



Christopher P. Jordan, M.D.

Jordan Digestive Diagnostic Center, 649 Guy Road, Clayton, NC 27520

Phone: 919-938-4404 | Fax: 919-938-3055

Layman's Guide to Death with Dignity

It is becoming increasingly difficult to die peacefully, whether in North Carolina or anywhere else in the United States today. If you had the choice, you would probably wish to live a long, healthy and happy life and then die suddenly in your sleep. For a few people, death does come quickly - they have a massive heart attack or stroke or an accident, and it's all over in a matter of minutes. But most of you will face a quite different end to your life. You may become ill and deteriorate over weeks or months or years, or a sudden accident or catastrophic illness may occur. In either case, you may become unconscious or otherwise unable to make decisions. Unless you take certain steps before that happens, you will have no control over the medical decisions that are made for you during your final days.

As an alert, competent adult, you are able to exercise your right to make decisions concerning your own health care. You can decide to go ahead with certain treatments or operations or you can decide that you would prefer not to undergo them. The trouble arises when you are no longer alert and competent and can no longer make such decisions. Most of you will pass through that stage toward the end of your life, so you need to make your wishes known now about how you wish your health care managed at that time.

Medical technology has progressed so far in this country that it's often possible to keep people "alive" well beyond the point where their life has meaning or quality. Patients who can't communicate their wishes regarding their medical care can be kept alive by heart-lung resuscitation, breathing machines, artificial feeding and other methods. Many people see this as postponing death rather than sustaining life.

In earlier times, there were fewer heroic life-saving technologies, and most patients had a personal family physician who knew their wishes concerning life-sustaining measures and would be available and able to ensure a peaceful death with dignity. Today, a personal physician who knows your wishes is still the best safeguard against care you do not want. But many patients don't have a personal physician or, if they do, that physician may not be present when needed for these decisions. For these reasons, written expressions of your wishes have become very important. Public opinion and North Carolina law supports a person's right to make such personal decisions, so you or a loved one can die with the dignity you expect.

You may have heard of a living will, one such document that safeguards certain legal rights you have regarding the kind of care you'll receive at the end of your life. But those rights only apply to people who are terminally and incurably ill, or in a persistent vegetative state. An example of terminally and incurably ill would be people in the last stages of cancer or heart disease. An example of persistent vegetative state would be people with brain injuries from accidents - their eyes open, they can move and react to pain, but they cannot respond purposefully to the world around them; they are not aware.



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The living will does not apply to people who have had a stroke and lapse into coma. Such people are totally and completely unresponsive, but not terminally and incurably ill, nor are they in a persistent vegetative state. Sometimes they can breathe unaided and their heart beats, but that is the extent of their life. The living will also does not apply to people who develop severe dementia. These individuals undergo progressive and untreatable mental degeneration and eventually become totally unable to care for themselves. None of these people can be helped by a living will until just before they die because until then, they cannot be defined as terminally and incurably ill or in a persistent vegetative state, and that can be many years after they become ill.

Advance care documents state the kind of care you expect at the end of your life should you become unable to speak and decide for yourself. The living will, the health care power of attorney, and the medical directive are the advance care documents that let competent people instruct their family, physicians, friends, lawyers, clergy and others important in their lives about their wishes for medical care.

This document was written to help people who want to die with dignity. It explains what advance care documents can do and discusses the shortcomings of each. It is the result of the cooperative efforts of most of the people who could be involved in helping you during the last months of your life: physicians, nurses, emergency medical personnel, clergy, ethicists, attorneys, and representatives of nursing homes, hospices, home health agencies and hospitals. We all want you to be able to decide for yourself what you do and do not want done to you when you are no longer able to speak for yourself and have your wishes carried out.

North Carolina statutory living will and health care power of attorney forms are linked to this document. Examine them carefully. You might want to consult with your family, physician, friends, attorney and clergy.

Advance Care Documents - The Living Will

North Carolina has a law (the Right to a Natural Death Act) that says you can execute a living will (exactly as presented in the attached living will form) and that it will be honored. In effect, when you execute a living will you state that you do not want your life to be prolonged by extraordinary means or artificial nutrition or hydration if you choose in the event of a terminal and incurable condition or a persistent vegetative state. A living will is simple to fill out and only requires the signature of two witnesses (who are not related to you) and a notary public. It is a good starting place for people who want to control the end of their life. You write and sign a living will when you are mentally alert and competent. It remains effective when you can no longer direct your health care. This is the first and easiest step to ensure your death with dignity.

