UTAH COMMISSION ON AGING

TOOL KIT FOR ADVANCE HEALTHCARE PLANNING

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INTRODUCTION

If you are looking at this Tool Kit, you may be thinking of creating an advance health care directive or living will. You should be aware that having a written advance directive by itself does not ensure that your wishes will be understood and respected. Studies have shown that standard advance directive forms do little to influence end-of-life decisions without:
1) informed, thoughtful reflection about your wishes and values, and
2) personal communication between you and your likely decision-makers before a crisis occurs.

WHY A TOOL KIT?

Good advance planning for health care decisions is a continuing conversation – about values, priorities, the meaning of one's life, and quality of life. To help you in this process, this Tool Kit contains a variety of self-help worksheets, suggestions, and resources. There are 10 Tools in all, each clearly labeled and user-friendly.

TOOL KIT CONTENTS:

Tool #1

SELECTING YOUR HEALTH CARE AGENT

WHY APPOINT A HEALTH CARE AGENT?

Choosing an agent is among the single most important thing that you can do as part of planning for possible future incapacity and end-of-life care. By choosing an agent, you identify the person who ***you*** want to make decisions for you. If you do not choose an agent and you lose the ability to make your own health care decisions, the law decides who gets to make decisions for you. Failure to appoint an agent could lead to the need for a guardian, who is appointed by a court in a potentially costly legal process.

WHO CAN'T BE AN AGENT?

You cannot name your health care provider (doctor, nurse, social worker), or an owner, operator, or employee of a health care facility where you are receiving care, unless the agent is related to you by blood, marriage, or adoption.

WHAT TO DO AFTER YOU CHOOSE A HEALTH CARE AGENT

- Talk to your agent about the qualifications outlined on the next page of this tool.
- Ask permission to name him or her as your agent.
- Work through the rest of the Tool Kit together. Do the Health Care Agent IQ Test in Tool #7.
- Make sure your agent gets a copy of your Advance Health Care Directive, and make sure your agent knows how to get the original copy of your Directive.
- Tell family members, your physician, and close friends who you have chosen as your agent.

Tool #1

When you decide to pick someone to speak for you in a medical crisis, in case you are not able to speak for yourself, there are several things to think about. This tool will help you decide who the best person is. Usually it is best to name one person or agent to serve at a time, with at least one alternate, or back-up person, in case the first person is not available when needed.

Compare up to 3 people with this tool. The person best suited to be your Health Care Agent or Surrogate will meet most or all of these qualifications...

	Name #1:	Name #2:	Name #3:	
				1. Meets the legal criteria in your state for acting as agent? (This is a must! See next page.)
				2. Would be willing to speak on your behalf.
				3. Would be able to act on your wishes and separate his/her own feelings from yours.
				4. Lives close by or could travel to be at your side if needed.
				5. Knows you well and understands what's important to you.
				6. Could handle the responsibility.
				7. Will talk with you now about sensitive issues and will listen to your wishes.
				8. Will likely be available long into the future.
				9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
				10. Can be a strong advocate in the face of an unresponsive doctor or institution.

This worksheet adapted by the American Bar Association's Commission on Law and Aging from R. Pearlman, et. al., ***Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will ,*** Veterans Administration Medical Center, Seattle, Washington**.**

Tool #2

Are Some Conditions Worse than Death?

Name & Date_____

This worksheet helps you to think about situations in which you would ***not*** want medical treatments intended to keep you alive. These days, many treatments can keep people alive even if there is *no* chance that the treatment will reverse or improve their condition. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: On the following pages, circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the *Comment* lines.

1. **Definitely want** treatments that might keep you alive.
2. **Probably would want** treatments that might keep you alive.
3. **Unsure of what you want.**
4. **Probably would NOT want** treatments that might keep you alive.
5. **Definitely do NOT want** treatments that might keep you alive.

Tool #2

What If You . . .

Definitely Want Treatment ⟷ **Definitely Do Not Want Treatment**

a. No longer can walk but get around in a wheel chair.

1 2 3 4 5

*Comment*_____

b. No longer can get outside. – You spend all day at home.

1 2 3 4 5

*Comment*_____

c. No longer can contribute to your family's well being.

1 2 3 4 5

*Comment*_____

d. Rely on medications that may have side effects.

1 2 3 4 5

*Comment*_____

e. Experience nausea, diarrhea, and fatigue some of the time.

1 2 3 4 5

*Comment*_____

f. Are on a feeding tube to keep you alive.

1 2 3 4 5

*Comment*_____

g. Are on a kidney dialysis machine to keep you alive.

1 2 3 4 5

*Comment*_____

h. Are on a breathing machine to keep you alive.

1 2 3 4 5

*Comment*_____

What If You . . .

Definitely Want Treatment ⟷ **Definitely Do Not Want Treatment**

i. Need someone to take care of you 24 hours a day.

