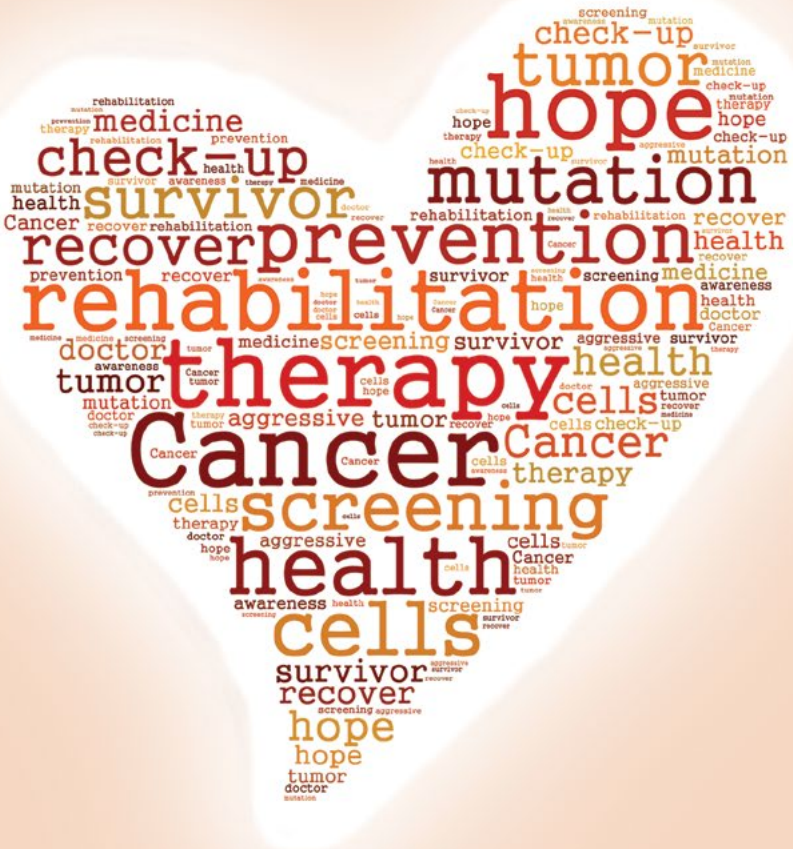

Patient Legal Handbook

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Legal obstacles have the potential to contribute to negative patient outcomes. Understanding how to navigate these obstacles can bring peace-of-mind and assist patients toward better health.

1. Taking Time from Work

The Family and Medical Leave Act (FMLA) gives eligible employees the right to take up to 12 weeks of unpaid, job and health benefit-protected leave per year. FMLA applies to all employers with 50 or more employees. A worker may be eligible if all of the following conditions apply:

- An employee has worked for his/her employer at least 12 months,
- An employee has worked at least 1,250 hours within the past 12 months,
- An employee has worked at a company location with 50 or more employees within a 75-mile radius.

A worker is eligible to receive up to 12 weeks of unpaid leave each year for any of the following reasons:

- Birth and care of the employee's newborn child,
- Employee placement of an adopted or foster care child,
- Caregiving for an immediate family member, such as spouse, child or parent, with a serious health condition requiring a doctor's care,
- Employee inability to work due to a serious health condition.

Follow these rules to request FMLA leave:

- Give at least 30 days' notice or notice as soon as possible,
- Provide enough information to substantiate the need for FMLA leave, with its expected time and duration,
- If required by employer, fill out the FMLA Medical Certification Form or other medical certification form. The healthcare provider must complete a certification form to verify the employee's health condition.

For more information, call (202) 693-0066 to speak with the Department of Labor, Family Medical Leave Act, customer service or visit http://www.dol.gov.

2. Staying Employed During and After Medical Treatment

While some people continue working during cancer treatments, others need time off or flexible schedules. Depending on employer size, a worker may be entitled to protection under both the Americans with Disabilities Act (ADA) and FMLA. Also, most states have fair employment laws that provide protection for disabled workers.

ADA applies to businesses with 15 or more workers and requires employers to make reasonable work environment or work policy changes (accommodations) so an employee can perform the essential functions of his/her job. This applies as long as the accommodations do not create an undue hardship for the employer. Reasonable accommodations can include flex-time, work from home, use of special equipment or time off, as long as these changes are not too inconvenient or expensive for the employer.

