

CHAPTER 15: PLANNING FOR THE FUTURE

INTRODUCTION

Each person on this earth will be here for only a limited amount of time. From the moment of our birth, we are on incredible, forward-moving journey that will one day end. The date and hour of our deaths are a mystery to us. In our day-to-day lives that are so full of life, we seldom think of death.

A diagnosis of cancer breaks through our routine and reminds us what we have known all along – that our time here is limited. Tomorrow and the future are suddenly thrown into doubt. Whether the questions are spoken aloud or in the solitude of the mind, everyone with cancer asks them:

What is going to happen to me?
Am I going to die?
What will happen to my loved ones if I die?

The thought of dying is frightening to many people. Yet death is part of every life. We all must face it one day. For some of us, it will be sooner; for others, it will be later. Perhaps you will die of cancer, or perhaps you will not. Nonetheless, having cancer reminds us to prepare for death, whenever it may come.

One of the aspects of death many people find frightening is lack of control over the situation. You have an opportunity now to prepare for death, whether it comes in a month or many years from now. Taking the time to prepare for death allows you to have some control over how that time of your life will unfold. The plans you make now may not be needed for many years. Nevertheless, having plans in place may give you peace of mind that when the time comes, you will be prepared.

Whether you are pursuing *curative intent* therapy or *palliative care*, the topics in this chapter are relevant. Unlike people who die unexpectedly of accidental injuries, a heart attack, or a

stroke, many people diagnosed with cancer feel they have been given a reminder about life and death. Now is a good time to consider doing things you may have been postponing. You have time to make preparations and do things you want or need to do.

This chapter reviews information about planning for the end of your life. It is not offered to upset you or diminish your sense of hope, but rather to help you. This book was written to provide you with information that will hopefully contribute to your well-being by bringing a sense of understanding and peace of mind to your journey with lung cancer. You can make many choices and plans now that will have far-reaching consequences for yourself and others. We encourage you to use this information to make the best choices for yourself and your loved ones.

GETTING YOUR PAPERWORK IN ORDER

‘Getting your affairs in order’ is a phrase we have all heard. Yet, when it comes to doing it, many of us have no idea where to start. In general, we are talking about collecting and organizing your personal papers. These would include such things as legal papers, income and investment information, loan papers, credit card information, insurance policies, etc. The reason for doing this is to make things easier for your family in the event of your death.

When I was diagnosed with lung cancer, I had just lost my husband the year before to brain cancer. So everything in the will and all the financial accounts had been put into my name. When the doctors asked me if I wanted to get thing in order, of course it was an awful feeling. I went down to my social worker's office to talk it over with her. She was wonderful. She helped me understand that it is just a good thing to do, and that no one knows when something may happen. I might get hit by a truck tomorrow. It was just good to have things in place. She helped me realize it wasn't so scary. I had always thought that if you filled out a will that meant you were going to die. But I went to my financial planner who took care of everything with my late husband. I had no idea what all I needed to do until [my financial planner] helped me. He was wonderful. After that, I just felt like I had things taken care of. I was still in the thick of it emotionally, so it was good not to have to spend a lot of time thinking about getting my affairs in order.

– Judy, diagnosed with limited SCLC in 1998 at age 57

You may just need to make sure your files are current if you already have your personal papers organized. If your papers are scattered, it is best to collect them in one location and

organize them. Be sure a trusted family member or friend knows where all your important papers are located. If you keep some of your papers in a safe deposit box and it is in your name only, you may want to grant another person access to the box. Giving a second person access ensures that your family can get to any paperwork they need. Be sure someone you trust has the combination if your papers are kept in a personal safe.

Personal Papers

Personal records are documents and information that relate to your history. Important information to gather for your personal records includes:

- full legal name
- any previous legal names you have used including your maiden name if you're a married woman
- birth certificate; if you do not have a birth certificate, you can request a certified copy from the vital records division in the state of your birth
- social security number
- military records
- names, addresses, and telephone numbers of previous employers and approximate dates of employment
- name, address, and telephone number of your personal attorney, if applicable
- pre-arranged funeral or burial arrangement documents

Financial Records

Your financial records include information about bank accounts, investments, real estate, insurance policies, credit cards, loans, deeds, titles, etc.

