Instructions for Completing the Advance Health Care Directive Form

The Advance Health Care Directive Form helps others give you the care you want when you cannot make decisions or communicate for yourself. The first part of the form lets you name someone to be your health care agent. The second part of the form tells others how to make end-of-life care decisions for you.

You can benefit from completing an Advance Directive at any age. You could have an accident or get sick. You might live with a mental or physical illness that leaves you unable to make decisions at times. Without an Advance Directive, those making decisions for you may not know what you want. Worse still, your family and friends could argue over the care you should get. Or they could disagree about who gets to make decisions for you. Help your family and friends to help you: name an agent and tell your agent and family about your health care wishes.

Introduction

Utah’s Advance Directive has four parts:

Part I: Allows you to name another person to make health care decisions for you when you cannot make decisions or speak for yourself.

Part II: Allows you to record your wishes about health care in writing.

Part III: Tells you how to revoke or change this directive.

Part IV: Makes your directive legal.

Fill out as few or as many parts as you like. This is your document; change it as you like so that it states your wishes. If you want to make changes after you have signed the form, fill out a new form and destroy the old one.

Important things to know about Advance Directives:

• You have the right to accept or refuse health care. This is true even after you have signed an Advance Directive. It is true even if the Advance Directive gives different directions.

• You do not have to complete an advance directive. It is illegal for anyone to require you to fill out a directive.

• You have the right to appoint a health care agent to make decisions for you.

• You have the right to put your end-of-life care and other health care wishes in writing.

• You may fill out all of this Advance Directive, or just parts of it.

You may use any Advance Directive form (not only the one in this booklet) if it is properly signed and witnessed. Beware of forms that are very different from those in this booklet. Other forms may be legal, but forms that are long, complicated, or different from the one in this booklet might be hard for your health care providers to follow.
Part I: Choosing Your Health Care Agent

Please read all instructions for before you fill out your Advance Directive. Read about how your agent should make decisions and about the power you are giving to your agent. Choose an agent you trust. Choose someone who will respect your choices. Naming an agent is the single most important thing you do in your Advance Directive.

How to choose a Health Care Agent

The best way to get your health care wishes followed is to appoint a health care agent. Your agent should:

- Know you and know your end-of-life and health care wishes.
- Be willing to speak for you when you cannot speak for yourself.
- Do what you want, not what the agent thinks is good for you.
- Be able to act for you when needed:
  - Someone who lives far away may not be the best choice.

The following people cannot be your agent:

- A person under age 18.
- Your healthcare provider, including the owner or operator of a care facility serving you (unless the person is your spouse or a close relative).
- An employee of your health care provider (unless the person is your spouse or a close relative).

You can appoint an alternate agent to make decisions for you if your agent is unavailable, or is unable or unwilling to serve as your agent.

No one can force you to appoint an agent, including a health care provider, an insurer, or even a family member.

Always get permission from the person you want to name as agent before you fill out this part of your Advance Directive.

Your Agent’s Job

If you can make your own health care decisions, your agent should not make decisions for you, unless you want your agent’s help. When you cannot make or communicate choices, your agent should:

- Always try to include you in decisions, to the greatest extent possible.
- Follow the instructions you have given in the past, unless there is a good reason not to.
- Make the decision your agent thinks you would have made under the circumstances.

Your Agent’s Power

If you do not limit or expand your agent’s power, the Advance Directive form gives your agent the power to:

- Consent to, refuse, or withdraw any health care. This may include care to prolong life, such as food and fluids by tube, antibiotics, CPR (cardiopulmonary resuscitation), dialysis, and mental health care, such as convulsive therapy and psychoactive medications. You can limit or expand your agent’s authority in boxes E or F of Part I.
- Hire and fire health care providers.
- Ask questions and get answers from health care providers.
- Consent to admission or transfer to a health care provider or facility, including a mental health facility, subject to the limits in Boxes E or F of Part I.
- Get copies of medical records.
- Ask for consultations or second opinions.

When does your agent have power to manage your health care?
Your agent’s powers begin when you cannot make or communicate health care decisions for yourself.

- A physician, nurse practitioner, or physician assistant who has personally examined you must find that you lack the capacity to make a health care decision. To have capacity, you must be able to:
  - Understand your medical condition.
  - Understand and weigh the risks and benefits of treatment choices.
  - Communicate your choice to your health care provider.

- You may continue to make your own health care decisions if you disagree with the physician’s finding that you lack capacity.

- Only a court can take away your right to make your own health care decisions. A health care provider can continue to treat you to keep your health stable during the time it takes for a court to decide whether you have the ability to make your own health care decisions.

- Your right to make your own decisions may be limited in an emergency.

Your agent’s powers end if:

- You have the ability to make your own decisions.
- You revoke the Advance Directive.
- You disqualify your agent.
- You name a new agent.

