



Research Medical Center

Patient Rights and Responsibilities

Ethics Consultation

Sometimes patients and families need help with difficult ethical decisions. At Research Medical Center you may request a consultation with the Ethics Committee. This group consists of doctors, nurses, a hospital administrator, a representative from the community, a minister, a social worker and occasionally other individuals such as patient representatives, psychologists, attorneys, etc. Consultations with the Ethics Committee are informal and nonjudgmental. While an Ethics Committee cannot mandate any particular course of action, such as treatment or no treatment, it can make suggestions and help patients, family and providers explore various options. There is no charge for this service.

If you need help with difficult choices or to discuss ethical questions or issues with someone on the Ethics Committee, please contact your nurse. A member of the Ethics Committee or the hospital staff will contact you, and if a full consultation is appropriate and available, the Ethics Committee will meet with you. The patient/family and possibly others involved in the care will be invited. We believe that through open and honest discussion in a non-judgmental atmosphere, ethical concerns affecting the care of the patient can be satisfactorily resolved.

Healthcare Treatment Directives, Advance Directives, and/or Living Wills

You should talk to your doctor about your choices concerning your healthcare treatment. However, it is also recommended that you write out your wishes to make them clear if you are later unable to communicate them. This process of writing down your wishes can be accomplished by completing a living will, an advance directive, a Health Care Treatment Directive (HCTD) and/or a Durable Power of Attorney for Healthcare (DPAHC).

- A living will is a written, signed, dated and witnessed document that allows individuals to state they do not want death-prolonging procedures performed. Living wills are effective if you have a terminal condition, will die in a short time and are unable to communicate your wishes.
- An advance directive is a general term used to describe any verbal communication of a competent patient's treatment decisions or any written document, such as a living will or Durable Power of Attorney for Healthcare, signed and dated by a competent patient, that sets forth your treatment decisions.
- A Durable Power of Attorney for Healthcare is a document that provides you with the right to name an individual as an agent to make healthcare decisions for you should you ever be in a situation where you are no longer able to make your own decisions or choose not to make your own decisions. You may choose anyone whom you trust to speak for you to assist your healthcare providers in determining which treatment options you would have chosen for yourself. In Missouri the DPAHC must be notarized; in Kansas it may either be witnessed by two individuals or notarized. Additional information about these directives:
 - Please let your nurse and physician know immediately if you have any type of healthcare treatment directive. It is critical that you discuss any healthcare directives with your family and healthcare providers. Advance directives assist us with providing you the care you believe to be appropriate to your situation.
 - You may make your wishes known verbally to any healthcare provider.
 - You may revoke any directive at any time. If you wish to revoke or cancel one of these documents, please notify your physician or nurse.

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- We can assist you if you do not have a directive but are interested in invoking one. You may contact your nurse, physician, social worker, a patient representative or the pastoral care department to receive further information and instructions on advance directives. Your attorney may also draft such documents for you.
- This hospital, as a part of HCA Midwest, recognizes both state and federal laws that entitle patients to make personal healthcare treatment decisions. All patients will be provided an appropriate level of care whether or not they have put in writing their wishes about healthcare treatments.
- Your directives will be honored as permitted by law and hospital policy. During the pre-operative, operative and immediate post-operative recovery period and/or any time you might be under anesthesia, your physician may elect to suspend your directive. This will be discussed with you or your surrogate prior to the procedure.
- This hospital, as a part of HCA Midwest, recognizes both state and federal laws that entitle patients to make personal healthcare treatment decisions. All patients will be provided an appropriate level of care whether or not they have put in writing their wishes about healthcare treatments. Advance directives assist us with providing you the care you believe to be appropriate to your situation.

Interpreter and Translator Services

In order to communicate accurately and effectively in a language you can understand, Research Medical Center provides interpreter and language translator services free of charge. If you, a member of your family, caregiver, or legal representative have a need for these services or for adaptive communication devices, please inform your nurse or a member of the hospital staff.

RMC Non-Discrimination Policy

We make no distinction in the availability of services; admission, transfer or discharge of patients; or in the care we provide based on age, gender, disability, race, color, religion, or national origin. In compliance with Federal regulations and the ADA, all patients will be afforded equal opportunities and care.

Patient Bill of Rights and Responsibilities

We believe that our mutual respect for rights and responsibilities will contribute to an improved outcome and greater satisfaction with your care in all care settings within Research Medical Center.