Keep records of all employer and/or human resource conversations regarding accommodation requests. An employer must provide reasonable accommodations under ADA unless it can show the accommodation to be an undue hardship on its operations. It is important to consider that what may be reasonable for one person may not be reasonable for another, depending on job, employer and/or accommodation. Employer/employee negotiations may be necessary regarding what kind of accommodation will be best for both parties. For more information about ADA, contact the Equal Employment Opportunity Commission (EEOC) at (800) 669-4000 or visit www.eeoc.gov.

3. Exhausting Medical Leave or Sick Time

Although FMLA provides up to 12 weeks of job-protected leave, and some employers offer more, sometimes it is not enough. If an

employee exhausts his/her 12-week FMLA leave and needs additional time, or is not eligible for FMLA leave, it is possible to ask for a medical leave extension or to request time off as a reasonable accommodation under ADA.

Remember that employers do not have to grant indefinite leave extensions or accommodation requests if the accommodation would be an undue hardship to the employer. For instance, it may be an undue hardship for an employer to keep a job open indefinitely should a doctor not be able to estimate a return date. A leave extension is more likely to be granted if a return-to-work date is specified. For example, an employer is less likely to consider a few extra days or one additional week of leave, or 12 additional days, an undue hardship. For more information about ADA, contact EEOC at (800) 669-4000 or visit www.eeoc.gov.

4. Keeping Health Insurance after Terminating Employment

Keeping work-based health insurance may be important in covering cancer care costs once employments stops. The Consolidated Omnibus Budget Reconciliation Act (COBRA) allows workers to keep their employer's health coverage after leaving their job. Under COBRA, a person does not have to worry about changing doctors or rescheduling treatment.

COBRA applies to employers with 20 or more employees. A "qualifying event," such as reduction of work hours or voluntary or involuntary termination of employment, determines eligibility for COBRA, which provides a maximum of 18 months of continued coverage. Some states have mini-COBRA laws that generally apply to employers with fewer than 20 employees. Contact the state department of insurance to learn more.

If eligible for COBRA, follow these steps to obtain coverage:

1) Notify the employer's health plan of the qualifying event;
2) Choose COBRA within 60 days of terminating employment;
3) Pay the first premium within 45 days of choosing COBRA;
4) Pay the monthly premiums on time.

The monthly premium can be as much as 102 percent of what the employer was paying. If a person is eligible for COBRA and Medicaid, he/she may also be eligible for a state Health Insurance Premium Payment Program (HIPP). Contact the state department of insurance to find out whether it has an HIPP program and how to qualify. Alternatively, upon termination of employment, a person may be eligible for a Special Enrollment Period to purchase new insurance. See page 11 to learn more. For questions about COBRA, contact the U.S. Department of Labor, Employee Benefits Security Administration, at (202) 693-8300 or (866) 444-3272 or visit www.dol.gov/ebsa.

5. Applying for a Job with a History of Cancer

ADA and state fair employment laws generally prohibit employers from discriminating against people with disabilities at all stages of the employment process, which includes hiring. Employers are not allowed to ask a person if they have or have ever had cancer when applying for a job. However, employers can ask about a person's ability to perform certain tasks. And, they can ask a person to describe or show them how he/she will perform the duties of the job, with or without reasonable accommodations.

Generally speaking, employers cannot make applicants take a physical exam before being offered a job. However, if all new employees in similar jobs are required to have a medical exam, an applicant may be offered a job conditionally dependent upon medical exam results, which must be job-related and consistent with employer business needs. An employer cannot reject an applicant due to information the medical exam reveals about his/her disability, unless reasons for rejection are job-related and necessary to conduct business.

An applicant is not required to offer information about having cancer or another disability when applying for a job. However, if accommodations are necessary to apply for a job or to perform essential job functions, an applicant may want to tell the employer that he/she has a disability. Employers are only required to provide reasonable accommodations if they know or should have known about accommodation needs. They do not have to make accommodations for a person who is not otherwise qualified for the job. Employers do

not have to remove essential functions, create new jobs or lower production standards to accommodate a person with disabilities. For more information, visit the EEOC frequently asked questions page at https://eeoc.custhelp.com/app/answers/list or call (800) 669-4000.

