

# When Serious Illness Strikes: Everything *Else* You Need to Know



Information and Resources on Insurance,  
Employment, & Other Practical Issues  
Presented Through a Cancer Lens

McHenry County, IL

2019 ~ Third Edition

THE  
COMMUNITY  
FOUNDATION  
FOR McHENRY COUNTY

AN AFFILIATE OF  
THE CHICAGO COMMUNITY TRUST

TRIAGE  
CANCER

THE  
COMMUNITY  
FOUNDATION  
FOR McHENRY COUNTY

AN AFFILIATE OF  
THE CHICAGO COMMUNITY TRUST

This handbook was made possible through funding from The Community Foundation for McHenry County, an affiliate of The Chicago Community Trust. The Community Foundation for McHenry County is a tax-exempt 501(c)(3) public foundation established in 2001, to accept donor-directed funds and unrestricted endowments to grant seed or expansion money for unmet social, cultural, educational, and charitable needs throughout McHenry County. While providing philanthropic-minded citizens and nonprofit agencies with a central, local administered foundation, The Community Foundation for McHenry County also seeks to be a community partner, and at times leader, in addressing local needs.

630 N. Route 31, Suite 101 ♦ Crystal Lake, IL 60012  
Tel: 815.338.4483 ♦ Fax: 815.334.8613 ♦ [Give@MCCFdN.org](mailto:Give@MCCFdN.org) ♦ [www.mccfdn.org](http://www.mccfdn.org)



This handbook was created by Triage Cancer, a national non-profit organization. Triage Cancer provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources. For more information, or to request a speaker or author for a cancer survivorship event, please contact Triage Cancer.

Tel: 424.258.4NAV ♦ Fax: 424.258.7064  
[Info@TriageCancer.org](mailto:Info@TriageCancer.org) ♦ [www.TriageCancer.org](http://www.TriageCancer.org)

*A special thanks to the Family Health Partnership Clinic for helping conceive and coordinate this project.*

## Table of Contents

<u>Introduction</u>	4
<u>Commonly Used Abbreviations</u>	5
<u>Health Insurance</u> .....	6
Health Insurance Policy Terms .....	6
Types of Health Insurance .....	8
Group Health Insurance plans .....	8
Individual Health Insurance Plans .....	8
State Health Insurance Marketplaces.....	9
Open Health Insurance Market .....	12
Options for Young Adults .....	12
Government Sponsored Insurance .....	13
Medicare .....	13
Medicaid .....	18
Illinois Breast & Cervical Cancer Program .....	21
Consumer Rights and Protections .....	21
ACA's Consumer Benefit Reforms .....	21
Clinical Trials Laws .....	23
Insurance Coverage for Oral Chemotherapy .....	24
Women's Health & Cancer Rights Act (WHCRA) .....	24
Insurance Coverage for Cancer Screenings .....	25
Accessing Medical Records .....	26
Health Insurance Appeals .....	27
Making Health Insurance Choices .....	30
Tips for Picking a Plan .....	30
Health Insurance Options after a Life-Changing Event .....	32
Consolidated Omnibus Budget Reconciliation Act (COBRA) .....	32
Illinois Continuation Law .....	33
Special Enrollment Periods (SEPs) .....	34
<u>Employment and Cancer</u> .....	37
Where to Find Employment Rights .....	38
Fair Employment Laws .....	39
Americans with Disabilities Act (ADA) .....	39
Job Search Process & ADA Protections .....	42
Illinois Human Rights Act (IHRA) .....	43
Discrimination Complaint Process .....	43

<b>Taking Time off Work .....</b>	47
Family and Medical Leave Act (FMLA) .....	47
Illinois State Leave Law .....	51
When FMLA or State Leave Law is Exhausted .....	51
Medical Certification .....	51
Filing A complaint .....	52
 <b>Disability Insurance .....</b>	54
Disability Insurance Basics .....	54
Federal Disability Insurance Programs.....	54
Social Security Disability Insurance (SSDI) .....	55
Supplemental Security Income (SSI) .....	58
Illinois Supplemental Payment .....	60
Appealing a Social Security Administration Determination .....	60
 <b>Estate Planning .....</b>	62
Estate Planning Basics .....	62
Creating an Estate Plan .....	65
Decisions about Property and Final Wishes .....	65
Wills .....	66
Trusts .....	69
Decisions about Medical Care .....	71
Advanced Health Care Directives .....	71
Decisions about Finances .....	73
Power of Attorney for Property .....	73
Practical Matters .....	74
Digital Afterlife .....	74
Funeral Arrangements .....	75
Legacy Planning .....	76
Storing Documents .....	76
 <b>Other Financial Tips .....</b>	78
 <b>Conclusion .....</b>	83
 <b>Resources .....</b>	84
 <b>Appendix .....</b>	105

## **Introduction**

When diagnosed with cancer, many patients and their families become experts in several areas of medicine. They learn all there is to know about their diagnosis, the best treatments, possible side effects, and so on. They may join support groups to learn about new coping techniques, talk to a nutritionist, or participate in an exercise program. What many people don't realize is that they also may need to learn about the law. The health care system in the United States is based on numerous laws and if one does not learn about their rights and the benefits they may be entitled to, they may find themselves unable to access treatment, paying too much out of pocket for their care, losing their health insurance coverage or jobs, or acquiring large amounts of medical debt.

This handbook is designed for patients, caregivers, and health care professionals. The goal is to provide information and resources on laws that may be relevant to those coping with cancer. Sections will introduce you to people who are facing cancer-related legal issues, explain the laws that may be applicable, highlight the most valuable pieces of information, and provide the contact information for government agencies or cancer organizations that may be useful.

### ***Additional Materials and Resources***

Throughout this handbook there are links to additional educational materials that can be downloaded for free. Additionally, we have included links to handouts, checklists, and resources that may be useful as you navigate your cancer diagnosis and treatment. Health care professionals should feel free to use these resources with their patients. Hardcopies of these materials can be requested from Triage Cancer at <https://triagecancer.org/materialrequest>.

### ***Disclaimer***

Please keep in mind that this handbook is designed to provide general information on the topics presented. It is provided with the understanding that the authors are not engaged in rendering any legal, medical or other professional advice or services by its publication. The information provided should not be used as a substitute for professional services. Resources included in this handbook are not explicitly or implicitly endorsed, recommended, or approved by Triage Cancer or the McHenry County Community Foundation.

## Health Insurance

### *Meet Sarah*

Sarah is 42 and has been an accountant for the last 10 years at a small firm (25 employees) in Woodstock, IL. When diagnosed with stage II lung cancer, she had surgery and chemotherapy treatment for almost 2 years. She is still experiencing some fatigue, cognitive difficulties, and some neuropathy in her feet and thinks that she may need to stop working. Sarah is very concerned about what she is going to do for health insurance if she is forced to leave her job because of her pre-existing condition.

Health insurance in the United States is complex and multifaceted. Individuals diagnosed with cancer and their caregivers are faced with navigating a complex health care system, which is often changing, and maintaining health insurance coverage to access quality health care. Even individuals who have health insurance may still experience the devastating financial impact of a cancer diagnosis. One way to help mitigate the potential financial burden is for individuals to have adequate health insurance, to understand what is covered by their health insurance policies, and to know how their policies work.

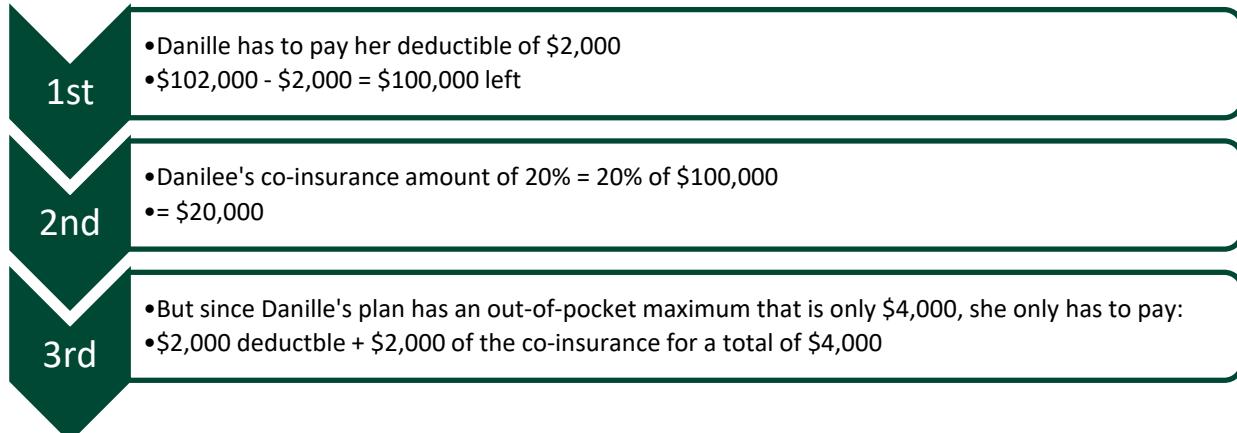
### I. Health Insurance Policy Terms

Health insurance policies will use terms to explain the coverage and costs they provide. Understanding these terms is critical in order to make the most of your policies.

- Premium: the monthly payment to have health insurance coverage. Individuals will pay this amount each month to have coverage, even if they never see a health care professional. It is similar to paying for car insurance all year, but never getting into an accident.
- Deductible: a fixed dollar amount that individuals are responsible for paying before their health insurance policy begins to pay for their health care. The amount of the deductible will depend on the plan. Plans may have a \$0 deductible and some may have a \$5,000 deductible. For example, if Rachel's deductible is \$1,000, her plan will not pay for her covered medical expenses until she has paid \$1,000 out of pocket. This is also referred to as "meeting the deductible." However, it is important to note that deductibles may not apply to all services (e.g., some preventative services) and that not all out-of-pocket payments will count towards a deductible (e.g., some plans do not apply co-payments towards the deductible).