Your agent and health care providers should try to include you in your health care decisions for as long as you want to be included. This is true even if your decision making capacity is impaired, unless there is a very good reason not to include you.

Now that you have thought about who to name as your health care agent and how much power that person should have, fill out Part I of your Advance Directive.

Making decisions easier for your agent

There are ways to make end-of-life decisions easier for an agent or family member who has to make decisions for you when you cannot make decisions for yourself. These steps also increase the chances that your wishes will be followed.

- Name the person who you want to make decisions for you when you can’t make your own health care decisions in Part I of your Advance Directive.

- Explore the discussion in Part II of this booklet about advance health care decision making, then talk and talk, then talk some more about your wishes with your agent and with your family. Even if you name an agent who is not a member of your family, there is some chance that your family will have to make a medical decision. It is most likely that your wishes will be followed if family members hear your wishes from you before a crisis.

If you do not choose an agent...

You do not have to appoint an agent, but that means that the law will choose who makes your health care decisions if you cannot make decisions for yourself. The law lists family members who can, if they are willing, become your health care surrogate if you lose health care decision making capacity. If no family member is able or willing to serve, an individual who is close to you can serve as your surrogate. If you want someone other than family to make decisions for you, you should appoint an agent.

If you want to limit a surrogate’s authority, you should complete a directive and state that you wish to limit the authority of either your appointed agent or any default decision maker. If this is your preference, you may also wish to consult an attorney about how to assure that this preference is honored.

Part I: Appointing Your Agent

Now that you have thought about who your agent should be, or whether you wish to appoint an agent, it is time to fill in the Advance Directive form.
A: No Agent
Place your initials in this box if you do not wish to name an agent in this form.

B: My Agent
If you wish to appoint an agent, enter the information requested in this box.

C: My Alternate Agent
If you want to appoint an agent, it is a good idea to also appoint an alternate who can serve if your appointed agent is unable or unwilling to serve. Complete this box to appoint an alternate agent.

D: Agent’s Authority
Unless you limit your agent’s authority, your agent has the authority to make any health care decision that you could make, as explained in this box. You can draw a line through any power in this box that you do not want your agent to have. You can also say more about the power you want your agent to have in Part I, F.

E: Other Authority
You can give even more power to your agent in the following two sections:

Access to Medical Records
- If you want your agent to be able to get your medical records as soon as you sign the Advance Directive, initial over “YES”
- If you do not want your agent to get your medical records unless you have been found to lack decision making capacity, initial over “NO”

If you do not make a choice, “NO” is assumed to be your choice.

Admitting you to a care facility
- If you want your agent to be able to move you into a licensed health care facility, such as a nursing home or assisted living facility for long-term placement, initial “YES” in the second line of this box. Long-term placement means that you will live in the facility; the facility becomes your home. This is not the same as rehabilitation, respite, or convalescent care that you might need to get better after an injury or illness.
- If you choose “NO,” a health care facility could become your home without your consent only if a court orders it.

If you do not make a choice, “NO” is assumed to be your choice.

F: Limits/Expansion of Authority
You can write specific instructions about your agent’s power in this box. You can decrease or increase your agent’s power by writing instructions in this box.

G: Nomination of Guardian
If you appoint an agent in your advance directive, it is less likely that you would ever need a court-appointed guardian. Circumstances could, however, trigger the need for you to have a court-appointed guardian.

A guardian may be given the power to manage your money and other assets, depending on the size of your estate. Remember that this will happen only if a court finds that you cannot manage your own money and assets. If you want your agent to manage your health care and a different person to manage your money, you should get advice about completing a power of attorney for finances or a nomination of conservator form.

- If you initial “YES” in this box and you need a court-appointed guardian, your agent will be first in line to become your guardian.
- If you initial “NO” in this box and you have not appointed a guardian in a different form, but you do need a court-appointed guardian, a judge will appoint a guardian – usually your closest family member.

H: Consent to Participate in Medical Research
Sometimes, taking part in medical research or clinical trials can get care for you that
will help you. Other times, there may be no chance that you will be helped, but your participation might help others in the future. Some people want their agent to have the legal ability to give consent to participate in medical research, even if that research will not benefit them.

- Initial over “YES” if you want your agent to have the power to give permission for you to participate in medical research or a clinical trial, whether or not you may be helped.
- Initial over “NO” if you do not want your agent to have the power to enroll you in medical research or a clinical trial.

I: Organ Donation

There are ways that you can show that you want to donate organs at the time of your death. This box is a back-up system. With this box, you can give your agent the power to consent to organ donation on your behalf.

- If you do not want your agent to have the power to consent to organ donation, initial over “NO.”
- If you want your agent to be able to decide if your organs should be donated, initial over “YES.”

