Legal Guide for Cancer Patients
INTRODUCTION

If you are reading the introduction to this Guide, it is likely that you or someone you care about is fighting or has fought a battle with cancer. It is also likely that in addition to dealing with treatment decisions like radiation versus chemotherapy, numerous doctors’ visits, telling family, friends and co-workers, and simply coming to terms with this illness, you are overwhelmed by the myriad of other issues that one is confronted with when you or a loved one receives a cancer diagnosis. Such issues include guardianship for cancer survivors with children, employment issues, insurance coverage, and concerns about privacy, to name just a few.

This Guide, prepared by a committee of Texas attorneys, is intended to be an informative resource upon which you or your loved one can rely to answer legal questions like, “Am I entitled to time off work?” “Should I have a will?” and “How do I tell my doctors that I don’t want to be placed on life support if my condition is terminal?” Each attorney who helped prepare this Guide has been personally touched by cancer in some way - whether through family or after personally fighting the battle - and drew upon those experiences while preparing this guide. We hope it answers many of the legal questions that are on your mind.

Cancer often forces us to contemplate our own mortality in a new way, and causes us to think about estate planning and other end-of-life issues. That said, in today’s world, cancer is a battle that is so often won. Therefore, please do not be alarmed by the end-of-life advice found in this Guide, including our recommendation that you have a will. We should all have a will, but it sometimes it takes a serious illness before we really give it much thought.

We hope that this Guide will provide answers to many of the questions you face during this journey and most importantly, we wish you victory in this fight!

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(The issues covered in this Guide are changing on a regular basis. As a result, we encourage you to check for updates to the TYLA Legal Guide for Cancer Patients website at www.tyla.org.)
NOTICE: The Texas Young Lawyers Association prepared this Guide to help you understand the laws that affect your daily life and to help familiarize you with the legal issues that may surface during a battle with cancer. Please note that this Guide is solely intended to provide general information only and is not a substitute for legal counsel. The laws outlined in the Guide are subject to change at any time. If you have a specific legal problem, we suggest that you consult an attorney.

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What is informed consent?

Consent is your authorization or permission to a health care provider to perform a certain procedure or treatment. Informed consent is the permission to perform a certain procedure or treatment after you have been advised of the risks or hazards inherent in the procedure or treatment that could influence you in deciding whether or not to consent.

What information is necessary to obtain informed consent?

Generally, the physician or health-care provider must disclose to you those risks or hazards that could influence a reasonable person in making the decision of whether to consent to the treatment. You should be advised not only of the risks and hazards of treatment, but also of the alternative treatments and the probable result if you remain untreated. In addition, the healthcare provider should explain to you the procedure to be performed, additional procedures that may be needed, benefits derived from the procedure, and consequences of not undergoing the procedure.

Who must obtain informed consent?

Generally, the attending physician must obtain your informed consent. In cases of referral, the referring physician has no duty to obtain informed consent for procedures performed by the other physician if the referring physician does not participate in the procedure. Except in emergency situations, informed consent should be obtained when the patient is able to consider the decision to consent at a reasonable time prior to the treatment.

Who is the Texas Medical Disclosure Panel?

The Texas Medical Disclosure Panel is created (i) to determine which risks and hazards related to medical care and surgical procedures must be disclosed by health care providers or physicians to you or those persons authorized to consent for you; and (ii) to establish the general form and substance of such disclosures.

Before you give consent to any medical care or surgical procedure that appears on the disclosure panel’s list requiring disclosure, the physician or health care provider shall disclose to you the risks and hazards involved in that kind of care or procedure. The Texas Medical Disclosure Panel list of procedures requiring full
disclosure may be found in the Texas Administrative Code at the following website: http://info.sos.state.tx.us/pls/pub/readtac$ext.ViewTAC?tac_view=3&ti=25&pt=7.\(^{(1)}\)

Consent to medical care that appears on the disclosure panel’s list is effective if (1) it is given in writing, signed by you or a person authorized to give the consent and by a competent witness; and (2) the written consent specifically states the risks and hazards that are involved in the medical care or surgical procedure in the form and to the degree required by the disclosure panel.\(^{(2)}\)

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(2) Texas Civil Practice and Remedies Code, § 74.102-74.105 (2006).
INTRODUCTION

The following information regarding insurance coverage is based upon the Health Insurance Portability and Accountability Act of 1996 (also known as “HIPAA”), a federal law which sets forth standards for health insurance in the United States. In many instances, HIPAA supercedes or “trumps” conflicting state law. Therefore, the requirements for health insurance coverage may vary widely from state to state. You can consult your state Department of Insurance, your health care provider, your company’s benefits coordinator, a local attorney, and/or cancer patient advocate regarding the specific rules and regulations which govern health insurance coverage in your state. It is also important to note that significant differences often exist between group and individual policies.

Does my insurance policy cover treatment for cancer?

Review the “exclusions” section of your policy. Some policies explicitly state whether certain illnesses, such as cancer, are covered or not (excluded). If you have any questions contact your health insurer.

Can my insurance company raise my premium if I need cancer treatment?

No. Your group health insurer may not require you (as a condition of enrollment or continued enrollment under the plan) to pay a premium, which is greater than the premium for a similarly situated individual enrolled in the plan on the basis of any health status-related factor such as cancer.

Can my insurance company cancel my policy or refuse to renew my policy if I am diagnosed with cancer?

No. Your health insurance may not be canceled or not renewed by the health insurance issuer based on the fact that you have been diagnosed with cancer.

What is a “pre-existing condition” provision and how does that affect my insurance coverage?

If you were diagnosed with cancer before your group health insurance coverage became effective, your insurer may consider you to have a pre-existing condition. A “pre-existing condition” provision is defined as an exception in your insurance policy that excludes or limits coverage for a disease or condition, such as cancer, for a specified period after the effective date of coverage.
Policies can differ with regard to pre-existing conditions, and the specific wording of that provision of the policy can greatly impact what is covered or excluded. For example the provision might only apply to coverage for a disease or condition during a specific time period (for example 6 months prior to the enrollment date of the new policy). In these situations if you previously received a diagnosis, care, or treatment for a disease or condition within the specified time-frame, the insurer can consider it a pre-existing condition, which will likely preclude coverage for 12 months, or 18 months if you did not enroll in the plan when first eligible. Be aware that providing false misleading information on an insurance application constitutes fraud, which could render your policy void, or result in cancellation of all benefits and/or criminal charges.

My policy excludes cancer treatment

Some individual (non-group) insurance plans contain a provision, which denies coverage completely for specific diseases or conditions which can include cancer. If possible, it is better to identify such exclusions as soon as possible and obtain supplemental coverage. Obtaining additional coverage after a diagnosis of cancer will likely be very difficult.

My policy excludes cancer treatment for a specified period of time

Some insurance plans contain a pre-existing condition provision, which denies coverage for a specified period of time if you received medical advice, diagnosis, care, or treatment for cancer for a period of time prior to the effective date of your coverage. Under federal law this waiting period may be no longer than one year. Some plans may also require that you be “treatment free” during this waiting period before you qualify for coverage.

However, according to HIPAA any pre-existing condition exclusion period must be reduced by the period of time the individual has maintained health insurance coverage without a break of 63 consecutive days or more immediately before enrolling in the new health insurance plan.

So, for example, if your current policy has a pre-existing provision that has a 6 month waiting period before you qualify for coverage, and you had insurance coverage without a break for 90 days immediately before you enrolled in your current policy, you would qualify for coverage under your current policy in 3 months instead of 6 months because you would get credit for the 90 days of coverage under your previous plan. If you only had 62 days (or less) of coverage without a break immediately before enrolling in your current plan, you would still have to wait 6 months before you qualified for coverage under the pre-existing provision of your current policy. But, if your current policy had a pre-existing provision with a 6 month waiting
period before you qualify for coverage, and you had insurance coverage without a break for 180 days immediately before you enrolled in your current policy, you would qualify for coverage for treatment right away because you would get “credit” for your 180 days of previous coverage.

If my new policy has a waiting period, is that a break in my coverage?

No. If your current group health plan or group health insurance coverage has a waiting period (i.e., a period of time you must wait until you are eligible to be covered for benefits under the plan), that waiting period does not count against you as a break in coverage for purposes of a pre-existing condition provision in your policy.

For example, let’s say the health insurance through your new employer requires you to wait 90 days before you are covered by the insurance. At your old job, you had health insurance for a year and were still covered when you started your new job (no break in coverage). Your new policy contains a pre-existing condition provision that has an exclusion period of one year. Since the waiting period does not count as a break in coverage, your exclusion period for any pre-existing condition in this example would be reduced by one year.

What happens if I “max out” my existing policy?

Since most policies provide benefits up to a stated dollar amount, make sure you carefully review your policy, so you are aware of what the benefit cap is on your plan and monitor your use of those benefits. If you think you will exhaust your benefits, start looking for new or supplemental insurance. You may not be able to obtain additional coverage for ongoing or recent treatment.

Remember that even if your new insurance has a pre-existing condition clause which, has a waiting period of one year or less before you are eligible to receive coverage for cancer treatments, if you had continuous coverage of 63 days or more immediately preceding the effective date of your new policy, you will get “credit” for the number of consecutive days of coverage from your old policy, which could result in either immediate coverage or a shorter waiting period.

What are my insurance options if I can no longer work and lose my insurance, and what are my options if I do not have insurance?

The Consolidated Omnibus Budget Reconciliation Act or COBRA is a federal law that provides a temporary extension of health coverage for up to 18 months through an individual’s employer (with 20 or more employees) which may be extended up to a maximum of 36 months, if that individual, for example:

• Works fewer hours; or
• Loses his/her job (for any reason other than gross misconduct); or
• Gets divorced from, or becomes legally separated from, a partner who has the medical insurance, or if the partner with the insurance dies; or
• Becomes eligible for Medicare benefits; or
• Loses dependent child status under an existing policy

Usually, your employer pays a part of the premium for active employees. COBRA coverage is typically more expensive because you are generally responsible for paying the entire monthly premium plus a 2% fee. Some group plans give individuals the option of converting the plan into an individual policy at the end of the COBRA continuation coverage period.

For more information, go to: http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html

IMPORTANT INSURANCE TERMS AND DEFINITIONS:

DISABILITY BENEFITS

Long-Term Disability Insurance
Long-term disability insurance typically replaces a portion of your income, sometimes for as long as five years or until you turn 65. Check to see if you have long-term disability insurance, either through your employer or under an individual policy you purchased. If you have long-term disability insurance, review the definition of “disability” under your policy to see if you qualify. Depending on how the policy defines “disability” cancer may qualify.

Social Security Disability
Social Security provides benefits to someone with a total disability. To qualify for social security disability benefits, you must have worked at a job covered by Social Security and also meet Social Security’s definition of disability.

Social Security considers you disabled if you cannot perform work that you had in the past and if Social Security decides that you cannot adjust to other work duties because of your medical condition(s). Your disability must also last or be expected to last for at least one year, or be of the type that is likely to result in death.

Social Security will generally pay monthly cash benefits to people who have been unable to work for a year or more due to disability. If you qualify, these benefits usually continue until you are able to work again on a regular basis.
**Supplemental Security Income (SSI)**

SSI is a federal income supplement program. Many things are considered to determine if you qualify for SSI, including, but not limited to, your age, any disabilities you have and your income. If you qualify, SSI provides monthly assistance to cover expenses for basic needs such as food, clothing and shelter.

For more information on Social Security Disability, go to:
http://www.ssa.gov/disability/

**MEDICARE**

Medicare is a government-sponsored health insurance program for people 65 and older or people younger than 65 who are disabled or have End-Stage Renal disease (permanent kidney failure requiring dialysis or transplant). You or your spouse must also have worked for at least 10 years in Medicare-covered employment, and you must be a citizen or permanent resident of the United States.

**Part A**

Disability Part A covers care in (i) hospitals as an inpatient, (ii) critical access hospitals (small facilities that give limited outpatient and inpatient services to people in rural areas), (iii) skilled nursing facilities, (iv) hospice facilities, and (v) some home health companies. Part A coverage is usually free. If you or your spouse did not pay Medicare taxes while you worked, and you are 65 years of age or older, you may be able to purchase Part A coverage.

**Part B**

Disability Part B covers doctors’ services, outpatient hospital care, and some other medical services that Part A does not cover, such as the services of physical and occupational therapists, and some home health care. Part B helps pay for these covered services and health care supplies when they are medically necessary. You have to pay a monthly premium for Part B coverage.

**MEDIGAP**

If you receive Medicare, you may be able to supplement your Medicare coverage with a Medigap policy. A Medigap policy is health insurance sold by private insurance companies to fill the “gaps” in some of the health care costs that your Medicare plan doesn’t cover. There are 12 different standardized Medigap policies you may choose based on your needs. In Texas, Medigap insurance companies may reject applications from non-elderly persons with disabilities.

For more information about Medicare, go to http://www.medicare.gov or call 1-800-MEDICARE.
MEDICAID

Medicaid is another government-sponsored health insurance program that may help low income citizens with medical costs. Medicaid is administered by individual states and is therefore subject to state guidelines. Depending on your state’s rules, you may have to make a co-payment for some medical services. Eligibility is based on factors such as your age; whether you are pregnant, disabled, blind, or aged; your income and resources; and whether you are a U.S. citizen or a lawfully admitted immigrant.

For more information about Medicaid, call 1-800-252-8263 or go to: http://www.cms.hhs.gov/home/medicaid.asp

HEALTH INSURANCE RISK POOLS

Health insurance risk pools, also know as Guaranteed Access Programs, are special health insurance programs created by state legislators for individuals who cannot obtain adequate health insurance coverage as a result of their medical condition. Essentially, risk pool insurance serves as a last resort for those who cannot obtain health insurance from any other source, or only have access to private insurance that is restricted or has extremely high rates. The cost of risk pool insurance is higher than regular insurance, but states cap the amount that can be charged to keep the premium amount relatively reasonable.

