

Advance Directive Tool Kit

This purpose of this Tool Kit is to assist you in thinking about advance planning for health care decisions. This Tool Kit can be used to help you focus your thoughts on your medical preferences and to facilitate continuing conversation about advance medical planning. Some “tools” offer suggestions while others discuss additional resources. There is no right or wrong way to use this Tool Kit. It is recommended that you utilize the “tools” provided in a manner that makes you comfortable.

Prepared by the Virginia Bar Association Health Law Section Council based on forms created by the American Bar Association, Commission on Legal Problems of the Elderly

Advance Medical Directive Workshop Tool Kit Tool #1

Things to Think About When Selecting Your Health Care Agent

1. Would this person be willing to speak on your behalf?
2. Would this person be able to act on your wishes and separate his/her own feelings from yours?
3. Does this person live close by or could he or she travel to be at your side if needed?
4. Does this person know you well and understands what's important to you?
5. Could this person handle the responsibility?
6. Will this person talk with you now about sensitive issues and will he/she listen to your wishes?
7. Will this person likely be available long into the future?
8. Would this person be able to handle conflicting opinions between family members, friends, and medical personnel?
9. Can this person be a strong advocate in the face of an unresponsive doctor or institution?



Talk to your health care agent about the qualifications listed above.

Ask permission to name him or her as your health care agent.

Discuss your health care wishes and values and fears.

Make sure your health care agent gets an original copy of your advance directive.

Tell family members and close friends who you picked.

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Personal Medical Preferences

To assist you in making your medical preferences clear to your health care provider, consider responding to the questions below. Use the questions as a guide to focus your thoughts on your medical preferences.

PERSONAL MEDICAL PREFERENCES

If I am incapable of making an informed decision regarding my health care, I would direct my health care providers to follow my instructions as set forth below.

1. If my death from a terminal condition is imminent and even if life-sustaining procedures are used there is no reasonable expectation of my recovery:

_____ I direct that my life not be extended by life-sustaining procedures, including the administration of nutrition and hydration artificially.

_____ I direct that my life not be extended by life-sustaining procedures, except that if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.

2. If I am in a persistent vegetative state, that is, if I am not conscious and am not aware of my environment nor able to interact with other and there is no reasonable expectation of my recovery:

_____ I direct that my life not be extended by life-sustaining procedures, including the administration of nutrition and hydration artificially.

_____ I direct that my life not be extended by life-sustaining procedures, except that if I am unable to take food by mouth, I wish to receive nutrition and hydration artificially.

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Personal Priorities & Spiritual Values Important to Your Medical Decisions

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 the questions below.

PERSONAL PRIORITIES/CONCERNS

1. What are your fears regarding the end of life?
2. 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?
3. Would you want to have a hospice team or other palliative care (i.e., comfort care) available to you?

SPIRITUAL/RELIGIOUS MATTERS OF IMPORTANCE TO YOU

4. What is important for others to know about the spiritual or religious part of your life?
5. 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?

Advance Medical Directive Workshop Tool Kit Tool #4

After Death Decisions To Think About Now

ORGAN AND TISSUE DONATION

DID YOU KNOW?

More than 68,000 patients are on the national organ transplant waiting list. Each day, 13 of them will die because the organs they need have not been donated. Every 16 minutes, a new name will be added to that waiting list.

Organs you can donate: Heart, Kidneys, Pancreas, Lungs, Liver, and Intestines.

Tissue you can donate: Cornea, Skin, Bone marrow, Heart valves, and Connective tissue.

To be transplanted, organs must receive blood until they are removed from the body of the donor. Therefore, it may be necessary to place the donor on a breathing machine temporarily or provide other organ-sustaining treatment.

If you are older or seriously ill, you may or may not have organs or tissue suitable for transplant. Doctors evaluate the options at or near the time of death.

The body of an organ donor can still be shown and buried after death.

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. Would you consider donating viable **ORGANS** for transplant? If so, which ones?
2. Would you consider donating viable **TISSUES** for transplant? If so, which ones?

Attention! If you answered **Yes** for either of the above, be sure to consider writing this into your health care Advance Directive. You may also fill out an organ donor card or register as an organ donor when you renew your driver's license. But be sure to tell your health care agent and loved ones. Make sure they will support your wishes. Even with an organ donor card, hospitals may ask your health care 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 consider doing this?

If you answer Yes, you should 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. But, this kind of donation must be accepted by the medical institution. Note that total body donation is **not** an option if you also choose to be an organ or tissue donor.

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

What To Do After Signing Your Health Care Advance Directive

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...

Make a new advance directive if your old one no longer reflects your wishes. Ask about the proper way to cancel or amend your existing directive in your state. If you change your advance directive, it is important to notify everyone who has copies of your old medical directive forms.

WHAT TO DO WITH YOUR ADVANCE DIRECTIVE

- Make sure your health care agent knows where to find the original.
2. 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.
 3. 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.
 4. Keep the original copy of your health care advance directive and these work sheets or other notes some place they can be easily found.
 5. Carry an advance directive wallet card with you.
 6. Some organizations offer to register advance directives electronically and enable health care institutions to access them electronically. Some churches and synagogues keep advance directive on file for members. You may wish to consider such a service.

