University of California, San Francisco. We depend on grants, license agreements, gifts, and donations to keep the website up and running and free to the public. Every little bit helps. If you would like to make a donation, please visit this site:

https:// prepareforyourcare.org/support

Question: Did someone send me to PREPARE because they think I am dying?

Answer: No. This type of planning and preparation is for all adults, at any age or stage of health. Someone could review PREPARE at age 18 or 80. For example, Step 1 of the PREPARE website is about choosing the right medical decision maker. We all should do this. And, no matter what stage of life or health, this will help make sure our family, friends, and medical providers know our wishes so they will not have to guess. This makes sure, that even if we do get very sick, we can have a say in our healthcare.

CONCERNS ABOUT THE TOPIC OF ADVANCE CARE PLANNING

Question: A few examples from the PREPARE videos are about end of life care. I am not ready to think about my end of life care. Is PREPARE still right for me?

Answer: Yes, advance care planning is much more than care you want at the very end of life. It can be done by anyone at any age or stage in life.

It is about taking the time to prepare and think about what is most important to your life and your medical care both now and in the future. Sharing this information with the people close to you is the best gift you can give them so that they can make better medical decisions for you if they ever need to in the future. It is also the best way to make sure you have a voice in your healthcare now and in the future.

Question: What if I am not ready to complete an advance directive? Is PREPARE right for me?

Answer: Many people are not ready to complete a legal advance directive form and that is OK. PREPARE can help you just get started. The website and videos will walk you through the steps to begin the process of deciding what is most important to you and your health care so you can begin to share that with your loved ones and medical providers. It can also help you decide on the right medical decision maker. Even watching one video can be helpful.

Question: Can I change my mind about my medical wishes? What do I do if I change my wishes?

Answer: You can always change your mind about your medical wishes at any time. This is your choice. If you create a PREPARE account the website will save your answers. That way, if you ever want to come back to change your answers over time, it is easy to do. Otherwise, you may need to start the PREPARE questions over from scratch. If you do change your mind about your wishes, and you have completed a PREPARE advance directive, update this form. Give the new form to your medical decision maker and medical providers. Destroy old forms.

Question: Doesn't health insurance determine what care you get. Will ACP planning even help?

Answer: Advance care planning will not fix all the problems in the health care system. However, the best way you can prepare yourself and your family and friends to advocate to get the care you want is by deciding what matters most to you and discussing this with your friends, family, and medical providers. Having an advance directive form may also be important to make sure your wishes are in your medical records.

Question: How does knowing what is important in my life actually translate into the type of medical care that is right for me?

Answer: Medical providers try to match medical treatments to what is best of people and what represents quality of life for them. This is different for each person. Knowing what is most important in your life and sharing that with your family, friends, and medical providers is the best way to make sure that what is important to you is aligned with your medical care. For example, there is a video in Step 2 where a couple is talking about the care of medical care they would want if they were very sick and unable to speak for themselves. Different things were important to each of them which would have led to one person wanting to pursue ICU treatments and a breathing machine. For the other person, this was not part of his goals and he would want to focus on comfort care.

Question: Can you just give me a laundry list of all of the possible health situations so I can say for sure what I want done in each situation?

Answer: PREPARE and the advance directives focus on people's values and overall goals for life and medical care because life is unpredictable. It hard for people to know exactly what they want in every medical situation or be able to anticipate every medical situation and what will be happening in their life and in their family at that time. Knowing what is important, overall can help you, your family and friends, and your medical providers decide on the care that is best for you over time. However, some people have very strong wishes for medical care in specific situations. If you do, you can write these wishes down on the PREPARE easy-to-read advance directive.

DECISION MAKERS:

Question: Are there other names for a medical decision maker?

Answer: Yes. Sometimes this person is called a surrogate or proxy decision maker, a patient advocate, or durable power of attorney for health care. However, all these terms mean the same thing.

Question: What are the responsibilities (job) of a decision maker?

Answer: This information can be found on Page 3 and 4 of your states' easy-to-read advance directive. In most states, if you are not able, a medical decision maker may choose these things for you:

- doctors, nurses, social workers, caregivers
- hospitals, clinics, nursing homes
- medications, tests, or treatments
- who can look at your medical information
- what happens to your body and organs after you die

Depending on how you fill out the form, here are more decisions your medical decision maker can make:

Start or stop life support or medical treatments, such as:

- CPR or cardiopulmonary resuscitation
- Breathing machine or ventilator
- Dialysis
- Feeding Tube

- Blood and water transfusions (IV)
- Surgery
- Medicines

End of life decisions your medical decision maker can make:

- call in a religious or spiritual leader
- decide if you die at home or in the hospital
- decide about autopsy or organ donation
- decide about burial or cremation

Question: Does my medical decision maker have a say in BOTH my health care and my finances?

Answer: A medical decision maker, sometimes also called a Durable Power of Attorney for Healthcare ONLY has a say about your medical care. They do not have a say about your finances. There is a separate durable power of attorney for finances form that can be filled out. Ask your social worker or lawyer about these separate forms.