The type of coverage offered through risk pool insurance - and requirements to obtain such coverage - vary from state to state. For example, in Texas to qualify for Texas Risk Pool coverage, you must have documentation of at least one of the following:

• a written refusal or rejection, based on health reasons, by a health carrier for substantially similar individual hospital, medical, or surgical coverage.
• a certification from an agent or salaried representative of a health carrier on the Health Pool’s certification form, stating that the agent or salaried representative is unable to obtain substantially similar individual hospital, medical, or surgical coverage for you from a health carrier the agent or salaried representative represents because, based on that health carrier’s underwriting guidelines, you will be declined for coverage as a result of a medical condition.
• an offer of substantially similar individual hospital, medical, or surgical coverage with riders excluding certain health conditions you have.
• a rate quote from a health carrier offering to provide substantially similar individual hospital, medical, or surgical coverage at rates that are higher than the rates of the Health Pool.
• diagnosis of one of the medical conditions specified by the Texas Health Pool Board of Directors.
• proof that health coverage has been maintained for the previous 18 months with no gap in coverage greater than 63 days, with the most recent coverage being with an employer-sponsored plan, government plan, or church plan. For more information, contact your state department of insurance.

LIFE INSURANCE

Living Benefits
If you need immediate financial resources, you might consider accelerating your life insurance policy’s “living benefits.” Life insurance policies living benefits sometimes include financial options for insureds with life threatening illnesses and conditions. Financial options could include, for example, waiver of premium, loan programs, or ways to withdraw some of the face value or cash value of your policy.

Viatical Benefits
To generate some immediate income, some patients try to sell their life insurance policies. This is known as a viatical, which means the sale of a life insurance policy, usually by an insured with a short life expectancy, to a third party for a lump sum payment. The value of a life insurance policy is negotiable, but is generally sold for between 60 and 80% of the face value of the policy.

For more information, contact your insurance agent to discuss your life insurance policy benefits.

HILL-BURTON PROGRAM
The Hill-Burton Program is a federal program that provides funds to hospitals and other medical facilities, so those hospitals and facilities are able to provide free or reduced cost medical care for patients who are unable to pay. To qualify for free Hill-Burton care, your income must be at or below the current U.S. Department of Health and Human Services poverty guidelines. You may qualify for reduced-cost Hill-Burton care if your income is as much as two times (triple for nursing home care) the U.S. Department of Health and Human Services poverty guidelines. You may apply for Hill-Burton assistance at any time before or after you have received care.

For more information, call the Hill-Burton hotline at 1-800-638-0742 or visit their website: http://www.hrsa.gov/hillburton/

OTHER OPTIONS TO CONSIDER
• Consult with an independent broker who might be able to find coverage for you that fits your needs.
• Try to find an employer or join a professional or fraternal organization that offers a “guaranteed issue” insurance plan. A guaranteed issue plan offers coverage regardless of health history.
• Ask about school life insurance, if you are the parent of a school-aged child.
• Contact your state department of insurance to see if your state offers an “open enrollment” period, which allows people with pre-existing conditions or who are otherwise considered high-risk to purchase individual health insurance policies.
• See if you qualify for veteran’s benefits by contacting the Department of Veterans Affairs at 1-800-827-1000 or www.va.gov

TIPS FOR MANAGING YOUR MEDICAL INSURANCE

Here are suggestions from the American Cancer Society (www.cancer.org) for managing your medical insurance:

• Become familiar with your individual insurance plan and its provisions. If you think you might need additional insurance, ask your insurance carrier whether it is available.
• Submit claims for all medical expenses even when you are uncertain about your coverage.
• Keep accurate and complete records of claims submitted, pending and paid.
• Keep copies of all paperwork related to your claims, such as letters of medical necessity, bills, receipts, requests for sick leave, and correspondence with insurance companies.
• Get a caseworker, a hospital financial counselor, or a social worker to help you if your finances are limited. Often, companies or hospitals can work with you to make acceptable payment arrangements if you make them aware of your situation.
• Submit your bills as you receive them. If you become overwhelmed with bills, get help. Contact local support organizations, such as your American Cancer Society or your state’s government agencies for additional assistance.
• Do not allow your medical insurance to expire. Pay premiums in full and on time. It is often difficult to get new insurance. Additionally, utilize COBRA to continue coverage in the event you lose or leave your job. This will provide continuity of coverage until you are employed again and can be covered by a new group or individual health plan.
INTRODUCTION

This chapter is intended to be a brief explanation of the HIPAA Privacy Rule, which is a federal law that was developed to help protect your right to privacy and security in connection with the electronic transmission of your health information.

What is HIPAA?

The Standards for Privacy of Individually Identifiable Health Information (the Privacy Rule) were passed as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). According to the Privacy Rule, all health care providers and health plans are considered “covered entities” that are required to safeguard your information by complying with the Privacy Rule. These “covered entities,” along with their vendors or “business associates” (defined below) with whom they share health information, must prepare and establish specific policies, procedures and forms for the purpose of ensuring the protection of your health information. (3)

Throughout this chapter you will see words identified in quotation marks, which are terms commonly used by the Privacy Rule and require your particular attention.

What is a covered entity?

A “covered entity” is any entity that is required by law to comply with the Privacy Rule. In general, a “covered entity” includes: (1) health care providers; and (2) and health plans that transmit health information in electronic form. (4)

Health Care Provider

A “health care provider” is a provider of medical or health services and any other person or organization that furnishes, bills, or is paid for health care in the normal course of business. Examples of health care providers include physicians, hospitals, home health agencies and providers of durable medical equipment.

(3) Examples of “protected health information” include a person’s name, along with all identifiable information about an individual, such as a telephone number, health history, diagnosis, claims history, address, and social security number.

(4) Along with health care providers and health plans, health care clearinghouses are covered entities. A “health care clearinghouse” includes any public or private entity, including a billing service, repricing company or community health information system that processes or helps to process health information.
**Health Plan**

A “health plan” includes group health plans, health insurance issuers, health maintenance organizations, employee welfare benefits plans, and any other individual or group plan that provides or pays for the cost of medical care. This category will include virtually all group health plans, HMOs, and government health programs (Medicare, CHAMPUS, etc.).

**What is a business associate?**

A “business associate” is a person or entity that arranges, performs, or assists a covered entity in an activity involving the use or disclosure of protected health information. These activities include claims processing, claims administration, data analysis, utilization review, quality assurance, benefit management, and any other similar activity covered by the Privacy Rule.

Examples of business associates are persons providing claims processing, legal services, data aggregation, actuarial services, or other services involving the use of protected health information.

**Why is the covered entity vs. business associate distinction important?**

Covered entities are automatically subject to the HIPAA Privacy Rule. Covered entities are required under HIPAA to sign agreements with their business associates that obligate the business associates to act in accordance with the Privacy Rule to safeguard protected health information. Business associates only become subject to HIPAA when the business associate agreement has been signed and becomes effective.

**What is Protected Health Information?**

“Protected Health Information” or “PHI” is basically individually identifiable health information that either identifies the individual or patient directly or would allow someone to identify the individual or patient indirectly.

Examples of PHI include your name, address, social security number, health history, claims history, information about a doctor’s visit, or information about your health condition.

**What is the Privacy Rule?**

The Privacy Rule is the rule that covered entities and business associates must follow to safeguard and protect your PHI. The general rule is that a covered entity or its business associate may not use or disclose PHI except as otherwise permitted under the law.
When may PHI be used or disclosed?

_Treatment, Payment, or Health Care Operations_

The Privacy Rule permits PHI to be used or disclosed in several instances. For example, your own PHI may be disclosed to you. Also, your PHI could be disclosed to others pursuant to a valid authorization signed by you.

The Privacy Rule allows covered entities to disclose PHI for purposes of (1) “treatment,” (2) “payment,” or (3) “health care operations.”

_Family Members Exception_

There are certain circumstances in which PHI, without a written authorization from you, may be disclosed to family members or other people as long as you have a right to agree or object before your PHI is disclosed.

_Public Welfare Exceptions_

The Privacy Rule also lists several circumstances, relating to public health or legal/governmental proceedings, in which your PHI may be used or disclosed without your consent or authorization and without giving you an opportunity to agree or object. Most of these circumstances will apply in clinical settings. (5)

_De-Identification Exception_

Covered entities may also disclose information that has been de-identified (information from which all identifying characteristics have been removed) in accordance with the Privacy Rule, which provides specific rules regarding de-identifying PHI. PHI may be de-identified by removing information, such as your: name; geographic subdivision smaller than a state, including address, county, and zip code; all elements of dates, including birth date, admission dates, etc.; contact numbers and addresses; social security number; medical record numbers; account numbers; health plan beneficiary numbers; vehicle, device, or biometric identifiers; photographic or other images; or any other unique identifying characteristic. To the extent that health information has been de-identified in accordance with the Privacy Rule, it is not PHI and is not subject to the regulations.

(5) A covered entity may, to varying degrees, disclose PHI: (1) if required by law; (2) for public health activities; (3) to report abuse, neglect, or domestic violence; (4) for health oversight activities; (5) for judicial and administrative proceedings; (6) for law enforcement purposes; (7) for cadaveric organ, tissue or eye donation; (8) for clinical research purposes; (9) to avoid a serious threat to health or safety; and (10) for specialized government functions. Each of these categories has specific definitions of activities that fit within these categories, and each has limits on the information that may be disclosed.
**Incidental Uses and Disclosures**

An incidental use or disclosure of your PHI is permitted to the extent that it occurs as a by-product of a use or disclosure otherwise allowed under the Privacy Rule. An incidental use or disclosure is permissible only to the extent that a covered entity applies reasonable safeguards as required by the minimum necessary standards explained below.

**What is the “minimum necessary” standard?**

As a general rule, when the covered entity or business associate uses or discloses your PHI, the “minimum necessary” standard applies, meaning that reasonable efforts must be taken to limit the disclosure of your PHI to the minimum information necessary to accomplish the intended purpose of the use or disclosure.

**What is a notice and when is it used?**

The Privacy Rule requires covered entities to give notice to you regarding your rights under the Privacy Rule and the potential uses and disclosures of your PHI. The Privacy Rule contains very specific information about the format of the notice and the information the notice must provide, which include: (1) a specific statement that informs you of the purpose of the notice; (2) a description with at least one example of the types of uses and disclosures the covered entity may make with regard to treatment, payment, or health care operation purposes; (3) a description of the other purposes for which the covered entity may be permitted or required to use or disclose PHI without your authorization; and (4) separate statements required if the covered entity is engaged in certain activities listed in the Privacy Rule. (6)

**What is an authorization form and when is it used?**

An authorization allows the covered entity or business associate to use or disclose your PHI to a particular person or entity for a specific purpose. An example of when an authorization may be signed by the patient is when PHI is disclosed for marketing purposes. In general, an authorization permits the disclosure of your PHI to a non-covered entity or a non-business associate, if you decide to sign the authorization. (7)

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(6) These activities include, for example, contacting the individual for appointment reminders, sending information about treatment alternatives or other health-related benefits or services and fund-raising activities.

(7) The Privacy Rule requires that the authorization: (1) describe the information to be used or disclosed in a specific and meaningful way; (2) name or otherwise specifically identify the person or class of persons to whom the disclosure may be made; (3) contains an expiration date or an expiration event that relates to you or the purpose of the use or disclosure; (4) contains statements regarding your right to revoke the authorization in writing, the exceptions to the right to revoke, and a description of how to revoke the authorization; (5) contains a statement that the information disclosed may be subject to disclosure by the recipient and may not be protected by the authorization once in the hands of the recipient; and (6) contains your signature and the date.
What are the major differences between the notice and authorization?

The notice is a document that advises you about how the covered entity will use or disclose your PHI and what steps the covered entity will take to protect your PHI. The authorization is a form that you decide whether or not to sign in order for a covered entity to use or disclose your PHI for reasons other than treatment, payment or health care operation purposes.

What rights do you have with regard to your PHI?

The Privacy Rule affords you the right to access your PHI, the right to amend your PHI, and the right to an accounting of disclosures of your PHI. These rights are explained in the notice form.

When is the Privacy Rule effective?

The Privacy Rule is currently in effect. In general, covered entities must have been in compliance by April 14, 2003. However, small health plans (health plans with annual receipts of $5 million or less) must have been in compliance by April 14, 2004.

What happens if a covered entity or its business associate violates the Privacy Rule?

The Department of Health and Human Services may conduct a compliance review of any covered entity to determine whether that entity is in compliance with the Privacy Rule.

How does HIPAA interact with state laws?

The Privacy Rule is a federal law. In general, if there is a conflict between the federal and state law, then the federal Privacy Rule should apply. However, the Privacy Rule also requires that if the laws of a particular state conflict with the Privacy Rule and the state law is more stringent (provides more protections) then the state law, or the portion of the state's law that is more stringent will apply instead of the federal Privacy Rule.
INTRODUCTION

A clinical trial is a study conducted by cancer researchers to discover new methods for cancer prevention, diagnosis and treatment that are safe and effective. The drugs and procedures used in clinical trials have been researched in successful laboratory and/or animal studies. Each study comes with a unique set of rights and responsibilities and can also affect privacy concerns and insurance coverage.

What are the different types of clinical trials?

- Treatment Trials—test new ways to treat cancer.
- Prevention Trials—test ways to prevent cancer, to prevent cancer survivors from relapsing with the same type of cancer, and to prevent cancer patients and/or survivors from developing a new type of cancer.
- Screening Trials—look for the best way to find cancer, especially in its early stages.
- Quality of Life or Supportive Care Trials—discover ways to improve the quality of life and comfort level of cancer patients.
- Diagnostic Trials—study tests and procedures that will identify cancer more accurately.
- Genetic Studies—look at issue such as how genetic makeup can affect detection, diagnosis or response to cancer treatment.

What should I know before agreeing to participate in a clinical trial?

Before you make the decision to participate in a clinical trial, you must first determine the potential risks and benefits of the trial, as well as your rights and responsibilities as a participant. With that knowledge, your decision to participate in a clinical trial is referred to as informed consent. For more information, please see the Informed Consent section of this Cancer Guide.