A list of documents to include in your financial records includes:

- account numbers and recent statements for all your bank accounts including checking accounts, savings accounts, and certificates of deposit (CDs)
 - if you have a personal banker, note his or her name and telephone number
- list and location of savings bonds

- safe deposit box information
- account numbers and recent statements for your investment and retirement accounts including IRAs, 401Ks, pension funds, bond funds, and stock or trading accounts
 - if you have an investment advisor or financial consultant, note his or her name and telephone number
- federal and state income tax returns from the past 2-3 years
- the deed to any property (real estate) you own
- property tax documents
- original insurance policies including house, car, medical, and life insurance
 - include names and telephone numbers of agents or other contacts for each policy
- Medicare information
- Social Security information including any benefits you have received
- credit card policies, account numbers, and recent statements including current balances
- loan papers and account numbers for car loans, mortgage accounts, and personal loans
- titles of vehicles and registration information
- list and location of valuables including jewelry, collections, family heirlooms, etc.

Legal Documents

Any legal documents you have are important even if they are from the distant past.

Examples of legal documents to keep in your personal papers include:

- marriage certificate(s)
- divorce papers
- adoption papers
- your *will* or trust documents
- durable power of attorney documents
- *advance directive* or *living will*

- *health care power of attorney* documents; include contact information for your appointed health care agent

Collecting this information can be a sizable task. You may want to ask a family member or friend to help you collect and organize this information. Whatever you can do now will help make things easier for your family in the future. Working on this task with a family member may also give you an opportunity to talk about things that otherwise might be difficult to bring up in day-to-day conversation.

Special Considerations for Your Family

There are a number of things you and your family should be aware of that may take place after your death. Preparing ahead of time can make things easier for everyone involved.

- joint checking accounts

There are different types of joint checking accounts in terms of the rights of the surviving person to access the money in the account. The money in an account that has limited right of survivorship may be frozen for a period of time after the death of one of the joint owners. The bank will not freeze a joint account that has absolute right of survivorship. Check with your bank to see what kind of joint account you have. You may need to change the type of account you have or open a separate account for your spouse to be sure he or she has immediate access to cash after your death.

- gift taxes

The federal government and some states have inheritance taxes. You may be able to avoid some of these taxes for your family members by transferring assets to them before your death. A certified public accountant, tax consultant, or estate-planning lawyer can advise you about such transfers.

- Social Security and retirement benefits

If you are receiving social security benefits, your family needs to be aware that they are not entitled to continue receiving these benefits after you die. Your spouse and/or minor children may be eligible to receive their own social security benefits, but they are not entitled to your benefits. If they receive money for you

after your death, this money will have to be returned. The same holds true for most retirement benefits.

- insurance policies

If you are the primary holder of your house, car, and/or health insurance, your spouse will need to arrange to have these accounts changed after your death.

You may be able to make changes to your policies now to avoid your spouse having to handle this later. Contact your insurance agents to check what can be done now and what needs to be done later.

- credit card accounts

Any credit card accounts where you are the primary cardholder and your spouse is an authorized user will be closed if you die. Your spouse will not be able to use these accounts. Your spouse may want to consider establishing a credit card account in his or her own name now to avoid being left without a valid credit card.

- income taxes

Special tax rules apply to people who usually file a joint return when one person in the couple dies. Talk with your spouse to be sure he or she knows this. A tax consultant can advise your spouse about what needs to be done.

ESTATE PLANNING

Estate planning involves making plans for how you want your personal property and money handled after your death. Many people mistakenly believe only very wealthy people need a will. Others do not think a will is necessary because they assume their assets (anything of value) will automatically go to their family members. The truth of the situation is that if you die without a will or other estate-planning document, the state will decide what happens to your property. Each state has its own inheritance laws, which vary considerably. An *intestate estate* is the estate (assets) of a person who died without a will or other estate-planning document. An intestate estate will be distributed according to formulas set out in state law.

This section presents basic information about estate planning. Depending on the size of your estate (the value of your assets) and the complexity of your wishes, you may want to consult with an estate planning lawyer, financial consultant, and/or tax consultant.