Part II: Your Health Care Wishes (“Living Will”)

Before filling out this part of your Advance Directive, consider some facts about end-of-life decision making. If you have the ability to make your own healthcare decisions, your providers should follow your instructions when a decision needs to be made. This is true even if your decisions are different from your written Advance Directive.

End-of-life decision making can be complicated and hard.

Have you heard or said, “Pull the plug if I am a vegetable,” or “Don’t keep me alive on machines”? These directions are common, but they may not help when you face a life-threatening illness or injury. Usually, decisions have to be made due to accident or illness where the outcome is uncertain.

“Don’t keep me alive on machines” may be what you want if you were to need a ventilator to keep you alive for the rest of your life. But if being on a ventilator for a few days would let you go home from the hospital, breathing on your own, and as healthy as you were before you were hospitalized, you might want to be kept alive on machines for a few days. Some people live satisfying lives even when they depend on “machines.”

Advance health care planning is harder and more complicated than you may think.

Remember that written directions are usually worse decision makers than an agent.

Research shows that it is very hard to make decisions about health care in advance because:
- It is hard to predict what decisions will have to be made; and
- It is hard to know what the circumstances will be when a crisis occurs, and how the circumstances may change your preferences.

Hopefully, when a crisis happens, your agent will know how you were feeling before you lost the ability to decide. An agent who knows your wishes can consider what health care decisions will honor your wishes. An agent who knows your wishes is more likely to make the right decision than a piece of paper you filled out some time in the past.
Even if you know what decisions will need to be made, you might change your mind. Research shows that what people think they would want is often not what they want when it is time for a decision about end-of-life care. People sometimes think that they could not live if faced with disability or illness. But many people find they want to continue to live, even when they have a disability or illness they thought they could not live with.

On the other hand, some people think they would want all care available to keep them alive. But when faced with care that has many burdens for little possible gain, they may choose to decline care.

By appointing an agent to make decisions, and by giving your agent flexibility, you allow your agent to consider and weigh circumstances and facts as they are when a decision must be made.

**Comfort measures**

Even if life-sustaining treatments are stopped, you should receive comfort measures. If you have a life-threatening illness, talk to your provider about getting care that may improve your ability to live your life in the way you want to live it for the time you have left.

**Before you fill out Part II**

Record your end-of-life wishes in Part II of your Advance Directive only after you:

- Consider the uncertainty of making specific end-of-life decisions when the circumstances surrounding the decisions are unknown
- Ask your doctor whether you are suffering from a life-threatening or life-limiting illness
- Ask your doctor about end-of-life decisions that may have to be made
- Consider working through the Tool Kit for Advance Health Care Planning to fine-tune your preferences. You can get this document at www.carefordying.org
- Discuss your wishes with your health care provider, your agent, and close family members
- Decide which of the form’s options best suits your wishes

If the form does not allow you to express your wishes, you can write your wishes separately. Be aware, however, that this choice increases the chances that your wishes may be harder for a health care provider to understand or follow. Write out your wishes and review them with primary health care provider to make sure they say what you want before you write them into the form.

Now that you have thought about your end-of-life care wishes, fill out Part II of your Advance Directive (Page 3 of the form).

**Part II: Your Health Care Wishes**

In this part of your Advance Directive, you can say how you want end-of-life care decisions made.

**Option 1: I choose to let my agent decide.**

I have chosen my agent carefully. I have talked with my agent about my health care wishes. I trust my agent to make the health care decisions for me that I would make under the circumstances.

This option does not give instructions about your end-of-life care wishes. Instead, it gives your agent the right to stop life-sustaining care when your agent thinks you would want care to be stopped. Life-sustaining care includes food and fluids by tube, antibiotics, CPR, and dialysis.

**Option 2: I choose to prolong life.**

Regardless of my condition or prognosis, I want my healthcare team to try to prolong my life as long as possible within
the limits of generally accepted health care standards.

By choosing Option 2, you are telling healthcare providers that your goal of care is to stay alive.

Option 3: I choose not to receive care for the purpose of prolonging life, including food and fluids by tube, antibiotics, CPR, or dialysis being used to prolong my life. I always want comfort care and routine medical care that will keep me as comfortable and functional as possible, even if that care may prolong my life.

By choosing this option, you make a choice not to receive life-sustaining care. Life-sustaining care includes food and fluids by tube, antibiotics, CPR, and dialysis. This choice does not mean that you do not want health care. You should always receive comfort care and routine medical care intended to keep you as comfortable and functional as possible.

If you choose Option 3, you must also choose either (a) or (b).

