

Talking *Now* About Later: *Advance Care Planning Your Way*

What is Advance Care Planning?

It is a term that refers to discussions and decisions that affect the way we live through the end of our lives. It is more than the dramatic things we see on television, like resuscitation and high-tech equipment that keeps people alive, or seemingly brings them back from death. Advance care planning also includes a thoughtful dialogue with those closest to us about what has been important to us yesterday and today, and what we believe will still be important to us on the last day of our lives.

There have been studies about the quality of this nation's end-of-life medical care that, no doubt, contribute to our reticence to discuss it; health care is not yet what we want it to be. But statistics and studies do not describe *you*. How we live and how we relate to those around us are ours alone. Our advance care plans, from the smallest detail – "I want bright red nail polish" – to the broadest philosophical statement – "I believe that life is a gift and I must do everything on this earth to continue it" – can put us in touch with what makes each of us unique. Thinking about dying is part of life, and it presents an opportunity to review all that is most precious to us with the people we love.

So when should this dialogue start? If not today, there are benchmarks that offer logical starting points. Even our first issue of *Modern Maturity* reminds us that our life, with its values and priorities, is precious, and that we'd like to live it that way to the last moment.

The final months, weeks or days of this life may come in a flash or with measured steps, but it will be the memory and legacy of those we love. Planning for this time is both a personal satisfaction and a loving gift.

"Dying is the most embarrassing thing that can ever happen to you, because someone's got to take care of all your details." artist Andy Warhol

Warhol, not necessarily known as a great philosopher, hit the nail on the head. In today's culture, we may carefully schedule every quarter-hour, take three months to cost out the purchase of a car, or buy cell phones to stay in control. Yet many of us defer any thought of how we will live the end of our lives, whenever that may be – those details – to family, friends, or even total strangers. Others of us have been able to make few choices in our lives, especially about health care. It may require a shift of perspective to claim this right and plan ahead, but there is help available.

We *will* face choices in life's last chapter. Whether we will be in a position to make them ourselves is unknown, but we know we can make them now.

What are the choices?

We know many of the decision points, but the specifics of your life and family may suggest others.

- ◆ What makes your life worth living?
- ◆ What could make life unbearable?
- ◆ Who could make decisions for you if you could not speak for yourself?
- ◆ Would you want your life to be sustained at all costs?...
- ◆ and if not, what are the conditions or qualifications for that decision?
- ◆ Would you want to be resuscitated, and under what circumstances?
- ◆ Who do you want to care for you?
- ◆ Where do you want to be?
- ◆ What and who do you want around you?
- ◆ What are the financial implications of your choices?
- ◆ At what point would you welcome hospice care?
- ◆ What are the most important things you want others to know at the end of your life?

Why are there choices?

Each of us is unique. We come from different nations, races and traditions. A wide array of religious beliefs have shaped individual values and ethics. Some people have a circle of family or friends who expect to care for each other, while others are concerned about being alone. The rich and the poor, the insured and uninsured, know that care can be costly. Not every community offers appropriate supportive resources.

Most important, we cannot say what other people's lives mean to them, or expect them to understand what we value in our own. How can we tell our loved ones, our doctors or hospitals to "do what you think best" if we have not taken time to talk about what "best" means for us?

When should we talk about these plans?

It is unrealistic to think that such important and far-reaching choices can be made quickly. Advance care planning is an ongoing process. It can start today at the birth of a child, or a birthday, wedding or anniversary. It may fit well with the annual physical examination, a consultation about wills or trusts, the family reunion, a personal health scare, a meeting with a spiritual counselor, or a Sunday dinner. But it should continue as life evolves and circumstances change.

How do I start?

The first step may be the most awkward, both within families and professional relationships. This is a serious topic, but remember that a light heart can make these discussions easier. Here are some suggestions that may help initiate conversations about your planning:

- ◆ *Thanks for the birthday gift. Here is something else you can do for me, a conversation about ...*
- ◆ *My doctor said I have nothing to worry about and you're stuck with me. I'd like to take advantage of this good fortune by beginning to make some plans.*
- ◆ *While we're here together, I hope we can talk about the important things in our lives that we want to hang on to.*
- ◆ *You have a lot of responsibilities. I'd like to make some plans that can spare you some hard decisions.*

It may be harder to ask a family member to plan for end-of-life care. Here are some suggestions for broaching the subject:

- ◆ *Seeing what is going on with Doug reminds me that you have never told me what you would want.*
- ◆ *I'm glad you've made some decisions about your property. There are some other important decisions I'd like to talk about.*
- ◆ *I'm relieved that I talked about an advance directive with my doctor. I'd like to show you what it covers and see if I could help you make one.*
- ◆ *Last night's TV show made me realize I have no idea what you would want if you were very ill and couldn't tell me about your own decisions. Can we talk about that?*

What if there is resistance?

If your family is not used to talking over important matters, some may balk at discussing this topic. Family members do not always share common values. When long-standing conflicts exist, or if most conversations end in arguments, summoning a spirit of cooperation may seem impossible.

Acknowledge the difficulty; perhaps it can't be fixed at this time. Try a frank approach:

- ◆ *I know you don't like to talk about these things, but I'd like to show you some papers that may help.*
- ◆ *We have our differences but neither of us is getting any younger. I'd like to think we could talk about plans for later and avoid misunderstandings.*
- ◆ *I'm considering some choices that I'd like you to respect. I'd be glad to hear about your advance care plans, too.*

There are some excellent documents that can help you think and talk about advance care planning. While nothing replaces your conversation with your family, a paper may provide a starting point. Consider asking a third party to help this conversation happen: a mutually trusted friend, a spiritual advisor, or an elder law attorney may help.

