Advance Care Planning

Planning for the course ahead

These materials do not constitute legal advice or legally effective documents. Please consult your personal attorney.
Control Your Healthcare Decisions

You have the ability to make decisions regarding your medical care, even when you are too sick or injured to make your wishes known. This is called "advance care planning" and can include documents (such as advance health care directives) that help make your treatment preferences known to your health care team and loved ones.

If you plan now, you can make sure your wishes are known. This can help you receive the kind of care you want and relieve your loved ones from making difficult and stressful choices.

This booklet will help you understand the different aspects of advance care planning. If you decide you want to complete specific advance care planning documents, we can provide you with additional information.

However, your most important task is thinking about these major decisions and talking about them with those close to you. That is the heart of advance care planning.
What is Advance Care Planning? How Might Specific Advance Care Planning Documents Help You?

Advance care planning helps you to establish and communicate the kinds of care that fit with your preferences at times when you cannot participate in decision making because of serious illness or injury. Advance care planning documents are written instructions that reflect your wishes for health care. These documents can guide major medical decision-making if you become so ill you are unable to speak for yourself.

In an advance care planning document, you can:

- Name someone to make medical decisions for you when you cannot make or communicate your treatment preferences.
- Make known what medical treatments you do and do not want to have.

Reasons for Advance Health Care Planning Documents

Advance care planning documents contain useful information about what you value and what is important to you. They can be a gift to your family and friends. In the event that you become unable to make or communicate your treatment preferences, your health care providers will look for documents that you have already completed or for other documentation that you have offered about your health care wishes. If no documents

Advance Health Care Planning Documents can be a gift to your family and friends.
are available, they will turn to those close to you for guidance, who may or may not know what kind of treatments you would want. The next sections provide information to help you make an advance care plan.

**Making and Documenting Advance Care Planning Decisions**

There are five key steps to successful advance care planning:

1. **Think** – Think about what matters to you.
2. **Talk** – Talk about your wishes with your family, friends, and health care provider(s). Your health care providers will document these conversations in your medical record.
3. **Put it in Writing** – Document your choices and decisions so they will be ready when needed.
4. **Share** – Share your documents with your family, friends, and health care provider(s).
5. **Review** – Review your advance care plan periodically with your health care providers and loved ones, including any documents you created, at least once a year.

You can read more about these steps on the following pages.
Think

The following questions may help you to think about what matters most to you. Give yourself plenty of time to think through what you would prefer to have happen or not happen if you became seriously ill or injured. You may find it helpful to write down your thoughts.

- **Who would you want to speak on your behalf about health care decisions if you could not communicate for yourself?**

- **What is your understanding of your health and well-being?**

- **What are your health care goals or priorities?**

- **What things give you strength or make you feel good about your life?**

- **Have you had good experiences with receiving health care? Did you experience anything that you didn’t understand or that made you feel bad?**

- **What fears or concerns do you have about your future health?**

- **How much do your family and friends already know about your priorities and wishes?**

- **How prepared do your family and friends feel about their ability to discuss your priorities and wishes with members of your health care team?**
Talk

Now that you have thought about what matters most to you, you may be ready to share your thoughts with:

- Your family
- Your health care provider(s)
- Those closest to you
- Anyone who is likely to be involved in your future health care decisions

This can be a hard conversation to start. It is important to remember this is something you will discuss more than one time. The more you talk about your choices for care, the more comfortable you and your family will become.

Here are some ideas for starting your conversation:

- With family or those closest to you
  
  "Did you hear what happened with ______________? That got me thinking, and I want to make sure you know what my preferences for care are, in case you ever have to speak for me."

  "There's something I've been thinking about for a while that I want to share. I really need you to listen carefully."

- With health care provider(s)
  
  "I've been thinking about my own future health care decisions if I were to get sicker or could not communicate what I wanted. Can I make an appointment to discuss my wishes with you?"

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Making Your Treatment Choices

Many medical treatments may be offered to help save or prolong your life if you are seriously ill or injured. Many people want these treatments if the treatments are likely to prolong life or restore health. However, some people set limits on these treatments to best suit them. For example, a person may want to decline a treatment that may not change how long they can live or be very effective. As another example, some people do not want their life prolonged by a device or machine if they are unable to communicate with or see family, or are in constant severe pain. Some people may also choose to have these treatments for a limited time. This allows a trial period to see whether the treatments will help them.

All these treatment choices are best made by you, in light of your own values and goals. Whether or not you choose to decline certain treatments, your health care providers will try to lessen your pain or other uncomfortable symptoms. You don’t have to make these choices alone – talk with your primary health care provider about your options, or ask if you can meet with a palliative care specialist. Also talk with your family members about the kind of treatments you do and do not want.

The following chart includes some general information about the types of life-prolonging treatments that you may consider, as well as alternatives if you decide to forego these treatments.