IF YOU DON'T WANT EMERGENCY CPR, ONE MORE STEP...

After completing your Advance Directive, **you may have to take one more step if you want to avoid CPR (cardio-pulmonary resuscitation) or other life support when an ambulance (911) is called.**

Some people with serious and irreversible conditions do not want an emergency medical team to give them CPR if their heart stops. If this is your wish, ask how to get a DNR Order (Do-Not-Resuscitate Order) that will be respected outside of hospitals. These are also called *Out-of-Hospital DNR Orders*, *Comfort-Care-Only Orders*, or by other similar names. They usually require your physician's signature and your consent. You will get a special identifying bracelet or document that must be visible if you have a medical crisis. If the emergency medical team sees the proper bracelet or document upon arrival, you can expect to receive all necessary comfort care -- but not life support.

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Guide for Health Care Agent

If you are in a position to make medical decisions for someone else, this guide is for you. If you have been named in someone's medical power of attorney or other advance directive, then you may be referred to as the person's *proxy*, *agent*, *attorney-in-fact*, *surrogate*, or *representative*. These are all essentially the same job. Even if you have not been named, you may be called upon to participate in medical decisions for close family or friends who are in a medical crisis and cannot speak for themselves.

EXACTLY WHAT ARE YOUR DUTIES AS AN AGENT?

Your duties depend on what the person's advance directive says and upon state law. You have to read the advance directive and ask about state law. Your duties begin when the individual loses the ability to make health care decisions on his or her own.

In general, you will have authority to make any and all decisions a patient would make for him or herself, if able. This includes:

1. Receiving the same medical information the individual would receive.
2. Conferring with the medical team.
3. Reviewing the medical chart.
4. Asking questions and getting explanations.
5. Discussing treatment options.
6. Requesting consultations and second opinions.
7. Consenting to or refusing medical tests or treatments, including life-sustaining treatment.
8. Authorizing a transfer to another physician or institution, including another type of facility (such as a hospital or skilled nursing home).

HOW TO MAKE MEDICAL DECISIONS

STEPS FOR A HEALTH CARE AGENT TO FOLLOW

Deciding for a loved one (whom we will call Mary)

1. **Find out the medical facts.** This requires talking to the doctors and getting a complete picture of the situation. Questions you can use:
 - ▶ What is the name of Mary's condition?
 - ▶ If you don't know exactly what's wrong, what are the possibilities?
 - ▶ Are tests needed to know more? Will the outcome of more testing make any difference in how you treat her, or in how she wants to be treated? (If not, why do the test?)
 - ▶ What is the purpose of each test? Do these tests have risks associated with them?
 - ▶ Is the information you need worth the risk of the test?
 - ▶ What is her condition doing to her now?
 - ▶ How do you explain her symptoms?
 - ▶ What usually happens with this disease?
 - ▶ What do you think now will be the likely course of this disease or condition?
 - ▶ How severe or advanced is her case?

2. **Find out the options.** Make sure the physician describes the risks and benefits of each option. You may want to ask:
 - ▶ How will this option make Mary improve or feel better?
 - ▶ What is the success rate statistically? What is success?
 - ▶ 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?
 - ▶ What defines "success" for this option? (It may not be what Mary would consider a success.)
 - ▶ What will it mean to her quality of life?
 - ▶ If she is to die, how might it affect the circumstances of her death? (For example, will it likely require hospitalization instead of home care?)
 - ▶ What are the possible side effects?
 - ▶ What option do you recommend, and why?

3. **Figure out how Mary would decide if she knew all the facts and options.** You have three possible approaches to making the decision:
 - ▶ One - If you know preferences, follow them.
 - ▶ Two - If you do not know Mary's wishes for the specific decision at hand, but you have evidence of what she might want, you can try to figure out how she would decide. This is called *substituted judgment*, and it requires you imagining yourself in the patient's position. Consider her values, religious beliefs, past decisions, and past statements she has made. The aim is to choose as Mary would probably choose, **even if it is not what you would choose for yourself.**
 - ▶ Three - If you have very little or no knowledge of what Mary would want, then you and the doctors will have to make a decision based on what a reasonable person in the same situation would decide. This is called making decisions in the patient's *best interest*. Evaluate the benefits and burdens of the proposed treatment. For example, will the treatment cause Mary pain or suffering? Is it likely to make Mary better?

THINGS A HEALTH CARE AGENT CAN DO TO MAKE DECISIONS EASIER ...

- DO prepare in advance with the individual. Learn what is important to your loved one in making health care decisions. Do this before he or she loses the ability to decide. Talk about beliefs and values regarding living, and dying. Talk about spiritual beliefs.

- DO make yourself and your role known to the medical staff. Make sure the advance directive is in the medical chart. Keep a copy yourself, handy, to show to people involved in the individual's medical care. Keep in touch with these people.