1 2 3 4 5

*Comment*_____

j. Can no longer control your bladder.

1 2 3 4 5

*Comment*_____

k. Can no longer control your bowels.

1 2 3 4 5

*Comment*_____

l. Live in a nursing home.

1 2 3 4 5

*Comment*_____

m. Can no longer think or talk clearly.

1 2 3 4 5

*Comment*_____

n. Can no longer recognize family or friends.

1 2 3 4 5

*Comment*_____

o. Other:

1 2 3 4 5

*Explain*_____

This worksheet adapted by the American Bar Association's Commission on Law and Aging from R. Pearlman, et. al., ***Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will,*** Veterans Administration Medical Center, Seattle, Washington**.**

How Do You Weigh Odds of Survival?

Name & Date_____

People evaluate the pros and cons of medical treatments in very personal ways. This explains why some people choose a treatment and others reject it. There is a question that helps to explain this difference: How much would you be willing to endure if your chance of regaining your current health was high? What if your chances of regaining health were low?

Answer the questions below to assess your willingness to take such risks.

Imagine that you are seriously ill. The doctors are recommending treatment for your illness, but the treatments may have side effects, such as pain, nausea, vomiting, or weakness. While pain and other side effects can usually be managed effectively, in very few cases, the side effects are difficult to manage. You may also experience social isolation and be prevented from seeing friends or family for extended periods of time. Question: Would you be willing to endu re such severe side effects if the chance that you would regain my current health was:

	(Circle one answer for each)		
High (over 80%)	**Yes**	**Not sure**	**No**
Moderate (50%)	**Yes**	**Not sure**	**No**
Low (20%)	**Yes**	**Not sure**	**No**
Very low (less than 2%)	**Yes**	**Not sure**	**No**

This worksheet adapted by the American Bar Association's Commission on Law and Aging from R. Pearlman, et. al., ***Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will,*** Veterans Administration Medical Center, Seattle, Washington**.**

Tool #4

Personal Priorities and Spiritual Values Important to Your Medical Decisions

Name & Date_____

People have personal priorities and spiritual beliefs that effect their medical decisions. This is especially true at the end of life with regard to the use of life-sustaining treatments. To make your values and beliefs more clear, consider answering the questions below. Use more paper if you need more space.

PERSONAL PRIORITIES/CONCERNS

1. What do you most value about your physical or mental well being? For example, do you most love to be outdoors? To be able to read or listen to music? To be aware of your surroundings and who is with you? Seeing, tasting, touching?

2. What are your fears regarding the end of life?

3. Would you want to be sedated if it were necessary to control your pain, even if it makes you drowsy or puts you to sleep much of the time?

4. Would you want to have a hospice or other palliative care team (i.e., comfort care) available to you?

This Worksheet adapted by the American Bar Association's Commission on Law and Aging from ***Caring Conversations***, a workbook published by the Midwest Bioethics Center, 1021-1025 Jefferson Street, Kansas City, MO 64105

5. If you could plan it today, what would the last day or week of your life be like? -- For example…
   - Where would you be? What would your environment be like?
   - Who would be present?
   - What would you be doing?
   - What would you eat if you could eat?
   - What would be your final words or last acts?

6. Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time?

7. How do you want to be remembered? (If you wrote your own epitaph or obituary, what would it say?)

8. What are your wishes for a mem orial service – for example, the songs or readings you want, or the people you hope will participate?

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SPIRITUAL/RELIGIOUS MATTERS OF IMPORTANCE TO YOU

9. How would you describe your spiritual or religious life?

10. What gives your life its purpose and meaning?

11. What is important for others to know about the spiritual or religious part of your life?

12. What do you need for comfort and support as you journey near death? For example, to pray with a member of the clergy? To have others pray for you? To be read to from spiritual or religious texts? To have music playing in your room? To be held?

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Other Decisions to Think About Now

Name & Date_____

After the death of a loved one, family and friends are often left with some tough decisions. You can help ease the pain and anxiety by making your wishes -- about burial, autopsy and organ donations -- clear in advance.

1. Do you want to donate viable ORGANS for transplant? *(Circle one)*

Yes	If **Yes**, *check one:*
Not sure	____ I will donate any organs.
No	____ Donate just the following: _____

2. Do you want to donate viable TISSUES for transplant? *(Circle one)*

Yes	If **Yes**, *check one:*
Not sure	____ I will donate any organs.
No	____ Donate just the following: _____

Attention! If you circled **Yes** for either of the above, be sure to register as an organ donor when you renew your driver's license and register with the Utah Organ Donor Registry at www.yesutah.org.

But be sure to tell your agent and family that you want to be a donor. Make sure they will support your wishes. Even with an organ donor card, hospitals will ask your agent or family to sign a consent form.

3. If you do ***not*** donate organs or tissue, you may choose to donate your WHOLE BODY for medical research or education. Would you like to do this?