- Coinsurance or cost-share: the difference in what the insurance company will pay for an individual's medical expenses and what the individual pays for the medical expenses. For example, Ross has an 80/20 plan that has an allowed amount for an office visit of \$100. If Ross has met his deductible, his coinsurance payment of 20% would be \$20. The health insurance plan pays the remaining 80%.
- Co-payment: a fixed dollar amount individuals pay for a covered health care service, usually at the time of service (e.g., visit the doctor or obtain a prescription drug from a pharmacy). The amount can vary by the type of covered health care service and can be anywhere from \$1 to upwards of \$250.
- Out-of-pocket maximum: a fixed dollar amount that caps how much individuals are responsible for paying out of pocket during a policy period (usually one year). After individuals reach that cap, the health insurance policy pays 100% for covered essential health benefits (EHBs) for the rest of the year. This limit typically includes deductibles, coinsurance, and co-payments made towards EHBs. This limit does not include premiums, balance billing amounts for non-network providers, other out-of-network cost-sharing, or spending for non-EHBs. With some limited exceptions, the maximum out-of-pocket cost limit for any Health Insurance Marketplace plan for 2019 can be no more than \$7,900 for an individual plan and \$15,800 for a family plan. Keep in mind that some types of health insurance policies are not required to have an out-of-pocket maximum, including short-term health plans, Original Medicare (i.e., Parts A and B), and grandfathered health plans.

To better illustrate how all of this works in real life, consider Danielle's story. Danielle has a health insurance plan with a \$2,000 deductible, an 80%/20% coinsurance, and an out of pocket maximum of \$4,000. Danielle goes to the hospital and ends up with a \$102,000 hospital bill. How much of that bill does she have to pay?



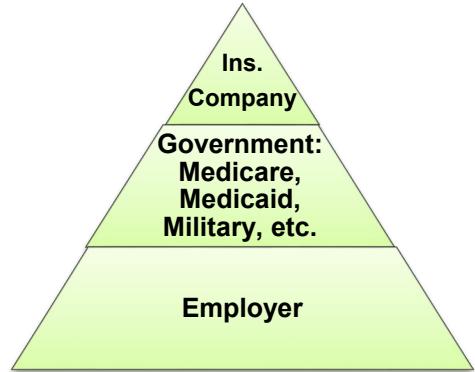
Understanding the terms used in your health insurance policy and how the out-of-pocket maximum works can be one of the most effective ways to reduce the financial burden that often accompanies a cancer diagnosis.

## II. Types of Health Insurance

There are three main types of health insurance offered in the United States: group, individual, and government sponsored.

### A. Group Health Insurance Plans

Group health insurance is typically provided through an employer or other group that you belong to (e.g., a union). There are two types of group health insurance plans: funded and self-funded. These are also sometimes referred to as insured and self-insured. A funded plan is where the employer purchases health insurance policies for its employees from a health insurance company; the employer and the employee each pay a portion of the premium. Some employers pay for the full cost of the premium for their employees. A self-funded plan is one in which the employer pays directly for the employees' health care costs. The employee may also contribute toward these costs. Often times, an employer will contract with a third party administrator to manage their self-funded plan. Typically, these third party administrators are health insurance companies so it can be confusing to consumers. It is important to know what type of plan you belong to because laws may apply differently. If you are unsure of what type of plan you have through your employer, you can contact the plan administrator or call the phone number on the back of your health insurance card.



### B. Individual Health Insurance Plans

If you do not have a health insurance plan through your employer, or the employer sponsored plan does not meet your needs, you may want to consider purchasing an individual plan. There are several ways to go about doing this including working with an insurance broker, purchasing online directly from a health insurance company, or purchasing a plan through the state health insurance Marketplace. Although it is called "individual" insurance, these plans can also be purchased for a family.

### *State Health Insurance Marketplaces*

The Patient Protection and Affordable Care Act (also known as: Affordable Care Act; ACA; and Obamacare) created a new way for individuals, families, and small businesses to get private health insurance: the State Health Insurance Marketplace. These Marketplaces were originally referred to as exchanges. The Marketplace is like a health insurance shopping mall where individuals can buy a plan from a private health insurance company, or can get help determining if they are eligible for Medicaid.

Whether you are uninsured, or just want to explore new options, the goal behind the Marketplace is to give you more choice and control over your health insurance coverage. The Marketplace is designed to help you find health insurance that fits your budget, with less confusion and hassle.

Every health insurance plan in the new Marketplace must offer comprehensive coverage of Essential Health Benefits (EHB). EHB include items and services in these categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative<sup>1</sup> services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

The Marketplace will also help you compare all of your insurance options based on price, benefits, and other features that may be important to you, in plain language that makes sense, so you will get a clear picture of what you will pay and what you will get before you make a choice.

All plans must show you that information in a new document called the Summary of Benefits and Coverage (SBC). The SBC is an easy to read, standardized chart that explains the key information for each health insurance plan. Because every plan must provide their information in the same format, it is easier to compare your choices. For more information about the SBC requirements, visit <https://www.healthcare.gov/health-care-law-protections/summary-of-benefits-and-coverage/>.

---

<sup>1</sup> Habilitative services, like rehabilitative services, generally include occupational and physical therapy. However, habilitative services help people acquire, maintain, or improve skills and functioning.

Almost everyone who does not have insurance through their employer can use the Health Insurance Marketplace to explore their health insurance options. The only requirements to get insurance through the Marketplace are:

- You must live in the U.S.
- You must be a U.S. citizen or national (or lawfully present)
- You cannot be currently incarcerated

Consumers typically have the choice between purchasing several different plans in these Marketplaces. However, all health insurance companies that want to sell their plans through the Marketplace must offer these standardized plan levels: Platinum, Gold, Silver, Bronze, and Catastrophic. The difference between these plan levels is the amount of money that you pay out of pocket for your health care costs ("cost share"). For example:

- Platinum: plan pays 90% - you pay 10%
- Gold: plan pays 80% - you pay 20%
- Silver: plan pays 70% - you pay 30%
- Bronze: plan pays 60% - you pay 40%
- Catastrophic plans will only be available to individuals under 30 and those individuals who are exempt from the individual mandate

Every state has a Health Insurance Marketplace, but each state's Marketplace will operate a little differently. States can create and run their own Marketplace, or have a Marketplace run by HHS. States may also choose to partner with HHS to run their Marketplace, like Illinois.

#### *Financial Assistance to Purchase Plans in the Marketplace*

The ACA provides financial assistance to individuals who buy health insurance in the Marketplace, based on their household size and income level. There are two different types of financial assistance in the Marketplace:

- Premium tax credits, which reduce the amount that you pay for their monthly premiums to have health insurance
- Cost-sharing subsidies, also known as cost-sharing reductions, which help to lower deductibles, co-payments, and coinsurance

As of January 1, 2014, tax credits have been available to U.S. citizens, and those who are lawfully present in the United States, who purchase a health insurance policy through their

state's Health Insurance Marketplace and who have incomes between 138% and 400% of the Federal Poverty Level (FPL), which in 2019 translates to approximately \$16,753 and \$ 48,560. The tax credit is sent directly to your insurance company and applied to your premium, so you pay less out of your own pocket. The amount of financial assistance you are eligible for depends on how much income you or your family earns.

#### *Purchasing Insurance Through a Marketplace*

Each year there is a period of time when you can shop for and purchase health insurance in the Marketplace. This is referred to as open enrollment. The open enrollment period for 2019 began on November 1, 2018, and ran through December 15, 2018. During open enrollment, you can "window shop," compare options, renew coverage, switch plans, or opt out of purchasing insurance all together. The rationale behind having a set open enrollment period each year is to avoid situations where people wait until they get sick to purchase health insurance coverage. However, the ACA recognized that life changes do not always happen during a specific time of year. Therefore, there is a Special Enrollment Period (SEP) for people who have experienced certain "qualifying events." For example, losing health insurance through a job, aging out of a parent's policy, or exhausting COBRA coverage.

During a SEP, you have 60 days to shop for, and buy, new health insurance coverage in the Marketplace. SEPs also provide the opportunity to add family members to a policy after a marriage, birth, or adoption. On June 23, 2017, the rules around special enrollment were changed by HHS and there are a few extra steps that you have to take. You are now required to submit additional information to HealthCare.gov for a pre-enrollment verification of eligibility for a SEP. What this means is that once you choose a plan, the Marketplace will "pend" the enrollment and you will have 30 days to submit documents to confirm their SEP eligibility before coverage will start. When you submit an application on HealthCare.gov, you will receive a notice with a list of documents they need to submit to provide this confirmation.

As soon as the SEP is verified, the Marketplace will send your information to the health insurance company and coverage will start based on when the SEP started and when a plan was chosen. In some cases, this will be retroactive.

For more information and to see a copy of the various notices you may receive, visit the CMS Center for Consumer Information and Insurance Oversight website. More information on SEP-qualifying events can be found at <https://www.healthcare.gov/coverage-outside-open-enrollment/special-enrollment-period/>. For more information about the Marketplace in Illinois, visit <https://getcovered.illinois.gov/en> or [www.HealthCare.gov](http://www.HealthCare.gov).

### *Open Health Insurance Market*

Health insurance is also sold outside of the ACA Health Insurance Marketplace. Individuals can go directly to insurance companies, agents, brokers, and online health insurance sellers to purchase these health insurance plans. There are several reasons that individuals may choose to purchase a plan outside of the Marketplace. For example, in some states, the plans sold through the Marketplace have limited networks of providers. For some individuals diagnosed with cancer, having the ability to see a wider network of providers is necessary. Furthermore, in some states, the Marketplace does not offer higher level policies (i.e., gold or platinum). So for individuals seeking a policy that provides a higher level cost-share, purchasing plans in the open market may be their only option. Most plans sold in the open health insurance market still have to follow the consumer protections included in the ACA. However, you should keep in mind that if you purchase a policy outside of the Marketplace you will not be eligible for financial assistance. It can be in your best interest to, at a minimum, check the policies available to you through the state Marketplace, before purchasing a policy in the open market. Additionally, if you choose to shop in the open market, you must do your best to be a savvy consumer. Some brokers may try to sell individuals short-term policies, which are often referred to as "junk insurance." These plans will likely exclude coverage for any care related to a preexisting condition (e.g., cancer), essentially making the insurance useless. Furthermore, there have been several reports of scams in recent years. To protect yourself, you can check with the Illinois Department of Insurance to ensure that the company is properly licensed (<https://insurance.illinois.gov>).

### *Additional Health Insurance Options for Children and Young Adults*

Under the ACA, eligible young adults now have the option of staying on their parent's health insurance plan until they are 26 years old. These young adults do not have to be dependents under IRS standards, can live on their own, be married, and even have their own children. This rule gives young adults additional options and helps to bridge the gap that may occur between leaving school and finding a job that offers health insurance benefits.