Besides family, who else needs to be involved?

Many people with living wills or health care powers of attorney have, unfortunately, never discussed them with others. While executing documents is important, the most vital part of the process is the discussion that leads up to them.

Be sure that your ongoing discussions include the person(s) who would be:

- ◆ your caregiver
- ◆ your healthcare decision-maker (proxy)
- ◆ your physician

Also include:

- ◆ close family or friends on whom you would rely for support
- ◆ anyone who is a beneficiary of your estate
- ◆ your clergyperson or spiritual advisor

The goal is to have a dialogue with anyone who might be called upon to make decisions for you, or who might be affected by their implementation. It is helpful to include someone who understands and supports your values and choices.

How can I know what I'd want at life's end?

The questions asked earlier in *What are the Choices?* may give some guidance. It often takes a lot of thinking and talking to come up with answers that feel right. You may want to talk with friends or family members who have lost a loved one about their experiences: What worked well? What do they wish they could change? Ask your doctor what he or she would like you to consider. Your personal or family medical history may provide clues.

What should my plans include?

The most important element of advance care planning is your philosophy of living and dying. There is no right or wrong philosophy, but there is your way. Whatever document you eventually use should clearly reflect a basic belief that, if the best medical care cannot return you to a life worth living as you define it, you either do or do not want your life sustained by any means.

Of course, there can be gray areas around:

- ◆ differing medical opinions
- ◆ how a worthwhile life is defined
- ◆ which treatments are meant to prolong life and which are for comfort only

Even the issue of resuscitation seems muddled. Many people feel concerned that they may be "written off" if they agree not to be resuscitated. Some do not realize that resuscitation is only begun if one has already died, and therefore has a low success rate.

Because of these gray areas, it is likely that additional decisions will be required down the road. The second most important element of your plan is the choice of a person who can make decisions for you if you cannot make them yourself. It is vital that the decision-maker be part of discussions on care planning, and that he or she understands your values.

You may also want to include quality-of-life factors –what you’d like to see, hear, smell, touch; personal messages to others; or after-death matters, such as organ donation, feelings about autopsy, and preferences about services or rituals. Legal matters such as guardianship may be included, but consult an attorney first.

This may be the time to learn more about hospice care if you are not sure what it provides. Contact your local hospice for a brochure; you can locate the hospice near you through the National Hospice and Palliative Care Organization (NHPCO). If hospice care fits with your wishes, tell your doctor and your family, and make that choice a part of your care planning.

How do I record my plans?

You may have heard of advance directives called Living Wills and Durable Powers of Attorney for Health Care. The first is a statement about the care you choose if you are terminally ill. The power of attorney names a decision-maker, or proxy, to speak for you in any situation when you cannot make your own health care decisions. This document may or may not include some guidance as to your values. Every state has adopted language for these documents that will be honored within its boundaries, and many states honor directives from other states. To find the directives used in your state, download the appropriate forms at internet sites for AARP or NHPCO.

Some organizations have developed their own easy-to-understand documents to aid family discussions. One of the most popular directives is called Five Wishes, and it is accepted as a legal document in most states.

This is hard--why do I need an advance directive?

Yes – this is very serious stuff. The burden of advance care planning is that we are discussing and acknowledging our own mortality and the mortality of people we dearly love. You may wish you could avoid it, but you and those dear to you may pay a heavy price for this denial.

Persons who consider, discuss, and commit their wishes about end-of-life care to paper gain:

- ◆ personal power in decisions that could otherwise leave them powerless
- ◆ an opportunity to live every day according to their own values
- ◆ peace of mind for themselves and those they love
- ◆ avoidance of situations that are personally, spiritually, or financially painful
- ◆ responsibility for their own decisions
- ◆ an intimate understanding of those who will be caregivers and decision-makers

For people of faith, these well-considered plans are also an affirmation that death does not have the last word.

Can I change my plans?

You can always change your plans, and probably should. We continue to be presented with new challenges and opportunities, and family roles can change. Think of opportunities to review your plans.

- ◆ Remind your family doctor that you want to discuss end-of-life health care at each annual exam.
- ◆ Preparation and changes of wills or trusts should include health care planning changes.
- ◆ Every birthday and every loss can prompt a personal re-evaluation.

What do I do with these papers?

Make more copies than you can imagine needing and be sure they are dated in case you amend them. Distribute copies to the following, noting that you have done so for later replacement.

- ◆ Your primary **physician** and all other physicians who treat you must understand your wishes.
- ◆ Your **decision-maker** should have several copies.
- ◆ All **family members** will feel included and valued by knowing your wishes.
- ◆ **Clergy** will be prepared to support your decisions.
- ◆ **When traveling**, put a copy in the glove compartment of your car, and in a purse or briefcase if you will be out of town.
- ◆ Take a copy to the **hospital** for any admission.
- ◆ Put a note in your **wallet** that you have an advance directive and who to contact.

Are there other resources?

Watch for workshops or lectures in your local media. Your area hospital may offer information and assistance, as do organizations for seniors. Hospices, the experts in end-of-life care, are excellent sources of information.