6. Paying Bills When Unable to Work

Several government programs provide financial benefits to individuals and families. Social Security Supplemental Security Income (SSI) is a Federal program funded by general tax revenues. It is based on financial need and is designed to help aged, blind and disabled people who have little or no income. It provides cash to meet basic needs for food, clothing and shelter.

Social Security Disability Insurance (SSDI) pays disability benefits to workers and certain family members if they work long enough and have a medical condition that prevents them from working, or is expected to prevent them from working, for at least 12 months or end in death.

- **SSI.** Income and resources are used to determine a person's eligibility to meet the program's financial requirements. For 2016, the SSI monthly maximum Federal amount is $733 for an eligible individual and $1100 for an eligible individual with an eligible spouse. Some states supplement the fixed amount, and the program usually provides annual cost-of-living adjustments (COLA).
- **SSDI.** Benefits are based on lifetime work history and how much money the worker has paid into the system through Social Security taxes. The monthly disability benefit is based on average lifetime earnings. To find out how much a person would receive if approved for SSDI, create an account on the Social Security website, or call the Social Security Administration.

In addition to SSI and SSDI, some employers offer private disability benefits. Individuals can also purchase private disability insurance before they get sick. If applicable, check the policy to see what the eligibility requirements are to collect benefits. Also, some states have short-term disability programs.

For other forms of financial assistance, check with local service organizations like Kiwanis, Rotary Club or Lions Club; private financial assistance programs like Salvation Army, Lutheran Social Services, Jewish Social Services and Catholic Charities; non-profit organizations like American Cancer Society and Patient Advocate Foundation; and cancer-specific programs that focus on assisting patients with certain types of cancer like Leukemia and Lymphoma Society, American Kidney Fund and The Pink Fund.

7. Planning for Loved Ones after Death

Speaking with an estate planning lawyer is a good starting point to make sure loved ones are provided for after a person's death. The lawyer may recommend a will, which is a legal document that directs who will receive a person's property after he/she dies. It is also used to name a guardian for minor children and their assets. Below are several ways to create a will:

- **Holographic or Handwritten Will.** Some states allow holographic wills, which are completely written in the person's own handwriting, signed and dated. It expresses how assets are to be distributed. It is not necessary to have this will notarized or signed by witnesses, and any typed material may invalidate the will. Check with an attorney to see what states these wills are valid in.
- **Statutory Will.** These fill-in-the-blank will forms are available in some states and may work well if the person does not have a large or complicated estate or assets.
- **Lawyer-Prepared Will.** Estate planning lawyers make sure wills follow state law. They can also offer suggestions about estate planning options, explain potential tax benefits and provide information on ways in which property can be transferred.

For more complicated estates, a trust may be a better option than a will. A trust is a written agreement naming beneficiaries who will be given, or who will inherit, assets. It is between the person who owns assets (trustor) and the person named to manage assets held in trust (trustee). Depending on the type, it may be revocable or changed during the asset holder's lifetime. After he/she passes away, it cannot be changed.

Once a person creates a trust, he/she must transfer assets from his/her name to the name of the trust. Several types of trusts exist, but the most common is a "living trust." This type is created while the asset holder is alive, and it allows the person to act as his/her own trustee until death, when another trustee takes over. With a living trust, it may be advisable to also draft a "pour over" will to cover assets not listed in the trust at death. For more information about advance planning, contact the state bar association or Cancer Legal Resource Center (CLRC).

8. Ensuring Wishes Are Carried Out

The Advance Health Care Directive (AHCD) is a set of written instructions communicating a person's wishes about medical care should he/she be unable to make decisions. Since state laws and definitions of incapacity vary by state, contact CLRC for more information. AHCD forms are available online and contain four parts:

- **Power of Attorney for Health Care** names someone to make medical decisions for a person who has become incapacitated. It is vital to speak with the person appointed with this power so they understand the patient's wishes. A separate power of attorney must be completed should a person want to appoint someone to make decisions regarding legal or financial affairs.
- **Living Will** provides instructions about life-sustaining medical treatment. Be sure to speak with health care professionals to understand all medical options.
- **Organ Donation** expresses a person's wishes about specific organ and/or tissue donation.
- **Primary Physician** records the contact information for a person's primary doctor.