Also under the ACA, children under the age of 19 cannot be denied when trying to purchase an individual health insurance policy because of a pre-existing condition. These are often referred to as "child-only plans." These types of plans may be a great option for families where the parents do not have employer-sponsored health insurance or when their plan at work does not cover dependents (i.e., their children).

### C. Government Sponsored Insurance

The government, at both state and federal levels, finances health care in many different forms, however, the largest government-sponsored health care programs are Medicare and Medicaid.

#### *Medicare*

Medicare is a federally run health insurance program available to only three groups of people. In order to be eligible for Medicare you must fall into one of the following categories:

- Be 65 years or older and be eligible for Social Security Retirement benefits; or
- Be under 65 years old, have certain disabilities, and have received Social Security Disability Insurance (SSDI) benefits for 24 months; or
- Have End-Stage Renal Disease or amyotrophic lateral sclerosis (ALS).

There are four parts to Medicare, A-D, each of which provides different services and benefits.

#### *Part A*

Part A is hospital insurance and helps to pay for inpatient care in a hospital or skilled nursing facility (following a hospital stay), some home health care, and hospice care. Typically, if you are 65 years of age or older, you will receive Part A automatically and for free. If you do not have enough work history during which you paid Social Security taxes, you may be required to pay a premium of up to \$437 each month in 2019. If you do not elect Part A when you first become eligible, your monthly premium may go up 10 percent. You will then have to pay this higher premium for twice the number of years you could have had Part A, but didn't sign up.

#### *Part B*

Part B is medical insurance and helps to pay for doctors' services and many other medical services and supplies that are not covered by hospital insurance. Most people will pay a premium of \$135.50 per month for Part B in 2019. Part B has an 80/20 co-insurance and no out-of-pocket maximum. If you enroll in Part B late, your monthly premium for Part B may go up 10 percent for each full 12-month period that you could have had Part B, but didn't sign up for it.

Parts A and B together are often referred to as "Original Medicare." Individuals who have Original Medicare are entitled to receive services from any health care provider or facility that accepts Medicare nationwide. In other words, there is a national network of providers.

## *Part D*

Part D is prescription drug coverage that will help to pay for medications doctors prescribe. Part D premiums generally range from \$10–\$100 per month (depending on the plans available in the area and on the specific plan chosen). Part D has four coverage stages: (1) deductible, (2) initial coverage, (3) coverage gap, or donut hole, and (4) catastrophic coverage. You will pay a different amount for your prescription drugs depending on your current stage. The maximum deductible, in 2019, is \$415.

After individuals reach their deductible, Medicare will pay 75% of their prescription drug costs and they will pay 25%, up to \$3,820 in total drug costs—this is the initial coverage stage. In 2019, once you and your plan spends \$3,820 on covered drugs, you enter the coverage gap. This amount may change each year. This gap is commonly referred to as the “donut hole.” Prior to the ACA, once individuals fell into the donut hole, they were responsible for 100% of their prescription drug costs. This gap in coverage forced seniors and people with disabilities with Medicare to pay astronomical prices out-of-pocket for their medications. The ACA addressed this problem by slowly closing the donut hole gap over time.

In 2019, this is how a standard Medicare Part D plan works:

- Jamie pays a \$415 deductible for her prescription drugs.
- Then Medicare pays 75% of Jamie’s prescription drug costs and Jamie is responsible for paying 25%, until she reaches \$3,820 in total drug costs (i.e., the initial coverage limit).
- If Jamie is taking brand name drugs, she will continue to pay 25% of those costs and Medicare will pay 75%.
- However, if Jamie is taking a generic version of a drug she will still fall into the donut hole, until she reaches \$5,100 in total drug costs. During this time, Medicare will cover 63% percent of Jamie’s generic drug costs and she will be responsible for 37%.
- Once Jamie’s out-of-pocket costs \$5,100 during the year, Medicare will cover 95% of her prescription drug costs and Jamie will pay 5% (or \$3.35 for generics and \$8.35 for brand-name drugs, whichever is greater) for the rest of the year.

By 2020, the donut hole will be closed for both generic and brand name drugs. This means that if you have a Part D plan in 2020, after you pay your deductible, you will be responsible for 25% of your prescription drug costs, until your out of pocket costs reach approximately \$5,200<sup>2</sup>, then you enter the catastrophic phase and will be responsible for 5% of your prescription drug costs (or a nominal dollar amount, whichever is greater).

---

<sup>2</sup> Note: HHS has not released a final amount for 2020, this is simply an estimate based on prior years.

### *Part C (Medicare Advantage)*

Part C is an alternative option to electing Parts A and B. Part C is also known as a Medicare Advantage Plan. Part C plans are provided through private health insurers. Similar to individual insurance, there are different types of Medicare Advantage plans (e.g., PPO, HMO, etc.).

Each Part C plan is able to set its own premiums, deductibles, services, and out-of-pocket maximums. However, the out-of-pocket maximum for 2019 cannot be more than \$6,700. If you choose a Part C plan, you will pay at least the premium for Part B, and may pay more to cover additional services being offered in the plan (e.g., vision, hearing, and dental coverage). In 2019, the estimated average monthly Part C plan premium was \$28 (above the Part B premium), but premiums ranged from \$0 to more than \$200. Many Medicare Advantage plans have a network of providers and do not provide coverage for services received out of that network. If the plan you pick does provide some coverage for out-of-network services, you will likely have to pay more to see those providers because they are out of the plan's network. Part C plans may or may not include prescription coverage. If they do not provide prescription drug coverage, you can also purchase a Part D plan.

<b>Pros of Medicare Advantage Plans</b>	<b>Cons of Medicare Advantage Plans</b>
Out-of-pocket maximum is at most \$6,700 a year	Could have a small network of providers = out-of-network providers not part of out-of-pocket max, if covered at all
Many plans cost exactly the same amount as a Part B plan	Plans are difficult to compare since no two plans are alike
Usually includes drug coverage (without separate premium/deductible)	Usually only localized coverage (i.e., no nationwide coverage)
Can include "extras" like dental, vision	Primarily HMO plans that require referrals from primary care physicians to see specialists
Can switch to another Advantage plan or Original Medicare during open enrollment	May not be able to get Medigap later

### *Medicare Supplemental (Medigap) Plans*

Part B of Medicare has an 80/20 cost-share, and no out-of-pocket maximum, which can result in a significant financial burden for individuals with Medicare who are diagnosed with expensive medical conditions like cancer. In order to help individuals pay for the 20% cost-share amount and other things that Medicare does not cover, Medicare created an option to purchase additional coverage through a Medicare supplement insurance policy, commonly called a Medigap plan. These supplemental insurance plans are purchased through a private insurer and

cover items and services that Medicare does not cover. There are different Medigap plans, named by letters A–N<sup>3</sup>, which are offered by private health insurance companies. Medigap policies are regulated and standardized by federal and state law, which means that while any insurance company can sell a Medigap policy, the policies are standardized.

For more information or to find a Medigap plans in your area visit

[www.medicare.gov/supplement-other-insurance/compare-medigap/compare-medigap.html](http://www.medicare.gov/supplement-other-insurance/compare-medigap/compare-medigap.html)

Medigap policies are only available to individuals who purchase Original Medicare (Parts A and B). Individuals who opt for a Medicare Advantage Plan (Part C) are ineligible to purchase a Medigap policy. Although Medigap plans have an additional monthly premium, the premium amount may be significantly less than paying the 20% cost-share out-of-pocket. Take Jimmy for example:

Jimmy is almost 65, lives in Crystal Lake, and is weighing his Medicare options. He is about to start chemo that will last a year. He has heard that his IV chemo treatment is covered under Medicare Part B, but Part B has an 80/20 cost-share. His drug costs will be \$10,000 per month. He isn't interested in a Medicare Advantage plan, because he spends part of the year in Florida and therefore, wants to see providers in both states. He wants a Medicare option with the lowest out-of-pocket costs. He has two main options: Original Medicare or Original Medicare plus a Medigap plan. The chart below illustrates how much each option will cost Jimmy.

	Option 1: Original Medicare	Option 2: Original Medicare + Medigap Plan F, which costs \$300 per month
Part B premium	\$134 per month x 12 = \$1,608	\$134 per month x 12 = \$1,608
Part B deductible	\$183	\$0 (Medigap Plan F picks up Part B deductible)
Part B 20% Cost-Share	\$10,000 x 20% = \$2,000 x 12 months = \$24,000 (note: just for his chemo)	\$0 (Medigap Plan F picks up Part B cost-share)
Medigap Premium	\$0	\$300 per month x 12 = \$3,600
<b>Total Annual Costs</b>	<b>\$1,608 + \$183 + \$24,000 = \$25,791</b>	<b>\$1,608 + \$3,600 = \$5,208</b>

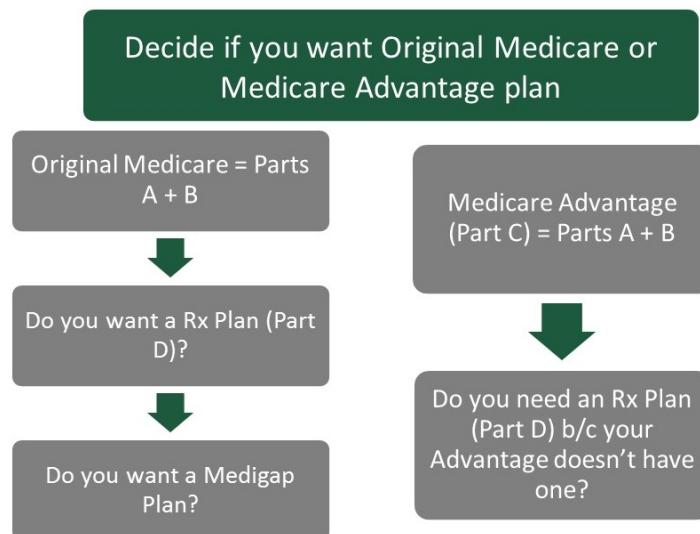
As you can see, while option two means that Jimmy will have to pay an additionally \$300 a month for his Medigap premium, because the Medigap plan picks up his Part B deductible and the 20% cost-share, he ends up saving over \$20,000 for the year. Ultimately, Jimmy's story

<sup>3</sup> Plans C and F will be closed to new enrollees starting in 2020.

illustrates that while you are spending more on premiums when you buy a Medigap plan, you may end up saving a substantial amount in the long run.