- DO stay informed about the person's condition as it changes. Medical conditions change. Staff at the hospital change. Identify the person who can best keep you informed of the individual's condition. Stay involved and be flexible.

- DO keep the family informed, if appropriate. You may have the legal authority to make medical decisions even if family members disagree. However most proxies are more comfortable if there is agreement among loved ones. Good communication can foster consensus. But you may also need help in resolving family disagreements. Ask for the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor. Or ask for the ethics committee or ethics consultant.

- DO advocate on the patient's behalf and assert yourself with the medical team, if necessary. Some medical people may not be as comfortable as others with your involvement. You may disagree with the doctor's recommendations. Sometimes, it is hard to disagree with medical professionals and institutional authorities. If you need help communicating or are feeling overwhelmed, you can ask for help from the facility's patient representative or ombudsman, social worker, clergy or spiritual advisor.

Advance Medical Directive Workshop Tool Kit Tool #7

Resources:

Advance Planning for Health Care

Here are some in-depth resources about end-of-life issues and advance medical directive forms.

GUIDES AND HANDBOOKS

Caring Conversations Workbook, published by the Center for Practical Bioethics Harzfeld Building, 1111 Main Street, Suite 500, Kansas City, MO 64105-2116. This is both a workbook and advance directive. It can be downloaded for free from: <http://www.practicalbioethics.org/>. A comprehensive do-it-yourself workbook on planning for end-of-life care. (Parts of this Tool Kit were adapted from this publication.)

A Good Death: Challenges Choices and Care Options, by Charles Meyer (1998). Down-to-earth, lay-language explanation of the implications of end-of-life care decisions from a religious and spiritual perspective. A 64-page paperback available in many bookstores.

Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, MD, and Joan Harrold, MD (NY: Oxford University Press, 1999), available through the web site of Americans for Better Care of the Dying www.abcd-caring.org. A most comprehensive and readable 242-page guide to dealing with serious, eventually fatal illness.

Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Measures Only and the Elderly Patient, by Hank Dunn. A&A Publishers, Inc. P.O. Box 1098, Herndon, VA 20172-1098 (Tel. 703-707-0169). Web site: www.hardchoices.com. A concise and helpful 48-page booklet on end-of-life decisions concerning resuscitation, food and fluids, hospitalization, and cure versus comfort care.

Making Health Care Decisions for Others: A Guide To Being A Health Care Proxy or Surrogate, by the Division of Bioethics, Dept. of Epidemiology and Social Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY. Available on their web site: www.montefiore.org/prof/clinical/desm/progserv/bioethics/index.html. A guide every proxy or agent needs to read. (Parts of this Tool Kit were adapted from this publication.)

Your Life Your Choices – Planning for Future Medical Decisions: How to Prepare a Personalized Living Will, by Robert Pearlman, *et al.* and the Veterans Administration Medical Center, Seattle, WA. A comprehensive do-it-yourself workbook on planning for

end-of-life care. (Parts of this Tool Kit were adapted from this publication.) Order through the National Technical Information Service web site: www.ntis.gov.

ORGANIZATIONS

Last Acts – a national communications campaign to improve care and caring at the end of life. The campaign supports initiatives to improve professional skills and institutional environments for care, and to increase public involvement. Last Acts can be reached through Partnerships for Caring (see below) or through their web page:

www.lastacts.org .

Partnership for Caring, Inc., 1035 30th Street, NW, Washington, D.C.20007-3823. (Tel.1-800-989-9455). Provides a wealth of educational material on end-of-life care, advance directives, and health care decision-making, including state-specific forms and instructions for completing them. Many of their materials can be downloaded from their web site www.partnershipforcaring.org .

Americans for Better Care of the Dying, 2175 K Street, NW, Suite 820, Washington, DC 20037-1803 (Tel. 202-530-9864). ABCD is a non-profit public charity dedicated to social, professional, and policy reform aimed to improve the care system for patients with serious illness, and their families. Web page: www.abcd-caring.org .

ADVANCE DIRECTIVE FORMS OF SPECIAL INTEREST

Five Wishes Advance Directive. Published by Aging with Dignity. This nationally used and very popular advance directive focuses on ways of talking about health care wishes and needs. Can be purchased and downloaded from their web site: www.agingwithdignity.org. Also available by mail order from P.O. Box 11180, Tallahassee, FL 32302-3180.

Caring Conversations Workbook, published by the Midwest Bioethics Center. This is both a workbook and advance directive. See Guides and Handbooks above.

Shape Your Health Care Future with Health Care Advance Directives. Published jointly by the American Bar Association, the American Medical Association, and the American Association of Retired Persons. Available for free on the ABA web site at: www.abanet.org/elderly .

The Medical Directive, by Linda L. Emanuel, M.D., and Ezekiel J. Emanuel, M.D. This more medically-oriented advance directive includes six illness scenarios. For each, you consider possible medical interventions and goals of medical care. It also includes a proxy designation form. Can be purchased and downloaded from their web site: <http://medicaldirective.org>.