Wills

A will is a written document that directs how you want your assets distributed after your death. The term will is actually a shortened version of the legal term *last will and testament*. In your will, you can appoint someone as your *executor* or personal representative. The executor is responsible for distributing your property according to the instructions in your will. It is usually in your best interest to name an executor. If you do not name an executor, the court may require a lawyer or financial officer be hired to serve as the executor of your estate. In this instance, the money to pay the court-appointed executor is taken from the estate. Depending on the complexity of your estate and will, the fees for a hired executor can be substantial.

Many people postpone preparing a will because they are concerned about expensive legal fees. Numerous self-help books and legal software programs are available to help you prepare a simple will if that is something you would like to consider. Preparing your own will may be an option if the distribution of your estate is simple, for example, leaving all your assets to your spouse. If you decide to prepare your own will, it is best to have a lawyer look it over to be certain it is valid.

It is usually best to have a lawyer draft your will if any of the following circumstances apply to your situation:

- you plan to split your estate among several people
- you plan to donate money to charity
- you will be giving gifts to minors
- you want some or all of your assets placed in a trust (see below for information about trusts)
- you own property in more than one state
- you want to forgive debts that others owe you
- you have any other special stipulations for your will

Your local bar association chapter (a professional organization for lawyers) can help you find a lawyer who specializes in estate planning or direct you toward free or low cost legal services in your area. The American Bar Association Internet site has a directory of pro-bono (free) legal services listed by state at www.abanet.org/legalservices/probono/directory.html#. Local senior citizen organizations may also be able to recommend estate-planning specialists. Some community-based programs provide free legal services. Your oncology nurse or social worker may be able to help you find such programs.

If you have a spouse who will survive you, it is very important for him or her to have a will also. This is especially important if you have children or other dependents.

**We already had a will in place before I was diagnosed. However, it was now time to update it. It is just something that had to be done. We have children and we needed to make sure things were in place – just in case. It's not something we continually focused on, but we wanted to make sure that things would be taken care of.
– Janet, diagnosed with stage IV NSCLC in 2000 at age 46**

Guardianship

You may need to address guardianship in your will if you are the parent or guardian of one or more minors (children less than 18 years of age). Generally, the surviving parent of a minor child will be granted custody unless he or she is unfit or unable to parent. In the event your child's other parent is deceased, cannot be located, or is unfit to parent, another adult must be named as the minor's legal guardian. It is in the best interest of your child to name a legal guardian in your will if any of these circumstances apply to your situation. If you do not name a guardian for your child, the court will appoint one.

Probate

Probate is the formal court process whereby a judge or other court-appointed official makes a legal decision about whether the will presented to the court requesting that a deceased person's assets be distributed is valid. A probated will is one in which the court has made a legally binding determination that the document presented is in fact the last will and testament of the deceased person. A will must be probated before the assets of the estate can be distributed.

Some assets are not subject to the probate process, that is, some assets are not considered part of a person's estate. Life insurance policies, certificates of deposit (CD's), savings accounts, and annuity accounts are usually not considered part of your estate because they have a named beneficiary (a person to whom the value of the policy or account is paid if you die). You may want to check these policies or accounts to be certain the person you originally named as beneficiary is in fact the person you want to receive the funds.

Trusts

A trust can be used as another type of estate planning. A trust is a legal arrangement concerning the ownership and distribution of property. Once you set up a trust, it becomes a legal entity separate from you. If you set up a trust while you are alive, you can transfer any or all your assets to the trust including your home, property, retirement accounts, etc. You can also make the trust the beneficiary of your life insurance policy, annuities, and savings accounts. One of the advantages of a trust is that it is not subject to probate, which means the time and cost of probate can be by-passed. When you set up a trust, you prepare a trust document that outlines the distribution of the assets in the event of your death. You can also specify conditions you want attached to the distribution of the assets. For example, you may want to leave money to your grandchildren, but do not want them to have access to the money until they graduate from college. The manager of the trust will hold the money for your grandchildren until the conditions of distribution are met. Trusts can also be used to distribute money in installments to people or charities.

A trust established while you are alive is called a living trust. A living trust can be set up so that you are able to change the terms or conditions of the trust any time you wish (a revocable trust). Once the owner (the grantor) of a trust dies, the terms and conditions of the trust can no longer be changed, that is, it becomes an irrevocable trust. You can also arrange to have one or more trusts established after your death. This is generally done within a will and is subject to probate.