### *Enrolling in Medicare*

Choosing the right Medicare plan can be daunting. In an attempt to simplify the process, the following figure illustrates the two paths you can take when signing up for Medicare benefits.



For more information about Medicare and its services please visit: [www.Medicare.gov](http://www.Medicare.gov) or <https://triagecancer.org/healthinsurance> to download Triage Cancer's Quick Guide to Medicare at <https://triagecancer.org/QuickGuide-Medicare>. Finally, watch the Triage Cancer webinar *Medicare: An In-Depth Look at* <https://triagecancer.org/past-webinars>.

If you qualify for Medicare because you are 65 years or older and you need assistance, contact the Senior Health Insurance Program (SHIP). SHIP is a free insurance counseling service sponsored by the Illinois Department of Financial and Professional Regulation, Division of Insurance to assist Medicare beneficiaries and their caregivers. Specifically, SHIP counselors are trained to:

- Answer questions about Medicare, Medicare supplement insurance, long-term care insurance, Medicare Advantage plans and other health insurance
- Answer questions about Part D
- Organize and assist in filing Medicare and Medicare supplement claims
- Appeal claim denials
- Answer question about and help complete applications for "Extra Help," a federal program to assist low-income seniors with the costs associated with Medicare D

SHIP is not affiliated with any insurance company and does not sell any insurance. The SHIP site that provides counseling for the McHenry County area is Centegra Health System. Counseling sessions are held at Centegra Hospital in McHenry, Centegra Hospital in Woodstock and at The Wellness Center at Sun City Huntley for Del Webb residents. For questions or to schedule an appointment in McHenry County, call (815) 759-4203. To reach the SHIP hotline, call (800) 548-9034.

### *Medicaid*

Medicaid is the federal health insurance program for some individuals who have limited assets and low incomes. Under the ACA, Medicaid eligibility has expanded. To avoid confusion, *traditional Medicaid* refers to the program in existence before January 1, 2014, and *Medicaid expansion* refers to expansion of the program after January 1, 2014. Even in Illinois, where Medicaid has been expanded, the traditional Medicaid option still exists.

#### *Traditional Medicaid*

To be eligible for traditional Medicaid, one must have limited assets, a low income, and fall into at least one of the following categories:

- Have a disability<sup>4</sup>
- Be blind
- Have a minor child or children
- Be a child less than 19 years old
- Be a pregnant woman (coverage will last until six months after the child is born)
- Have been diagnosed with breast or cervical cancer through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

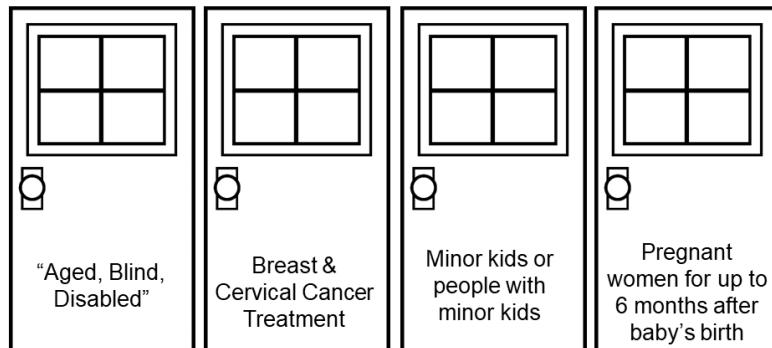
---

<sup>4</sup> You may be deemed disabled by the U.S. Social Security Administration (SSA) if you cannot do work that you did before; the SSA decides that you cannot adjust to other work because of your medical condition(s); and your disability has lasted or is expected to last for at least one year or to result in death. See U.S. Social Security Administration, *Disability Benefits*, <https://www.ssa.gov/benefits/disability/> (last visited Jan. 2, 2018).

These categories can be thought of as different doors into Medicaid, as illustrated in the figure below.

## Medicaid before 1/1/14

Eligibility: low income + low assets +



If an individual has too high of an income or too many assets, but is otherwise eligible for Medicaid, they may be able to participate in the Spend-down program. The Spend-down program, run by the Illinois Department of Health and Family Services (HFS), allows people to pay for a portion of their health care costs, up to a certain amount that is determined based on their income and asset level. Once a person can show that they have paid their pre-determined amount towards health care costs, Medicaid will pick up the remainder of the costs. Several types of expenses are eligible for the Spend-down program such as doctor services, hospital services, nursing home services, prescription medicines and medical supplies, health insurance premiums, transportation to and from medical care and co-payments or deductibles. You are able to submit bills each month to prove that you have met your spend-down amount. However, if you have large bills you can submit them all at once and you may get a card showing that you have met the amount for several future months. Once you apply for this program, HFS will pay for medical care for the previous three months if you meet the Spend-down requirements for those months. So if you apply for medical benefits in December and met the spend-down requirements for the previous three months, HFS may pay for medical care you got in September, October, and November.

### **Spend-Down Example**

Your spend-down amount is \$200. You have a doctor bill for \$100 and a hospital bill for \$900 on the same day. You will owe only the \$100 doctor bill and \$100 of the hospital bill. The hospital will bill HFS for the remaining \$800.

If you are approved to participate in the Spend-down program and you also fall into the “aged, blind, disabled” category, you may also be eligible for the Pay-In Spend-down program. If you are eligible, HFS will automatically send you the enrollment forms. Once you are enrolled you can meet your Spend-down in one of three ways:

- Directly paying your monthly spend-down amount to HFS;
- Paying for your medical expenses out of pocket until you meet your spend-down amount, then send the proof to HFS; or
- A combination of paying out of pocket for your medical expenses and directly paying a certain amount to HFS.

If you are working, have a disability, and aren't able to get employer sponsored or individual health insurance, you may be eligible for the Health Benefits for Workers with Disabilities Program (HBWD). Under this program you can pay a monthly premium, based on your income level, to have Medicaid coverage. In order to be eligible, you must meet all of the following criteria:

- Have a monthly income of less than 350% of the FPL (in 2019 this is an income of \$3,433 a month per year for an individual);
- Have less than \$25,000 in assets; and
- Be between 16 and 65 years old.

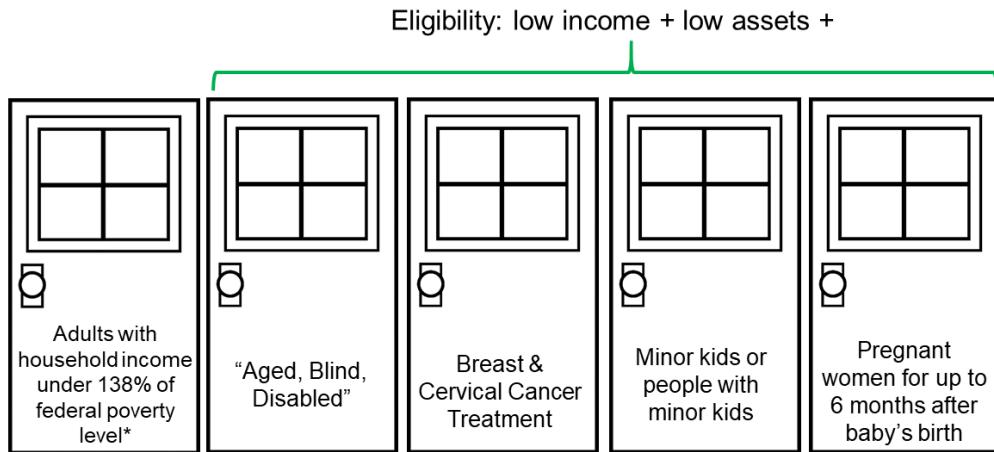
For more information about the Illinois Medicaid Spend-down, the Pay-In Spend-down, or the HBWD programs, visit

[www2.illinois.gov/hfs/MedicalPrograms/Brochures/Pages/HFS591SP.aspx](http://www2.illinois.gov/hfs/MedicalPrograms/Brochures/Pages/HFS591SP.aspx).

### *Medicaid Expansion*

One of the major flaws in traditional Medicaid is that it does not provide health care coverage to childless adults with low incomes. Furthermore, the resource test for traditional Medicaid was often a barrier to access. Individuals were forced to deplete any savings before becoming eligible for health care services under Medicaid. The ACA expanded who may access Medicaid by creating a category of "newly eligible" individuals. These are individuals who have incomes that are at or below 138% of the Federal Poverty Level (FPL). In 2019, 138% of the FPL equals an annual income of \$16,753 for an individual and \$34,638 for a family of four. This figure illustrates the Medicaid program as of January 1, 2014. The four original doors to enter the Medicaid program still exist with the same income and asset requirements. However, now there is a fifth way to enter the program, based solely on income.

## Medicaid as of 1/1/14



If you believe you are eligible for Medicaid under the new program, you can submit an application at any point during the year at <https://abe.illinois.gov/abe/access/>.

### *Illinois Breast and Cervical Cancer Program (IBCCP)*

The Illinois Breast and Cervical Cancer Program (IBCCP) provides free mammograms, breast exams, pelvic exams, and Pap tests to certain women. In order to be eligible for the IBCCP program, a woman must live in Illinois, be without health insurance, and generally must be between 35 and 64 years old. In some instances, younger women with a genetic predisposition to breast cancer may be deemed eligible. In addition to providing screening, the IBCCP will pay for treatment for women who are diagnosed with breast cancer. For additional information, call the McHenry County Department of Health at (815) 334-0232.

### III. Consumer Rights and Protections

Arguably, every American is a consumer of health care at some point in their lives. There are various laws and benefits that exist to protect health care consumers. This section describes some of the consumer protections that are relevant to individuals with a cancer diagnosis.

#### A. ACA's Consumer Benefit Reforms

In addition to providing certain individuals with new health insurance options, the ACA made significant reforms as to how health insurance companies can do business and provided health

care consumers with additional protections. The following examples are only a few of the protections that have an impact on the cancer community.