Living wills have limited applications. A living will executed in North Carolina may not be valid in another state since living will laws differ in virtually every state that has one. Living wills don't apply to people in a coma or with severe dementia unless they are also terminally and incurably ill. There



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is also a continuing controversy about what is and is not meant by a "desire that my life not be prolonged by extraordinary means." (Does it just mean don't restart my heart if it stops, or does it mean don't treat my pneumonia?) But because North Carolina law protects doctors, nurses and other healthcare personnel who honor your properly executed living will, it is an excellent way of having your wishes carried out.

Health Care Power of Attorney

There is a better chance that your wishes expressed in your living will or medical directives will be carried out if you discuss them in advance with your physician and with your next of kin. Even better, you can also name someone to make healthcare decisions for you (your surrogate) by executing a health care power of attorney. Your surrogate can be anyone you choose from your spouse or adult children to a friend or attorney.

A durable power of attorney is a document that people have drawn up to give someone else the power to handle their business affairs for them should they become unable to act for themselves. A health care power of attorney does the same thing regarding medical care. Your surrogate makes healthcare decisions for you when you no longer can. North Carolina law allows you to give extensive directions to your surrogate, including incorporation of medical directives, and protects healthcare personnel who comply with the surrogate's instructions on your behalf. For example, it may be made broad enough to cover withholding life sustaining procedures or artificial feeding and hydration for severe dementia. A NC statutory health care power of attorney form is linked to this document. Study it, talk about it, and modify it, if you wish. It is legally protected and will provide clear evidence of your intentions.

The Medical Directive

Because of the shortcomings of the living will, there was a movement in North Carolina toward the use of medical directives. This trend, however, subsided upon passage of the more flexible health care power of attorney. Nevertheless, a medical directive still may be used.

With a medical directive you may specify in advance, while you are mentally alert and competent, certain situations in which you do or don't wish certain medical interventions done to you. You can say, for instance, that if you have severe dementia and you develop pneumonia, you do want antibiotics given to you to treat the pneumonia. Or you can say that if you have severe dementia and then have a stroke and are unable to swallow food, you don't want a feeding tube put into you. You can limit the place you receive care, such as refusing transfer to a hospital as long as you can be kept comfortable at home or in a nursing home.

The power to execute a medical directive comes from your virtually unlimited right as a mentally alert and competent adult to refuse treatment. A medical directive is valuable evidence of decisions you made while you were competent for use in time when you are not competent. Remember, if



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you incorporate it into your health care power of attorney, you give additional legal protections to caregivers who follow your wishes.

Of course, it's impossible to foresee all the situations that might happen to you, but stating your wishes for some situations will be a helpful guide for those who will be making decisions about your care.

All advance care documents have shortcomings, of course. In an ideal situation you would remain awake and alert and pain-free, giving all the needed directions for your own care. No advance care documents can take the place of the alert and competent patient, nor can they give you an absolute guarantee that your wishes will be followed. There can be no absolute guarantees as long as there are other people around your bedside telling your doctor to do more. But there is little question that the people involved in your care will do their best to abide by your wishes if you have gone to the trouble of filling out a living will and/or a health care power of attorney. Besides just filling out documents, though, it is very important to discuss your wishes with your family and your physician. What these steps taken together provide is clear and convincing evidence of your wish to die with dignity, the best possible way to assure today that you will die that way in the future.

Where to Put Your Advance Care Documents

No advance care document will do any good if it is not placed where it can be located when needed. It should certainly be placed in your medical record in your doctor's office; another copy should be in your home. If you are receiving hospice care, home health care or are in a nursing home, a copy should be in the office of that agency or facility.

Certain people besides your doctor should also have a copy of your advance care documents: your spouse, your surrogate, and your next of kin. In addition, you may also want to give copies to your adult children, one or more close friends, your clergy or pastor, the nurse or home health aide who takes care of you or any other person you feel should have access to or know about the documents.

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PO Box 27167 Raleigh, NC 27611