There are several different kinds of trusts. Although there can be clear advantages to trusts depending on how you want to distribute your estate, trusts can be very complex legal and

financial arrangements. It is usually best to work with a lawyer and financial advisor who are experienced in the use of trusts for estate planning.

All my children have a copy of my will and the trust. I didn't want any surprises. We are and have always been very open in talking with one another. Two of my daughters currently have access to my account. I didn't want to have them try to pay for something if I was unable to write a check. I wanted to make it easy on them. It was a little difficult when my children first saw the trust. My other daughter didn't have access to the account and was offended. But we talked about the situation and she understood. We have been fine since. I know what works for us may not work for everyone, but what I think always works is honesty.

– Anita, diagnosed with stage I NSCLC in 1991 at age 60

ADVANCE CARE PLANNING

Advance care planning is working with your health care providers to plan for the kind of medical care you want and do not want at the end of your life. This planning is best done well in advance of your need for end of life care. With advance care planning, you can make your medical care choices known to your doctors now in case you become unable to clearly express your wishes at a later time. An advance directive is a written document that outlines your end of life medical care choices. A living will is an advance directive that applies specifically to a person who has a terminal illness. Many people use the terms living will and advance directive interchangeably.

The Patient Self-Determination Act (PSDA) is a federal law passed in 1990 that requires medical providers to inform all adult patients about their rights to accept or refuse medical or surgical treatment and to execute an advance directive. Every state and the District of Columbia have laws pertaining to the validity of advance directives. Although the details of these laws vary, they all give people the legal right to state in advance what kind of medical care they want and do not want if they come to a point where they cannot make their choices known to others.

In an advance directive, you grant another person permission to make medical choices on your behalf. Granting someone the right to make medical choices for you is called medical

or health care power of attorney. The person you give this right to should be someone you trust to fulfill your wishes and with whom you have discussed your preferences in detail. The legal term for this person varies from one state to another, but common terms are surrogate, proxy, or agent. For simplicity, the term agent is used in this chapter. You may want to consider having a back-up health care agent. The back-up agent would fill in for the primary agent if he or she could not be reached. Keep in mind, your health care agent is consulted only in a situation where you are unable to speak for yourself due to circumstances such as unconsciousness or permanent confusion.

You can grant a family member medical power of attorney. In some cases, it may be difficult for a family member to carry out your wishes if you are near death. This is especially true if your wishes differ from your family member's personal beliefs about your choices. If you are concerned that carrying out your wishes may place too much stress on a family member, it may be preferable to appoint someone outside your immediate family. A trusted friend may be a practical alternative. It is not necessary to appoint an agent as part of an advance directive unless you live in New York, Michigan, or Massachusetts. The laws of these three states require the appointment of a health care agent to make medical decisions for you if you are unable to make your wishes known, but do not authorize living wills without an agent. Alaska places some limitations of what kinds of decisions your health care agent can make on your behalf. The other 46 states and the District of Columbia authorize advance directives and medical power of attorney.¹

**I had three really close friends and a brother whom I had thought [of] for a health care agent. But they all passed away prior to my diagnosis. So instead of assigning someone who I hardly know, I spoke with the woman I had entrusted with my financial affairs. I approached her and we talked everything over. We both felt comfortable with her making decisions if need be. You need to have someone who can make these decisions, and I feel completely confident in her decisions.
— Dorothy, diagnosed with stage IIIA NSCLC in 1998 at age 68**

If you live in a state that authorizes both advance directives and medical power of attorney, consider having both. Having both documents provides the assurance of having the advance directive in place if your health care agent cannot be reached.

¹ According to state legislation as of March, 2003.

Executing An Advance Directive

Forms are available from many sources to create an advance directive. Because state laws for advance directives vary, you need to be sure you use an advance directive form that is suited for your state. Many oncologists and oncology social workers have advance care forms or can tell you where to get them. Most hospitals and home health and hospice agencies also have advance directive forms. Your public library is another possible resource; if they do not have the forms, they can help you find out where to get them.

Advance directive forms have directions for how to fill them out. Follow the directions carefully, especially the directions for signing the form and having it witnessed. An advance directive that is not properly witnessed may not be valid.