#### *Lifetime and Annual Limits*

Many insurance plans had limits on the amount of benefits someone could use during each year, or over their entire lifetime. These are called annual limits or lifetime limits. These benefit limits were very easy to reach, especially when you were being treated for a serious medical condition, such as cancer. Once a limit was reached, it left that person virtually uninsured. As of September 23, 2010, insurance companies are no longer allowed to impose lifetime or annual limits on payments for essential health benefits. The exact definition for essential health benefits will differ from state to state and from year to year, but will generally include items and services in these categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. In 2018, Illinois became the first state to change its benchmark plan by choosing a new plan with provisions to help combat opioid abuse and provide additional mental health coverage. More details about the benchmark plan that will start in 2020 can be found at [https://www2.illinois.gov/IISNews/18098-DOI\\_Essential\\_Health\\_Benefit-benchmark\\_plan\\_Release.pdf](https://www2.illinois.gov/IISNews/18098-DOI_Essential_Health_Benefit-benchmark_plan_Release.pdf).

#### *Rescissions*

In the past, insurance companies often cancelled individuals' policies, if they got sick. The ACA prohibits insurers from canceling someone's plan unless that individual failed to pay his or her monthly premiums, committed fraud, or made an intentional misrepresentation of a material fact (i.e., lied about something very important) about their medical history on their initial application for coverage. Furthermore, if an insurance company rescinds a policy, they must provide a minimum of 30 days' notice to the enrollee and include in that notice information on the enrollee's right to appeal the rescission decision.

#### *Preexisting Condition Protections and Premium Rating*

Prior to the ACA, health insurance companies were able to charge higher premiums or even outright deny selling coverage to someone with a pre-existing medical condition. As of January 1, 2014, no one can be denied health insurance coverage because of a pre-existing condition. Also, in 2014, insurance companies will be limited in what they can consider to decide how

much to charge you for your monthly premiums. Specifically, insurance companies will only be able to look at the type of plan you are purchasing (i.e., individual or family plan), your age,<sup>5</sup> your tobacco use, and your rating area (zip code) to determine how much you will be charged for insurance coverage.

## B. Clinical Trials Laws

Participating in a clinical trial might be an excellent option for someone diagnosed with cancer. The company sponsoring the clinical trial will usually cover the prescription drug, treatment, or procedure being tested, but that leaves the “routine costs” of care left to pay, including doctor visits, blood tests, scans, etc. Depending on what type of health insurance you have, some of those costs will be covered.

### *Private Insurance*

Illinois<sup>6</sup> is one of the 37 states (and the District of Columbia) which have laws that require insurance companies to cover those routine costs for individuals who decide to participate in an eligible clinical trial. Therefore, as of January 1, 2012, most Illinois private and group health insurance plans have been required to pay for any of your routine costs associated with Phase II, III, or IV cancer clinical trials.

As of January 1, 2014, the ACA required that non-grandfathered health plans (i.e., those that were created after March 23, 2010) cannot deny a qualified individual participation in an approved clinical trial, or deny or limit the coverage of “routine costs” in connection with participation in the trial. An “approved clinical trial” is one that tests ways to prevent, detect, or treat cancer and are funded or approved by the federal government and have submitted a U.S. Food and Drug Administration Investigational New Drug (IND) application or are exempt from IND requirements. “Routine costs” are those that would normally be involved in standard care, such as doctor visits, blood tests, imaging scans, and so on.

### *Medicaid*

The federal government does not require states to cover individuals who participate in clinical trials through state Medicaid plans, so coverage depends on the state. The Illinois Medicaid department does not provide clear blanket guidance on if Medicaid will cover participation in

---

<sup>5</sup> Currently there is a 3:1 ration. This means that, at most, a 64-year-old can only be charged three times more than a similarly situated 21-year-old for the same plan.

<sup>6</sup> Qualified Clinical Cancer Trials Law

clinical trials. Therefore, individuals who are covered by Medicaid and wish to participate in a clinical trial should contact their DFS representative for more details.

#### *Medicare*

Like private insurance, Medicare covers the routine costs of items and services in covered research studies. Examples of these items and services include room and board at a hospital, the treatment of side effects and complications that may occur as a result of the study, and operations to implant an item that is being tested. For more information about Medicare coverage for clinical trials, visit <https://www.medicare.gov/coverage/clinical-research-studies.html>

#### *TRICARE and VA*

TRICARE will reimburse the medical costs related to taking part in National Cancer Institute (NCI)-sponsored trials for cancer prevention and treatment. VA allows eligible veterans to participate in NCI-sponsored clinical trials at VA medical centers.

For specific information about other state's laws, visit <https://triagecancer.org/statelaws>. For more information about clinical trials, including how to find an appropriate trial for you, please visit <https://triagecancer.org/clinical-trials> or watch <https://triagecancer.org/video-clinicaltrials>.

### C. Insurance Coverage for Oral Chemotherapy

Oral cancer medications are typically covered under a health plan's pharmacy benefit. This means that patients are often required to pay higher out-of-pocket co-pays to fill these prescriptions. There are often no intravenous (IV) substitutes for oral chemotherapy drugs. Illinois is one of 43 states and the District of Columbia that have enacted an oral chemotherapy access law.<sup>7</sup> In these states, insurance companies are required to treat and cover oral chemotherapy the same way they would cover intravenous chemotherapy. For more information about other state's laws visit <https://triagecancer.org/statelaws>.

### D. Women's Health and Cancer Rights Act (WHCRA)

The Women's Health and Cancer Rights Act (WHCRA) is a federal law that may be especially important to women who are diagnosed with breast cancer. This law requires that if an insurance company covers a mastectomy or partial mastectomy (a.k.a. a lumpectomy), it must

---

<sup>7</sup> 215 ILCS 5/3562.19

also cover the reconstruction costs. Those costs can include reconstruction on the breast that the mastectomy was performed on, the reconstruction of the other breast to achieve a symmetrical (balanced) appearance, prostheses, and/or implants. In addition to what many people think of as “reconstruction costs,” insurance companies must pay for the treatment of any physical complications of a mastectomy, such as lymphedema.

If a patient has a mastectomy while covered by one plan, but then moves to another health insurance plan before having reconstructive surgery, the new plan must also pay for the reconstructive surgery if they would have covered the original mastectomy.

While WHRCA applies to most health insurance plans, it does not apply to Medicaid and Medicare. For more information on WHCRA, please visit [www.dol.gov/ebsa/publications/whcra.html](http://www.dol.gov/ebsa/publications/whcra.html).

#### E. Insurance Coverage for Cancer Screenings

Insurance coverage for cancer screenings varies by federal and state law and by type of insurance coverage (e.g., private insurance, Medicare, Medicaid). For example, in Illinois, insurance companies are required to cover clinical breast exams at least once every three years for women 20 – 39 years old and annually for women over 40.<sup>8</sup> Routine mammograms must be provided annually for women over 40, and women over 35 are entitled to one baseline mammogram.<sup>9</sup> Women under 40 who may be at high risk for breast cancer may also be covered. These services are required to be provided free of charge, without a co-pay or being subject to a deductible.

The ACA does not change these state law protections; however, it does require any new health insurance plans to offer free preventative care, including some cancer screenings. This provision does not apply to grandfathered plans, meaning plans that were in existence at the time the ACA was signed into law on March 23, 2010. Plans may lose their grandfathered status at any time if they make a substantial change to the plan such as significantly cutting benefits or increasing out-of-pocket spending for policy holders. In 2019, there are only a few grandfathered plans left. If you are unsure if your employer sponsored plan is considered grandfathered, you can ask the person at your job that deals with employee benefits or call the number on the back of your insurance card.

---

<sup>8</sup> 215 ILCS 5/356g.5

<sup>9</sup> 215 ILCS 5/356g(a-5)

“Free” means that not only will the insurance plan cover the cancer screening, but they cannot apply any costs to your deductible, or charge you a co-pay or co-insurance amount. Some of the cancer-related preventable services include:

- Breast cancer mammography screenings every 1 to 2 years for women over 40
- Cervical Cancer screening for sexually active women
- Colorectal cancer screening for adults over 50
- Genetic counseling and BRCA testing
- Immunizations for the Human Papillomavirus (HPV)
- Tobacco use screening and cessation interventions

For the complete list of preventative services to which this new provision applies, which can be found at <https://www.healthcare.gov/coverage/preventive-care-benefits/>. Even if your plan is self-insured, this new provision may apply to you.

#### IV. Accessing Medical Records

It may become necessary to obtain a copy of your medical records. In fact, it can be useful for you to always keep a copy of your own medical records. Generally, you, or your representative, are legally entitled access to your medical records under the federal Health Insurance Portability and Accountability Act (HIPAA). Illinois law<sup>10</sup> provides you with additional rights to access your records. For example, once you request your records, your health care provider must give them to you within 30 days. If you are not provided with your records, you have the right to sue in Illinois Circuit Court. Once you obtain your records you may find mistakes or omissions. You have the legal right to add or amend your medical records in order to make them accurate or more complete. Lastly, your medical provider is not allowed to withhold your records from you because you have an outstanding balance with them. Keep in mind that health care providers are entitled to charge a fee for providing you with a copy of your records. In 2019, the fees were:

- Paper:** \$1.07 per page for the first 25 pages, \$0.71 per page for pages 26 to 50, and \$0.36 per page for each page in excess of 50.
- Electronic records:** cannot exceed 50% of the per page charge for paper copies. This charge includes the cost of each CD, DVD, or other storage media.
- X-rays and pictures:** The facility or practitioner can charge for the reasonable cost of duplication of any record material or information that cannot be routinely copied or duplicated on a standard copy machine, such as x-rays films or pictures.

**Accessing Medical Records Tip:**  
Doctors are typically not charged for copies of medical records. Ask your health care provider if s/he is willing to request the records for you to avoid a fee.

---

<sup>10</sup> 735 ILCS 5/8 - 2006

- Additionally, health care facilities and practitioners are permitted to charge \$28.44 for processing the request and the actual postage or shipping cost.

## V. Health Insurance Appeals

At some point in your cancer journey you may be faced with a denial of coverage for your treatment from your insurance company. Therefore, you may be forced to become a self-advocate and appeal the decision. There are two types of appeals: internal and external (aka independent). In Illinois, you are required to exhaust your plan's internal review appeals process before you are able to seek an external review, unless there is an extraordinary or compelling case. Each company may have a different internal appeals process and you must follow that process exactly. If you are unsure about your company's process, contact them and ask for it in writing. If you have an employer-sponsored health insurance plan, the law that governs is the Employee Retirement Income Security Act (ERISA). ERISA requires that health plans let policy holders (i) see their plan documents, (ii) prohibits charging a fee to file an internal appeal, and (iii) have a maximum of two levels of internal appeals.