Question: What about Conservatorship?

Answer: People who are conserved are those individuals whose doctors and lawyers have determined they can no longer make their own medical decisions. In this case, a court appoints another party to be a conservator. This conservator can then make medical decisions for this person. They cannot fill out an advance directive for this person, but they can talk with the medical team and be involved in physicians' orders for medical care.

Question: What makes a good decision maker?

Answer: This information can be found in Step 1 of the PREPARE website and on Page 3 of the easy-to-read advance directive.

The website says that:

A good medical decision maker is a family member or friend who:

- is 18 years of age or older
- can talk to you about your wishes
- can be there for you when you need them
- you trust to follow your wishes and do what is best for you
- you trust to know your medical information
- is not afraid to ask doctors questions and speak up about your wishes

ADVANCE DIRECTIVES:

Question: What should I do with this advance directive once I fill it out?

Answer: We recommend giving a copy to your family, friends, and your medical providers. It is important to make sure your medical providers put this into your medical record. However, different hospitals do not share medical records between them. That is why it is so important for you to share your forms with as many people as possible. Some people keep this information on their phone (you can take a picture of your advance directive pages).

Question: Does this advance directive form really count?

Answer: Yes. Doctors take this very seriously. The important part is to talk to your family, friends, and medical providers about your wishes. It is also important to bring in the advance directive to your medical providers so they can put a copy into your medical record.

Question: My state has laws about Durable Power of Attorney Forms and Living Will Forms. Does this form cover both? Can I fill out just Part 1 for a Medical Decision Maker or Part 2 for my Medical Wishes?

Answer: This form meets the legal requirements for both Durable Power of Attorney and Living Will documents for your state. Yes, you can fill out only Part 1 or Part 2. This is your choice.

Question: Can I write down what I would want if I were to get dementia (or any other specific wishes such as wanting or not wanting blood transfusions or dialysis)?

Answer: This form is to act as a general guide because it is impossible to know about all the medical situations and treatments you may need in the future. Some people have had experiences themselves, with friends, or with family, or have religious beliefs that help them know they would or would not want certain treatment. If you feel strongly about a particular treatment, you can write this information on page 10 of the easy-to- read advance directive. (If you are using the PREPARE Question Guide, you can write this on page 7). The advance directive gives you space to write all the things that may be important to you about your medical care.

*Note: If you want to add other wishes or attach other forms, you can place them right after page 10 of the easy-to-read advance directive. These other forms can be a part of our legal easy-to-read advance directives because all of your wishes are important.

Question: How do I make this form legal?

Answer: You will have to sign and date the form. Then, every US state has its own laws for final steps to make the forms legal. Some states require witnesses, a notary public, both or neither. Page 11 of the easy-to-read advance directive lists out that state's specific rules about how to make the form legal.

Question: Who can be a witness for my advance directive? What are they responsible for?

Answer: Every US state has its own laws about witnesses. Witnesses are people who may need to sign the form saying that it really was you who filled out and signed the advance directive. Page 11 and 12 of the easy-to-read advance directive will tell you about the rules in your state for witnesses.

Question: Does my advance directive work in other states?

Answer: Every US state has its own advance directive law. Some states accept other states' advance directives, but a few of them do not. In these cases, it is up to the doctor to accept an out-of-state form. If you live or visit several states, there is a BIG benefit of filling out the form on the PREPARE website. If you sign up and create an account, PREPARE can save your answers on a very safe and secure site (server).

Question: What is a notary public and do I need one to sign my advance directive?

Answer: A notary has special training to make forms legal. They can sign and put their stamp on the form to say that it really was you who signed filled out and signed the advance directive. Notaries often charge a small fee for a signature and may take fingerprints. See page 11 of the PREPARE advance directive to see if your state requires a notary public to sign your form.

Question: Is the advance directive the same thing as that bright pink form called a POLST (aka POST, MOST, MOLST)?

Answer: A POLST is called a Physician's Orders for Life Sustaining Treatment. It can be called other things in other states such as POST, MOST, MOLST. While many forms are on bright pink pieces of paper, the colors may be different in your state.

There are very BIG differences between an advance directive and POLST forms.

- An advance directive is a form that you fill out about your medical decision makers and what is most important to you and your medical care. An advance directive can be completed by a person at any age or stage in health.
- The POLST form is a medical ORDER that only a doctor or nurse fills out. That
 form is only about life sustaining treatment, such as CPR or going to the hospital
 and has checkboxes. That form does not allow you to name a decision maker.
 The POLST form is meant for very sick people near the end of their life.

Question: I have heard that some states have right to die laws. Can I write this on my advance directive? Will this directive give me or my medical decision maker that power?

Answer: Every US state has its own laws about this and this request is different from an advance directive. Please talk to your doctor in your state about this. If you feel strongly about this issue, you can write your wishes on Page 10 of the easy-to-read advance directive. It is always helpful for your loved ones and medical providers to know the health situations that would be considered not good quality of life to you. But, right to die laws require specific forms and procedures that are very specific for that request. You would have to ask your doctor about further information in your state.