You or your representatives have the right to:

1. Considerate and respectful care and to have the decisions made about your care based on your care, treatment and service needs. The effectiveness and safety of your care, treatment or services is not based on your ability to pay.
2. Treatment, care, and services within the hospital's capacity and mission and in compliance with law and regulation.
3. Obtain complete information about your diagnosis, plan of treatment and prognosis from your physician in terms which you can understand.
4. Receive from your physician the information needed for you to give your permission for any procedure or treatment.
5. Refuse treatment and be told what might happen because of your decision in accordance with law and regulation.
6. Expect that should an internal or external review result in the denial of care, treatment, services, or payment, the hospital will make decisions regarding the ongoing provision of care, treatment, services, discharge or transfer based on the assessed needs of the patient. The patient and/or the family will be involved in these decisions as allowed by law.
7. Participate in developing and implementing a care plan, to participate in resolving dilemmas about your care, treatment and services, and to involve your family or surrogate decision maker, as appropriate and as allowed by law, in your care, treatment, and service decisions.
8. Have an advance directive (such as a living will, healthcare proxy, or Durable Power of Attorney for Healthcare) concerning treatment or designating a surrogate decision maker and to expect the hospital will honor that directive as permitted by law and hospital policy, including psychiatric advance directives.

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(Patient Rights and Responsibilities continued)

9. Request a consult with the hospital Ethics Committee. To request a consult, ask your doctor, nurse or any other staff member involved in your care. This person will call a member of the Ethics Committee. Members of the Ethics Committee are available to provide information regarding healthcare decisions, talk about concerns and be a support for the patient, family, physician or other caregivers.
10. Have the hospital address your wishes related to end-of-life decisions.
11. Have, as required by state and federal laws, all activities, conversation, and records related to your medical care kept confidential.
12. Have consent be obtained for recording or filming made for purposes other than identification, diagnosis, or treatment of your condition. You also have the right to rescind your consent and to request the cessation of any recording or filming.
13. Be informed about the outcomes of your care, treatment, and services that have been provided, including unanticipated outcomes.
14. Know that this hospital recognizes your right to and need for effective communication.
 - You have the right to have visitors, make phone calls and receive mail.
 - You have the right to an interpreter (including translation) to be provided free of charge.
 - You have the right to have your communication needs addressed if you have any vision, speech, hearing, language or cognitive impairment and assistive devices provided free of charge.
15. Communicate any concerns about any aspect of your care, without being subject to coercion, discrimination, reprisal, or unreasonable interruption of care, treatment, and services including the ability to request a room change if you are dissatisfied.
16. Confidentiality, privacy and security.
17. Refuse to see anyone not officially connected with your care.
18. Have cultural, psychosocial, spiritual, and personal values, beliefs, and preferences respected. This includes the ability to wear clothing and other symbolic items as long as they do not interfere with your care and the right to pastoral and other spiritual services.
19. A reasonably safe environment.
20. Know the name and professional status of your caregiver.
21. Obtain, at your expense, another physician's opinion about your care.
22. Receive an explanation of your bill and receive information about charges for which you are responsible.
23. Know what hospital rules apply to your conduct as a patient.
24. Reasonable response to your requests.
25. Assessment and control to the extent possible of your pain.
26. Personal dignity.
27. Have family or representative and his/her own physician notified promptly of admission.
28. Be free from all forms of abuse or harassment.
29. Access protective and advocacy services. Information on these numbers is provided at the end of this section.
30. Be free from restraints or seclusion that are not medically necessary or used as means of coercion, discipline, staff convenience or retaliation.
31. Special protection if you are a subject in a research study or clinical trial. We further recognize that the personal relationships between physician, patient and hospital staff are important for the best medical care. Indeed, these are your partners in a healthcare team. As part of this team, we expect you to assume the following responsibilities:

You or your representatives are responsible for:

1. Giving complete information about your medical history and the medications you are taking.
2. Letting us know when you do not understand instructions.
3. Following the care, treatment and service plan developed for you.

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(Patient Rights and Responsibilities continued)

4. Accepting the consequences of not following instructions.
5. Following the hospital's rules and regulations.
6. Showing respect and consideration of the hospital's staff and property as well as other patients' and their property.
7. Respecting the hospital's visiting rules and regulations and respecting other patients' privacy by keeping noise to a minimum and using appropriate language while in the hospital.
8. Letting your physician or nurse know of changes in your health.
9. Meeting your financial commitments. You are responsible for your hospital bill and giving information needed to file an insurance claim.
10. Letting us know your needs.
11. Telling the nursing staff when you have personal valuables with you. The hospital cannot be responsible for items not placed in the hospital safe.
12. For providing complete information and documentation relating to the existence or non-existence of an advance directive.

Your Satisfaction

If you have any concerns regarding any of the items discussed in this document or concerns regarding any aspect of your care, please contact your nurse, physician, the patient representative at (816) 276-4252, a social worker or the pastoral care department at (816) 276-3530.