   Yes **Not sure** **No**

   If you circle Yes, you must contact a medical institution to which you are interested in making this donation. Medical schools, research facilities and other agencies need to study bodies to gain greater understanding of disease mechanisms in humans. Note that total body donation is ***not*** an option if you also choose to be an organ or tissue donor.

   The University of Utah School of Medicine has a body donor program. Information is available at http://www.neuro.utah.edu/bodydonor/ or

   University of Utah, Department of Neurobiology and Anatomy
   401 MREB
   Salt Lake City, Utah 84132-3401
   Phone (8 a.m.-4 p.m.): (801) 581-6728
   Phone (After hours, weekends, and holidays): (801) 581-2121

4. Would you agree to an autopsy? (Autopsies, done after death, are used for diagnostic and research purposes. The body can still be viewed and buried.)

   Yes **Not sure** **No**

Burial Arrangements

5. I would prefer to be: *(circle one)*

Buried **Cremated** **No Preference**

6. I would like my remains to be placed:

7. What are your thoughts about your memorial service – such as songs or readings you want, or the people you hope will participate?

8. Other preferences:

Conversation Scripts: Getting Past the Resistance

Why Talk About Medical Preferences in Advance?

Communication is the single most important step in health care planning. Talk about your wishes with the people who may be called upon to speak or decide for you. Why?

1. No matter what your advance directive says, others will not fully understand your wishes. The more thoroughly you communicate, the easier it will be for everyone to honor and respect your wishes.
2. It will help you think about what you want. Others will ask you questions or tell you things that will make you think about your wishes in another way.
3. It will help your loved ones make difficult decisions with less pain, doubt, and anxiety.
4. It may save money. Sometimes families continue medical treatments long past the point where they are helpful, simply because they are unsure what their loved one would have wanted. This is emotionally and financially costly… and unnecessary.
5. It may even bring your family closer together.

Starting the Discussion

There's no right way to start, nor is there a "right" time to talk about your wishes. The discussion does not necessarily have to be somber and mournful. Here are some suggestions for getting started:

- Start with a story of someone else's experience:

  "Do you remember what happened to so-and-so and what his family went through? I don't want you to have to go through that with me. That's why I want to talk about this now, while we can."

  "Neither Richard Nixon nor Jackie Kennedy was placed on life support. I wonder if they had Advance Directives and made what they wanted clear in advance."

- Blame it on your attorney:

  "Mr. Darrow, my lawyer, says that before I complete some legal documents, I need to talk over with you some plans about end-of-life medical care."

- Use the worksheets provided in this packet to guide the discussion.

- Use a letter, tape, or video recording as a starting point. At first, it may be easier for people to hear what you have to say if you are not there. Afterwards they may be more ready to sit down and talk with you.

Resistance to the Discussion is Common, for example…

"Mom, I don't see what good it does to talk about such things. It's all in God's hands anyway."

"Dad, I already know you don't want any heroic measures if things are really bad. There's nothing more we need to discuss about it. We'll do the right thing if the situation arises."

"I just can't talk about this. It's too painful, and talking about it just makes it more likely that it will happen."

In Response…

- Be firm and straightforward.

  "I know this makes you feel uncomfortable, but I need you to listen, to hear what I have to say. It's very important to me."

  "Yes, death is in God's hands, but how we live until that moment is in our hands, and that's what I need to talk to you about."

  "If it is too overwhelming for you right now, I understand. But let's make an appointment for a specific time to sit down together to discuss this. All right?"

- Point out the possible consequences of not talking now.

  "If we don't talk about this now, we could both end up in a situation that is even more uncomfortable. I'd really like to avoid that if I could."

- Ask someone to be your spokesperson.

  If you are able to connect well with one family member or friend, ask this person to initiate and lead the discussion with other family members or your doctor. This may make your job of explaining, clarifying, and answering questions easier.

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Health Care Agent IQ Test

How well does your agent or familyt know your health care wishes? This short test can give you some sense of how well you have communicated your wishes to them. Consider this a tool to promote better conversation and understanding.

INSTRUCTIONS:

Step 1:
Answer the 10 questions using the **Personal Medical Preferences** questionnaire.

Step 2:
Ask your health care agent, alternate agent, and any family member, or close friend who may be involved in making medical decisions for you to complete **the Agent Understanding of Your Personal Medical Preferences**. The questions are the same. Don't reveal your answers until after the person completes the questionnaire. Those answering the questions should answer the questions in the way they think *you* would answer. (Try the same test with your doctor, too.)

Step 3:
GRADING – Count one point for each question on which you and your agent (or you and your doctor) gave the *same* answer. Their "Agent IQ" is rated as follows:

Points	Grade	
10	*Superior*	… You are doing a great job communicating!
8 – 9	*Good*	… Need some fine tuning!
6 – 7	*Fair*	… More discussion needed.
5 or below	*Poor*	… You have a lot of talking to do!