Once you have filed your internal appeal, the insurance company must provide you with a decision within 15 days if it is a non-urgent situation, or 24 hours if it is urgent. If you do not receive a decision from your health plan within those time frames, you may contact the Illinois Department of Insurance at:

The Office of Consumer Health Insurance (OCHI) ~ Illinois Department of Insurance

320 West Washington Street  
Springfield, Illinois 62767-0001  
(877) 527-9431 or [www.insurance.illinois.gov](http://www.insurance.illinois.gov)

### Internal Appeals Tips

- Be patient & persistent
- Use appeals tracking sheet to write everything down
- Get decisions in writing
- Pay attention to deadlines
- Send items via certified mail
- Get a copy of your files from the insurance company

If you have exhausted your company's internal appeals process and the decision is still not favorable to you, you may be able to file an external medical review (also known as independent medical review). In Illinois, the Health Carrier External Review Act entitles you to an external review for health insurance claims that have been denied.<sup>11</sup> Unlike internal reviews, where your insurance company is still the decision maker, external reviews utilize a completely independent medical review organization. The decision of this independent body is typically binding on both parties. You must seek external medical review within four (4) months

<sup>11</sup> 215 ILCS 180/25

from the date you receive written notification that you have exhausted the internal appeal process. You should be able to seek an external medical review (EMR) when the denial for coverage of services was because:

- The service was not "Medically Necessary"; or
- The service is considered "Experimental/investigational"; or
- The condition is "Pre-existing"; or
- Your coverage is being rescinded (cancelled) for a reason other than non-payment of premium or contributions.

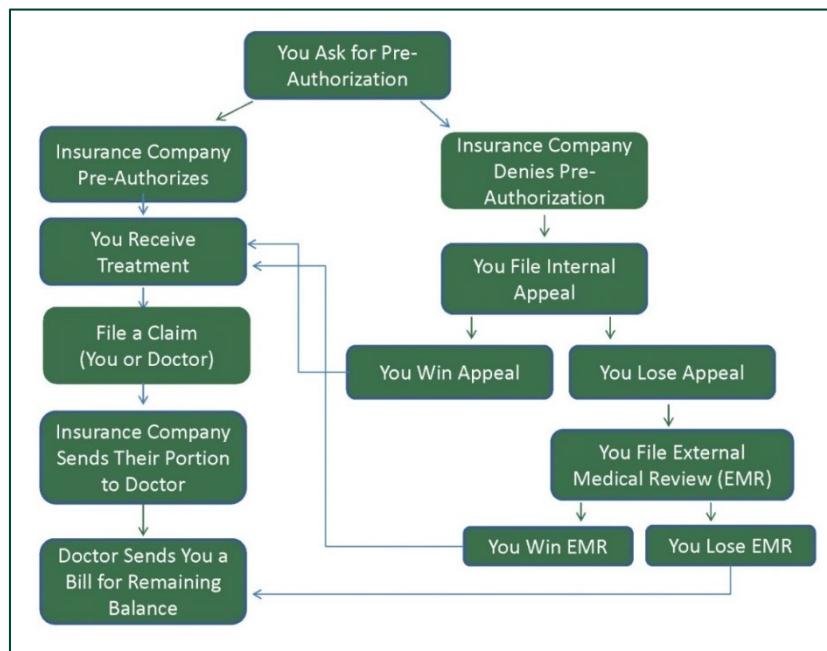
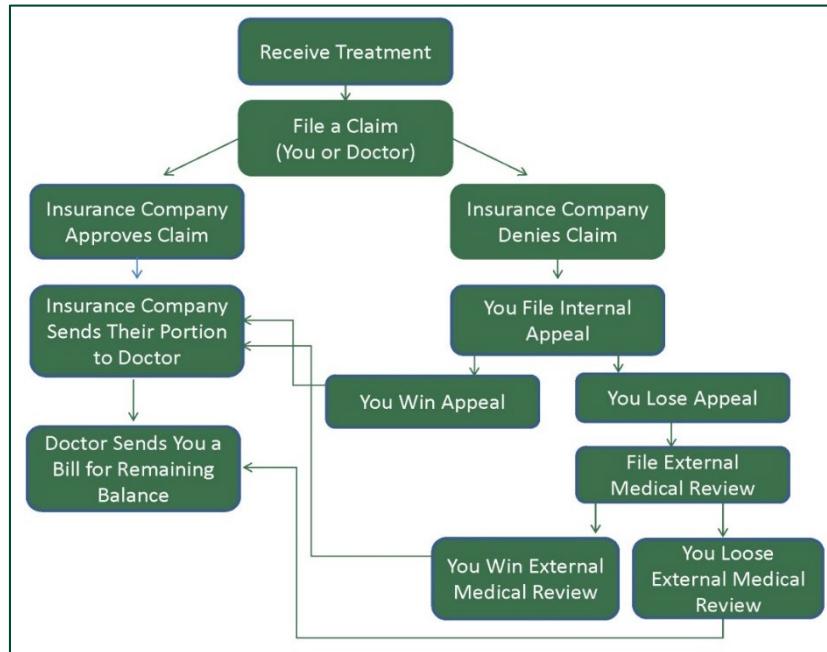
You will likely not qualify for EMR if:

- you have coverage through Medicare, Medicaid, Federal Employees Health Benefits Program, Tricare or other military coverage;
- you are part of a self-insured employer or union plan (unless your employer or union plan has opted for the state process);
- you have a group plan issued in another state;
- the coverage is for a specified disease (such as cancer only); specified accident or accident only, credit, dental, disability income, hospital indemnity, long-term care, vision, or other limited supplemental benefits.

More information about external medical review can be found at:

[www.insurance.illinois.gov/ExternalReview/default.asp](http://www.insurance.illinois.gov/ExternalReview/default.asp). Triage Cancer has created an appeals tracking sheet to help you through this process. That sheet, the Illinois DOI external medical review application, and other relevant forms are included in the Appendix of this Handbook. Additional copies can be printed for free at <https://triagecancer.org/AppealTrackingForm>.

These flow charts demonstrate the typical life-cycle of an appeal. The first is if you are submitting a claim after you have received a treatment or service. The second is the process if you requested a pre-authorization from your insurance company to cover a service before you receive it.



## VI. Making Health Insurance Choices

Americans have more options for health insurance than ever before, however, most of us are never taught how to choose the best plan for us.

### A. Tips for Picking a Plan

Three key factors are important to compare when considering health insurance options: (1) costs; (2) the health care providers covered by the plan; and (3) whether or not recommended prescriptions drugs are included on the list of covered drugs (formulary).

#### *Math Matters*

When comparing prices for different plans, many individuals only look at the monthly premium. However, for individuals with an expensive medical condition such as cancer, it is imperative to not only focus on the monthly premium of a plan, but to also pay attention to the out-of-pocket maximums.

As discussed earlier in the chapter, the out-of-pocket maximum is defined as the most amount of money an individual will pay on his or her own, each year, for medical expenses.<sup>12</sup> Assuming you expect to receive enough medical care throughout the year to meet the out-of-pocket maximum, in order to assess the total annual cost of an insurance plan, use this formula:

$$[\text{monthly premium} \times 12 \text{ (months)}] + \text{out-of-pocket maximum} = \text{total annual cost}$$

This formula can be used when comparing plans sold in the state Marketplace, plans offered by an employer, between Marketplace plans and employer plans, and between different Medicare Advantage or Part D plans. In some cases, choosing a plan with a higher monthly premium and a lower out-of-pocket maximum can save you thousands of dollars each year.

Take Madeline for example:

Madeline is currently in treatment for cancer and is being offered three different health insurance plans from her employer. Assuming she will reach her out-of-pocket maximum (OOP) during the year, which option is the most affordable?

---

<sup>12</sup> Typically, only for in-network services. Also keep in mind that some plans outside of the marketplace (e.g., employer plans) may carve out the deductible or co-pays from the out of pocket maximum. It is worthwhile to check with your plan to see how they define the out of pocket maximum.

Plan A. HMO: \$25 Premium; \$2,500 Deductible; 70/30 Cost-share amount; \$8,000 OOP

$$\boxed{\$25 \times 12 \text{ months} = \$300 + \$8,000 = \$8,300}$$

Plan B. PPO: \$100 Premium; \$1,500 Deductible; 80/20 Cost-share amount; \$6,000 OOP

$$\boxed{\$100 \times 12 \text{ months} = \$1,200 + \$6,000 = \$7,200}$$

Plan C. PPO: \$200 Premium; \$0 Deductible; 90/10 Cost-share amount; \$4,000 OOP

$$\boxed{\$200 \times 12 \text{ months} = \$2,400 + \$4,000 = \$6,400}$$

Just based on the math, Plan C is the least expensive, even though it has a higher monthly premium. However, there are additional things to take into consideration. You also want to look at the deductible; some plans have a higher monthly premium and a lower deductible. The advantage of these plans is that while they are more expensive monthly, they start covering a high percentage of the cost-share immediately. This helps to spread the costs out over the year, rather than requiring a large lump-sum payment up front.

#### *Provider Networks*

You also should consider the network of providers when choosing a health insurance plan. Some plans will not cover visits to out-of-network providers at all, and others only cover those services in a limited way. Additionally, most plans only apply out-of-pocket payments to in-network providers to the annual out-of-pocket maximum. Therefore, if you pick plans with limited provider networks, which do not include your health care providers, you will end up with higher out-of-pocket costs.

#### *Formularies*

Similarly, it is worthwhile to review the prescription drug formularies for each plan you are considering. Be sure to communicate with your health care team about any existing or anticipated prescription drug needs. Picking a plan that covers your prescription drug needs can greatly reduce out-of-pocket costs.

## B. Health Insurance Options after a Life-Changing Event

Obtaining health insurance is not a one-time task. You will likely have several different policies throughout your life, and the source of those policies may also change as your life circumstances change. You will likely have to make decisions about their health insurance coverage if you find yourself in a situation where you are losing your existing coverage.

### *Employer-Sponsored Health Insurance*

When you receive your health insurance coverage through an employer, it can compound the overwhelming nature of having to make decisions about taking time off, switching jobs, or ending your employment. Fortunately, there are several laws that enable individuals with cancer to maintain their employer-sponsored health insurance coverage.