Advance directive forms may use words that are unfamiliar to you. Terms you need to understand are described below. If you are uncertain about the meaning of any of the terms on an advance directive form, take it to your doctor or nurse and ask about the terms. You need to understand all of the terms on the advance directive form before filling it out and signing it.

- artificial nutrition and hydration – food and water fed to a person through a tube when he or she cannot eat or drink enough to sustain life
- comfort care – care that helps keep a person comfortable but is not intended to prolong life; bathing, applying lotion to the skin, grooming, and keeping a person's lips moist are examples of comfort care
- cardiopulmonary resuscitation (CPR) – medical efforts to restart the heart if it stops beating and artificially breathing for a person if he or she stops breathing
- death delaying procedure – another term for life-sustaining treatment; any medical treatment used to keep a person from dying including such things as CPR, breathing machines, artificial nutrition and hydration
- Do-Not-Resuscitate order (DNR) – a DNR order is a doctor's written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) if a person stops breathing or if his/her heart stops beating

- life-sustaining treatment – any medical treatment used to delay a person’s death; a ventilator (breathing machine), CPR, and artificial nutrition and hydration are examples of life-sustaining treatments
- persistent vegetative state – the condition of a person who is unconscious with no hope of regaining consciousness even with medical treatment; the person may have some body movements and at times, his or her eyes may be open, but as far as the doctors can tell, the person can no longer think or respond
- terminal illness – an ongoing illness that has no known cure; a disease that doctors expect will lead to a person’s death even with medical treatment; life-sustaining treatments may prolong the life of a person with a terminal illness but they will not prevent death from the illness
- withdrawing treatment – discontinuing life-sustaining treatments after they have been used for a certain period of time
- withholding treatment – not beginning any life-sustaining treatments

The signed original of your advance directive and/or medical power of attorney document should be stored in a safe place such as a fireproof cabinet or safe deposit box. Give your primary health care agent and his or her back-up copies of these papers. Give another copy to each of your health care providers. You may want to give some of your family members copies, too. Distributing copies of your advance directive to these people helps insure that if a time comes when the advance directive is needed, it will be available. Advance directives and medical power of attorney documents do not have a time limit. They are valid until you destroy them or revoke them in writing.

An advance directive can bring you peace of mind in knowing that your wishes about your health care will be fulfilled even if you get to a point where you cannot express your choices. Many who have advance directives say it gives them a sense of self-determination. Advance directives can also prevent your family members from having to make very difficult, stressful, and emotional decisions. In this way, many people consider advance directives one way they can take care of their family members.

I am an attorney. I work with people every day to set up advanced directives, and I didn't even have one for myself until after I was diagnosed. I appointed my mother and fiancé as my health care agents – not that they had to make the decisions cooperatively. Whomever the medical staff could get a hold of first would be fine. I also arranged my wishes for life support. Having done that, I felt so much better. It was a relief to me to know it would relieve the stress of my family.
– Joanne, diagnosed with stage IIIA NSCLC in 2001 at age 52

END OF LIFE CARE

Where Do You Want to Be?

One of the choices to be made about your end of life care is where you want that care to take place. The three most common choices are a hospital, a *hospice* facility, or your home. It is often helpful to think about these choices well in advance of when you will need this type of care.

Hospital Care

Hospital care is usually the choice of people who want life-sustaining treatments for as long as possible. This kind of care includes treatments such as intravenous fluids, artificial feeding through a tube, and assisted breathing. While these measures will not prevent death, they may keep you alive longer than if you did not receive them. If you do not want life-sustaining treatments at the end of your life, another choice may be better suited to your wishes.

Hospice Care

The word hospice describes a system of care for dying people and their families. Approximately 80-90% of hospice care takes place in the home of the patient. Hospice facilities are also available in some communities for people who want to receive hospice care outside their home. These facilities offer specially designed inpatient accommodations devoted exclusively to the care of people who are dying. There are no established visiting hours at these facilities, although patients can set limits on who they want to see and when.

The principles that guide hospice care include²:

- Hospice care is designed to provide comfort and support to patients and their families when a terminal illness no longer responds to curative or life-prolonging treatments.
- The goal of hospice care is to improve the quality of a person's last days by offering comfort and dignity.
- Hospice care addresses all symptoms of a disease with special emphasis on controlling pain and discomfort.
- Hospice addresses the emotional, social, and spiritual impact of the disease on the dying person and his or her loved ones.
- Hospice focuses on quality rather than quantity of life.
- Hospice care does not prolong life and does not speed the dying process.
- Hospice offers grief counseling services to families before and after their loved one's death.