You may voice your concerns either verbally or in writing. (Research Medical Center 2316 E. Meyer Blvd., Kansas City, MO 64132 Attn: Patient Representative.) We make every attempt to address your complaints at your bedside. If we are unable to resolve your complaint to your satisfaction within 24 hours, a formal grievance will be initiated. All grievances receive acknowledgement in writing within 7 days and investigations and resolution processes are normally finalized within 7 days. If we are unable to finalize your grievance within 7 days we will keep you informed in writing of the process. You have the right to appeal any decisions that are made and our staff will assist you with this.

If your concerns are not resolved to your satisfaction, you have the right to ask for and receive information about outside agencies that may be able to help you. Your patient representative will assist you with this. You may also advise the Missouri Department of Health at (573) 751-6303, The Joint Commission at 1-800-994-6610 or The Office of Civil Rights at (816) 268-0550 of your concerns.

- Missouri Department of Health Complaint Hotline (573) 751-6303
- Department of Health & Human Services Office for Civil Rights (816) 426-7278
- Primaris (800) 735-6776
- Child Abuse Hotline (800) 392-3738
- The Joint Commission (800) 994-6610



Research Medical Center

Discharge Planning

Hospital Discharge Planning is a service to assist patients in arranging care following a hospital stay. These services may include home care, nursing home care, rehabilitative care, outpatient treatment and other needs as prescribed by your physician. The hospital's Discharge Planning Department can help facilitate a smooth transition.

Why is discharge planning important?

Hospital recuperation periods are usually short, so at discharge, some patients may require post-hospital services. At Research Medical Center, we understand that patients who are ill and hospitalized often have concerns and needs that must be addressed. The Discharge Planning Department has a team of nurse case managers and medical social workers available to assist you with those concerns and needs. We are a resource for the patient, family, and the healthcare team. We focus on coordinating patient care services to ensure the highest level of care and a safe discharge.

Although it seems early, discharge planning actually begins at admission and continues throughout your hospital stay. The physicians, nurses and other healthcare team members will work with you and/or your designee to formulate a safe discharge plan. With a referral from your physician or nurse, one of our team members will discuss discharge planning with you and/or your designee and healthcare team member to determine if any services, such as home health services, skilled nursing facilities, short-term rehabilitation, subacute care, hospice or other community resources will be needed after discharge. The discharge planner will collaborate with the healthcare team and physicians to ensure an appropriate and safe discharge plan.

How do I obtain discharge planning services?

While hospitalized, if you think you may need further healthcare services following your stay, ask your doctor or nurse to contact the hospital Discharge Planning Department on your behalf. We are here to help you in any way possible. Please feel free to call with any questions. Our goal is for you to be very satisfied with your discharge planning services.

Case Management: (816) 276-4264

Department Hours: Monday through Friday (8 a.m. to 4:30 p.m.)

After hours, please notify the nursing supervisor if assistance is required.

What can patients do if they feel they are not ready for discharge?

If you disagree with your discharge, then ask the hospital for Hospital Notice of Non-coverage; or, if you are in a Medicare HMO, a Notice for Discharge and Appeal Rights. These written notices will contain: the notice is not an official Medicare determination; when your financial obligation will begin; and the address and toll-free phone number of Missouri PRO. Call Missouri PRO right away to have your discharge reviewed. You will be notified within two working days if continued hospital inpatient care is approved. To obtain more information about your rights as a Medicare beneficiary, call 1-800- 347-1016 and ask for a free copy of "A Guide to Medicare: Rights and Preventive Services."

Thank you for choosing Research Medical Center for your healthcare needs.



Caring Conversations[®]

Making your wishes known for end-of-life care



workbook

This workbook belongs to

Date _____

This workbook includes a questionnaire to help you have “caring conversations,” an advance directive document, and a list of the most frequently asked questions about advance directives.

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Caring Conversations

Preface

We live within webs of social relationships — family, school, work, faith. We mark many of the predictable landmarks of our lives with social rituals — birthdays, graduations, weddings, retirements, deaths. However, social rituals that mark life’s last chapter are uncommon. Without such rituals, dying in America is marked in other ways.

Patients die in pain that could and should be managed. Seriously ill patients and their families needlessly suffer spiritual, psychological, and social distress. Too often, the financial costs of caring for dying patients are catastrophic, but the benefits of the care are marginal. Preferences concerning care are not expressed or heard, or they are heard but not respected. The value of life’s last chapter may be missed entirely.