Agent IQ Test
Step 1: Personal Medical Preferences

Complete this questionnaire by yourself.

1. Imagine that you had Alzheimer's Disease and it had progressed to the point where you could not recognize or converse with your loved ones. When spoon feeding was no longer possible, would you want to be fed by a tube into your stomach? *(Choose one)*

   YES **NO** **I am uncertain**

2. Which of the following do you fear *most* near the end of life? *(Choose one)*

   a. Being in pain
   b. Losing the ability to think
   c. Being a financial burden on loved ones

3. Imagine that…

   - You are now seriously ill, you cannot make health care decisions but if you are successfully treated, doctors think you will be able to regain the ability to make your own decisions, and doctors are recommending chemotherapy.
   - This chemotherapy may have side effects, such as nausea, vomiting, and weakness that could last for two to three months, though a skilled palliative care physician can help to manage most of these side effects. You may not be able to be around family or friends as much as you would want.

   Would you be willing to endure the side effects if the chance of regaining your current health was <u>less than 2 percent</u>? *(Choose one)*

   YES **NO** **I am uncertain**

4. In the same scenario, suppose that your condition is clearly terminal, but the chemotherapy might give you 6 additional months of life. Would you want the chemotherapy even though it has side effects? *(Choose one)*

   YES **NO** **I am uncertain**

5. If you were terminally ill with a condition that caused much pain and prevented you from communicating your health care wishes, would you want to be sedated, even to the point of unconsciousness, if it were necessary to control your pain? *Note, however, that sedation for pain management is necessary for very few of all patients at the end of life. (Choose one)*

   YES **NO** **I am uncertain**

6. Imagine that…
   - You have moderate dementia causing mental confusion. About half the time, you recognize and interact with friends and loved ones on a simple level.
   - You also have circulatory problems, which resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

   Would you want the operation to remove your leg? (*Choose one)*

   YES **NO** **I am uncertain**

7. Is it more important for you to: (a) have your specific treatment preferences followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made? *(Choose one)*

   a. Have specific preferences followed, even if there is disagreement.
   b. Have family and friends all in agreement.
   c. I am uncertain.

8. Imagine that…
   - You are physically frail and you need help with most routine daily activities – dressing, bathing, eating, and going to the toilet.
   - You live in a nursing home.
   - Your mind is fairly clear and capable most of the time, and
   - You have had pneumonia or other lung infections four times in the last year. Each time you had to be hospitalized for several days and given antibiotics through an I-V tube.

   The next time you get pneumonia, do you want aggressive antibiotic treatment again or just comfort care until death comes? *(Choose one)*

   a. Antibiotic treatment
   b. Comfort care
   c. I am uncertain

9. Imagine that…
   - You are in a permanent coma, and
   - You are dependent on a tube inserted into your stomach for nutrition and hydration, for food and water.

   Would it be important to you that decisions about your treatment be guided by particular religious beliefs or spiritual values that you hold? *(Choose one)*

   YES **NO** **I am uncertain**

10. If your heart, kidneys, pancreas, lungs and liver could all be used in transplant operations to save lives, would you want to donate them at death? *(Choose one)*

    YES **NO** **I am uncertain**

- END -

Agent IQ Test
Step 2: Agent Understanding of Your Personal Medical Preferences

To be completed by your named health care agent, family member, close friend or physician.

Instructions: Answer the following questions in the way you think *"N"* (name: _____) would answer.

1. Imagine that ***N*** had Alzheimer's Disease and had progressed to the point where he/she could not recognize or converse with loved ones. When spoon feeding was no longer possible, would he/she want to be fed by the insertion of a tube into the stomach? *(Choose one)*

   YES **NO** **I am uncertain**

2. Which of the following do you think ***N*** fears *most* near the end of life? *(Choose one)*

   a. Being in pain
   b. Losing the ability to think
   c. Being a financial burden on loved ones

3. Imagine that ***N***.

   - Is now seriously ill, cannot make health care decisions but if ***N*** is successfully treated, doctors think ***N*** will be able to regain the ability to make decisions, and doctors are recommending chemotherapy.
   - This chemotherapy may have side effects, such as nausea, vomiting, and weakness that could last for two to three months, though a skilled palliative care physician can help to manage most of these side effects. ***N*** will not be able to be around family or friends as much as ***N*** would want.