Hospice care is recommended when life expectancy is six months or less. Medicare and most insurance plans cover hospice care if your doctor stipulates this life expectancy. Your doctor needs to make the initial referral to a hospice program for you. Hospice staff meets with your doctor to discuss your medical history, current symptoms, and *supportive care* treatments. After meeting with your doctor, hospice staff will meet with you and your family to explain hospice care and services, discuss your current symptoms, and answer any questions you may have. The hospice staff will work with a hospice doctor to develop a care plan for you. The care plan will be adjusted as needed over the course of your care. Hospice services include:

- nursing care
- home health aides
- medical equipment and supplies
- nutritional counseling

² Adapted from "What Is Hospice?" from the Hospice Foundation of America® at www.hospicefoundation.org.

- respite care – staff or volunteers come into the home to give family members free time to do errands or have some quiet time
- grief counseling
- chaplain services
- social services

Since hospice care does not aim to prolong life, when death occurs, there is no attempt to resuscitate the patient (to restart the heart or breathing).

Some resources to help you locate hospice programs in your area include:

- Hospice Foundation of America
800-854-3402
- American Hospice Foundation
Internet search at www.americanhospice.org/ahfdb.htm
- National Hospice Foundation
Internet search at www.nhpco.org
800-646-6460

We found that the doctors at the hospitals... don't talk about dying.... They just said Janet had 6 to 9 months to live. When we heard this Janet turned to me and said, "I want you to do two things: one, be cheerful around me, and two, keep me out of the hospital." I did my best to do both. In order to keep Janet out of the hospital, we had a wonderful nurse with hospice, Maureen. She came once a week. Janet always looked forward to Maureen's visits; she took care of all the medical things for us. She was straightforward and answered my questions. She was always compassionate and cheerful when she came. If Janet was in pain, Maureen would adjust the meds to make her comfortable. Janet died happily in her own home with her children all around her. Because of hospice, she had as good of death as one could have.

– David, husband of Janet who was diagnosed with extensive SCLC in 2001 at age 79

Resuscitation

The term *resuscitation* describes medical treatments used to restart the heart if it stops beating and restore breathing if it stops. When the heart and breathing stop and resuscitation is not performed, death has occurred. If you are facing death, it is important to consider ahead of time whether you want resuscitation. This can be a difficult decision. You may want to talk with your family and/or a spiritual advisor to help you sort through your thoughts and

feelings about this topic. Whatever you decide, it is important to make your choice about the use of resuscitation known to your health care providers and family so your wishes can be carried out.

I was aware [my surgery] was dangerous. I made sure my doctors understood that I wanted to be a survivor and if that meant resuscitation, then that's what they should do. I can understand if people don't want to be resuscitated, but I felt I was in good health in every other way. And I was going to be a survivor!

– Rita, diagnosed with stage I NSCLC in 2001 at age 58

If You Want Resuscitation

If you are in a hospital, resuscitation is the normal procedure when someone's heart and breathing stop. No special requests or forms are needed to insure that resuscitation will take place.

If you are at home, you need to be sure your family members know that you want resuscitation. In the event your heart and breathing stop, they need to call 911 immediately to request an ambulance. Emergency medical personnel must perform CPR on anyone whose heart and breathing has stopped. If your family members know how to perform CPR, they should begin CPR until the ambulance arrives.

If You Do Not Want Resuscitation

Resuscitation is the standard medical response when someone's heart and breathing stop. Therefore, if you do not want resuscitation, you must take actions to make your wishes known. This is one of the main purposes of an advance directive. Talk with your family members and health care agent (if you have one) in advance about what they need to do or not do in specific circumstances to insure that your wishes are carried out.

If you are admitted to a hospital, a family member or your health care agent must be certain the hospital staff has a copy of your advance directive in your medical chart. In addition, your doctor needs to write a Do Not Resuscitate (DNR) order on your chart. This is very important. If a signed DNR order from a doctor is not on your

chart, resuscitation is legally required even if your advance directive has been provided.