This *Caring Conversations* workbook provides a social ritual to help you and your loved ones plan the kind of healthcare you will want at the end of life. Sharing the information in *Caring Conversations* allows others to understand and respect your wishes and moderates the tension that patients and their families experience during a last illness.

This workbook is intended to prompt you, your family, and friends to think about these issues now, while you are able to respond to specific questions. Sharing the workbook can help you and your loved ones find peace of mind. Your preferences may change over time, so revisit your workbook regularly and modify it as necessary. We invite you to use the workbook to prepare yourself and others to have caring conversations.

How to Use This Book

Reflect, Talk, Appoint, Act

This workbook is designed to help you reflect on decisions you may have to make in the future regarding your healthcare and how you wish to be treated when you are too ill to speak for yourself. It is also a tool to help you communicate these wishes to your loved ones and healthcare providers.

Talking with your loved ones is probably the most important and caring thing you can do to ensure that your loved ones and friends will know how you want to be cared for during the last chapter of your life. Advances in modern medicine have added years to our lives, but there comes a time for each of us when decisions will have to be made about continuing or discontinuing treatment, and how we want to die.

Caring Conversations can empower your loved ones and friends to act for you when that day comes. It can also help you identify an agent, a durable power of attorney for healthcare, whom you can designate to make your healthcare decisions. Ideally, your durable power of attorney will be a family member or close friend: someone who knows and understands your values, someone who will act

on your wishes with tenacity and courage. Naming and instructing your durable power of attorney is much easier in the context of having a caring conversation. Your choice of a surrogate decision maker (an agent) can then be formalized using the documents included in this workbook. You may also wish to complete a Healthcare Treatment Directive to help inform and guide your agent.

Some people may not want to appoint an agent or may not be able to identify the person they want to make decisions for them when they are no longer able to make or communicate their wishes. In such cases, you can still specify the kind of healthcare treatment you want by completing a Healthcare Treatment Directive and giving copies to your healthcare providers, friends, and loved ones.

For many people, the end of life is a call to complete unfinished business. It offers a time and opportunity to reexamine the relationships, events, values, decisions, and tasks that are most important to us. Preparing for this last chapter of our life is difficult and requires reflection. *Who am I? Who is important in my life? Whom do I want near me, or do I want to be alone?*

This workbook provides a series of questions to help you think about a future when you may no longer be able to make decisions. It will help communicate your preferences to those who may be called on to make decisions for you — loved ones

and healthcare providers — if you cannot speak for yourself.

You may want to complete this book alone, before you have a caring conversation. Or you may choose to fill it out with someone during a caring conversation. Even if you have already shared these thoughts, we urge you to talk about them again from time to time. Caring conversations affirm life; they ensure that your values and preferences will be known, remembered, and honored. They also give confidence and peace of mind to those we ask to act on our behalf.

As you consider the following questions imagine that you are in the last six months of your life. Use additional paper if needed and skip any questions you are not ready to answer. There are no “right” or “wrong” answers.

• With whom do you want to have your caring conversation? _____

• What do you most want them to know? _____

• When and where will you have your caring conversations? _____

• What life events have given you the most joy?

• What life events have saddened you the most, or caused you regret? _____

• What ethical, religious, or spiritual beliefs do you hold that influence your thoughts about life and your thinking about dying? _____

• What concerns do you have about your health or future healthcare? _____

• What are your fears regarding the end of your life?

• What do you most value about your physical or mental well-being (e.g., do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? How important is seeing, tasting, touching)? _____

• Are there circumstances under which you would refuse or discontinue treatment that might prolong your life? If so, describe those circumstances. _____

• If you could plan it today, what would the last day of your life be like? (Where would you be? What would you be doing? What would you eat? What music would you listen to? What would be your final words and your last acts?) _____

• How do you want to be remembered? _____

• If you wrote your own epitaph, what would it say?

End-of-Life Decisions

- What gives your life its purpose and meaning? _____

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

- If forgiveness is important to you, from whom will you seek it, and how? _____

- What spiritual, religious, and psychosocial support do you want as you journey near death? (Do you want to pray with a member of the clergy, be read to from spiritual or religious texts, or listen to poetry or music?)

- Whom do you want to make your healthcare decisions when you cannot make them for yourself? _____

- Who would be your second choice? _____

- How important is it to you to receive good pain management? (For example, would you want to be sedated if it were necessary to control your pain?)

- If you could no longer swallow, and there was no reasonable hope for recovery, would you want to be tube fed? _____

- Would you want to have a palliative or comfort care consultation? _____

• If the opportunity to participate in a research study were available, would you want your agent to consider your participation?