   Would ***N*** be willing to endure the side effects if the chance of regaining his/her current health was <u>less than 2 percent</u>? *(Choose one)*

   YES **NO** ***N*** **would be uncertain**

4. In the same scenario, suppose that his/her condition is clearly terminal, but the chemotherapy might give 6 additional months of life. Would ***N*** want the same chemotherapy? *(Choose one)*

   YES **NO** ***N*** **would be uncertain**

5. If ***N*** were terminally ill with a condition that caused much pain, would ***N*** want to be sedated, even to the point of unconsciousness, if it were necessary to control the pain? *Note, however, that sedation for pain management is necessary for very few patients at the end of life. (Choose one)*

   YES **NO** ***N*** **would be uncertain**

6. Imagine that ***N.***
   - Has moderate dementia causing mental confusion. About half the time, ***N*** recognizes and interacts with friends and loved ones on a simple level.
   - ***N*** also has circulatory problems, which resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

   Would ***N*** want the operation to remove the leg? *(Choose one)*

   YES **NO** ***N*** **would be uncertain**

7. Is it more important for ***N*** to: (a) have his/her specific treatment preferences followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made? *(Choose one)*

   a. Have specific preferences followed, even if there is disagreement.
   b. Have family and friends all in agreement.
   c. ***N*** would be uncertain.

8. Imagine that ***N.***

- Is physically frail and needs help with most routine daily activities – dressing, bathing, eating, and going to the toilet.
- Lives in a nursing home.
- Mentally, is fairly clear and capable most of the time, and
- Has had pneumonia or other lung infections four times in the last year. Each time ***N*** had to be hospitalized for several days and given antibiotics through an I-V tube.

The next time ***N*** gets pneumonia, do you think he/she would want aggressive antibiotic treatment again or just comfort care until death comes? *(Choose one)*

a. Antibiotic treatment
b. Comfort care
c. ***N*** would be uncertain

9. Imagine that ***N*** …

- Is in a permanent coma, and
- Is dependent on a tube inserted into the stomach for nutrition and hydration, for food and water.

Would it be important to ***N*** that decisions about ***N***'s treatment be guided by particular religious beliefs or spiritual values held by ***N*** ? *(Choose one)*

YES **NO** ***N*** **would be uncertain**

10. If N's heart, kidneys, pancreas, lungs, and liver could all be used in transplant operations to save lives, would he/she want to donate them at death? *(Choose one)*

YES **NO** ***N*** **would be uncertain**

- END -

ADVANCE HEALTH CARE PLANNING

Good Advance Planning is a Continuing Conversation

Advance planning for health care is always a work in progress. That's because circumstances change, and lives change. Even your values and priorities can change.

What are Advance Directives?

Advance Health Care Directives (also sometimes called Living Wills or Special Power of Attorney for Health Care) are documents that instruct your health care provider about:

- Who should make decisions for you if you cannot make or communicate decisions about your health care (your agent).
- What decisions your agent can make.
- When you would want or not want life sustaining care.

Utah has an **Advance Health Care Directive** form that went into effect on January 1st, 2008. If you have an old Living Will or Special Power of Attorney, you should consider completing a new Directive on the new form.

Completing an Advance Directive will help to communicate your wishes to your health care providers when you cannot speak for yourself.

You do not need an Advance Health Care Directive, Living Will, or any other document, to tell your doctor that you do not want life-sustaining or prolonging treatments. Your instructions to your doctor should be honored, even if your doctor, family members, or your health care agent disagree with your instructions. If your doctor is unwilling to follow your instructions, he or she should transfer your care to another doctor.

Remember: Do not try to complete and sign an advance directive until you have carefully thought through your options and choices.

Five Times to Re-Examine Your Health Care Wishes

1. Before each annual physical exam.
2. At the start of each decade of your life.
3. After any major life change – such as a birth in the family, marriage, divorce, re-marriage, and especially after the death of a loved one.
4. After any major medical change – such as being diagnosed with a serious disease or terminal illness. Or if such conditions worsen.
5. After losing your ability to live independently.

If Your Wishes Change

You can make a new advance directive if your wishes change.

To revoke an old advance directive, you may destroy the old one, write "revoked" across the old one, write a new one, or tell someone that you want to revoke it. If you tell someone that you want to revoke the advance directive, you should do so in the presence of an adult witness who should then sign and date a written statement confirming that you have revoked the advance directive. If you change your advance directives, it is important to notify everyone who has a copy of your old forms.

What To Do With Your Advance Directive

1. Keep the original copy of your health care advance directive and these work sheets or other notes in a place where they can be easily found. Do not lock your directive in a safe deposit box, safe, or other inaccessible location.
2. Give your agent a copy of the directive plus any worksheets or notes. Make sure your agent knows where to find the original.
3. Give your doctor a copy of your directive. Make certain it is put in your medical record. Make sure your doctor will support your wishes. If your doctor has objections, you need to work them out or find another doctor.
4. If entering a hospital or nursing home, take a copy of your directive with you and ask that it be placed in your medical record.

Medical Orders

Medical care is provided based on orders signed by physicians or other authorized medical professionals, such as nurse practitioners or physician assistants. Advance directives can serve as the basis of a medical order, but an advance directive is not, by itself, a medical order.