Power of Attorney for Financial Affairs allows a person (principal) to appoint someone (agent) to make financial decisions if he/she is unable to do so. In most states, it must be signed and notarized. A power of attorney ends at death when a will or trust takes effect.

- **Durable Power of Attorney** becomes effective at signing and can last through incapacity. The agent can make financial decisions for a person even though he/she is able to make such decisions. This can be useful for someone who may not want to focus on daily financial affairs.
- **Non-durable Power of Attorney** becomes effective at signing, but the agent will lose power if the person becomes incapacitated. This may be useful if a person wants to designate one person to help while competent and a different person to help while incapacitated.
- **Springing Power of Attorney** goes into effect when a certain condition or event occurs, for example, when a person becomes incapacitated. Or, a military person may grant power of attorney only during overseas deployment.

Talk to an estate planning attorney. The National Academy of Elder Law Attorneys lists attorneys with special expertise in this area by state. Or, call CLRC for more information.

9. Understanding Health Plan Coverage

A health insurance policy is an agreement between purchaser and insurance company. It lists medical benefits, such as tests, drugs and treatment, the insurance company agrees to cover in terms of a percentage (usually 100, 90 or 50) or dollar amount. It also lists services not covered. Read the policy carefully to understand fully the coverage agreement. Call the insurance company or speak to a licensed insurance representative with any questions or concerns.

The Affordable Care Act (ACA) requires all new major medical health insurance plans to offer "minimum essential coverage." Short-term health plans and fixed or limited benefit, voluntary or supplemental insurance, such as cancer, are not required to conform to ACA and, therefore, do not meet the following 10 basic health benefits of minimum essential coverage: emergency services; hospitalization;

lab work; maternity and newborn care; mental health and substance use disorder services; outpatient services; prescription drugs; rehabilitative and habilitative services and devices; preventive and wellness services, and chronic disease management; and pediatric services.

To verify plan coverage, review the summary plan description, evidence of coverage booklet available online, or call the insurance company and ask them to mail hard copies. If participating in an employer group health plan, ask Human Resources for a description of covered benefits. A person should become familiar with health coverage before he/she needs it. This will avoid surprises and additional costs later.

10. Appealing Health Plan Claim Denials

If a person has private health insurance and his/her insurance company denies a claim payment or terminates health coverage, options to appeal do exist. When an insurance company receives a request, it is required to review and to explain its decision. It must also let the insured know how to appeal its decision. Insurance laws require this process to start and to complete in a timely manner. Below are two ways to appeal a health plan claim denial:

1) **Internal Appeal.** An insured has a right to an internal appeal if a claim is denied. Ask the insurance company to conduct a full and fair review of its decision. If the case is urgent, the insurance company must expedite this process and generally has to respond within 72 hours. To file an internal appeal, complete all forms required by the health insurer, or write a letter to the insurer. Be sure to include name, claim number and health insurance ID number. Submit any additional, relevant information, such as doctors' letters. Internal appeals processes may vary depending on carrier and type of insurance policy.
2) **External Review.** If an internal appeal fails, ask for an independent medical review or external appeal by a third party. In urgent situations, request an external review even if the internal appeals process is not complete. External review requests must be in writing and filed within 60 days. The notice sent by the health plan provider should provide a request timeline. During the external review process, a reviewer who is independent from the insurance company reviews the information and makes a binding decision regarding coverage and/or payment. Contact the state insurance department for more information on the external review at http://www.naic.org/state_web_map.htm.

11. Obtaining New Health Insurance

If a person is either unable to obtain employer provided health insurance or has recently terminated employment and does not qualify for Medicaid or Medicare, he/she may be able to purchase new insurance directly. This is done through an insurance company or broker, or through the state's health insurance Marketplace.

Purchasing Marketplace health coverage is the only way to receive tax credits to lower monthly premiums, if a person qualifies based on household income. Apply for Marketplace health coverage online, by phone, with a paper application or with the help of a trained assister in the community.