What are the potential problems with the clinical trial process?

One possible problem that arises in clinical trials is the lack of informed consent by a participant. There are federal and state laws that regulate what constitutes informed consent (see the Informed Consent section of this Cancer Guide for more information). If these guidelines have not been strictly followed, the people in charge of the clinical trial could be liable for any damage caused by their failure to get informed consent from any and all participants.
Another potential problem with a clinical trial could involve the process used for the study itself. For example, the researchers conducting the clinical trial could perform a procedure incorrectly or the study itself could be inherently unsafe.

Privacy issues in clinical trials are also unique. While most studies mask patients’ names, the records themselves can become part of the study. Because trials are research studies, complete confidentiality cannot be guaranteed. Be sure to ask your physician about any concerns you might have with regard to privacy.

Finally, clinical trial treatments may not be covered by your insurance policy. However, other means of funding may be available, and your physician and/or a hospital social worker should be able to help you locate appropriate funding.

HELPFUL RESOURCES:

National Cancer Institute
1-800-4-CANCER
http://www.cancer.gov/clinicaltrials

American Cancer Society
1-800-ACS-2345
http://www.cancer.org

THE FOLLOWING CLINICAL TRIAL REFERENCES ARE SUGGESTED BY THE AMERICAN CANCER SOCIETY:


ECRI: Should I Enter a Clinical Trial? A Patient Reference Guide for Adults with a Serious or Life-Threatening Illness. ECRI; February 2002.

Available at: www.ecri.org/Patient_Information/Patient_Reference_Guide/prg.pdf


INTRODUCTION

Approximately forty percent of the more than one million Americans diagnosed with some form of cancer each year are working-age adults. Nearly ten million Americans have a history of cancer. These statistics highlight the importance of understanding the legal rights and protections that exist in the workplace for cancer patients and survivors.

EMPLOYMENT LAWS PROTECTING CANCER PATIENTS

The two federal employment statutes that most affect those diagnosed with cancer (or those with a history of cancer) are the Family and Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA). While this section of the Guide focuses only on these two federal statutes, it is important to note that there are also a number of state statutes that may provide additional rights and protections in the employment context. Information regarding individual state law information can often be found on the Internet, including links on the websites referenced at the end of this section.

THE FAMILY AND MEDICAL LEAVE ACT

What is the purpose and scope of the FMLA?

The purpose of the FMLA is to provide eligible employees with the right to take family and medical leave under certain circumstances. The Wage and Hour Division of the U.S. Department of Labor (DOL) is the federal agency responsible for enforcing the FMLA and for establishing regulations regarding the protections offered by the Act.

The FMLA applies to private employers with fifty or more employees for twenty calendar work weeks in the current or preceding calendar year. A covered employer must provide eligible employees with up to twelve work weeks of unpaid, job-protected leave in certain family and medical situations.

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(8) The FMLA and ADA are two of the most complex statutes in employment discrimination jurisprudence and continue to be the subject of litigation throughout the United States. Thus, the Committee recommends that you contact an attorney and/or the U.S. Equal Employment Opportunity Commission, the U.S. Department of Labor, or an appropriate advocacy group regarding the most up-to-date information on these statutes, including their applicability under specific circumstances and the meaning of any terms used in these statutes.

(9) This section deals only with the scope of protection for employees of private employers. Public employees, however, are also entitled to certain protections for family and medical leave and disability-related discrimination. Information regarding protections for public employees, including useful links, can be found on the Internet, including the U.S. Department of Labor and the U.S. Equal Employment Opportunity Commission websites.
On January 16, 2009, new FMLA regulations became effective. For additional information regarding FMLA, visit the Department of Labor’s website at www.dol.gov. The revised regulations alter the notice and certification requirements associated with FMLA leave (as discussed more fully below), in an effort to foster better communications between employers and employees.

Who is an eligible employee?

To be “eligible” for leave under the FMLA, an employee must have been employed: (1) for at least twelve months by the employer with respect to whom the leave is sought; (2) for at least 1,250 hours in the twelve-month period immediately preceding the leave request; and (3) at a work site where the employer employs at least fifty or more employees within a seventy-five mile radius.\(^{10}\) The twelve-month employment period need not be consecutive. Moreover, only hours actually worked will count toward the 1,250 hour eligibility requirement.

Under what circumstances can I request leave under the FMLA?

An employee may request FMLA leave under the following circumstances: (1) for the birth and care of a child, or for the placement of a child for adoption or foster care; (2) for a serious health condition of the employee’s spouse, parent, or child that requires the employee to miss work and care for the family member; or (3) for a serious health condition of the employee that prevents the employee from performing one or more of the essential functions\(^{11}\) of his or her position.

The new regulations clarify the necessary documentation that an employer can require in connection with leave requests related to caring for a spouse, parent, or child with a serious health condition.

How does the FMLA define a “serious health condition”?

A “serious health condition” under the FMLA is defined as an illness, injury, impairment, or physical or mental condition involving: (1) inpatient care in a hospital, hospice, or residential medical care facility; or (2) continuous treatment by a health care provider. Any periods of incapacity or follow-up treatment related to inpatient care are also protected under the FMLA. The new regulations have detailed

\(^{10}\) Notably, state law, collective bargaining agreements, and an employer’s own family and medical leave policy (often located in an employee handbook or a policy manual) may offer benefits more generous than those provided by the FMLA. Thus, it is important to confirm whether such additional benefits exist and, if so, how they may apply to your specific need for family and medical leave.

\(^{11}\) The DOL incorporates the ADA definition of an “essential function” into the FMLA regulations. The ADA definition of an essential function is discussed in greater detail under the ADA section. Furthermore, given the recent amendments to the ADA, coverage may become more expansive.
requirements about when and the number of times an employee must visit a health-care provider in a specified period of time in order to qualify under the FMLA.

**Does the FMLA allow me to take leave in smaller blocks of time or reduce my hours?**

Yes. Where medically necessary, an employee may be able to take leave intermittently (e.g., for a day or limited number of hours) or request a reduced leave schedule (e.g., reducing the number of hours or days worked). A reduced leave schedule may be used in a variety of situations, including where an employee is recovering from a serious health condition and needs to reduce his or her work schedule or working hours. Intermittent leave is taken in separate blocks of time for a single qualifying reason and may be taken due to a serious health condition that requires periodic medical treatments, such as chemotherapy. Review your employer’s policies as to the increments in which your employer requires leave to be taken. The employee must make a “reasonable effort” to avoid disruption at the workplace. However, if the treatment is deemed a medical necessity by the healthcare provider, the medical determination prevails.

During such intermittent or reduced leave schedule, the employer may, in some cases, temporarily transfer the employee to an alternate position with equivalent pay and benefits to accommodate periods of leave or limited capacity. The equivalent pay and benefit requirement applies even if the new position reduces the number of hours to a level where the employee would not otherwise be entitled to such pay and benefits. The employer may not, however, transfer an employee into a position to discourage the employee from taking leave or to otherwise retaliate against the employee for seeking leave. Once the intermittent or reduced leave is no longer needed, the employer must return non-key employees to the same or substantially similar position (discussed below).

**What notice do I need to provide my employer and when?**

The new regulations modify the timing and content of the notice an employee must provide to an employer when leave is requested. Employees are required to follow established call-in procedures for calling in absences and requesting leave. A failure to follow these procedures could result in an employer delaying or denying the leave request. Where the need for leave is foreseeable, the employee should give the employer at least thirty-days advance notice of the need for leave, including its duration. Further, the employee should attempt to schedule the leave, if possible, so that it is not unduly disruptive to the operations of the employer. In those situations where the need for leave is not foreseeable, an employee must give notice as soon as
practicable after discovering the need for leave. Calling in “sick” is not enough to trigger an employer’s obligation to determine if the leave is FMLA-protected. While federal law does not require an employee to specifically mention the FMLA when requesting leave, the employee must give sufficient information to put the employer on notice that the requested leave may qualify as FMLA leave. The employer can then inquire further, if necessary, regarding the specific circumstances of the requested leave. However, if the reason for the leave request relates to previously provided FMLA-protected leave, the employee must specifically reference the qualifying reason for the leave in notifying the employer under the new regulations.

Once notice has been given, it is the employer's responsibility to inform the employee that the requested leave will be counted as FMLA leave within five business days of the request, absent extenuating circumstances (compared to a two-day turnaround required under the old regulations). If the employee is ineligible for leave, the employer must provide at least one reason explaining the denial of the request for leave. The employer must also provide notice to the employee detailing the employee's obligations under the FMLA and the consequences for failing to meet them. Many employers will use a form provided by the DOL (known as Form 381) to provide such notification. A copy of the form can be found on the DOL website.

May an employer seek medical certifications or examinations in response to an FMLA request?

Yes. An employer may require a medical certification from the employee’s health care provider attesting to the serious health condition of the employee or relevant family member. The employer may not, however, seek more information than is contained in the optional DOL FMLA certification form (known as Form 380). The DOL form focuses on information concerning the specific health condition at issue, including the date the condition began, probable duration of the condition, whether the condition meets the definition of a “serious health condition” and the medical facts that support such conclusion. The form also addresses whether intermittent leave will be necessary and the scope of such intermittent leave, whether the employee will be unable to perform the essential functions of his or her position, and, if the leave involves the serious health condition of a family member, information regarding the need to care for the

(12) Such notice includes whether the employee will be required to provide a medical certification and consequences for failing to do so, the employee’s right to use paid leave during the FMLA period and/or whether the employer will require the employee to substitute such paid leave, whether the employee will be required to pay group health insurance premiums and consequences for failing to do so, whether a fitness-for-duty certificate will be required upon returning to work, whether the employee will be classified as a key employee, and the employee’s right to job restoration. The Notice must also include a statement of the employee’s essential job functions, if the employer will require that those functions be addressed in a fitness-for-duty certification.
family member. Under the new regulations, the new form specifically allows doctors to provide a diagnosis, however employers cannot reject certifications that do not contain diagnoses. Many employers opt to use the DOL form in connection with such certifications. A copy of the form can be found on the DOL website.

Where the need for leave is foreseeable and the employee has provided the thirty-days advance notice, then the certification should be provided before the leave begins. Where the thirty-days notice is not possible, the employer must allow the employee at least fifteen calendar days to provide the certification. The employee must provide the certification within this timeframe or as soon as practicable under the circumstances. However, an employer must allow additional time where the employee has made diligent good faith efforts to comply with this timing requirement. Under the new rule, an employer may contact the employee’s health care provider directly regarding any medical certification. However, the employer must be given a HIPAA release by the employee so that the employer can obtain clarification and confirmation of authenticity of any information provided. A failure by the employee to provide this release could result in denial of the leave request. If the employer determines a certification is incomplete or insufficient, the employer must state in writing what additional information is necessary and allow the employee seven calendar days to cure the deficiency.

**What if my employer disagrees with my doctor?**

Where the employer has reason to question the validity of the initial certification, the employer may request a second opinion from a different health care provider, at the employer’s expense, as long as it is not by a health care provider that is employed or used by the employer on any regular basis. Should the second certification conflict with the initial certification, the employer can request a third certification, at its own expense. The employer and employee must jointly agree upon the third health care provider, whose opinion will be final and binding on the certification. The employer can also request a recertification from the employee, usually every thirty days after the estimated duration has expired, and a fitness-for-duty certification when an employee is ready to return to work (as long as the employer has a uniformly-applied practice of requiring such fitness-for-duty certifications when an employee returns from a medically-related leave). If a period of leave longer than thirty days is provided, certification cannot occur before the time period expires, unless circumstances change, or an employer has reason to doubt the validity of the initial certification. Although the prior regulations did not allow fitness-for-duty certifications when an employee uses intermittent leave, the new regulations allow employers to obtain this certification every thirty days if the employer has reasonable safety concerns.
Will I lose my benefit coverage while on FMLA leave?

Generally, no. During an FMLA leave, an employer must continue employer-provided group health insurance during the term of the leave, as if the employee had not taken leave. Thus, any changes to the group health plan that take place during an employee’s FMLA leave must be applied or offered to the employee.

Under some special circumstances, an employer’s obligation to continue group health benefits during the FMLA leave will end, including where: (1) the employer-employee relationship would have terminated if the employee had not taken leave; (2) the employee fails to return to work at the expiration of the leave (absent special circumstances); (3) the employee elects not to retain group health care coverage; and (4) the employee’s premium payment is more than thirty-days overdue, despite sufficient notice (usually at least fifteen days) from the employer.

Who pays for benefits during FMLA leave?

The employer can require the employee to pay his or her share of the insurance premiums paid by the employer during the leave period, which can be done in a variety of ways, including having the employee make the premium payment: (1) at the same time it would have been paid via a payroll deduction; (2) on the same schedule as payments are made under COBRA; or (3) pursuant to a reasonable payment agreement between the employer and employee. The employer must give reasonable notice of the employee’s payment option(s) and the employee will generally have the choice to discontinue benefit coverage during the FMLA-leave period.

Do I have to use up my vacation time/PTO during FMLA leave?

An eligible employee may also elect, or the employer may require, that the employee use any accrued, but unused paid leave during the FMLA leave period. Any employer requiring such leave substitution should notify the employee in advance in writing. Such notification is most often contained in an FMLA policy in an employee handbook. Where leave substitution results in a paid FMLA leave, the employee’s share of the group health plan insurance premiums should be paid by the method that is normally used by the employer during any paid leave (which is often done as a payroll deduction).

Do I get my same job back when I return from FMLA leave?

Yes, in most cases. In general, federal law requires employers to place non-key employees returning from FMLA leave (or who no longer need intermittent or reduced schedule leave) in the same or a substantially equivalent position. An employee is normally entitled to such restoration even where he or she has been
replaced or his or her position has been restructured to accommodate the employee’s absence as a result of the leave. The position must have equivalent pay (including unconditional pay increases), benefits, and other terms and conditions of employment (such as promotion opportunities, skill, hours, location, responsibility, etc.).