Utah law allows medical orders that address life-sustaining care, such as CPR, the use of antibiotics, or the use of tube feeding and IV fluids. Orders may have different names: Life with Dignity Order, Physician Order for Life-Sustaining Treatment (POLST), or Emergency Medical Services Do Not Resuscitate Order (EMS-DNR).

These orders are not relevant to most healthy people who want life-sustaining care provided in an emergency. But people who are facing a life-threatening illness or who have specific preferences about specific types of care may want an order that will be followed by emergency services personnel, emergency rooms, or health care facilities. Specifically, any person who would not want CPR must work with a health care provider to complete one of these orders

Tool #10 contains a sample POLST form. If you want a medical order to address your end-of-life care wishes, ask your health care provider to work with you to complete the POLST form.

Tool #9

Making Medical Decisions

It is often hard to make medical decisions, especially ones that involve end-of-life care. Many people say they do not want to die slowly, hooked up to machines or fed artificially through tubes, but how do you know when care will only prolong death, or whether care will restore the patient to life.

Use the steps on the next page to help you decide.

Find Out the Medical Facts and Evaluate Options

To understand a current condition and need for tests, ask the health care provider:

a. What is the name of the condition?
b. What is the condition doing to the patient now?
c. If you don't know exactly what's wrong, what are the possibilities?
d. Are tests needed to know more?
e. Will the outcome of more testing make any difference in how you treat the condition, or in how the patient would want to be treated? (If not, why do a test?)
f. What is the purpose of each test? Do these tests have risks associated with them?
g. Is the information you need worth the burdens of the test?

To understand the prognosis, ask:

a. What is the usual course of this disease or condition?
b. Is there a reason to think the patient's disease course will be different?
c. How severe or advanced is the condition in this case?
d. Would you be surprised if the patient were to die in 6 months? One year? Two years? Five years?

To evaluate proposed treatment, including end-of-life care, ask:

a. In the event of a crisis, what is the chance that treatment (for example with a ventilator, chemotherapy, or CPR) be effective in prolonging life? For how long might life be prolonged?

b. What is the success rate?

c. Would treatment be effective in restoring, improving, or maintaining function?

d. How would you define success for this treatment?

e. Is treatment likely to increase or decrease pain or other distressing side effects? Will the patient feel better?

f. Are there psychologically harmful side effects?

g. Will treatment impair social interaction?

h. Might the patient benefit from a time limited trial on life sustaining treatment?

i. What conditions might cause you to recommend that treatment be stopped or not started?

j. Can this procedure be done on a trial basis and then reevaluated? What is an appropriate amount of time for a trial? Are you willing to stop it after an agreed-upon trial?

k. If life sustaining treatments are used, how will you maximize and maintain comfort?

l. How might the treatment affect the circumstances of death? (For example, will it likely require hospitalization instead of home care?)

m. What option do you recommend, and why?

Adapted from Making Health Care Decisions for Others: A Guide To Being A Health Care Agent or Surrogate, by
The Division of Bioethics, Montefiore Medical Center,
Albert Einstein College of Medicine, Bronx, NY

Utah Advance Health Care Directive

***(Pursuant to Utah Code Section 75-2a-117, effective 2009)**[*]*

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.***

My Personal Information

Name: _____

Street Address: _____

City, State, Zip Code: _____

Telephone: (_____) _____ Cell Phone: (_____) _____

Birth Date: _____

Part I: My Agent (*Health Care Power of Attorney)*

A. No Agent

If you do not want to name an agent, initial the box below, then go to Part II; do not name an agent in B or C below. No one can force you to name an agent.

_____ **I do not want to choose an agent.**

B. My Agent

Agent's Name: _____

Street Address: _____

City, State, Zip Code: _____

Home Phone: (_____) _____ Cell Phone: (_____) _____

Work Phone: (_____) _____

C. My Alternate Agent

This person will serve as your agent if your agent, named above, is unable or unwilling to serve.

Alternate Agent's Name: _____

Street Address: _____

City, State, Zip Code: _____

Home Phone: (_____) _____ Cell Phone: (_____) _____

Work Phone: (_____) _____

Part I: My Agent (*continued)*

D. Agent's Authority

If I cannot make decisions or speak for myself (in other words, after my physician or another authorized provider finds that I lack health care decision making capacity under Section 75-2a-104 of the Advance Health Care Directive Act), my agent has the power to make any health care decision I could have made such as, but not limited to:

- Consent to, refuse, or withdraw any health care. This may include care to prolong my life such as food and fluids by tube, use of antibiotics, CPR (cardiopulmonary resuscitation), and dialysis, and mental health care, such as convulsive therapy and psychoactive medications. This authority is subject to any limits in paragraph F of Part I or in Part II of this directive.
- 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 health care facility, including a mental health facility, subject to any limits in paragraphs E or F of Part I.
- Get copies of my medical records.
- Ask for consultations or second opinions.