Outside the annual Open Enrollment Period, a person can enroll in coverage only if he/she has a Special Enrollment Period due to a "qualifying event," or is applying for Medicaid or the Children's Health Insurance Program (CHIP). Below are the four ways to apply for Marketplace health coverage:

1) **Apply online.** Create an account; fill out a Marketplace application, and view eligibility results online. Visit https://www.healthcare.gov/get-coverage/ for more information.
2) **Apply by phone.** A customer service representative will help choose a plan, fill out an application and review eligibility. Call (800) 318-2596 to apply.
3) **Apply with in-person help.** An assister can meet in-person, help choose a plan and fill out an online or paper application, and review eligibility. Visit https://localhelp.healthcare.gov for people and organizations that can help.
4) **Apply by mail.** People also have the option to fill out and mail in a paper application. Eligibility results will come in the mail. If possible, then either create a Marketplace account online

or contact the Marketplace Call Center to choose a plan and enroll. Visit https://marketplace.cms.gov/applications-and-forms/marketplace-application-for-family.pdf for an application and https://marketplace.cms.gov/applications-and-forms/marketplace-application-for-family-instructions.pdf for instructions.

12. Knowing How a Cancer Diagnosis Affects Insurance

Federal laws that protect against genetic discrimination are explained below:

- **Genetic Information Nondiscrimination Act** (GINA) forbids genetic discrimination in both employment and health insurance, but the latter does not apply to supplemental or voluntary insurance like life, long-term care or disability. GINA defines genetic information as family medical history, one's genetic test results or that of a family member, and use of genetic services.

  A person's current health status or diseases and conditions he/she has developed are not genetic information. Health insurance companies are not allowed to restrict enrollment or to adjust premiums in both group and individual plans, contribution amounts or coverage terms based on genetic information. GINA does not apply to Veterans Health Administration (VA), Indian Health Service (IHS), TRICARE military health system or Federal Employees Health Benefits Program, although other laws provide protection.
- **Health Insurance Portability and Accountability Act** (HIPAA) prohibits group plans and individual plans from using genetic information to determine insurance eligibility.
- **Affordable Care Act** (ACA) prohibits insurance companies from basing coverage decisions on medical history or pre-existing conditions and protects against genetic discrimination during eligibility. ACA does not apply to supplemental or voluntary insurance, such as life, long-term care, disability, cancer or other plans that cover specific illnesses.

State laws regulate supplemental or voluntary insurance like life, disability and specified illnesses, such as cancer. For additional information, contact the state department of insurance.

13. Learning about Experimental Treatment

If a patient is interested in participating in clinical trials or other experimental treatments, the first step is to speak with his/her doctor or other relevant healthcare professional. They may be able to recommend specific trials.

Several organizations have developed online computer-based systems to match patients with studies they may qualify or be eligible for. Some services also allow people to subscribe to mailing lists, which alert subscribers when new studies open.

- **American Cancer Society Clinical Trials Matching Service** helps find clinical trials that best match a patient's medical needs and personal preferences while helping researchers study more effective treatments for future patients. Access the American Cancer Society Clinical Trials Matching Service through www.cancer.org or by calling (800) 303-5691.
- **EmergingMed** provides free, confidential matching and referral services at www.emergingmed.com or call (877) 601-8601.

Clinical trials lists provide names and descriptions of new treatment clinical trials. They will often include a description of each study, criteria for patient eligibility and contact person. The following are some sources for clinical trials lists:

- **National Cancer Institute** (NCI) sponsors most government-funded cancer clinical trials. NCI has a list of active studies (those currently enrolling patients), as well as some privately funded studies. Find the list on their website at www.cancer.gov/clinicaltrials or by calling 1-800-4-CANCER (1-800-422-6237).
- **National Institutes of Health** (NIH) has an even larger database of clinical trials at www.clinicaltrials.gov.
- **Center Watch** (www.centerwatch.com) is a publishing and

information services company that keeps a list of both industry-sponsored and government-funded clinical trials for cancer and other diseases.

- **Private companies**, such as pharmaceutical or biotechnology firms, may list studies they sponsor on their websites or offer toll-free numbers to call. Some of these firms also offer matching systems for studies they sponsor. This can be helpful if a patient is interested in research on a particular experimental treatment and knows what company is developing it.

14. Understanding Medicare Health Coverage Options

A person may be eligible for Medicare if he/she is 65 years or older, or has been receiving Social Security Disability Insurance (SSDI) for two years or more. Medicare is health care coverage for people 65 years or older, under 65 years with certain disabilities or anyone with End-Stage Renal Disease.