The restoration obligation is not absolute, however. For example, an employee is not entitled to restoration where he or she would not have remained continuously employed during the leave period (such as where the employee would have been laid off, terminated for discipline based on conduct prior to the leave, or resigned his or her position prior to the leave). Nor is an employee entitled to job restoration where he or she is unwilling or unable to return to work after the expiration of the leave period (although there may be a requirement under the ADA to provide a reasonable accommodation, as discussed below). It is critical to note that an employee who voluntarily returns to a light-duty position because the employee is unable to resume working in his or her original position is not entitled to job restoration under the FMLA.

Further, “key employees” are not entitled to job restoration if it would cause “substantial and grievous economic injury” to the employer’s business operations. A key employee is defined as a salaried employee who is among the highest paid ten percent of all employees within a seventy-five mile radius of the worksite. A “substantial and grievous economic injury” is considered to exist where the restoration would result in substantial, long-term economic injury or otherwise threaten the financial stability of the employer’s operations – which is a more stringent standard than an “undue hardship” under the ADA (discussed below).

THE AMERICANS WITH DISABILITIES ACT

What is the purpose and scope of the ADA?

The purpose of the ADA is to dispense with misconceptions and stereotypes regarding individuals with disabilities and to prevent disability discrimination in employment. The U.S. Equal Employment Opportunity Commission (EEOC) is the federal agency responsible for enforcing the ADA and for establishing the regulations regarding the scope of protections offered by the Act.

The ADA (Title I) applies to private employers that employ fifteen or more employees for twenty or more calendar weeks in the current or preceding calendar year. The Act prohibits discrimination against a qualified individual with a disability and offers protection for both employees and job applicants.

What is a disability under the ADA?

An individual is “disabled” under the ADA if he or she: (1) has a physical or mental impairment that substantially limits one or more major life activities; (2) has
a record of such impairment; or (3) is regarded as having such an impairment. Cancer may be considered a disability under the ADA when it, or its side-effects (including treatment such as chemotherapy or even depression), substantially limit one or more of the individual’s major life activities.

**ADAAA Expands Definition of “Disability”**

Under the Americans With Disabilities Act Amendments Act (“ADAAA”), while cancer is not guaranteed to be a covered disability, it may now be easier for cancer patients to demonstrate that cancer limits a major life activity. The ADAAA expanded the list of major life activities and added a category to include “major bodily functions”, specifically: the immune system, digestive system, cell growth, neurological and brain functions, respiratory and circulatory systems, endocrine, and reproductive functions. The regulations also added hemic, lymphatic, musculoskeletal, special sense organs and skin, genitourinary, and cardiovascular to bodily functions.

In this same vein of broadening the definition of “disability” the regulations also call for a “common sense approach” to determining protection under this statute. The regulations also provide even more specific examples of impairments that will consistently meet the definition of a disability, including but not limited to cancer.

**What is a “major life activity”?**

Major life activities are those activities that the average person in the general population can perform with little or no difficulty. Major life activities include, but are not limited to, caring for oneself, performing manual tasks, interacting with others, speaking, seeing, hearing, learning, sleeping, walking, standing, lifting, bending, learning, reading, concentrating, thinking, communicating, working, breathing, eating, and reproduction. In some instances, “working” can be considered a major life activity, but only where the individual is significantly restricted in a class of jobs or broad range of jobs in various classes – as compared to the average person having comparable training, skills, and abilities.

**What does it mean to be “substantially limited” under the ADA?**

Determining whether an individual is “substantially limited” in a major life activity requires a case-by-case assessment of the individual’s condition, including: (1) the nature and severity of the impairment; (2) its duration or expected duration; and (3) its permanent or expected permanent or long-term impact. This determination is made by comparing the individual to the average person in the general population. Therefore, occasional or intermittent occurrences of an impairment are often not severe and permanent enough to be considered substantially limiting under the ADA.
However, impairments that are episodic or in remission are nonetheless considered disabilities so long as they would substantially limit a major life activity when active.

**How are “mitigating measures” considered?**

In determining whether an individual is substantially limited in a major life activity under the new regulations, the ameliorative effects of mitigating measures (with the sole exception of eye glasses) are not to be considered in weighing a disability. Therefore, an individual’s use of medication, and other medical equipment or supplies will not preclude an individual claiming an impairment, and thus the individual may still meet the substantially limited requirement in order to be “disabled” under the ADAAA.

**Is a disability under the ADA the same as a serious health condition under the FMLA?**

No, not necessarily, although there may be some overlap. A serious health condition under the FMLA, by definition, requires inpatient care or “continuing treatment.” A disability under the ADA, on the other hand, is a mental or physical impairment that substantially limits one or more major life activities, and requires more than temporary conditions like sprains or routine surgery. For example, if an employee has a routine appendectomy, the FMLA would be implicated (assuming the employee is eligible for leave under the FMLA and employed by a covered employer), but not necessarily the ADA, unless complications occur that qualify as a disability.

**Who is entitled to a reasonable accommodation under the ADA?**

Under the ADA, a covered employer is required to provide reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability, unless the employer can demonstrate that the accommodation would impose an undue hardship on the operation of its business. However, persons “regarded as disabled” are not entitled to a reasonable accommodation.

**Who is a “qualified individual with a disability”?**

An individual is a “qualified individual with a disability” where that individual can perform, with or without a reasonable accommodation, the essential functions of the position held or desired. Essential functions are those functions that are fundamental to the position, not marginal. A function may be essential if: (1) the reason

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(13) The DOL Regulations expressly state that a “serious health condition” under the FMLA must be analyzed separately from a “disability” under the ADA, because they represent different concepts.
the position exists is to perform that function; (2) there are a limited number of employees available to perform the function; and/or (3) the incumbent in the position is hired based on specialized expertise relating to such function.

In determining whether a function is essential, courts will look to several factors, including: (1) the employer’s judgment as to what functions are essential; (2) written job descriptions for the position; (3) the amount of time spent on the job performing the function; (4) the consequences of not requiring an employee to perform the function; (5) the terms of any collective bargaining agreement with a union (where applicable); and (6) the past and current work experience of employees in the same position. This determination must be made on a case-by-case basis.

How do I request a reasonable accommodation?

There are no magic words necessary to request a reasonable accommodation. Rather, the employee need only provide sufficient information to put the employer on notice that he or she needs an accommodation based upon a covered disability. Once the employee has requested an accommodation, the “interactive process” between the employer and employee begins. This process is an interactive and ongoing discussion between the employer and employee to determine whether the employee needs an accommodation and, if so, what accommodation is reasonable and appropriate under the circumstances. Throughout this process, the employee and, where applicable, the employee’s doctor, will inform the employer of the nature and limitations of the employee’s disability and suggest possible accommodations to enable the employee to perform the essential functions of the position. Since the passing of the ADAAA, it is expected courts will focus less on whether an employee has a “qualifying disability” and more on an employer’s response to a request to accommodation to determine whether a right under the ADA has been violated.

What are some examples of reasonable accommodations?

Reasonable accommodations must be tailored to the specific individual in need of an accommodation. Indeed, there may be as many possible accommodations as there are individuals requesting them. Examples of such accommodations include: (1) job restructuring; (2) providing time off of work or a modified schedule (for treatment or other medical needs); (3) simple physical changes to the workplace; (4) modifying a workplace policy; (5) reassigning non-essential functions to others; and (6) reassigning the employee to a different (vacant) position. Importantly, the accommodation selected by the employer need not be the one the employee selects or prefers, as long as it effectively accommodates the employee. But an employer is not required to provide an accommodation that results in an undue hardship (discussed below).
May an employer request medical certifications and other documentation in response to an accommodation request?

Yes. An employer may request reasonable medical documentation, including, but not limited to, documents substantiating that the employee: (1) has a covered disability under the ADA; and (2) needs a reasonable accommodation. The employer may not, however, seek the employee’s entire medical file or any documents that do not otherwise relate to the employee’s reasonable accommodation request.

Documentation will generally be considered sufficient if: (1) it is offered by a health care professional with the necessary expertise; (2) it describes the nature, severity, and duration of the impairment; (3) it describes the activities limited by the impairment; (4) it explains the extent to which the impairment limits the employee’s functional ability; and (5) it substantiates why the requested accommodation is needed. An employer may not use such requests as a means of retaliating against an employee who has requested an accommodation under the ADA.

Where the employee fails to provide sufficient documentation, the employer can request the missing information. The employer, however, should explain why the previous documentation was insufficient and give a reasonable period of time for the employee to provide the additional information needed. The employer can also ask the employee for permission to consult directly with the employee’s physician (with a release from the employee) or even request an examination by an employer-selected doctor, as long as the examination is limited to determining whether the employee is disabled under the ADA, the scope of any functional limitations, and any possible accommodations needed by the employee. All costs related to an employer-requested medical examination must be paid by the employer.

What is an “undue hardship”?

An “undue hardship” is an action that requires “significant difficulty or expense.” Factors considered by the courts in determining whether an accommodation constitutes an undue hardship include, but are not limited to: (1) the nature and cost of the accommodation at issue; (2) the overall financial resources of the employer’s facility, number of persons employed at the facility, the effect on the expenses and resources of the facility, or the impact otherwise of such accommodation on the operation of the facility; (3) the overall financial resources and overall size of the business of the employer; and (4) the type of operation engaged in by the employer, including the composition, structure, and functions of the workforce.

Are there any limitations on pre-employment medical examinations or inquiries?

Yes. An employer cannot inquire into whether an applicant has a disability before the potential employer has made a conditional offer of employment. For
example, an employer cannot inquire as to whether the applicant has or had cancer. But the employer may inquire as to whether the applicant can perform job-related functions. Once a conditional offer of employment has been made, an employer may conduct medical exams, but only if: (1) all applicants for the same job category are required to take such examinations; and (2) any examination criteria that screens out individuals is based on medical standards that are job-related and consistent with business necessity (and a reasonable accommodation will not allow the individual to perform the essential functions of the job).

**Are there any limitations on medical examinations or inquiries of employees?**

Yes. An employer cannot conduct medical examinations or inquire as to whether an existing employee has a disability, unless the examination and/or inquiry is job-related and consistent with business necessity. This does not prohibit an employer from seeking medical examinations or making inquiries with respect to whether an employee can perform the essential functions of the position.

**What does it mean to be “regarded as” disabled, or have a “record of” a disability?**

The ADA also offers protection to those “regarded as” having or with a “record of” a disability. Thus, an employer may not treat an individual differently based on the individual’s “history” or “record of” an impairment that substantially limits one or more major life activities. Further, an individual may come within the “regarded as” protection of the ADA if an employer either: (1) mistakenly believes an individual has an impairment that substantially limits one or more major life activities; or (2) believes that an actual, non-limiting impairment substantially limits one or more major life activities.

**Is extended leave a reasonable accommodation under ADA?**

The law is still developing with respect to the extent to which a leave of absence can serve as a reasonable accommodation under the ADA. The EEOC takes the position that flexible leave policies should be considered as a possible reasonable accommodation where appropriate and that, while any additional leave need not be a paid leave, employers should consider allowing the use of accrued leave or leave without pay, where it will not cause an undue hardship.

Unlike the FMLA, there is no annual limit for leave (as a reasonable accommodation) under the ADA. Still, some courts have held that lengthy, indefinite periods of time may constitute an undue hardship on the employer. Thus, while additional leave may be available as a reasonable accommodation, the requested time period must be reasonable under the circumstances.
HOW TO AVOID JOB DISCRIMINATION

Are lawsuits the best answer to a possible employment discrimination claim?

No, not necessarily. In many cases, lawsuits can be costly and time-consuming endeavors that may not result in addressing the alleged discrimination in the best way possible. It is, therefore, advisable to take steps that reduce an employee’s exposure to potential discrimination. If the employee nevertheless experiences discrimination, he or she should attempt to resolve the matter internally with the employer. If these steps fail, then the employee may consider pursuing legal action.

What steps can I take to reduce or remove the chance of discrimination in employment?

There are several steps that you can take to reduce or remove the possibility of discrimination in the workplace. These steps include: (1) not volunteering that you have or had cancer, unless necessary, such as when it directly impacts your ability to perform the job (and even then, only to those who have a need to know); (2) focusing on your ability to perform the essential functions of the position, rather than any limitations that you may have; (3) always being aware of your employment rights and the scope of permissible medical examinations and inquiries (ask for clarification if it appears that the employer has requested more than is permissible by law); and (4) applying for positions and promotions that you are qualified to perform.

What initial steps can I take in response to possible workplace discrimination?

At the outset of any employment relationship, you should familiarize yourself with the employer’s FMLA and equal employment opportunity policies, including any complaint-reporting procedure (usually contained in the employee handbook). If you believe you have been discriminated against and/or the subject of retaliation for asserting your rights under the FMLA, ADA, or otherwise, you should promptly follow the employer’s internal procedure and report the conduct. The complaint-reporting procedure may require reporting the conduct to a supervisor, member of management, or a member of the human resources department. It is also important to note that your spouse who assists you with care, and for example medical insurance coverage, is also protected against retaliation in the workplace.

Once reported, you should give the employer a reasonable amount of time to investigate and address the matter. Using this procedure may resolve the matter promptly and allow you to stay focused on your job, rather than focusing on potential litigation and dealing with a likely adversarial relationship with your employer. In some instances, failure to report the conduct internally can also adversely impact any future lawsuit. For example, under a number of state and federal employment
laws, an employer can argue that it is not liable for the allegedly discriminatory con-
duct of its employees where a complaining employee failed to put the employer on
notice of the conduct via the complaint-reporting procedure and, thereby, prevent-
ed the employer from investigating – and possibly resolving – the matter.

**ENFORCING YOUR LEGAL RIGHTS**

**How are legal rights enforced under the ADA and FMLA?**

ADA: In Texas, an individual will generally have 300 days from the alleged dis-
criminatory incident or “violation” to file a Charge of Discrimination with the
EEOC, which is a mandatory prerequisite to bringing a private civil action under the
ADA. Failure to satisfy this administrative remedy can bar any further legal action by
the person claiming discrimination. Once filed, the EEOC will process the Charge
and conduct an investigation. Thereafter, the EEOC will issue its determination and
articulate whether it believes that there is “cause” or “no cause” to believe that dis-
crimination took place. The EEOC will then issue a Notice of Right to Sue letter,
which will allow the individual (or “charging party”) to commence litigation. The
individual can also request a Notice of Right to Sue before completion of the admin-
istrative process (without waiting on a determination). In any event, an individual
will have 90 days from receipt of the Notice of Right to Sue to file a lawsuit.