If you are at home, be sure your family members and others who may be caring for you know not to call an ambulance if your heart and breathing stop. Emergency workers are required to perform CPR if they are called. Your doctor or hospice staff will tell your family members what to do if you die at home. This should be discussed well in advance so your family members are not frightened or confused about what to do.

The decision to forego resuscitation can be difficult for family members. Letting go of a loved one can be extremely emotional and painful. Talking about your decision with your loved ones ahead of time can make it easier for them to respect your wishes when the moment of carrying out your choice arrives.

Talking With Your Doctor About End Of Life Issues

Death is a very difficult topic for many people to think about. It is even harder for many people to talk about it. Your doctor may be hesitant to bring up end of life issues such as hospice care, advance directives, and resuscitation because he or she:

- does not want to offend you
- does not want to squelch your sense of hope
- is waiting for you to bring up these topics, or to give him or her a cue that you are ready and willing to talk about them
- is not completely comfortable talking about these issues

While it may be difficult to raise these issues with your doctor, it is important to do so if he or she does not. There may be an awkward moment or two when you first raise the topic, but both you and your doctor are likely to feel a sense of relief once these subjects have been discussed openly. If you are having difficulty bringing up end of life issues, tell your

oncology nurse you want to discuss them with your doctor. He or she can let your doctor know. This is often the sort of cue your doctor is waiting for to let him or her know you are ready to talk about these important issues.

FUNERAL AND MEMORIAL SERVICES

Since the beginning of recorded history, every culture has had special ceremonies and rituals to honor the dead. Psychologists and grief counselors tell us these ceremonies and rituals are an important part of the grieving and healing process. They allow family members and friends an opportunity to honor the life of their loved one, and to begin the process of saying good-bye to the earthly relationship they shared.

Depending on your cultural background and spiritual or philosophical beliefs, you may have specific preferences about what kind of ceremonies, rituals, and procedures you want following your death. If you so desire, you can make arrangements now to be sure your wishes are fulfilled.

When I was diagnosed, the doctor said I had a 40% chance to live as long as six months. He told me to get my things in order – so I did. I felt like cancer had taken away my freedom to choose. I had no choice. I had to go through chemotherapy. I had to have radiation in order to live. So at least if I was going to die, I was going to have a say. I went to the funeral home and picked out my casket, bought my burial site, and decided what I wanted on my head stone. I even decided what color my nails were to be painted. I wrote instructions to my daughters. I didn't want any flowers, and I meant it. I wanted contributions to go towards cancer research. Once I made all the arrangements, I felt relieved – not for myself, but to take the burden off my children.

– Barbara, diagnosed with extensive SCLC in 1997 at age 47

A funeral or memorial service is not required by any agency. It is a matter of personal choice. If you have strong feelings about not having a service, or if you want a service limited to family members, consider putting your request in writing as part of your will. It is usually best to discuss your decision with loved ones in advance.

In my mind, a funeral and ceremony is something for the loved ones who [are] left behind. So I have left it up to them since it won't bother me a bit; I'm no longer there at that point. My suspicion is they will not do anything being that my husband

does not like funerals. Out of respect for him, my daughters will probably let it go. In fact, my daughters are actually memorializing me now — while I'm still here. They come to see me more and we talk more. We are all much more open with faith and spirituality now.
— Joan, diagnosed with stage IV NSCLC in 1998 at age 56

Some people prefer to have friends and loved ones make donations to charitable organizations rather than sending flowers for a funeral or memorial service. You may want to write letters to your loved ones to be read at your funeral or memorial service. The choices are yours. Again, you can make your wishes known in your will, by talking with your family, and/or by making arrangements with the institution that will be handling your service.

One consideration is what you want to have happen to your body. Cremation and burial are the two most common options. If you have strong beliefs or wishes about these options, you can include your wishes in your will. You can also prearrange for the services you want. Some people do this to insure that their wishes are honored, and to spare their families from making arrangements when they are going through the immediate pain of losing their loved one.

Many people with cancer wonder about organ donation. People who die of cancer cannot donate their organs to others because the cancer can be transmitted to the recipient through the donated organ. An exception to this rule is the corneas of the eyes, which can be donated in most instances.