Medicare has several parts:

- **Part A** helps cover inpatient hospital care. It also includes coverage in critical access hospitals and skilled nursing facilities for a limited time but not custodial or long-term care. People do not usually pay a monthly premium for Part A coverage if they or their spouse paid Medicare taxes for at least 10 years while working.
- **Part B** helps cover medically necessary services like doctors' services, outpatient care and medical services Part A does not cover, such as many preventive services. If enrolled in Part B, the premium is usually taken from a person's monthly Social Security, Railroad Retirement or Office of Personnel Management (OPM) retirement check. In these cases, a person will not receive a bill for his/her premium. If not receiving a Social Security, Railroad Retirement or OPM retirement check, Medicare sends a monthly bill for the Part B premium.
- **Part C: Medicare Advantage** coverage consists of either preferred provider organizations (PPO) or health maintenance organizations (HMO), which is similar to private insurance that may be available through work. Part C includes all benefits and services covered under Parts A and B, and Medicare prescription drug coverage (Part D) as part of the plan. Part C is operated by Medicare-approved private insurance companies and may include extra benefits and services for an extra cost.
- **Part D** (Medicare prescription drug coverage), run by Medicare-approved private insurance companies, helps cover prescription drug costs and protects against future costs.

Keep in mind that Medicare usually only covers 80 percent of health care costs, which is why many people purchase supplemental insurance (Medigap) or may also be eligible for Medicaid. For more information about Medicare, visit www.medicare.gov or contact the State Health Insurance Assistance Program (SHIP).

15. Obtaining Health Coverage for Low Income Households

Medicaid is a state-run program that provides health care coverage for people with low income and limited resources. Each state has different rules about eligibility and applying for Medicaid. Many states have chosen to expand their Medicaid programs to cover all people who earn less than 138 percent of the Federal Poverty Line (about $16,000 per year for an individual).

In states that have not expanded Medicaid coverage, a person may qualify for Medicaid if he/she has limited income and is one or more of the following: 65 years or older; under 19 years; pregnant; living with a disability; a parent or adult caring for a child; an adult without dependent children (in certain states); and an eligible immigrant.

Upon enrolling, people can obtain health care benefits like doctor visits; hospital stays; long-term services and supports; preventive care, including immunizations, mammograms and colonoscopies; prenatal and maternity care; mental health care; necessary medications; and vision and dental care (for children).

Medicaid has expanded to about one-half of U.S. states and each state has different rules on how to qualify. For more information about state Medicaid programs and how to qualify, visit www.HealthCare.gov/do-i-qualify-for-medicaid.

16. Understanding End-of-Life Options for the Terminally Ill

If best efforts to cure, or to manage, cancer as a chronic condition fail, and the doctor says the cancer is terminal, patients have a range of available choices. Excellent pain and symptom management (referred to as "palliative care" or "comfort care") should be the goal. A patient's current care team can provide this, if they have the necessary skills. If there is any doubt, or if they are not skilled in palliative care, ask for referral to a palliative care specialist or to hospice. Hospice can be provided on an inpatient basis, but it is most often provided in-home with hospice nurses visiting on a regular basis.

A patient has the right to accept or to reject any life prolonging treatment, including medication, artificial food/fluid and respiratory support like a ventilator. Decisions about accepting or forgoing life prolonging treatment may change the timing of death and should be discussed fully and openly with the doctor and/or hospice team. A patient can also choose to stop ingesting food and fluid while receiving supportive palliative care and advance the time of death in this way. If pain and other distressing symptoms are not capable of being well-managed even with good palliative care, a patient may want to consider palliative sedation. Palliative sedation is a process where sedating medication is given to make a person unconscious and not aware of his/her symptoms, and food/fluid are withheld until death arrives.

All of the above choices are a person's right in every state. In some states a patient may also be able to ask for a prescription for medication he/she can ingest to achieve a peaceful death if the dying process is unbearable. This choice is known as "aid in dying" (also referred to as "death with dignity") and is openly available to mentally competent, terminally ill patients in some states, including Oregon, Washington, Vermont, Montana and California. The law in this area is rapidly evolving, so check with CLRC for details about whether this option is available in a particular state.

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