FMLA: Unlike the ADA, the FMLA does not have an administrative-exhaus-
tion requirement. Rather, the employee can immediately proceed with a private civil
action. An individual seeking relief under the FMLA must file his or her civil action
within two years of the alleged violation. This period is extended to three years in
cases where the employer engaged in a “willful” violation of the FMLA. An individ-
ual may also notify the DOL of any potential FMLA violations, in which case the
Secretary of Labor may investigate and thereafter bring a legal action against the
employer directly. Thus, an employee can file suit, file a complaint with the DOL,
or both. However, where the Secretary of Labor files a civil action against the
employer (based on the conduct complained of by the employee), the employee’s
individual right to bring a private action ends. Thus, an employee should consult
with an attorney and carefully select the option that is best suited to the employee’s
specific case.
USEFUL RESOURCES

U.S. Department of Labor (FMLA information)
www.dol.gov or 1-(866)-4-USA-DOL

U.S. Equal Employment Opportunity Commission (ADA information)
www.eeoc.gov or 1-(800)-669-4000

Advocacy, Incorporated (disability rights advocacy)
www.advocacyinc.org or 1-(800)-252-9108

Lance Armstrong Foundation/LIVESTRONG™ SurvivorCare (cancer survivor resources and information) www.livestrong.org or 1-(866)-235-7205

State Bar of Texas (general representation information)
www.texasbar.com or 1-(800)-252-9690

Find Law (general representation information)
www.findlaw.com
INTRODUCTION

One of the major issues facing many cancer patients—and family members that may be caring for a person afflicted with cancer—is the disability that may result from the disease itself or the effects of various cancer treatments, or both. Disability can affect cancer patients in two critical areas: (1) employment and (2) the inability to make important decisions about health care, finances and other personal matters. An individual's employment typically provides not only income, but critical benefits such as health insurance. Multiple issues, such as workplace discrimination and financial strain, may arise when cancer or cancer treatment affects a patient’s ability to work.

With respect to the inability to make important decisions, you should consider having certain legal documents, such as a medical power of attorney and a directive to physicians, prepared in the event that your illness or the treatment of your illness renders you unable to make medical decisions for yourself. Both of these key issues are discussed in detail in the: (1) Employment Law and (2) Estate Planning sections of this Guide, so they will not be the primary focus of this section on disability, but you should be aware of the overlapping nature of these topics and consult the Employment and Estate Planning sections for a more in-depth and informative analysis of these issues. The focus of this section is on resources to help you deal with disability that may result from cancer or its treatment.

At the outset, it is important to note that the definition of “disability” itself will likely vary, depending on whether a particular statute (such as the Americans with Disabilities Act) applies, or may even be referred to in a different way. For example, the Family and Medical Leave Act defines disability as a “serious health condition.” Various non-profit organizations that assist cancer patients may have also different guidelines. Thus, it is generally a good idea to consult with the public or private resources for guidance.

DISABILITY AND EMPLOYMENT
What can I do if my illness or the treatments for my illness impact my ability to work?

Cancer, cancer treatment, or the lingering effects of both following the end of treatment may affect a cancer survivor’s ability to do his or her job. Most employers treat cancer survivors fairly and legally, but sometimes employers discriminate against cancer survivors based upon: (1) unfair assumptions about what people who have survived cancer can or cannot do in the workplace; (2) fears about rising insur-
ance costs; (3) the time requirements needed for treatment and doctors’ appoint-
ments; (4) the need to travel for treatment; and (5) numerous other issues associat-
ed with cancer and its effects upon a person. As a result, some survivors have encoun-
tered problems such as dismissal, failure to be hired, demotion, denial of promotion,
denial of benefits, and undesirable transfers. The Americans with Disabilities Act (ADA) may protect you from certain discriminatory practices, and may require your employer to provide you with “reasonable accommodations” such as alternative work hours or changed job duties to allow you to perform the essential functions of your job. It may also protect individuals who have a relationship with someone who has been disabled by cancer or cancer treatment. Other legislation, such as the Family Medical and Leave Act (FMLA), which permits a person to take up to twelve weeks of unpaid leave in a year for, among other things, a serious health condition or to care for a seriously ill spouse, parent or child, may also assist those who are diagnosed with cancer and their loved ones. The FMLA protects the employee’s job during that time period.

This is a very brief summary of disability as it relates to employment, and is really intended only to make you aware that there are laws in place to protect you or your family member(s) in the event cancer makes it difficult to continue working. For a more detailed discussion, please consult the Employment Law section of this Guide.

INCAPACITY

How do I take care of myself in the event my health affects my ability to make decisions?

At some point in your life, whether it is from this fight with cancer or some other illness in the future, you may be become unable to make decisions about your health care or other important matters, such as your finances, due to the effects of the illness or due to the treatment of the illness. In the event of such incapacity, you should have several legal documents in place that either (1) delegate such decisions to a trusted friend or family member, and/or (2) make your wishes about such critical issues known to your caregivers. These documents, which are discussed in detail in the Estate Planning and End of Life sections of this Guide, include a power of attorney, a medical power of attorney, a will, and a directive to physicians. Please consult the Estate Planning and End of Life sections for more information and guidance regarding these matters.

FINANCIAL ISSUES ASSOCIATED WITH DISABILITY

What are some private resources for financial assistance and information? (14)

(14) Many of the resources are also excellent sources of information for a multitude of issues not related to finances.
There are many organizations that provide financial assistance for the costs associated with medical care. There are a number of programs offered by a variety of organizations, and each program may vary widely by location and organization. For example, there are organizations that have volunteer programs to help provide cancer patients with transportation to and from treatment, organizations that have “lending libraries” of wigs, hospital beds, wheelchairs and related products, and organizations that offer financial assistance to patients having trouble paying their bills. It is important to note that organizations frequently do not publicize the assistance and available services they may offer, so do not hesitate to inquire about any programs offered by a particular organization. Also, remember to investigate any local charities or non-profit organizations for additional assistance programs—there are numerous regional non-profit organizations that provide excellent financial assistance.

Resources to contact for financial assistance include (15):

**Cancer Care**

275 Seventh Avenue  
New York, NY 10001  
1-800-813-HOPE (1–800–813–4673)  
http://www.cancercare.org

CancerCare is a national nonprofit agency that offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Financial assistance is given in the form of limited grants for certain treatment expenses. Services are provided by oncology social workers and are available in person, over the telephone, and through the agency’s Web site. CancerCare’s reach also extends to professionals—providing education, information, and assistance. A section of the CancerCare Web site and some publications are available in Spanish, and staff can respond to calls and e-mails in Spanish. Information about financial assistance for all cancers is available at http://www.cancercare.org/get_help/assistance/cc_financial.php.

CancerCare has also partnered with the Susan G. Komen Breast Cancer Foundation to create the Linking A.R.M.S. program, which provides limited financial assistance for hormonal and oral chemotherapy, pain and antinausea medication, lymphedema supplies, and durable medical equipment for women with breast cancer.

(15) Many of these resources are listed on the website maintained by the National Coalition for Cancer Survivorship at www.canceradvocacy.org, and the National Cancer Institute at www.cancer.gov, and various other websites dealing with cancer.
**Leukemia and Lymphoma Society (LLS)**

1311 Mamaroneck Ave.
White Plains, NY 10605
(800) 955–4572
http://www.leukemia-lymphoma.org

The Leukemia and Lymphoma Society (LLS) offers information and financial aid to patients in significant financial need who have leukemia, non-Hodgkin’s lymphoma, Hodgkin’s lymphoma, or multiple myeloma. The LLS’s “Patient Financial Aid” Web page provides more information about the types of service available, application forms, and eligibility requirements at http://www.leukemia-lymphoma.org/all_page?item_id=4603.

**Lance Armstrong Foundation**

P.O. Box 161150
Austin, TX 78716-1150
(512) 236-8820 and (866) 235-7205
http://www.livestrong.org

LIVESTRONG™ SurvivorCare offers counseling services, help with financial, employment or insurance issues and information about treatment options and new treatments in development. LIVESTRONG™ SurvivorCare is a program of the Lance Armstrong Foundation, in partnership with CancerCare, Patient Advocate Foundation and EmergingMed. To speak to a case manager, call LIVESTRONG™ SurvivorCare toll-free at 866.235.7205 or visit www.livestrong.org

**National Association of Community Health Centers, Inc.**

1330 New Hampshire Avenue, NW, Suite 122
Washington, DC 20036
(202) 659-8008
www.nachc.com

The National Association of Community Health Centers provides a listing of local nonprofit, community-owned health care programs serving low income and medically under-served urban and rural communities.
**Needy Meds**  
www.needymeds.com

Needy Meds is a resource for free information about getting medications from pharmaceutical companies.

**Oncolink**  
Abramson Cancer Center of Pennsylvania  
3400 Spruce Street – 2 Donner  
Philadelphia, PA 19104-4283  
oncolink.upenn.edu

Oncolink, managed by the University of Pennsylvania, is a website for cancer-related information that includes a special section, Financial Issues for Patients, which provides information on reimbursement assistance programs.

**Partnership for Prescription Assistance**  
(888) 4PPA-NOW (1-888-477-2669)  
www.pparx.org

The Partnership for Prescription Assistance (PPA) brings together America’s pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that is right for them. Many will get them free or nearly free. Through this site, PPA offers a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies.

**Patient Advocate Foundation**  
780 Pilot House Drive, Suite 100-C  
Newport News, VA 23606  
(800) 532-5274  
www.patientadvocate.org

The Patient Advocate Foundation provides education and legal counseling about managed care, insurance, and financial issues for cancer patients.
The Road to Recovery is an ACS service program that provides transportation for cancer patients to their treatments and home again. Transportation is provided according to the needs and available resources in the community and can be arranged by calling the toll-free number or by contacting the local ACS office.

**Ronald McDonald Houses/Charities**
One Kroc Drive
Oak Brook, IL 60523
(630) 623–7048
http://www.rmhc.com

Ronald McDonald Houses provide a “home away from home” for families of seriously ill children receiving treatment at nearby hospitals. Ronald McDonald Houses are temporary residences near the medical facility, where family members can sleep, eat, relax, and find support from other families in similar situations. In return, families are asked to make a donation ranging on average from $5 to $20 per day, but if that isn’t possible, their stay is free. To search for a Ronald McDonald House location, go to http://www.rmhc.com/rmhc/index/search_house.html.

**Taking Charge of Money Matters**
(800) ACS-2345
www.cancer.org

The American Cancer Society offers Taking Charge of Money Matters, a workshop for people with cancer and their loved ones about financial concerns that may arise during or after cancer treatment, regardless of the person's health insurance coverage. The session provides an opportunity to discuss financial matters with guest speakers who are knowledgeable about financial planning. More information about this workshop is available on the ACS Web page at http://www.cancer.org/docroot/SHR/content/SHR_2.1_x_Taking_Charge_of_Money_Matters.asp?sitearea=SHR.

**Tender Loving Care®**
(800) ACS-2345
www.cancer.org
The American Cancer Society’s “tlc” Tender Loving Care® publication contains helpful articles and information, including products for women coping with cancer or any cancer treatment that causes hair loss. Products include wigs, hairpieces, breast forms, prostheses, bras, hats, turbans, swimwear, and helpful accessories at the lowest possible prices. The publication strives to help women facing cancer treatment cope with the appearance-related side effects of cancer. To request a copy of “tlc,” call 1–(800)–850–9445, or visit “tlc” at http://www.tlccatalog.org.

What are some governmental resources for financial assistance?

Medical Assistance Programs

The Breast and Cervical Cancer Treatment Act provides, in most states, Medicaid coverage for treatment to women who have been screened for and diagnosed with breast or cervical cancer, including precancerous conditions, through the National Breast and Cervical Cancer Early Detection Program. For more information about eligibility and contacts for this program, visit the Centers for Disease Control and Prevention’s (CDC) “Breast and Cervical Cancer Prevention and Treatment Act of 2000” Web page, which is located at http://www.cdc.gov/CANCER/nbccedp/law106-354.htm.

COBRA is a federal act allowing individuals who lose employer health insurance coverage to buy group insurance for themselves and their families for limited periods of time. This may be helpful to consider if you have a waiting period to get through before Medicare or Medicaid take effect. To apply, contact your employer or group health insurance plan.

Hill-Burton

(800) 638-0742 (Maryland residents call 1-800-492-0359).

Hill-Burton is a program through which hospitals receive construction and modernization funds from the Federal Government. Hospitals that receive Hill-Burton funds are required by law to provide a reasonable volume of services to people who cannot afford to pay for their hospitalization and make their services available to all residents in the facility’s area. Information about Hill-Burton facilities is available by calling the toll-free number or visiting the Web site listed above. A brochure about the program is available in Spanish.

Medicare is a federal health insurance for those 65 or older or those who have been receiving Social Security Disability benefits for a full two years, regardless of age. For more information on Medicare, contact the Medicare Rights Center at (212) 869-3850.
**Medicaid** is a joint federal and state run program that provides health insurance to people meeting income and asset restriction guidelines. Apply through your local Social Service/Public Welfare Department. Additional information can be found at www.cms.hhs.gov/home/medicaid.asp. The telephone number is 1-800-252-8263.

**State Children's Health Insurance Program (SCHIP)**

(877) 543–7669 (1–877–KIDS–NOW)

http://www.insurekidsnow.gov

The State Children’s Health Insurance Program (SCHIP) is a Federal-State partnership that offers low-cost or free health insurance coverage to uninsured infants, children, and teens. Callers will be referred to the program in their state for further information about what the program covers, who is eligible, and the minimum qualifications. In most states, uninsured children age 18 and younger whose families earn up to $34,100 a year (for a family of 4) are eligible. For a list of health insurance coverage and eligibility by state, go to http://www.insurekidsnow.gov/states.htm.