While organ donation is not an option for people with cancer, you can donate your body (in whole or in part) for scientific and medical research. Arrangements generally need to be made ahead of time for this type of donation. Medical schools and medical research institutions are the primary recipients of body donations for research purposes. If you live near a medical school, you may want to contact their anatomy department to learn more about their donation program. A list of body donation programs in the United States and contact information is available on the Internet from the University of Florida State

Anatomical Board at www.med.ufl.edu/anatbd/usprograms.html. There is usually a transportation fee charged by the funeral home to take a donated body to the site receiving the body.

You have the time to plan anything you want to have happen in the aftermath of your death. The choices are yours. Planning for your own death can be difficult because it brings up painful feelings of sadness and loss. Your family may resist you making plans because it is painful for them, too. However, planning now can give you the peace of mind of being sure things will be done as you wish. It may also present opportunities for you and your loved ones to talk about emotional but important matters. Sometimes the difficult things we face together bring us closer.

YOUR LEGACY

Your legacy is what you leave behind of yourself for your family, friends, and community. We all leave traces of ourselves behind when we pass from this world. We leave behind our love, the effects of love, and the fruits of our work and actions. If you are at a point in your life where you are preparing for death, you may want to think about the legacy that you want to leave behind. Your legacy can take any form you wish. It will be as unique as you are.

Some people keep a journal of their cancer experiences with notes to family and friends about what their efforts meant. Such a journal can be a source of comfort for your loved ones and may help them work through their grief. You may want to have a friend or family member help you make videotaped messages as a way to give special people in your life a permanent visual and auditory message from you. Personal letters are another option. A friend, loved one, or a hospice worker can write what you dictate if writing is difficult for you. Artists may choose to create small works of art for special people in their lives. Musicians may leave a special work or song for loved ones. There are no limits to what you can give as part of your legacy. Whatever you leave to those who love you will be invaluable because it came from your heart.

If you have significant financial assets, you may want to consider charitable donations to further causes that are dear to you. You can set up a scholarship fund or donate to the arts, medical research, or environmental causes. Any way you choose to give will be a special gift you contribute to the world you have shared with others.

Despite the hardships, cancer has changed my life by making it richer in every way and by allowing me the opportunity to help others who are affected by this devastating disease. In March 1999, when I recovered from my lung surgery, I started a Website called *Lung Cancer Online* for patients and families. At that time, there were few online resources for lung cancer, and those that existed were difficult to locate. *Lung Cancer Online* was designed as a comprehensive, annotated directory to the best sources of lung cancer information and services on the Internet. My intention was to save patients the time and aggravation of searching for valuable information. As a librarian, I also provide reference and referral services through the website. It is my great privilege to help and get to know so many lung cancer patients and family members in the course of my work.

— Karen, diagnosed with stage IV NSCLC in 1998 at age 38

My legacy is my children.

– Larry, diagnosed with stage II NSCLC in 1991 at age 53

SUMMARY

From the time of our birth, we are all moving closer to our death. Death is part of life. While we are busy with the day-to-day tasks and joys of living, we rarely think of death. A cancer diagnosis brings us face-to-face with the inevitable reality of death. While the reality of death can be sad and difficult to accept, it also brings opportunities.

Although your time left may be shorter than that of someone else, you do still have time. Each day brings new challenges and new opportunities. Someone like you once wrote:

Yesterday is history.

Tomorrow is a mystery.

Today is a gift.

That's why it's called the present

~ Anonymous

You have today. You can make choices about how you want to live the time you have in the present. You can do many things now that may make things easier for you and your loved ones in the future. Some of these tasks may be hard to think about but may ultimately bring

peace of mind for the future. We encourage you to allow others to help you with your preparations for the future. Those who love you are often looking for opportunities to help you. Allowing them to be of service to you may be one of the most generous gifts you can give them.

Consider what you want to leave behind in this world. It can be as simple and as personal as a letter to your family or as encompassing as funding a foundation. The parts of yourself you leave behind for others will be as unique and precious as you are.

I hope the information provided here will help bring you peace of mind and comfort. I hope it will help relieve you and your loved ones from as much pain, anxiety, and stress as possible. It is my wish that the information presented will contribute to a fulfilling, peaceful journey through the end of your life – whenever that may come to pass.