My agent cannot force health care against my will, even if a physician has found that I lack health care decision making capacity.

E. Other Authority

My agent has the powers below only if I initial the "***yes***" option that precedes the statement. I authorize my agent to:

____YES ____ NO Get copies of my medical records at any time, even when I can speak for myself.

____YES ____ NO Admit me to a licensed health care facility, such as a hospital, nursing home, assisted living, or other facility for long-term placement other than convalescent or recuperative care.

F. Limits/Expansion of Authority

I wish to limit or expand the powers of my health care agent as follows:

_____
_____
_____

G. Nomination of Guardian

Even though appointing an agent should help you avoid a guardianship, a guardianship may still be necessary. Initial the "YES" option if you want the court to appoint your agent or, if your agent is unable or unwilling to serve, your alternate agent, to serve as your guardian, if a guardianship is ever necessary.

____YES ____ NO I, being of sound mind and not acting under duress, fraud, or other undue influence, do hereby nominate my agent, or if my agent is unable or unwilling to serve, I hereby nominate my alternate agent, to serve as my guardian in the event that, after the date of this instrument, I become incapacitated.

H. Consent to Participate in Medical Research

____YES ____ NO I authorize my agent to consent to my participation in medical research or clinical trials, even if I may not benefit from the results.

I. Organ Donation

____YES ____ NO If I have not otherwise agreed to organ donation, my agent may consent to the donation of my organs for the purpose of organ transplantation.

Part II: My Health Care Wishes (*Living Will*)

I want my health care providers to follow the instructions I give them when I am being treated, even if my instructions conflict with these or other advance directives. My health care providers should always provide health care to keep me as comfortable and functional as possible.

***Choose only one** of the following options, numbered Option 1 through Option 4, by placing your initials before the numbered statement. Do not initial more than one option. If you do not wish to document end-of-life wishes, initial Option 4. You may choose to draw a line through the options that you are not choosing.*

Option 1	
_____ Initial	**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.
Additional comments:	

Option 2	
_____ Initial	**I choose to prolong life.** Regardless of my condition or prognosis, I want my health care team to try to prolong my life as long as possible within the limits of generally accepted health care standards.
Additional comments:	

Option 3		
_____ Initial	**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.	
If you choose this option, you must also choose either (a) or (b), below		
_____ Initial	(a) I put no limit on the ability of my health care provider or agent to withhold or withdraw life-sustaining care.	
_____ Initial	(b) My health care provider should withhold or withdraw life-sustaining care if ***at least one*** of the initialed conditions is met:	
If you selected (a), above, do not choose any options under (b).		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
Additional comments:		

Option 4	
_____ Initial	I do not wish to express preferences about health care wishes in this directive.
Additional comments	

Part II: My Health Care Wishes (*continued*)

Additional instructions about your health care wishes:

_____

_____

_____

If you do not want emergency medical service providers to provide CPR or other life sustaining measures, you must work with a physician or APRN to complete an order that reflects your wishes on a form approved by the Utah Department of Health.

Part III: Revoking or Changing a Directive

I may revoke or change this directive by:

- Writing "void" across the form, burning, tearing, or otherwise destroying or defacing this document or directing another person to do the same on my behalf;
- Signing a written revocation of the directive, or directing another person to sign a revocation on my behalf;
- Stating that I wish to revoke the directive in the presence of a witness who: is 18 years of age or older; will not be appointed as my agent in a substitute directive; will not become a default surrogate if the directive is revoked; and signs and dates a written document confirming my statement; or
- Signing a new directive. (***If you sign more than one Advance Health Care Directive, the most recent one applies.)***

Part IV: Making My Directive Legal

I sign this directive voluntarily. I understand the choices I have made and declare that I am emotionally and mentally competent to make this directive. My signature on this form revokes any living will or power of attorney form naming a health care agent that I have completed in the past.

_____ _____

Date Signature

_____

City, County, and State of Residence

I have witnessed the signing of this directive, I am 18 years of age or older, and I am not:

1. Related to the declarant by blood or marriage;
2. Entitled to any portion of the declarant's estate according to the laws of intestate succession of any state or jurisdiction or under any will or codicil of the declarant,
3. A beneficiary of a life insurance policy, trust, qualified plan, pay on death account, or transfer or death deed that is held, owned, made, or established by, or on behalf of, the declarant;
4. Entitled to benefit financially upon the death of the declarant;
5. Entitled to a right to, or interest in, real or personal property upon the death of the declarant;
6. Directly financially responsible for the declarant's medical care;
7. A health care provider who is providing care to the declarant or an administrator at a health care facility in which the declarant is receiving care; or
8. The appointed agent or alternate agent.