Senior Prescription plans are offered by many states that provide affordable access to medications for seniors. Contact your department of aging or local legal aid program for information.

**In-Kind Help**

**Food stamps** can provide financial help for buying food. If you are having problems paying for food, it is a good idea to apply for food stamps even if you’re not sure you qualify because you may just be approved.

**Home Energy Assistance Program (HEAP) and Weatherization Assistance Program** help low-income homeowners and renters pay for fuel and utility expenses, or help weatherize their homes.

There are a variety of state programs to help people subsidize housing costs, reduce property tax costs, provide exemption from rent increases, and make available emergency cash for crisis situations. Ask your local Social Service Department or hospital social worker about your state’s programs.

**Income Replacement Programs**

**NCI’s Cancer Information Services**

(800) 4-CANCER (1-800-422-6237)

www.cancer.gov
The National Cancer Institute’s Cancer Information Services offers an extensive listing of financial assistance for cancer care. Some, but not all, of the resources are listed here.

**Social Security Benefits**

There are several programs under the Social Security Act that provide financial assistance to individuals who qualify. These programs include disability insurance benefits, unemployment compensation, and supplemental security income for the disabled, and are discussed in more detail below. For more information about these programs, contact the Social Security Administration’s toll-free hotline at (800) 772-1213.

**Retirement Benefits Under Social Security**

To be eligible for retirement benefits, you need not be disabled or in financial difficulty. The only requirement is that you be of a certain age and have paid into the Social Security system.

Under certain circumstances, spouses or other related persons may receive additional benefits. For example, a widow, widower, surviving divorced spouse, child or parent of a person who was entitled to Social Security benefits may directly receive benefits if certain conditions are met.

The **Supplemental Security Income (SSI) Benefits** program is designed to provide income to people 65 or over whose income is below the federal minimum level, and who are blind or disabled. Eligibility is determined by need, not whether you have paid into Social Security when you worked. Although SSI payments can be quite small, in many states an individual receiving SSI benefits will automatically be eligible for Medicaid and also may receive a state supplemental payment. [http://www.ssa.gov/notices/supplemental-security-income](http://www.ssa.gov/notices/supplemental-security-income)

**Disability Insurance Benefits Under Social Security**

Disability benefits are designed to provide income to people who are unable to work because of a disability. You are entitled to receive disability benefits while you are disabled before the age of 65 if:

- You have enough Social Security earnings to be insured for disability;
- You apply for benefits;
- You have a physical or mental disability that prevents you from doing any substantial gainful work;
• The disability must be expected to last, or has lasted, at least 12 months, or must be expected to result in death; and
• You have been disabled for five consecutive months.

In some cases, spouses of disabled claimants also are entitled to benefits.

The amount of disability benefits is based on a sliding scale percentage of wages determined by elaborate, frequently changing formulas based on your age and past earnings. An employed person may not collect benefits. Workers may not receive both workers’ compensation and Social Security disability for the same illness. The medical records of individuals who apply for Social Security disability are evaluated according to regulations issued by the Social Security Administration. Individuals who are denied benefits may appeal to an administrative law judge.

To determine whether your cancer is a disability under the law, the Social Security Administration considers: (1) what type of cancer you have; (2) whether it has spread; and (3) how you are responding to treatment. Small tumors that have not spread and that respond to therapy usually do not constitute an impairment. For example, early stage breast cancer that is successfully treated with surgery is not considered a severe impairment. Cancer that has spread beyond regional lymph nodes, however, is usually considered a severe impairment. Otherwise, your diagnosis is evaluated on a case-by-case basis.

**Veteran’s Benefits**

The Department of Veterans Affairs (DVA) offers a variety of benefits to veterans. Although most disability benefits apply to veterans whose disability is related to their military service, some benefits are available to cancer survivor veterans.

Depending on when you served, your age, and your income, you may be eligible for a nonservice connected pension. An additional allowance may be paid if you are in a nursing home, need a home aid, or are housebound because of your illness.

Hospital care in VA facilities is provided to veterans who meet certain standards, such as those who are eligible for Medicaid, need care related to exposure to cancer-causing substances (such as Dioxin, Agent Orange, or nuclear fallout), have a VA pension, or have a limited income. Outpatient care and medical equipment also are available under certain circumstances.

(16) The definition of “disability” used by the Social Security Administration differs from the ADA definition of disability. For the ADA definition of disability, please refer to the Employment Law section.
Additionally, the DVA offers a variety of other benefits to qualified veterans, including life insurance, burial benefits, death pension to your dependents if your death is nonservice connected, and civil service preference certificates if you seek government employment. For more information, contact:

**Department of Veterans Affairs**
www.va.gov

**Department of Federal Benefits for Veterans and Dependents**
(800) 827-1000

**The Uniform Benefits Package Enrollment Service Center**
(877) 222-VETS (8387)

**DEDUCTING MEDICAL EXPENSES FROM YOUR TAXES**

Part of the money you spend on medical care for yourself, your spouse, and your dependents may be itemized deductions for federal income tax purposes. Consequently, you should keep track of your physician fees, prescription drug expenses, dental expenses, home nursing fees, hospital bills, medical insurance premiums that you (not your employer) paid, laboratory bills, and transportation and lodging if you sought medical care away from your home.

At the end of the calendar year, add up all of your medical expenses. From this number, you must then subtract a percentage of your gross income. You may deduct the balance from your income subject to federal income tax.

The Internal Revenue Service (IRS) has a number of free publications that describe potential deductions related to health care. An IRS counselor will also answer over the telephone your questions about the tax regulations.

**Internal Revenue Service**
(800) 829 1040 for information
(800) 829-3676 for publications
LIABILITY ISSUES

INTRODUCTION

Each year thousands of Texans receive health care treatment related to the detection and diagnosis of cancer. While advances in medicine have led to more favorable outcomes for many patients, even the most diligent treatment cannot guarantee positive results in every situation. In the vast majority of these instances, negative results occur despite the best efforts of those providing the treatment. Unfortunately, there are rare occasions when the actions or inactions of those professionals trusted to help with a patient’s care and treatment actually cause additional negative consequences for the patient. This chapter is intended to offer an overview of the rights and remedies available to patients and families who have been injured as a result of substandard health care in relation to their diagnosis and treatment.

What if my family or I have concerns about the quality of treatment that I have received?

If you feel that you have been harmed by a health care provider in either your diagnosis or follow-up treatment, finding an attorney with significant experience in medical liability cases is the best option for exploring a possible claim related to your illness. Over the last thirty years, Texas has developed a large body of specialized law related to medical liability cases. In 2003, the Texas legislature passed a sweeping tort reform bill that now governs all new medical liability actions. This measure contains both pre-suit requirements for medical liability cases as well as damage caps, which limit the maximum amount that a claimant in a medical liability action may recover from a health care provider.

What can I expect to recover if I bring a successful medical liability claim?

If you or your family members are successful obtaining a judgment in a medical liability case, you can expect to receive monetary compensation for the injuries you suffered as a result of the substandard care or treatment. This compensation can be broadly divided into two categories (i) economic damages; and (ii) non-economic damages. Types of damages commonly recoverable as economic damages include medical expenses, lost income, loss of future income, lost earning capacity, and household and domestic expenses. Non-economic damages are those damages awarded for the purpose of compensating a claimant for physical pain and suffering, mental or emotional anguish, loss of consortium, disfigurement, physical impairment, loss of companionship and society, loss of enjoyment of life, and any other non-pecuniary losses other than punitive damages.
In Texas, non-economic damages in medical liability cases are limited to $250,000 for all claims against individual health care providers. Additionally, non-economic damages awarded against health care institutions are limited to $250,000 for each institution with a total limit not to exceed $500,000 for all institutions involved in any given case. Finally, in cases with allegations relating to the death of a patient, the total amount of both economic and non-economic damages is further limited by a cap that is calculated based on fluctuations in the consumer price index. This cap on the total recovery allowed in what is known as a “wrongful death case” is currently approximately $1.6 million.

**How long do I have to explore a potential claim before filing suit?**

A lawsuit related to a medical liability claim must be filed within two years of the substandard treatment that caused the injuries to the patient. This period is generally known as the statute of limitations or simply the limitations period. As part of the current tort reform statute impacting medical liability cases, these cases are subject to a rigid two-year limitations period that does not include general exceptions for extending the limitations period that are available in other types of cases. However, minor children have until their fourteenth birthday to file a medical liability claim related to their care and treatment that occurred before their twelfth birthday.

In rare cases where the particular facts of a patient’s claim make it completely impossible to bring the claim within the two-year statute of limitations, the patient might be able to challenge the application of the two-year statute of limitations under the open courts provision of the Texas Constitution. The analysis of the courts’ system with regarding such constitutional challenges is complex, and successful challenges under this provision are very rare. If you feel you may have a claim that would support such a challenge, an attorney with experience in this type of claim should be consulted as soon as possible. However, even in instances where constitutional challenges to access to the courts system may be invoked, there is an absolute ten-year limitations period, known as a statute of repose, that applies to medical liability claims.

One question that arises in discussions of the limitations period in medical liability cases is: what point in time should be used to begin calculating the two-year limitations period? In cases where the exact date of the substandard care and treatment can be identified, the two-year period begins with that date. For example, in cases involving a substandard surgery, the two-year limitations period begins on the date of the surgery. In other cases, where the substandard care and treatment is not readily identifiable and the treatment extends over a number of days, the two-year limitations period can be calculated beginning on the last date of the relevant course.
of treatment, or in the case of hospital admissions, the last date of the relevant hospitalization.

In all medical liability cases, the patient making the claim is required to file a report authored by a competent expert witness supporting the claim within 120 days of filing suit. For this reason, it is important that patients who feel they may wish to pursue a medical liability claim not wait until the last few days or weeks of the two-year limitations period to consult an attorney, as it may be practically impossible for the patient’s attorney to obtain the required expert report on such short notice.
GUARDIANSHIP

INTRODUCTION

The purpose of this chapter is to outline potential legal issues which may arise when you have dependent children, or would like to designate a guardian for yourself should you become incapacitated.

MINOR CHILDREN AND GUARDIANSHIPS

Oftentimes and understandably, children take a back seat to the patient’s battle with cancer. As you know, it is always important to consider the needs - both long-term and short-term, emotional and physical - of your children. Listed below are topics that may be of assistance when considering issues surrounding the children of a cancer patient.

How can I secure my child's future in the event of my incapacity or death?

Guardianship is the most common method of pre-arranging who will take care of your child if you die or become incapacitated.

GUARDIANSHIPS

What is a guardianship?

A guardianship is a court-supervised administrator designated for a minor child or an incapacitated person. There are two types of guardianships: 1) of the person; and 2) of the estate. Legally speaking the child or incapacitated person is often referred to as the “ward.” A guardian of the person is in charge of the child’s care and custody. A guardian of the estate is also in charge of the child’s property and finances, if there is any money or property in the child’s name.

Because a guardianship is a court-supervised proceeding, there are specific rules regarding all areas of guardianship, and it is highly encouraged that you speak with a lawyer about the requirements and specifications of appointing a guardian for your child, or yourself should you become incapacitated. This is especially true when you are not married to the child’s other parent.

The type guardianship addressed in this section is legally referred to as “guardianship of a person,” namely a guardianship of your child, or yourself should you become incapacitated.

Who can be a guardian?

In general, the following may not be appointed a guardian (“ineligible people”):
• a minor;
• a person whose conduct is notoriously inappropriate;
• an incapacitated person;
• a person who is a party or whose parent is a party to a lawsuit concerning or affecting the welfare of the proposed ward (your child);
• a person who is indebted to the proposed ward, unless the person pays the debt before appointment;
• a person asserting a claim adverse to the proposed ward or the proposed ward’s property (real or personal);
• a person who, because of inexperience, lack of education, or other good reason is incapable of properly and prudently managing and controlling the ward or the ward’s estate;
• a person, institution or corporation found unsuitable by the court;
• a person disqualified in a declaration made by you in the event of your incapacity;
• a nonresident person (nonresident of the state of Texas) who has not filed with the court the name of a resident agent (person or entity residing in the State of Texas) to accept service of process in all actions or proceedings relating to the guardianship; or
• a person who is a private professional guardian and public guardian who is not certified.¹

When appointing a guardian, you, like the court, should consider the best interests of the child. Under the law, it is presumed not to be in the best interests of a child to appoint a person as guardian of the child, if that person has been convicted of (i) any sexual offense or (ii) aggravated assault. In addition, a guardian cannot have (i) injured a child, (ii) injured an elderly individual, (iii) disabled an individual, (iv) abandoned or endangered a child, or (v) committed incest.

**What does a guardian do?**

In general, a guardian has wide authority over the care, control and protection of the ward, but that right of control is not unlimited under the law. The guardian’s duties may be restricted by a court.

The guardian is entitled to establish the ward’s domicile, to care for, control and protect the ward, to provide the ward with clothing, food, medical care and shelter, and to consent to medical, psychiatric and surgical treatment on behalf of the ward. Furthermore, if approved by the court, the guardian may establish a trust for the ward solely for the purpose of the ward’s eligibility for medical assistance.

¹ Subchapter C, Chapter 111, Government Code.
How do I create a guardianship for my child?

Because it is important that your wishes for your child’s future are followed, and because the guardianship process is not easy, we strongly encourage you to seek an attorney to help you with this process. That being said, it is helpful to know that there are legal requirements for creating a guardianship for your child.