() Yes () No

• If yes, what levels of risk and benefit would you accept? (Check all that apply)

() Not greater than minimal risk

() Greater than minimal risk, but presenting the prospect of direct benefit to me

() Greater than minimal risk with no direct benefit to me but likely to yield knowledge about my disorder or condition

() Greater than minimal risk with no direct benefit to me and unlikely to yield knowledge about my disorder or condition, but which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health and welfare of other people

• Would you choose to continue or begin treatments that may prolong your life if you are . . . (please circle your response)

• No longer able to think for yourself.

Yes No

• No longer able to communicate with your family and friends.

Yes No

• Permanently unconscious or in a persistent vegetative state?

Yes No

• Of very advanced age.

Yes No

• What does very advanced age mean to you? _____

• Where do you want to be when you die? Would you prefer to be in a hospital, at home, or in a special place? _____

• What do you think would make you comfortable? Do you want privacy and quiet, or would you prefer to have the company of loved ones and friends? Would you want to be held? To review family photos, stories, and traditions? To listen to music?

• Do you wish to donate your organs and tissue? _____

• Do you want to donate your body for medical science? If yes, to what institution? _____

• Would you agree to an autopsy? _____

• Do you prefer burial or cremation? _____

Career, Legal, and Financial Decisions

- If work is still part of your life, are there duties and obligations to delegate or projects to finalize?

- Are there things you want friends and loved ones to know about the importance of work and career to you?

- Do you have a will, living trust, or other legal documents? If so, where are these documents located?

- Have you made financial arrangements that you want others to be aware of (e.g., long-term care insurance, transfers of property, providing for dependents, designating charitable contributions)? _____

- Where do you keep information about your bank account, insurance policies, stock certificates, deeds, titles? And who has access to this information? _____

Conclusion

Having caring conversations can provide confidence and peace of mind to those faced with making decisions for loved ones at the end of life.

The next section of this workbook includes a Durable Power of Attorney for Healthcare Decisions and a Healthcare Treatment Directive. These are legal documents. You may complete both forms.

The Durable Power of Attorney for Healthcare Decisions is your designation of a decision maker (an agent) to make healthcare decisions for you. It is valid in any state so long as it is notarized, signed, and witnessed. We encourage you to complete this form and give copies to your healthcare providers, family, friends, and loved ones.

The Healthcare Treatment Directive is also a legal form, valid in all states. You may use it to specify the kind of healthcare you want when you are no longer able to make or communicate your wishes. Your agent, if you have one, will be guided by this form when he or she is acting on your behalf. If you do not appoint an agent, it is important to complete this form and give copies of it to your healthcare providers, family, friends, and loved ones to help them know your preferences when you can no longer speak for yourself.

We also encourage you to continue having caring conversations. Your preferences and values may change over time, but making your desires known will give you and your loved ones peace of mind as you near the end of life.

Preparing an Advance Directive

Advance directive is a general term used in this workbook to describe both a Durable Power of Attorney for Healthcare Decisions and a Healthcare Treatment Directive. It is a term also used to refer to living wills and informal directives people may set down in letters or conversations.

An advance directive allows you to communicate your healthcare preferences when you can no longer make your own decisions. The U.S. Supreme Court has recognized that adults with decision-making capacity have a constitutional right to refuse any medical treatment, including ventilators and feeding tubes, and to name an agent to act on their behalf. State laws also support advance care planning.

This advance directive has been developed to help you document your wishes about healthcare. It has two parts:

1. **Durable Power of Attorney for Healthcare Decisions:** a document that allows you to name a person to make healthcare decisions for you.
2. **Healthcare Treatment Directive:** a document that allows you to state in advance your wishes regarding the kind of healthcare treatment you want when you cannot make or communicate these decisions.

You may complete one or both of these forms. They will be more helpful and informative if you discuss your wishes with your loved ones, friends, and healthcare providers as part of your advance care planning.

The Benefit of Communication

The greatest benefit of your advance directive is its power to communicate your wishes. Discuss your advance directive with your doctor, and make your wishes about healthcare known to your loved ones, friends, healthcare providers, clergy, and your attorney (if you have one), and others whom you trust to carry out your wishes.

Completing the *Caring Conversations* workbook first will make this process easier. It provides an opportunity for you to identify and communicate your goals and values. Discuss the workbook with those who care for you.

1. What is an advance directive?

Usually an advance directive is composed of two parts: the appointment of an agent to make healthcare decisions for you when you are unable to make these decisions for yourself (a durable power of attorney for healthcare); and a description of the kind of medical treatment you want when you are facing serious illness (e.g., a living will or healthcare treatment directive).