Option 3(a)

If you do not want any life-sustaining care provided to keep you alive, choose “(a) I put no limit on the ability of my health care provider or agent to withhold or withdraw life-sustaining care.” This means that, if your heart stops or you stop breathing or you face any other life-threatening condition, your health care provider should allow you to die. Most people who make this choice have a condition that may result in death, they have carefully weighed the benefits and burdens of life-sustaining care, and, after carefully weighing their options, they have decided that they want to be allowed to die without medical intervention. If this is your choice, do not choose any conditions under (b) and continue to Part III.

Option 3(b)

If you want life-sustaining care stopped only after certain conditions are met, choose “(b) My health care provider should withhold or withdraw life-sustaining care if at least one of the initialed conditions is met.” If you choose (b), you must also select at least one of the five following conditions to be used to determine when to stop life-sustaining care:

- I have a progressive illness that will cause death
- I am close to death and am unlikely to recover
- I cannot communicate and it is unlikely that my condition will improve
- I do not recognize my friends or family and it is unlikely that my condition will improve
- I am in a persistent vegetative state

Other:

Leave blank the line next to any condition that should not be considered when determining whether life-sustaining care should be stopped. You may also draw a line through any condition that should not be considered when determining when to stop life-sustaining care.

If you initial next to more than one condition, your health care provider should stop life-sustaining care after any one of the initialed conditions is met.

Option 3 Examples:

“I had a stroke 20 years ago, and I know I may have another one soon. I have had a full life, and I am ready to die if a stroke takes me. I do not want to be brought back if I have a stroke or any other life-threatening illness.”

To document this preference, in Part II, choose Option 3(a) then go to Part III.

“I have MS. It is aggressive, and I am likely to die from it, but I don’t want life-sustaining care stopped unless I am about to die or unless I am in a persistent vegetative state.”
To document this preference, in Part II, choose Option 3(b) and initial next to “I am close to death and I am unlikely to recover” and “I am in a persistent vegetative state.” Draw a line through the other three conditions.

“I am 35 and healthy, but if I ever had an accident or illness that left me unable to recognize or communicate with my family, or if I am diagnosed as being in a persistent vegetative state, I want nature to take its course and I want to be allowed to die.”

To document this preference, in Part II, choose Option 3(b) and initial next to “I cannot communicate and it is unlikely that my condition will improve, I do not recognize my friends or family and it is unlikely that my condition will improve”, and “I am in a persistent vegetative state.” Draw a line through the other conditions.

Option 4: I do not wish to express preferences about health care wishes in this directive.
You may choose to not document any preferences about health care by initialing Option 4.

Part III: Revoking or Changing Your Directive
You may revoke all or part of your Advance Directive by doing any of the following:

1. Writing “void” across the Advance Directive form, or burning, tearing, or otherwise destroying the document (or directing another person to do this for you)
2. Signing a written revocation (or cancellation) of the Advance Directive, or directing another person to sign a revocation for you
3. Stating that you wish to revoke your Advance Directive in the presence of a witness. The witness
   - must be 18 years or older
   - must not be your appointed agent in a substitute directive
4. Completing a new Advance Directive. (If you sign a new directive, the most recent one applies.)

Tell any health care provider or health care facility that has a copy of your advance directive if you have revoked your Advance Directive. Provide a copy of your new directive, once it is complete.

You may revoke your directive even if a physician has found that you lack health care decision making capacity.

Part IV: Completing Your Directive
Sign and date Part IV of your Advance Directive in the presence of a witness who is NOT:

1. Related to you by blood or marriage;
2. Entitled to any portion of your estate according to the laws of intestate succession of this state or under your will or codicil;
3. The beneficiary of a life insurance policy, trust, qualified plan, property or accounts held in POD, TOD, or co-ownership registration with the right of survivorship;

4. Financially responsible for your support or medical care;

5. A health care provider who is providing care to the you or an administrator at a health care facility in which you are receiving care; or

6. Your appointed agent or alternate agent.

**After You Sign Your Directive**

- Keep the original copy of your Advance Directive and work sheets or other notes where your agent can get the original document, if needed.

- Give your agent a copy of the Advance Directive plus any worksheets or notes. Also, give copies to other family members or friends who may have to make a medical decision for you if your agent is not available. Your wishes are most likely to be followed if your agent and family members agree on the plan of care.

- Give your primary health care provider a copy of your Advance Directive. Ask for it to be put in your medical record. Make sure your health care providers will support your wishes. If they will not, consider finding another provider.

- If you are admitted to a hospital or nursing home, provide a copy of your Advance Directive and ask that it be placed in your medical record.

**Updating your Advance Directive**

It is very important that your Advance Directive is always current. Review it once a year or when events in your life change. Think about the “5 D’s” to decide when you should change or update your Advance Directive.

The 5 D’s are:

- Decade birthday
- Diagnosis of life-threatening condition
- Deterioration of health status
- Divorce
- Death of someone close to you or that may affect your directive

You should also update address and contact information for your agent and alternate agent if this changes.