- When appointing a guardian for your child it MUST be in writing. A guardianship can be created in a will or in a written declaration of guardianship.
- If you appoint an eligible person as a guardian (see list above of ineligible persons) in a will, the will must meet the requirements of a valid will under Texas law. (See the Estate Planning section for more information regarding wills.)
- If you appoint an eligible guardian by a written declaration, the written declaration MUST be signed by you. (When using a declaration to create a guardianship, you are known as the “declarant.”) Also the declaration should be dated. If the declaration is handwritten, then it must be entirely in your handwriting. A declaration that is not written wholly in your handwriting may be signed by another person for you under your direction and in your presence; or
- If the declaration is not handwritten, then you will need to have it witnessed (i.e., “attested to”) in your presence by at least 2 credible witnesses 14 years of age or older, who are not named as a guardian or alternate guardian. This kind of declaration may have attached a “self-proving affidavit” signed by you and the witnesses attesting to your competence and the execution of the declaration. A self-proving affidavit is a document that would be attached to the declaration and would say you are competent, and that you intended to create the declaration.
- The declaration and any self-proving affidavit may be filed with the court at any time after the application for appointment of a guardian is filed and before a guardian is appointed.
- If the designated guardian does not qualify, is dead, refuses to serve, resigns, dies after being appointed guardian, or is otherwise unavailable to serve as guardian, the court shall appoint the next eligible designated alternate guardian named in the declaration. If the guardian and all alternate guardians do not qualify, the court shall appoint another person to serve.

Note: A declaration and affidavit in any form may be adequate to clearly indicate your intention to designate a guardian for your child.
REVOCATION
A will and declaration of guardianship may be revoked in any manner as provided in a will. (See the Estate Planning section of this Guide for further information).

Is there anything else I should know about guardianships?
In the event that you become permanently incapacitated or die, the declaration of guardianship and/or last will and testament will need to be filed with the proper probate court. Also, the guardian will need to fill out an application for guardianship with that probate court and abide by the guardianship requirements imposed by law and by the court.

GUARDIANSHIP IN CASE OF YOUR INCAPACITY
You can also designate a guardian for yourself should you become incapacitated and require a guardian of your person. This kind of guardianship of you as an incapacitated person follows most of the same requirements as a guardianship of your minor child. In other words, you can only appoint or designate eligible people to be your guardian.

How to Execute?
You will need to designate a guardian in writing. When creating a guardianship for yourself you will follow the same steps as if you were creating a declaration of guardianship for your child. (See section above discussing the creation of a guardianship for a child.). One important difference when creating a declaration of guardianship for yourself is that you can designate the people that you do not want to become your guardian. These designated people will be disqualified from being your guardian, in the event that your pre-selected guardian is unable to serve as your guardian.

What else should I know about a guardian for myself?
If you designate your spouse to serve as your guardian, and you subsequently divorce before a guardian is appointed, the provision of the declaration designating your spouse has no effect.
Revocation of a declaration of guardianship for yourself is revoked just like a guardianship for your child. (See above section)

What else?
Talk to your child about the cancer
Often the scariest part for a child dealing with a parent who has cancer is the lack of information. There are numerous resources out there for help in explaining
and dealing with cancer. Talk to the nurses regarding possible resources for kids (e.g., age appropriate books). In addition, contact your local American Cancer Society or Hospice for more help.

**Talk to your child about his or her future**

Children need to be reassured that they will be taken care of and provided for under any circumstance. Just as you would discuss with your child what to do in case of a fire, you need to talk to your child about how cancer will affect your child’s future.

**Let your child’s school administrators and counselors know about your condition**

It is important to let your child’s school know about what your child is having to deal with at home. Often school counselors will be able to provide a support group of other children that have, or are currently dealing with, a similar situation involving a parent with cancer. The more support the child has the better they can cope with the stress of dealing with a parent with cancer.

A child dealing with stress under these situations may begin to act out while in school, which gives the school a “heads-up” that your child needs assistance.
ESTATE PLANNING

INTRODUCTION

Although many people walk through life without ever executing a will, it is vitally important that all individuals conduct some type of estate planning, regardless of their health, age or financial status. It is common for people to wait until they become ill or leave on a long vacation to address estate planning issues, but the fact is that death is untimely, and it is never too early for one to take the appropriate steps necessary to secure their estate. Proper planning can give you the peace of mind that your property will pass according to your wishes and will also make the adjustment period much easier on your surviving family members. This section will describe some basic estate planning tools, including wills, trusts, general powers of attorney, medical powers of attorney, directives to physicians and probate.

Types of property

An individual’s estate consists of the real and personal property that he or she owns as of the date of death. Real property includes land and any improvements on land as well as oil, gas and other mineral interests. Personal property is all other types of property, including cash, cars, stocks, bonds, clothing, furniture, etc. If you live in what is called a “community property state,” such as Texas, then all property, whether real or personal, is characterized as either separate or community. Separate property is that which is owned before marriage or acquired during marriage by gift or inheritance. Community is all other property that is acquired by either spouse during the marriage. A person can only control the distribution of his or her separate property and his or her half of the community property, if any, in a will.

The disposition of some types of property cannot be controlled by a will. These properties are called “non-probate assets.” This type of property allows a person to name a beneficiary of the property upon his or her death, which will be carried out regardless of how the person’s will reads. The most common types of a non-probate assets are life insurance policies, IRAs and employee benefit plans. Upon the death of the policy owner, the proceeds go directly to the beneficiary or beneficiaries named in the policy, and the owner’s will has no bearing whatsoever on the disposition of the money. Another form of a non-probate asset is a bank account or certificate of deposit that is set up between two people and designated as “joint tenants with rights of survivorship.” Anytime you see the “rights of survivorship” language associated with an asset, ownership of the asset automatically transfers in full to the surviving person, outside of probate.
**What is a will?**

A last will and testament, or a “will,” is a legal document, which, if executed properly, allows the testator (person signing the will) to direct how his or her property will be distributed at death. In the will, the testator names an executor who gathers all of the property, pays the debts of the testator and then distributes the property according to the testator’s wishes.

Formal wills (discussed below) include language that allows an executor to act “free of court” while handling the estate business, which makes the probate process much easier on everyone involved. A will also gives the testator the opportunity to name a guardian to take custody of any minor children that may survive the testator, in addition to allowing the testator to designate the individual who will manage the minor’s inherited property until reaching a certain age. Further, different types of trusts (discussed below) can be set up in a will, which allows property to be held by one party (the trustee) for the benefit of another party (the beneficiary). It is recommended to always name alternates to each position (executor, guardian, trustee) in the event that the primary agent has died before the testator, cannot serve or is unwilling to serve.

Most individuals leave “all of their estate, of whatsoever kind and wheresoever situated” to the person(s) named in their will. Also, a “specific gift,” where a particular item is given to a person, can be described in a will. Specific gifts are carried out before any other provision in the will. For instance, a father may leave his prize, antique rifle to his son and then leave all of the rest of his property to his wife, if he wants to ensure that the rifle ends up in his son’s possession instead of possibly being sold or given away.

**What are the different types of wills?**

Texas recognizes three kinds of wills: oral (nuncupative), handwritten (holographic) and typewritten (formal). To execute any of these wills, the testator must (i) be at least 18 years old, or who is or has been lawfully married or serving in the armed forces; (ii) be of sound mind at the time of execution; (iii) not be fraudulently induced (forced or deceived) into executing the will; and (iv) have the current intention to give away their property when they die.

**Oral wills,** also called nuncupative wills, are not recommended as a good estate planning tool, but sometimes this is the only option for the testator. An oral will can only dispose of personal property – gifts of land (real property) cannot be made orally. Also, the only way that an oral will can be valid is if it is made during the testator’s last illness while at home, or unless he or she is taken away from home due to the illness and dies before returning home.
Probating (proving) an oral will is even more of a challenge. If the personal property gifted is worth more than $30.00, then at least three credible witnesses must appear in court and testify to the details of the oral will. On top of that, an oral will cannot be probated (proved) more than six months after the testator's death, unless the substance of the will was reduced to writing within six days after making the will. As you can see, the law does not favor oral wills, but they are available if all conditions are met.

Handwritten wills, or holographic wills, are recognized in Texas. The will can be written on anything, must be wholly in the handwriting of the testator, must show an intent to dispose of property, and must be signed by the testator. Type-written words in a handwritten will are invalid due to the problem of not being able to prove who added the language, or when it was inserted. Handwritten wills do not need to be witnessed, although the law requires that at least two witnesses who are familiar with the decedent’s handwriting must appear in court to prove the validity of the will. Problems often arise with handwritten wills due to their ambiguity. If the intent of the decedent is unclear then costly will contests are surely to follow, and the court must then decipher the disposition of the property. Although they are a bit more effective than an oral will, a handwritten will is still not as effective as a formal, type-written will drafted by an attorney, and is likely to be contested in a court of law.

Type-written wills, or formal wills, are the best type of will to ensure that all of your wishes are carried out in a proper manner. Formal wills are typed in full and signed by the testator and two witnesses. For a typewritten will to be valid it must be signed by the testator, witnessed by two credible individuals above the age of fourteen, and then signed by the witnesses in the presence of the testator. A beneficiary named in the will should never also act as a witness to the same will, or he or she may be precluded from inheriting any property under the will. A “self-proving affidavit” is also part of most formal wills, which precludes the executor from having to bring the witnesses to court in order to prove the validity of the will at the beginning of the probate process. Although formal wills can be prepared by anyone, an experienced attorney should always draft the will.

Remember that wills are never final and can be changed at any time by the testator. Handwritten changes to a formal will cannot be honored and might result in the entire will being voided. If only one or two changes are being made to an existing will, it is common for one to prepare a codicil to the original will. However, a codicil must be executed in the same manner as a formal will (see above), so it is a better practice to just have a new will prepared if any changes need to be made.

For further information please visit www.tyla.org and request a copy of the brochure entitled, “To Will or Not to Will.”
What happens if I die without a will?

If a person dies without a will, their property is disposed of according to state law, or what is called the “laws of intestate succession” and the decedent’s “heirs at law” inherit the property (dying “intestate” means dying without a will). The details of these laws are beyond the scope of this Guide, but they are very specific and the heirs have no choice but to follow the legislature’s inheritance guidelines in the absence of a will to indicate otherwise.

In some situations a person’s will may leave his property to the same people that would also be his heirs at law should he die intestate. However, it is very common that a person’s heirs at law are in fact not the same people that the testator would want to end up with his property, and the only way to avoid this problem is to execute a will.

Dying without a will can also cause many delays and end up costing much more than a standard probate. Instead of having an executor that can act free of court, an administration may have to be opened in court wherein a judge must approve every action taken on behalf of the estate by the administrator.

Do I need a trust?

A trust is the process by which a property owner (trustor/grantor/settlor) transfers legal title to an asset to a person or entity (trustee) who has the duty to hold and manage the asset for the benefit of one or more persons (beneficiaries). There are two major categories of trusts: those created in a will (testamentary trusts) and inter vivos trusts, commonly called living trusts.

Testamentary trusts are inserted into a will and become effective at the testator’s death. These types of trusts are usually created in order to provide for the management of assets on behalf of minors, disabled adults or irresponsible individuals. The testator can designate the age at which the beneficiary can take control of the assets in the trust language. These trusts are very common in most formal wills. Another type of trust placed in wills is the bypass trust or marital deduction trust. These trusts are utilized by married couples who have enough assets to be subject to federal estate tax. Estate tax is imposed if the decedent’s assets at death exceed the limitation imposed by law currently in effect for that year (i.e., the year of death). For instance, if you die anytime from 2006 until 2009, your estate will be subject to this tax if your assets total more than $2,000,000.00 (i.e., this is known as a tax exemption and any assets over this amount are taxed). In 2009, the tax exemption will increase to $3,500,000.00 and in 2010, the tax exemption will be repealed until 2011 when it will be set at $1,000,000.00. A marital deduction trust is a tool that can allow the beneficiaries of a married couple’s estate to avoid or minimize estate tax and is very valuable if the estate
is at risk of being taxed (at the time of updating of this article in 2009 and 2010, the federal estate tax rate in 2010 is 0% and is expected to be 55% in 2011).

Living trusts are created during the life of the testator and can be revocable or irrevocable. These types of trust can provide for asset management during the testator’s life in addition to disposing of the assets held in trust after the death of the testator. Although living trusts serve a definite purpose for some, most people do not need them. Individuals who benefit most from having a living trust are those who own property in numerous states or have a great deal of wealth. Beware of scam artists who contact you via telephone or place ads in the newspaper and try to convince you that a living trust will solve all of your estate problems. There are many common myths associated with living trusts. No matter what someone may tell you, a living trust will not reduce your tax liability, will not avoid the cost of settling your estate and will not protect your assets from creditors. A living trust will allow you to avoid probate, only if every asset you own is in the trust. Also, contrary to popular belief, a living trust can be contested by your heirs.

For further information please visit www.tyla.org and request a copy of the brochure entitled, “Living Trust Scams.”

What is involved in a probate?

Probating a will simply means “proving” a will in court so that the testator’s wishes can then be carried out by the executor. Before a judge will allow a will to be approved for probate, it must be established that the will meets the requirements of execution described above. Once approved by the court, the executor can begin gathering assets and passing the title from the testator to the beneficiaries. If the will is not proved in court then the decedent’s property passes to his heirs at law, as if he died without a will.

Many people are under the impression that the probate process is costly and time consuming. This might be true for large estates or in situations where a will contest is filed, but most probates can be finalized quickly and efficiently. Many courts have established methods of proving the will without even having to appear before a judge.

Power of Attorney

Powers of Attorney are an essential part of any estate plan and can enable a person (principal) to designate an agent (and alternate agent) to make business and health care decisions on their behalf. All adults, no matter what age, should have the proper powers of attorney in place in order to prepare for any type of situation wherein a person may become disabled yet still needs to conduct important business.
A common misconception is that powers of attorney stay in effect after the principal’s death. This is not true. A correctly executed power of attorney is only effective while the principal is alive. Upon death, the executor named in the person’s will takes over control of the estate.