2. Do I need both a Durable Power of Attorney for Healthcare Decisions and a Healthcare Treatment Directive?

While it is useful, it is not necessary to have both. However, situations may arise that your Healthcare Treatment Directive does not cover. To anticipate such events, you should name a person (agent) you can trust to make decisions for you. Be sure to discuss your *Caring Conversations* workbook (if you have one) and your Healthcare Treatment Directive with your agent.

3. How is your Healthcare Treatment Directive different from a living will?

The Healthcare Treatment Directive is similar to a living will because it is a signed, dated, and witnessed document that allows you to state in advance your wishes regarding treatment when you are seriously ill or at the end of life. The difference is that most living wills apply only when you are terminally ill. The Healthcare Treatment Directive becomes effective whenever you lose your ability to make and communicate decisions.

4. How is the Durable Power of Attorney for Healthcare Decisions different from other powers of attorney?

Powers of attorney usually address business and financial matters, and are no longer effective when you lose decisional capacity unless they are “durable.” A Durable Power of Attorney for Healthcare Decisions allows you to name a person (agent) to make healthcare decisions for you. It takes effect only when you lose the ability to make or communicate your own decisions. Some people choose to name separate

agents for business and healthcare decisions and must use separate documents to do so. The document in this book addresses healthcare matters only.

5. Whom should I name as my agent?

It is important that you name a person as your agent who knows your goals and values and whom you trust to carry out your wishes. You may name a family member, but it is not necessary to do so. You might choose your spouse, an adult child, a close friend or other loved one. Be sure to talk with your agent about your wishes in detail and confirm that he or she agrees to act on your behalf. When you complete your *Caring Conversations* workbook, share it with your agent.

6. If I have already completed a living will, or other advance directive, do I need a Healthcare Treatment Directive or Durable Power of Attorney for Healthcare Decisions?

Your living will may not be as comprehensive as the Healthcare Treatment Directive, and may not allow you to name an agent. If you decide to complete the Healthcare Treatment Directive or Durable Power of Attorney for Healthcare Decisions, notify persons to whom you have distributed your living will and give them a copy of your new advance directive. It is always a good idea to review any previously completed documents and discuss any needed changes with your healthcare providers.

7. Do I need an attorney to make a Healthcare Treatment Directive or a Durable Power of Attorney for Healthcare Decisions?

No. However, you may want to discuss your advance directive with your attorney, if you have one.

8. Do advance directives need to be witnessed or notarized?

Yes. Witnessing and notarizing requirements vary from state to state and from document to document. States typically require witnessing by two adults, and they may limit who may witness. Some states disqualify persons as witnesses who are related to you, who will inherit from you, or for whom you are financially responsible. Because of state-to-state differences, it is a good idea to have advance directives both witnessed and notarized.

9. Does the federal privacy rule known as HIPAA affect the ability of the agent I appoint as my durable power of attorney for healthcare to make healthcare decisions for me?

HIPAA does not apply to patients. People acting as agents under durable powers of attorney for healthcare have the same rights as the patients who appointed them. Therefore, HIPAA does not impede an agent's ability to make healthcare decisions.

Furthermore, HIPAA allows "covered entities," such as hospitals and nursing homes, to use or disclose the information contained in your durable power of attorney for healthcare document to help identify, locate, and notify your agent that he or she is needed.

10. What effect does HIPAA have on my healthcare directive?

HIPAA prohibits "covered entities," such as hospitals and nursing homes, from making unauthorized disclosures of "protected health information." When a copy of your healthcare directive is placed in your medical record, it becomes part of the protected health information. However, because HIPAA authorizes covered entities to disclose relevant protected health information to family members, other relatives, or close friends who are involved with a patient's care, HIPAA should not have any effect on your healthcare directive.

Giving copies of your healthcare directive to everyone who might advocate for your healthcare further ensures that HIPAA won't be an obstacle. You may make and distribute as many copies of your healthcare directive as you want.

11. What do I do with my completed advance directive?

Make copies of your advance directive to provide to any agent(s) named in your Durable Power of Attorney for Healthcare Decisions and other appropriate individuals (i.e., physicians, family, friends, clergy, and attorney).

- Discuss the details of your advance directive with these individuals.
- Ask your physician to make it part of your permanent medical record.
- Whenever you are hospitalized or go on a trip, take a copy with you.
- You may also want to register your advance directive with an online repository (e.g., uslivingwillregistry.com) so that your agent or healthcare providers can retrieve it electronically.

12. When does my advance directive go into effect?

So long as you can make decisions, it is both your right and your responsibility to make your own decisions. Therefore, your advance directive goes into effect only when you are no longer able to make or communicate your decisions.