### *Consolidated Omnibus Budget Reconciliation Act (COBRA)*

The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal law that allows people with group coverage to keep their existing coverage even though they have experienced a qualifying event. Qualifying events include: leaving or losing your job or reducing your work hours, the covered employee enrolling in Medicare, divorce from or death of the covered employee, or aging out of ones' parent's policy when turning 26. Under COBRA, you may be able to continue your employer sponsored health plan for 18 to 36 months, depending on which qualifying event you experience (*See the chart below*). To qualify for COBRA, one must work for a private employer with 20 or more employees or work for the state or federal government. While COBRA is a wonderful option for many, it can also be challenging because the employee or dependent becomes responsible for paying the entire amount the employer was paying for their health insurance and, in some cases, an additional 2% administrative fee. For example, your premium is \$400 per month. Perhaps your employer contributed \$200 and you contributed \$200 per month. You chose to move to part time and, therefore, no longer qualify for benefits at your job. You are entitled to elect COBRA coverage for 18 months. You will now be responsible for paying the entire \$400 monthly premium, and perhaps an additional \$8 per month (2% of \$400) for administrative fees.

#### **COBRA Eligibility**

- Experience a Qualifying Event
- Work for an Employer with 20+ Employees or State or Federal governments

<b>COBRA Qualifying Event</b>	<b>Maximum COBRA Coverage</b>
Employment ends or hours reduced	18 months
Loss of dependent child status	36 months
Employee enrolls in Medicare	36 months
Divorce or legal separation	36 months
Death of employee	36 months

There are two times when you can extend your COBRA coverage. First, if you have a second qualifying event during your first 18 months of COBRA coverage, you may be entitled to an 18-month extension for a maximum total of 36 months of coverage. Second, if you are deemed to be “disabled” by the Social Security Administration within the first 60 days of COBRA coverage, you may be entitled to an 11-month extension, for a total of 29 months of COBRA coverage. Keep in mind that during the 11-month extension, your premiums may go up to 150% of the cost of coverage.

It is important to remember that COBRA is not an actual health plan, but rather the right to keep the same health insurance you had while you were employed for an additional period of time. This can be extremely beneficial to someone that is in the middle of treatment because they would not have to find another health insurance policy that covers the same doctors and has the same prescription drug benefits.

For more information about COBRA, download the Triage Cancer Quick Guide to COBRA at <https://triagecancer.org/QuickGuide-COBRA>.

#### *Illinois Continuation Law*

Illinoisans who work for a small business are covered under the state continuation law (e.g., state COBRA law). This law allows individual to keep their group health insurance after they experience a qualifying event.<sup>13</sup> The Illinois Continuation Law applies to employers with 2 – 19 employees and provides coverage for up to 12 months. Unlike with the federal law, the cost of the monthly premium cannot be more than the group rate. In order to be eligible for this coverage you must have been covered under your employer’s health insurance plan for the three months immediately before you experience a qualifying event. Additionally, you have to mail your application for continuation coverage within 10 days of the qualifying event.

---

<sup>13</sup> 215 ILCS §§ 5/367e, 5/367.2, 5/367.2-5

### *Special Enrollment Periods (SEPs) for Marketplaces and Medicare*

If you experience a life-changing event that results in the loss of creditable coverage, you may be eligible for SEPs both through the State Health Insurance Marketplaces and through Medicare. Insurance purchased in the Marketplaces would be a completely new policy, unlike with COBRA coverage, and you may also be eligible for financial assistance.

Since 2014, Americans have more options to maintain health insurance coverage after losing their employer-sponsored insurance. However, if you are in this situation you must think strategically before making any decisions. Typically, once you pick a path, you cannot change your mind until the next open enrollment period. For example, if you decide to elect COBRA coverage after losing employer-sponsored insurance, you cannot decide midyear to stop paying the premiums and purchase a Marketplace plan instead. Voluntarily ending COBRA coverage will not trigger a SEP in the Marketplace, therefore, you would have to wait until the next open enrollment period to make changes.

There is a misconception that the ACA made COBRA irrelevant. COBRA is still a very important option for some individuals losing their employer-sponsored health insurance. For example, the coverage available under your employer's plan may be superior to the coverage available in the Marketplace. Or, perhaps the you have already reached the out-of-pocket maximum for the year. In that case, it may make more financial sense to pay the high COBRA premiums and know that is most likely all you will have to pay for your health care for the rest of the year. As discussed above, when making the decision between electing COBRA coverage or purchasing a new plan in the Marketplace, it is critical to "do the math" as well as compare the coverage.

### *Young Adults*

Under the ACA, eligible young adults now have the option of staying on their parents' health insurance plans until they are 26 years old.<sup>14</sup> These young adults do not have to be dependents under IRS standards; they can live on their own, be married, and even have their own children.<sup>15</sup> This rule gives young adults additional options and helps to bridge the gap that may occur between leaving school and finding a job that offers health insurance benefits. It is important to note, however, that "retiree-only" plans are not subject to this requirement. So, if a parent has a retiree-only plan, the young adults may not be able to get coverage.

---

<sup>14</sup> 45 C.F.R. § 147.120.

<sup>15</sup> *Id.*

If you are a young adult turning 26 and, therefore, are aging out of a parent's plan, there may be several options:

- If you are married, you may be able to join a spouse's employer-sponsored plan
- If your income is less than 138% of the FPL, you may be able to receive Medicaid
- If you have begun working, you may be eligible for an employer-sponsored plan
- You will be eligible for a SEP to buy coverage through the State Health Insurance Marketplaces
- If you have been receiving SSDI payments for 24 months, you will be eligible for Medicare

#### *Medicaid if Income Increases*

If you are losing access to Medicaid because your income or asset level has increased past the Medicaid eligibility threshold, and you are under 65, there may be several options:

- If you are under the age of 26, you may be able to join a parents' health insurance plan
- If you are married, you may be able to join a spouse's employer-sponsored plan
- If you have begun working, you may be eligible for an employer-sponsored plan
- You will be eligible for a SEP to buy coverage through the State Health Insurance Marketplaces
- If you are over 65 and are also enrolled in Medicare, you will maintain your Medicare coverage

#### *Medicare if No Longer Deemed Disabled*

If you are under 65 and have had access to Medicare due to having a disability you will lose your eligibility if the disability is no longer present. If you are in this situation, you may have several options:

- If you are under the age of 26, you may be able to join a parents' health insurance plan
- If you are married, you may be able to join a spouse's employer-sponsored plan
- If your income is less than 138% of the FPL, you may be able to receive Medicaid
- If you have begun working, you may be eligible for an employer-sponsored plan
- You will be eligible for a SEP to buy coverage through the State Health Insurance Marketplaces

As discussed above, when making the decision between various health insurance options, individuals should make sure to “do the math” as well as compare the coverage. Triage Cancer has a myriad of resources to help you understand health insurance basics and to choose the right plan for you. Visit <https://triagecancer.org/healthinsurance> for more information. For more step-by-step guidance of your health insurance options, visit <https://cancerfinances.org> and choose “Health Insurance.”

### *Remember Sarah?*

Sarah is 42 and has been an accountant for the last 10 years at a small firm (25 employees) in Woodstock, IL. When diagnosed with stage II lung cancer, she had surgery and chemotherapy treatment for almost 2 years. She is still experiencing some fatigue, cognitive difficulties, and some neuropathy in her feet and thinks that she may need to stop working. Sarah is very concerned about what she is going to do for health insurance if she is forced to leave her job because of her pre-existing condition.

### *What Are Sarah's Options?*

- Sarah is eligible to elect COBRA coverage for a minimum of 18 months
  - If Sarah exhausts her COBRA coverage, she will qualify for a SEP to purchase a plan through Illinois' Marketplace
- Sarah could choose to convert her group policy into an individual policy
- Sarah would qualify for a special enrollment period to purchase a plan through Illinois' Marketplace
- Sarah is unable to work because of her medical condition so she may be eligible for SSDI.  
After being on SSDI for 2 years, Sarah will become eligible for Medicare (*See Chapter on Disability Insurance*)
- Depending on her income, she may be eligible for Medicaid.

## Employment and Cancer

### *Meet Chris*

Chris is 24 years old and is a childhood cancer survivor. He is very excited about graduating from college in a few weeks. Chris has some trouble with mild depression, fatigue, anxiety, and memory problems, so he is taking a lighter load each semester, setting back his graduation date. He is ready to start looking for a job and is concerned about how to enter the job market with a history of cancer and his ongoing health issues. He is wondering if he has to disclose his medical history and if people will still hire him if he does.

A cancer diagnosis may have a significant impact on employment and income for people with cancer and their caregivers. While many patients continue to work through their treatment to maintain their income and access to health insurance coverage, this is not the only reason they choose to work. Sixty-five percent of cancer survivors surveyed reported that working can be an effective coping strategy, helping them to have a routine, providing a distraction from their health, and allowing them to feel productive.<sup>16</sup> For many of these reasons, a study found that 44% of people diagnosed with metastatic cancer continue to work.<sup>17</sup> However, not everyone diagnosed with cancer can work through treatment or even return to work after treatment has been completed. The most significant factor associated with no longer working was a higher burden of side effects.<sup>18</sup>

Employment issues can come into play at different times across the continuum of cancer care and there is also an employment continuum after a cancer diagnosis:

Employment Continuum after a Cancer Diagnosis					
Newly Diagnosed	Working through Treatment	Taking Time off Work	Returning to Work (same job)	Returning to Work (different job)	Retiring or Resigning from Work

<sup>16</sup> Press Release, Cancer and Careers, More Than Half of Cancer Patients and Survivors Are Concerned about Changes to Their Healthcare Access (June 14, 2017), <https://www.prnewswire.com/news-releases/more-than-half-of-cancer-patients-and-survivors-are-concerned-about-changes-to-their-healthcare-access-300473461.html>.

<sup>17</sup> Amye J. Tevaarwerk et al., *Working after a Metastatic Cancer Diagnosis: Factors Affecting Employment in the Metastatic Setting from ECOG-Acrins Symptom Outcomes and Practice Patterns Study*, 122 CANCER 438–46 (2015).

<sup>18</sup> *Id.*

## I. Where to Find Employment Rights and Benefits

At all stages along this continuum you may have access to a variety of rights and benefits. It is valuable to look in all of the following places to maximize your options. There are three key places to look for information about your employment rights and benefits: employment laws, employment contracts, and employer policies.

### A. Employment Laws

Laws that could provide relevant rights and benefits to individuals diagnosed with cancer include federal fair employment laws, state fair employment laws, federal leave laws, state and local leave laws, and other federal, state, and local wage and hour laws. Fair employment laws provide employees with protections against discrimination in the workplace. Federal, state, and local leave laws allow employees to take time off work and offer job protection.