<table>
<thead>
<tr>
<th>Why it’s done</th>
<th>How it’s done</th>
<th>What is the alternative?</th>
</tr>
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<tbody>
<tr>
<td><strong>Cardiopulmonary resuscitation, or CPR</strong></td>
<td>Tries to restart a normal heartbeat if your heart stops beating, or beats very irregularly, and your breathing stops</td>
<td>Natural dying with no use of resuscitation or intubation</td>
</tr>
<tr>
<td>- Health care providers press very hard on your chest many times and try to blow air into your lungs</td>
<td>- They may place a tube in your throat to get air to your lungs, also called intubation</td>
<td>- Doctors and nurses use ordinary treatments such as oxygen, antibiotics, IV fluids, unless you have directed otherwise</td>
</tr>
<tr>
<td>- Sometimes they give electric shocks to your heart</td>
<td>- Pain medicine or other treatments to provide comfort near death</td>
<td></td>
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**Breathing machine, or mechanical ventilation**

- A tube is placed through your mouth, nose, or an incision at the base of your neck. This is called intubation.
- The tube goes down your windpipe and into your lungs.
- The tube connects to a machine called a ventilator or respirator.
- Oxygen is provided by a face mask or two small nose prongs.
- Some face masks also use pressure to support breathing, these are called BIPAP or CPAP.

**Tube feeding**

- A feeding tube is placed through your nose, mouth, or abdominal wall, and into your stomach.
- Food is offered as desired.
- Food may be ground or pureed into a texture safer to swallow.
- Assistance with feeding by a caregiver may be necessary.

**Intravenous (IV) Fluids**

- A needle is placed into your vein.
- Liquids are offered as desired.
- Liquids may need to be thickened for safer swallowing.
- Mouth swabs can be used to keep mouth moist.

**Kidney dialysis**

- A tube is placed into a vein.
- The tube connects to a machine that removes waste and extra fluid from your blood and then returns the blood to your body.
- Health care provider will offer medications to help control uncomfortable symptoms caused by waste or extra fluid.

**Making and Documenting Advance Care Planning Decisions**

You may choose to forego all life-prolonging interventions and choose treatment exclusively focused on comfort. Such comfort measures may include medications for pain, wound care, oxygen, and nutrition. When comfort becomes your primary focus, you may also want to ask if hospice services are available to support you.
Put It In Writing

North Carolina has specific laws about certain advance care planning documents. Use of the forms is optional. If you decide that one of the documents would be helpful to you, you may complete the forms yourself. But you may wish to consult with a lawyer for a variety of reasons, including to get advice on how to make one or more documents legally effective.

Your health care providers can use your advance care planning documents to guide their actions. For example, creating a document that identifies your preferred health care power of attorney can help you be more sure of who will be making medical decisions for you if you are unable. Creating a document such as a living will gives you the opportunity to specify the types of medical treatment you would like to receive.

North Carolina offers two forms that you may wish to use in your advance care planning. We are happy to provide you with copies of those forms upon request or you may access them online.

- Declaration for a Natural Death (Living Will Form)
- Health Care Power of Attorney

There is another version of an advance care planning document that may be of interest to you as it combines the two kinds of forms above. We are happy to provide you with a copy upon request or you may access it online.

- The North Carolina Advance Directive Practical Form includes a living will (a statement of treatment preferences) and health care power of attorney (a statement about who will speak on your behalf if you cannot speak for yourself).

If you develop an advanced, serious illness you may consider completing additional forms. These forms
go into greater detail about what you do and do not want and require a medical provider’s signature. Talk with your doctor’s office about completing these forms.

- The Medical Order for Scope of Treatment (MOST) is a bright pink form you complete with your physician, nurse practitioner or physician assistant. The MOST form is intended for people who have an advanced, serious illness. It provides explicit medical orders guiding whether you want CPR, use of a breathing machine or ventilator, levels of care for other medical interventions, antibiotics, and artificial hydration or nutrition. It must be signed by you or your health care decision-maker and your medical provider. The MOST form should be reviewed yearly with you and your provider.

- The Portable Do Not Resuscitate (DNR) document is a provider order that instructs individuals not to perform CPR (cardiopulmonary resuscitation) if you stop breathing or your heart stops. It is helpful to decide about CPR before you are sick enough to need it. You must talk with your doctor about your health and your wishes before getting a Portable DNR order.

Additional information to think and talk about:

- Organ Donation is a process of giving an organ or part of an organ to another person after you pass away. There is no cost to you or your family if you choose to donate. If you wish to donate your organs, you can document your wishes in a variety of ways.

For more information visit the Donate Life North Carolina website at www.donatelifenc.org or call (919) 794-7693.

Note: This booklet does not talk about mental health advance care planning documents. Talk with your health care provider or attorney if you want to prepare that kind of document.
Share and Review Your Advance Care Planning Documents

Keep your advance care planning documents in a safe place where they can be easily found. Do not put them in a safety deposit box or in a home safe that only you can open. Give copies of your signed forms to those close to you.

A MOST form or portable DNR form should travel with you. If at home, place it in an easily accessible place such as your refrigerator or above your bed.

Also, give copies to your health care decision maker(s), your primary health care provider, and other providers you see regularly. Ask your health care provider to add the documents to your medical record.

Look over your advance care planning documents every few years. Review them at the time of major life events, such as marriage, the birth of a child, or the death of someone close to you. Decide whether you want to change any of your earlier choices.

Consult with a lawyer if you need help making sure that your documents are legally effective, registered as necessary, and that you have properly made them available to those who may need to rely on them.

You may change your advance care planning decisions at any time. To make any changes, discuss your wishes with your providers and ensure you follow the requirements of North Carolina law. Consult with a lawyer as needed.
Questions and Notes
For More Information

Please contact your Provider with questions and for more information about advance care planning. UNC REX Healthcare is proud to support you and your health.