13. How long will my advance directive be effective?

As a general rule, your advance directive is effective until the time of your death. We recommend that you review your advance directive periodically, especially when there is a change in your health status. Date and initial it following every review, and discuss any changes with your family, friends, and physician.

If you appoint an agent in a Durable Power of Attorney for Healthcare Decisions document, your agent can, in conformity with state law, make a few decisions following your death, for example, decisions about an autopsy, organ and tissue donation, and the disposition of your body.

14. May I change or revoke my advance directive?

Yes, you may change or revoke it at any time, either verbally or in writing.

15. Will my advance directive be valid in another state?

Yes, especially if it is both notarized and witnessed. The right to make an advance directive has been constitutionally affirmed.

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Durable Power of Attorney for Healthcare Decisions

■ **Take a copy of this with you whenever you go to the hospital or on a trip** ■

It is important to choose someone to make healthcare decisions for you when you cannot make or communicate decisions for yourself. Tell the person you choose what healthcare treatments you want. The person you choose will be your agent. He or she will have the right to make decisions for your healthcare. If you DO NOT choose someone to make decisions for you, write NONE on the line for the agent's name.

I, _____, SS# _____ (optional), appoint the person named in this document to be my agent to make my healthcare decisions.

This document is a Durable Power of Attorney for Healthcare Decisions. My agent's power shall not end if I become incapacitated or if there is uncertainty that I am dead. This document revokes any prior Durable Power of Attorney for Healthcare Decisions. My agent may not appoint anyone else to make decisions for me. My agent and caregivers are protected from any claims based on following this Durable Power of Attorney for Healthcare. My agent shall not be responsible for any costs associated with my care. I give my agent full power to make all decisions for me about my healthcare, including the power to direct the withholding or withdrawal of life-prolonging treatment, including artificially supplied nutrition and hydration/tube feeding. My agent is authorized to

- Consent, refuse, or withdraw consent to any care, procedure, treatment, or service to diagnose, treat, or maintain a physical or mental condition, including artificial nutrition and hydration;
- Permit, refuse, or withdraw permission to participate in federally regulated research related to my condition or disorder
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home, or other healthcare organization; and, employ or discharge healthcare personnel (any person who is authorized or permitted by the laws of the state to provide healthcare services) as he or she shall deem necessary for my physical, mental, or emotional well-being;
- Request, receive, review, and authorize sending any information regarding my physical or mental health, or my personal affairs, including medical and hospital records; and execute any releases that may be required to obtain such information;
- Move me into or out of any State or institution;
- Take legal action, if needed;
- Make decisions about autopsy, tissue and organ donation, and the disposition of my body in conformity with state law; and
- Become my guardian if one is needed.

In exercising this power, I expect my agent to be guided by my directions as we discussed them prior to this appointment and/or to be guided by my Healthcare Directive (see reverse side).

If you DO NOT want the person (agent) you name to be able to do one or other of the above things, draw a line through the statement and put your initials at the end of the line.

Agent's name _____ Phone _____ Email _____
Address _____

If you do not want to name an alternate, write "none."

Alternate Agent's name _____ Phone _____ Email _____
Address _____

Execution and Effective Date of Appointment

My agent's authority is effective immediately for the limited purpose of having full access to my medical records and to confer with my healthcare providers and me about my condition. My agent's authority to make all healthcare and related decisions for me is effective when and only when I cannot make my own healthcare decisions.

SIGN HERE for the *Durable Power of Attorney* and/or *Healthcare Directive* forms. Many states require notarization. It is recommended for the residents of all states. Please ask two persons to witness your signature who are not related to you or financially connected to your estate.

Signature _____ Date _____
Witness _____ Date _____ Witness _____ Date _____

Notarization:

On this _____ day of _____, in the year of _____, personally appeared before me the person signing, known by me to be the person who completed this document and acknowledged it as his/her free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____
Commission Expires _____

Healthcare Treatment Directive

■ If you only want to name a Durable Power of Attorney for Healthcare Decisions, draw a large X through this page. ■

I, _____, SS# _____ (optional) want everyone who cares for me to know what healthcare I want.

I always expect to be given care and treatment for pain or discomfort even if such care may affect how I sleep, eat, or breathe.

I would consent to, and want my agent to consider my participation in federally regulated research related to my disorder or condition.

I want my doctor to try treatments/interventions on a time-limited basis when the goal is to restore my health or help me experience a life in a way consistent with my values and wishes. I want such treatments/interventions withdrawn when they cannot achieve this goal or become too burdensome to me.