A statutory durable power of attorney, sometimes called a general power of attorney or a business power of attorney, allows the agent to make most business decisions on the principal’s behalf and sign the principal’s name on most documents. Obviously, your agent needs to be someone who you highly regard and trust because that person will be able to act on your behalf in almost any situation. However, a general power of attorney is extremely useful in the event that the principal becomes disabled and cannot make decisions for himself. If disability occurs and no power of attorney is in place, then a guardianship will have to be opened in court, which is very costly and time consuming. As a matter of convenience, a general power of attorney can be drafted so that it is effective upon execution, regardless of whether or not the principal is disabled. Most married couples have their powers of attorney drafted in this manner, so that one spouse can take care of family business if the other spouse is out of town, for example. If so desired, the power of attorney can be drafted, so that it is only effective if and when the principal is declared to be in a state where he is unable to handle his personal affairs. A general power of attorney does not need to be witnessed but it must be signed in the presence of a notary and should be recorded with the County Clerk in the county of the principal’s residence.

A medical power of attorney is a document which allows the principal to designate someone to make health care decisions on their behalf only if they cannot make the decision themselves. This is the key difference between the general power of attorney and the medical power of attorney (i.e., the medical power of attorney cannot be drafted so that it is effective immediately – the only time the agent can act is if the principal is unable to communicate with the physician). Further, this document only authorizes the agent to make health care decisions – no business activity can be conducted under a medical power of attorney. The medical power of attorney is discussed in more detail in the End of Life section of this Guide.

**Directive to Physicians**

A directive to physicians, commonly referred to as a “living will,” or an “advanced directive” is a document that that allows a competent adult to instruct his or her physician to withhold or withdraw life sustaining treatment in the event of a terminal or irreversible condition. Directives are best used and the most effective after fully informing your wishes to family members, who might contest the withdrawal of these actions. A complete description of the living will is discussed in the End of Life section of this Guide.
What is an Advanced Directive?

Advance Directives (“AD’s”) are more commonly known as “Living Wills.” An Advance Directive can be a Directive, a medical power of attorney, or an out-of-hospital Do Not Resuscitate (DNR) Order. Basically, ADs let the medical providers treating you know what your wishes are regarding the extent of treatment you want done to you in the event of a terminal condition.

Why should I make an Advance Directive, Living Will, etc.?

The number one reason it is important to consider making an Advance Directive is to let everyone know your wishes regarding your health care choices and end of life decisions. Although making an Advanced Directive presents difficult situations to think about, it is very important that your treatment preferences are followed in the event that you are unable to make decisions pertaining to your own health care. To make sure that those details are followed it is important to talk about your wishes with others. Discuss with family members/friends and medical staff your desires regarding the withholding and/or withdrawal of life-sustaining treatment and to what extent life-saving measures should be taken.

What is the difference between a Medical Power of Attorney, Directive to Physician and an out-of-hospital DNR?

**Medical Power of Attorney (MPOA)**

A document where you authorize another adult to make health care decisions on your behalf in the event you are no longer competent to make those decisions (i.e., you cannot communicate, or are not able to make treatment decisions based on reasonable medical information).

**Directive to Physician or “Directive”**

This document allows you, the patient, to inform the medical professional about your wishes for giving, withholding or withdrawing life-sustaining treatment in the event of a terminal or irreversible condition. One major difference in a Directive and a Medical Power of Attorney is that no agents are appointed in a Directive – it entails, you, the patient, directing your doctor to proceed in a certain manner regardless of what others may request. Note that if you execute both a Directive and a MPOA, the decisions made by you in a Directive supersede the authority given to your agent in the MPOA. If no Directive is executed, the agent designated in your MPOA will be able to make life-sustaining treatment decisions.
on your behalf. One of the more commonly referred to directives is the DNR, which informs medical providers of what measures you are okay with in the event of a terminal or irreversible medical condition.

**Out-of-Hospital DNR**

A legally binding specific document, prepared and signed by your attending physician, which documents your wishes and directs health care professionals acting in an out-of-hospital setting not to start or continue certain life-sustaining treatments (such as CPR, “advanced airway management,” artificial ventilation, defibrillation, etc.). For an out of hospital DNR to be effective, some type of bracelet or necklace must be worn by the patient in order to adequately notify EMS personnel that you have chosen to decline life saving measures.

**How do I create an Advanced Directive?**

Each type is different. We’ll take each type one by one and give some helpful information on executing these documents in each discussion section.

**DIRECTIVE TO PHYSICIANS**

A Directive does not have to be in writing. (However, having it in writing assures that you and your medical providers are clear about your wishes.) A written Directive may be in different forms, but the law requires that a written directive be signed by you, the “declarant” in the presence of TWO witnesses (see below for who can be a witness). You need to let your attending physician know that you have a written directive so that he or she can make the Directive a part of your medical record.

**Witnesses:**

- Must both be “competent adults” (that is, an adult who is able to understand and appreciate the nature and consequences of a treatment decision)
- One of the witnesses CANNOT be:
  - a person designed by you to make a treatment decision;
  - one of your relatives by blood or marriage;
  - anyone who is entitled to any part of your estate after your death;
  - your attending physician;
  - an employee of the attending physician;
  - an employee of the health care facility where you are a patient; or
  - any person who may have a claim against your estate after you die.

In the event that you are provided with a Directive form by your health care
provider, the law generally allows you to add additional directions other than those listed on the provided form. Also, in the directive you may designate a person to make treatment decisions for you in the event that you become incompetent or otherwise mentally or physically unable to communicate.

Note: YOUR DESIRE SUPERSEDES A DIRECTIVE! If you tell your medical provider that you have changed your mind about something in the Directive, they must obey your desire.

What happens if I become incompetent or unable to communicate and I do not have a Directive?

If you become “incompetent” or are incapable of communication then your attending physician and your legal guardian or medical power of attorney (MPOA) agent may make a treatment decision that may include a decision to withhold or withdraw life-sustaining treatment from you. (Incompetent means lacking the ability, based on reasonable medical judgment, to understand and appreciate the nature and consequences of a treatment decision, including the significant benefits and harms of and reasonable alternatives to a proposed treatment decision.)

If you do not have a legal guardian or a MPOA agent then your attending physician and one “eligible person” may make a treatment decision that may include a decision to withhold or withdraw life-sustaining treatment from you. Eligible persons include your spouse, your adult children, your parents, or your nearest living relative.

Note: Any treatment decisions made if you become incompetent or are incapable of communication must be based on knowledge of what YOU would want, if they know what your wishes are.

In the event that you do not have either a legal guardian, MPOA agent, or an “eligible person” from list above, then your attending physician would need to get another physician who is not involved in your treatment to concurrent to a treatment decision made by your attending physician.

What else should I know about a Directive?

If you have previously executed/created a Directive, the last Directive you executed will be the controlling directive.

If you have executed a Directive in another state or jurisdiction, it will be given the same effect as if it had been validly executed in Texas.

How do I Revoke a Directive?

Any Directive is effective until you revoke it or create another Directive. You or
someone else in your presence and at your direction/request can revoke a Directive by canceling it, defacing it, obliterating it, burning it, tearing it, or otherwise destroying it. You can also sign and date on the Directive your wish/intent to revoke the Directive.

If you use either method listed above, to revoke your Directive, the revocation will not be effective until your attending physician is notified of the revocation—either personally or by mail. You can mail in your notice of revocation to your attending physician, who will then record the revocation in your medical file.

You can also orally state your intent to revoke the directive. If you use this method, the revocation will not be effective until your attending physician is notified of the revocation.

**MEDICAL POWER OF ATTORNEY (MPOA):**

**How do I execute/designate a MPOA?**

A MPOA is a written document where you authorize another adult to make health care decisions on your behalf in the event you are no longer competent to make those decisions. The law requires that a MPOA be in writing and be signed by you, the “principal.” You must sign it in the presence of TWO witnesses who must also sign the MPOA (witnesses to a MPOA must meet the same requirements as witnesses to a Directive. See above.) Finally, you need to let your attending physician know that you have a MPOA so that he or she can make this document a part of your medical record.

If you are physically unable to sign the MPOA, then another person may sign for you using your name in your presence and noting that it was at your express direction.

**IMPORTANT NOTE**

- A MPOA is not effective unless you, before executing the MPOA, sign a statement that you have received a Disclosure Statement and that you have read and understood its contents.
- The law requires that the Disclosure Statement must be substantially in the form provided under Tex. Health & Safety Code § 166.163.

**Is a MPOA the same thing as a “statutory durable power of attorney”?**

No, a statutory durable power of attorney is when you authorize someone else to be your “attorney in fact” or your agent for all your business-type legal decisions. A MPOA is a document you execute where you authorize another adult to make
only health care decisions on your behalf in the event you are no longer competent to make those decisions.

(The statutory durable power of attorney is discussed in the Estate Planning section of the Guide.)

Who can be a MPOA agent?

Any adult (18 years or older) can be your MPOA, with the following exceptions:

- your health care provider;
- an employee of your health care provider unless the employee is one of your relatives;
- your residential care provider (i.e., your nursing home care provider); or
- an employee of your residential care provider unless the employee is one of your relatives

What can my MPOA agent do?

In general, the agent may make any health care decision on your behalf that you could make if you were competent. BUT, the agent may not consent to: voluntary inpatient mental health; convulsive (shock) treatment; “psychosurgery”; abortion; or your neglect through the omission of care primary intended to provide for your comfort.

What else do I need to know about MPOA?

Revoking a MPOA

A MPOA can be revoked:

- in writing or orally at any time by you to your agent (or a certified or licensed health or residential care provider); OR
- by any other act which shows a specific intent to revoke power, without regard to whether you are competent or without regard to your mental state; OR
- by the execution of a subsequent MPOA; OR
- by the divorce of you and your spouse IF your spouse was your authorized agent under the MPOA, unless your MPOA says otherwise.

OUT-OF-HOSPITAL DNR

What is an Out-of-Hospital DNR?

An Out-Of-Hospital DNR Order is a legally binding document that is required to be in the form discussed below. It is to be prepared and signed by your attending physician and directs health care professionals acting in an out-of-hospital setting
not to initiate or continue life-sustaining treatment, which includes cardiopulmonary resuscitation, advanced airway management, artificial ventilation, defibrillation, and/or transcutaneous cardiac pacing.

**How do I execute/create an Out-of-Hospital DNR Order?**

The law requires that a written out-of-hospital DNR order shall be on a standard form. Your attending physician or hospital should be able to provide you with an Out-of-Hospital DNR Order form.

Note: An Out-of-Hospital DNR Order does NOT have to be written! However, it must be made in the presence of two qualified witnesses and your attending physician. They will then sign the Order, which will then become part of your medical record.

Note: Your desire SUPERSEDES the Out-Of-Hospital DNR Order!

**How do I revoke an Out-of-Hospital DNR Order?**

You can revoke an Out-of-Hospital DNR Order by act (destroying the form and removing the DNR notification device), in writing or orally. Revocation can be accomplished by you, your legal guardian, a qualified relative, your MPOA agent who executed the out-of-hospital DNR order or another person in your presence and your direction.

Note: An oral revocation of an order takes effect only when you or a person who identifies himself or herself as the legal guardian, a qualified relative, or your agent communicates the intent to revoke the order to the responding health care professionals or the attending physician at the scene. The attending physician or the physician’s designee shall record the revocation of the order in your medical record.

**What else do I need to know about an Out-of-Hospital DNR’s?**

If you have a valid out-of-hospital DNR order you may wear a DNR identification device around the neck or on the wrist that lets other medical health care providers know that you have executed or issued a valid out-of-hospital DNR order or have a valid out-of-hospital DNR order executed or issued on the your behalf.

**ONE LAST THING TO CONSIDER:**

You may want to look into contacting local hospice about what services they can provide you. It’s important to note that a hospice does not just provide help with end of life decisions; they are a great source of information, provide assistance with pain management, and are an excellent source of emotional support.
Legal Guide for Cancer Patients

Helpful Resources

1. Advocacy, Inc. (disability rights advocacy)
   www.advocacyinc.org or 1-800-252-9108

2. American Cancer Society
   www.cancer.org or 1-800-ACS-2345 (1-800-227-2345)

3. CanCare
   www.cancare.org or (713)461-0028

4. Cancer Care, Inc.
   www.cancercare.org or 1-800-813-HOPE (1-800-813-4673)

5. Cancer.com:
   www.cancer.com or 1-888-227-5624

6. COBRA insurance
   www.dol.gov/ebsa/faqs/faq_consumer_cobra.html or 1-866-444-3272

7. Department of Veterans Affairs
   www.va.gov

8. Gilda’s Club
   www.gildasclub.org or 1-888-GILDA-4-U (1-888-445-3248)

9. Find Law
   www.findlaw.com

10. Lance Armstrong Foundation
    www.livestrong.org or (512)236-8820 and 1-866-235-7205

11. Medicaid
    www.cms.hhs.gov/home/medicaid.asp or 1-800-252-8263

12. Medicare
    www.medicare.gov or 1-800-MEDICARE (1-800-633-4227)

    www.nachc.com or (301)347-0400

14. National Cancer Institute
    www.cancer.gov or 1-800-4-CANCER (1-800-422-6237)
15. **Needy Meds**  
   www.needymeds.com or 215-625-9609

16. **Oncolink**  
   oncolink.upenn.edu

17. **Patient Advocate Foundation**  
   www.patientadvocate.org or 1-800-532-5274

18. **Pharmaceutical Research and Manufacturers of America (PhRMA)**  
   www.phrma.org or 1-202-835-3400

19. **Social Security**  
   www.socialsecurity.gov or www.ssa.gov/disability or 1-800-772-1213

20. **State Bar of Texas**  
   www.texasbar.com or 1-800-204-2222

21. **Susan G. Komen Breast Cancer Foundation**  
   www.komen.org or 1-800-462-9273

22. **Texas Department of Insurance**  
   www.tdi.state.tx.us or 1-800-252-3439

23. **Texas Law Help**  
   www.texaslawhelp.org

24. **Texas Legal Services Center**  
   www.tlsc.org or 1-800-622-2520

25. **U.S. Department of Labor**  
   www.dol.gov or 1-866-487-2365

   www.eeoc.gov or 1-800-669-4000

*Free legal help is also available for limited income Texans through the Texas Health Law Hotline:  www.texaslawhelp.org or 1-800-622-2520*