_____ _____

Signature of Witness Prin ted Name of Witness

_____ _____ _____ _____

Street Address City State Zip

If the witness is signing to confirm an oral directive, describe below the circumstances under which the directive was made.

_____

_____

Name: _____

Tool #10

Utah Department of Health
Bureau of Health Facility Licensing, Certification and Resident Assessment

State of Utah Health Care Facility Rule R432-031
Physician Order for Life Sustaining Treatment
(http://health.utah.gov/hflcra/forms.php)

Physician Order For Life Sustaining Treatment This is a physician order sheet based on patient/resident wishes and medical indications for life-sustaining treatment. If this is in the clinical record, this should be placed in a prominently visible part of the patient's record. When need occurs, first follow these orders, then contact the physician	Last Name of Patient/Resident: First Name/Middle Initial: Date of Birth:

(ANY SECTION NOT COMPLETED INDICATES ALL TREATMENT IN THAT SECTION WILL BE PROVIDED)

Section A Check one	**Treatment options** when the patient/resident **has no pulse and is not breathing** ___ Resuscitate ____ Do not attempt or continue any resuscitation (DNR)
Section B Check one	**Treatment options** when the patient/resident **has pulse and is breathing**. __Comfort measures only: Oral and body hygiene, reasonable efforts to offer food and fluids orally, medication, oxygen, positioning, warmth, and other measures to relieve pain and suffering. Privacy and respect for the dignity and humanity of the patient/resident. Other instructions: Transfer only if comfort measures can no longer be effectively managed at current setting. Transfer only if necessary to: _____ __ Limited additional interventions: Includes care above. May also include suction, treatment of airway obstruction, bag-mask/demand valve, monitor cardiac rhythm, medications, IV fluids. Transfer to hospital if indicated, but no endotracheal intubation or long-term life support measures. Other instructions, specify: _____ ___ Full treatment include all care above plus endotracheal intubation and cardioversion
Section C Check all that apply	**Antibiotics:** Comfort measures are always provided. ___ No antibiotics, except if needed for comfort ___ Oral antibiotics ___ Intravenous antibiotics ___ Intramuscular antibiotics Other Instructions:
Section D Check all that apply	Artificially administered fluid and nutrition: **Feeding Tube**: ___ No feeding tube ___ Defined trial period of feeding tube ___ Long-term feeding tube **IV Fluids**: ___ No IV fluids ___ Defined trial period of IV fluids ___ IV Fluids Other Instructions:
Section E Check all that apply	Discussed with ___ Patient/Resident ___ Legal Representative ___ Other, (specify): _____ Contact name and phone number:

A COPY OF THIS FORM MUST ACCOMPANY PATIENT/RESIDENT ON TRANSFER OR DISCHARGE (INCLUDING TRANSFERS TO HOSPITAL EMERGENCY DEPARTMENTS)

Tool #10

Patient/Resident preferences as a guide for physician order for life-sustaining treatment

Section F	I have given significant thought to life sustaining treatment. The following have further information regarding my preferences: Advance Directive ___ no ___ yes Living Will ___ no ___ yes Medical Treatment Plan ___ no ___ yes Court-appointed guardian ___ no ___ yes Power of attorney for health care ___ no ___ yes I expressed my preferences to my physician and/or health care provider(s) and agreed with the treatment order on this document. Please review these orders if there is a substantial permanent change in my health status, such as: Close to death Advance progressive illness Improved condition Permanently unconscious Extraordinary suffering Surgical procedures

Brief summary of medical condition:		
Signature of person preparing form (e.g., nurse or social worker)	Print name and phone number:	Date and time prepared
Signature of Physician or other Licensed Practitioner	Print Name: License number and phone number:	Date and time prepared
Patient/Resident Signature/Legal Representative (when possible)	Print name and phone number	Date and time signed

How to Change "Physician Order For Life Sustaining Treatment (POLST)"

This form, Physician Order For Life Sustaining Treatment, should be reviewed if:

1. The patient/resident is transferred from one care setting to another;
2. There is substantial permanent change in patient's/resident's health status; or
3. The patient/resident treatment preferences change.

Review Patient/Resident Preferences as a guide for Physician Order for Life Sustaining Treatment (Section F). Record the review in Review of Physician Order For Life Sustaining Treatment (Section G). To void this form, a physician draws a line through the Physician's Order and/or writes "VOID". Sign and date the form. If no form is completed full treatment may be provided.

Section G	**Review of Physician Order For Life Sustaining Treatment**		
Date of Review	Reviewer	Location of Review (e.g., hospital, NF, HH, clinic)	Outcome of Review
			___ No change ___ Form voided, no new form ___ Form voided, new form ___ Change reflected on form
			___ No change ___ Form voided, no new form ___ Form voided, new form ___ Change reflected on form
			___ No change ___ Form voided, no new form ___ Form voided, new form ___ Change reflected on form