I want my dying to be as natural as possible. Therefore, I direct that no treatment (including food or water by tube) be given just to keep my body functioning when I have

- a condition that will cause me to die soon, or
- a condition so bad (including substantial brain damage or brain disease) that I have no reasonable hope of achieving a quality of life that is acceptable to me.

An acceptable quality of life to me is one that includes the following capacities and values. (Describe here the things that are most important to you when you are making decisions to choose or refuse life-sustaining treatments.)

Examples: + recognize family or friends + make decisions + communicate
 + feed myself + take care of myself + be responsive to my environment

If you do not agree with one or other of the above statements, draw a line through the statement and put your initials at the end of the line.

In facing the end of my life, I expect my agent (if I have one) and my caregivers to honor my wishes, values, and directives.

For further clarification, please refer to my *Caring Conversations* Workbook, which is located at _____.

Be sure to sign the reverse side of this page even if you do not wish to appoint a Durable Power of Attorney for Healthcare Decisions

Talk about this form and your ideas about your healthcare with the person you have chosen to make decisions for you, your doctors, family, friends, and clergy. Give each of them a completed copy.

You may cancel or change this form at any time. You should review it often. Each time you review it, put your initials and the date here. _____

This document is provided as a service by the Center for Practical Bioethics.
For more information, call the Center for Practical Bioethics at 816-221-1100
Email – bioethic@practicalbioethics.org • Website – www.practicalbioethics.org

Frequently Asked Questions

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16. Can I expect healthcare providers to carry out the directions in my advance directive?

Yes, you should expect that your directions will be carried out. Healthcare providers have both legal and ethical duties to respect patient directions, whether verbal or written, within any limitations of state law. However, your directive is more likely to be known and honored if you have named an agent to act on your behalf. If your directive is not being honored, your agent or loved ones should ask for help from an ethics committee, social worker, chaplain, or ombudsman.

17. Will my advance directive be honored in an emergency situation?

Depending on your condition and orders written by your doctor and available to first responders, your advance directive may not be honored in an emergency.

However, after the emergency situation has passed, your agent will be able to make your directive known to the healthcare providers who will continue to care for you.

18. Will my advance directive prevent me from getting cardiopulmonary resuscitation (CPR) if my heart stops, or I stop breathing?

Not in most cases. A very specific document called a Do Not Resuscitate order (DNR order) must be authorized by your doctor for responders not to attempt resuscitation. We recommend that you discuss this serious matter with your doctor.

If your advance directive addresses the subject of resuscitation, it may be used as evidence of your consent to a DNR order during times of incapacity.

19. Can my advance directive or decisions made by my agent be overridden by my family members?

Advance directives and decisions made by an appointed agent are morally and legally binding. In practice, however, they are not always honored. The best assurance that they will not be overridden is conversation about these matters with your loved ones

and healthcare providers. Instruct your agent to use your healthcare treatment directive as a guideline. He or she may have to make decisions for you in clinical situations that you have not anticipated.

20. Can someone else complete an advance directive for me without my participation?

No, an advance directive is your statement of your preferences.

21. May I request that tube feedings be withheld or withdrawn?

Yes. In some states, a clear and specific instruction to decline tube feeding may be required.

22. May I state my wishes for donating organs or tissues in my advance directive?

Yes. You may also want to complete an organ donor card, and discuss your wishes with your loved ones. In some cases, state law may limit the power of your agent once you have died.

23. How can I describe what an “acceptable quality of life” means to me?

There is no right answer to this question; however, here are some things to consider:

- What is your own “bottom line?” Under what circumstances would dying naturally be preferable to sustaining life?
- Do religious values influence your treatment decisions? (If so, how?)
- How important is it for you to be able to care for yourself?
- What kind of living environment would you be willing to accept?
- How important is it to you to be able to recognize family and friends?

Conclusion

We encourage you to complete the *Caring Conversations* workbook, discuss your healthcare treatment preferences with those who care for you, and indicate that you have done so on your advance directive. The more you express your choices regarding end-of-life care, the more confidence and peace of mind you and your loved ones will have in making these decisions.



Caring Conversations[®]

Making your wishes known for end-of-life care

The Center for Practical Bioethics is a freestanding practical bioethics center.

Our vision is a society in which the dignity and health of all people are advanced through ethical discourse and action. Our mission is to raise and respond to ethical issues in health and healthcare. Our core value is respect for human dignity. We believe that all people have intrinsic worth, and we express this belief by promoting both autonomy and social justice in health and healthcare.

We welcome your interest in the *Caring Conversations* program. For more information about *Caring Conversations* or the Center for Practical Bioethics, please contact us at 816 221-1100, visit our website www.practicalbioethics.org, or email us at bioethic@practicalbioethics.org.



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*Please
place
stamp
here.*