### B. Employment Contracts

Employment contracts can provide for additional protections and benefits than those provided under the law. These include union contracts, collective bargaining agreements, and general employment contracts. In some cases, employees working under a contract may waive their rights to other protections and benefits. For example, employees who are members of a union (e.g., teachers) sometimes have their own retirement system into which they pay. Because they do not pay Social Security retirement taxes, they are unable to qualify for Social Security Disability Insurance benefits. However, they may have access to other disability insurance benefits under their union contract. Therefore, you must look not only to your federal and state law protections, but also check to see how your employment contracts might have an impact.

### C. Employer Policies

Laws only establish a minimum level of protection for employees in the workplace; however, many employers choose to create policies that are more protective than the legal requirement. For example, an employer can choose to offer health, dental, vision, life, and disability insurance options to employees. Employers may only offer access to coverage, or they may pick up some or all of the costs of those policies. Employers may also offer sick days,<sup>19</sup> vacation days, or other forms of paid time off beyond city and state requirements. Employers may allow for employees to donate their leave hours to co-workers in need. Employers may also establish policies allowing for the use of flex time, job-sharing, or even telecommuting. Financial

---

<sup>19</sup> Note: Some states and cities have laws that require certain or all employers to provide a minimum amount of sick time to their employees, e.g., Chicago Paid Sick Leave Ordinance

counseling and employee assistance programs may be additional benefits that employers provide, which may be useful for employees diagnosed with cancer.

If you are looking for information about your employers' policies, it is useful to review your employee handbook, manual, or policies and procedures document. If such a document is not available, you can talk with a human resources representative. If your company does not have a human resources department, then often the person on staff who handles employee benefits or an office manager can answer questions about company policies. Many employers also describe an internal process for employees who need to ask for a reasonable accommodation or medical leave, so that employees do not have to reinvent the wheel when trying to navigate how to access these benefits.

## II. Fair Employment Laws

### A. Americans with Disabilities Act

The Americans with Disabilities Act (ADA)<sup>20</sup> is a federal law, passed in 1990, that prohibits discrimination against qualified employees with disabilities.

In order to use the ADA's protections, you must be a qualified individual, which means that you can perform the essential functions of the job with or without a reasonable accommodation. According to the Equal Employment Opportunity Commission (EEOC), the federal agency responsible for enforcing the ADA, you should look at the following factors to determine if a job function is essential:

#### ADA Eligibility

- Be a qualified individual
- Work for private employer with 15+ employees, or state or local government
- Have a disability

- Whether the reason the position exists is to perform that function,
- The number of other employees available to perform the function or among whom the performance of the function can be distributed, and
- The degree of expertise or skill required to perform the function.<sup>21</sup>

You must also work for a private employer with 15 or more employees (or a state or local government of any size)<sup>22</sup> and you have a disability, as defined by the ADA.

<sup>20</sup> 42 U.S.C. § 12101, *et. seq.*

<sup>21</sup> [www.eeoc.gov/facts/ada17.html](http://www.eeoc.gov/facts/ada17.html)

<sup>22</sup> Federal employees covered by Rehabilitation Act of 1973 which is very similar to ADA

Under the ADA, a disability is a *physical or mental impairment that substantially limits a major life activity*. When dealing with cancer, often times it is not the cancer itself that creates the disability, but rather the side effects of treatment (e.g., nausea, cognitive difficulties, fatigue, neuropathy, depression, etc.).

A major life activity is anything that the *average person in the general population can perform with little or no difficulty*. For example, walking, talking, breathing, eating, sleeping, thinking, communicating, and operations of major bodily functions, are all considered major life activities.

Under the ADA's definition of a disability, the limitation to a major life activity must be substantial. In order to determine if your limitation is substantial, consider:

- The nature and severity of the disability;
- The duration (or expected duration) of the disability; and
- The permanent or long term impact of the disability.

The ADA applies to all phases of employment including: hiring, firing, applications, leave, reinstatement, promotions, testing and trainings, compensation and benefits.<sup>23</sup> This means that job applicants are protected, as well as employees.

Once you have determined that you are protected under the ADA, there are four ways to use those protections. First, if you currently have a physical or mental impairment that substantially limits a major life activity. For example, you are currently going through

- |  |
|--|
| <b><u>Four ways to use ADA</u></b>   |
| <ul style="list-style-type: none"><li><input type="checkbox"/> Currently</li><li><input type="checkbox"/> History</li><li><input type="checkbox"/> Regarded As</li><li><input type="checkbox"/> Association With</li></ul> |

treatment and are suffering from extreme nausea that makes getting through a work day without vomiting impossible. Second, you have a history of having a disability. For example, you are a cancer survivor with no current limitations, but a potential employer is refusing to hire you she is afraid you will have a reoccurrence. Third, you are regarded as having a disability. For example, you are going through treatment but are not experiencing any major side effects except hair loss, but your

employer is treating you differently because he perceives you to have a disability. Fourth, you have an “association with” a person with a disability. For example, you are the primary caregiver to your mother who is battling cancer and your employer is refusing to promote you because of your caregiver role. In all of these circumstances the ADA protects you against discrimination in the workplace.

---

<sup>23</sup> 42 U.S.C. §12112(a)

If you currently have a disability under the ADA, or have a history of having a disability, in addition to being protected from discrimination you are also entitled to a reasonable accommodation. A reasonable accommodation is “any change in the work environment or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities.” Some practical examples of reasonable accommodations include:

- Changing your work schedule (e.g., working from home, part or full-time, flexible schedule, schedule breaks, extended leave)
- Using technology (e.g., tape recorder or smartphone)
- Changing your physical work environment (e.g., moving desk location close to elevator)
- Changing workplace policy (e.g., allowing additional rest periods)
- Shifting job responsibilities
- Changing your job (e.g., moving to a vacant position)

Reasonable accommodations will depend on your disability and your job. If you are unsure of what reasonable accommodations may work for your situation, you can contact the Job Accommodation Network (JAN). JAN is a program of the U.S. Department of Labor. JAN also has a Searchable Online Accommodation Resource (SOAR) system that allows people to explore various accommodation options for people with different types of medical conditions in particular workplace settings ([www.askJAN.org](http://www.askJAN.org)). Additionally, Triage Cancer’s animated video *Dealing with Side Effects at Work* may be useful (<https://triagecancer.org/video-sideeffectsatwork>).

An employer is required to provide reasonable accommodations for a person with a disability, unless it would cause the employer an undue hardship. To be considered an undue hardship on the employer, the accommodation must require significant difficulty or expense for the employer.

You may ask your supervisor, another superior, or a human resources representative for a reasonable accommodation. You do not have to specifically mention the ADA or use the words “reasonable accommodation.” Additionally, the request does not need to be in writing, but it is a good idea to document any agreed upon reasonable accommodations in writing. While you must say that you are requesting this change in work environment due to a medical condition, you do not need to disclose the exact nature of that condition (e.g., you don’t necessarily have to tell your employer that you have been diagnosed with cancer) if you can provide sufficient information that describes the nature and duration of the impairment, the activity the impairment limits, and why you need a reasonable accommodation. If you are concerned about disclosing your diagnosis, talk with your healthcare team when you ask them to complete your medical certification paperwork for your employer. Tell them that you don’t want your

diagnosis included in the description of why you need an accommodation. Sometimes, information about symptoms you are experiencing is enough if it shows why you need the accommodation you are requesting. For more information about this topic view the Triage Cancer Quick Guide to Privacy, Disclosure, and Medical Certification at <https://triagecancer.org/QuickGuide-Disclosure>.

You can request a reasonable accommodation during the application process, when looking for a new job, or at any point during your employment. However, once you have started working it may be in your best interest to ask for a reasonable accommodation as soon as a problem or issue becomes known, before your work performance suffers.

If you have questions about the ADA or reasonable accommodations visit [www.eeoc.gov/policy/ada.html](http://www.eeoc.gov/policy/ada.html). Additionally, Triage Cancer has several resources to help you navigate the ADA and reasonable accommodations. For more information, visit <https://triagecancer.org/employment>.

#### *Job Search Process & ADA Protections*

When you are searching for a job, generally you do not need to disclose that you have cancer, a medical condition or a need for a reasonable accommodation on an application or in an interview. However, if you need an accommodation for the interview itself, you will need to disclose that you have a medical condition to justify why you need the accommodation.

During the application process, before a job offer is made, an employer may not ask about your health, the nature of the disability, or ask you to take a medical exam. This prohibition includes questions about how much sick leave you have taken in the past or if you have ever taken FMLA leave. Employers are only allowed to ask *if* you are able to perform the essential functions of the job and *how* you will perform the essential functions of the job.

Once you have been offered a job, an employer does have the right to make the offer conditional upon the results of a medical exam, only if every other employee in the same job category is also required to take the same exam. If you are not hired because of the results of that exam, the employer must be able to demonstrate that:

- Not hiring you is consistent with business necessity (e.g., you would pose a "direct threat" or a significant risk of substantial harm to the health or safety of yourself or others), and
- That threat cannot be eliminated or reduced significantly through reasonable accommodation.

All of your medical information, including any requests for reasonable accommodations, must be kept confidential and in a separate file from your personal file. Only the following people may have access to your personal medical information:

- Insurance carriers (health, life, and disability)
- Workers compensation offices
- Managers or supervisors (but only the information necessary to determine or implement a reasonable accommodation)
- First aid and safety personal (but only if information is necessary in emergency situations)

See the section below for information on how to file a complaint if you feel that your rights have been violated under the ADA.

#### B. Illinois Human Rights Act (IHRA)

The Illinois Human Rights Act (IHRA)<sup>24</sup> is the state version of the ADA, and prohibits discrimination in all employment practices against qualified individuals with disabilities who can perform the essential functions of the job, with or without reasonable accommodations. The IHRA applies to all private employers with one or more employees, and state or local governments of any size. Therefore, individuals who work for small businesses with less than 15 employees, who are not covered under the ADA, are protected by the IHRA. It is important to know which law you are protected under for the complaint process (*see Discrimination Complaint Process section below*). Under the IHRA, the definition of a disability is a “determinable physical or mental characteristic of a person which may result from disease, injury, congenital condition of birth or a function or disorder.” The requirements for reasonable accommodations are the same as under the ADA discussed above.

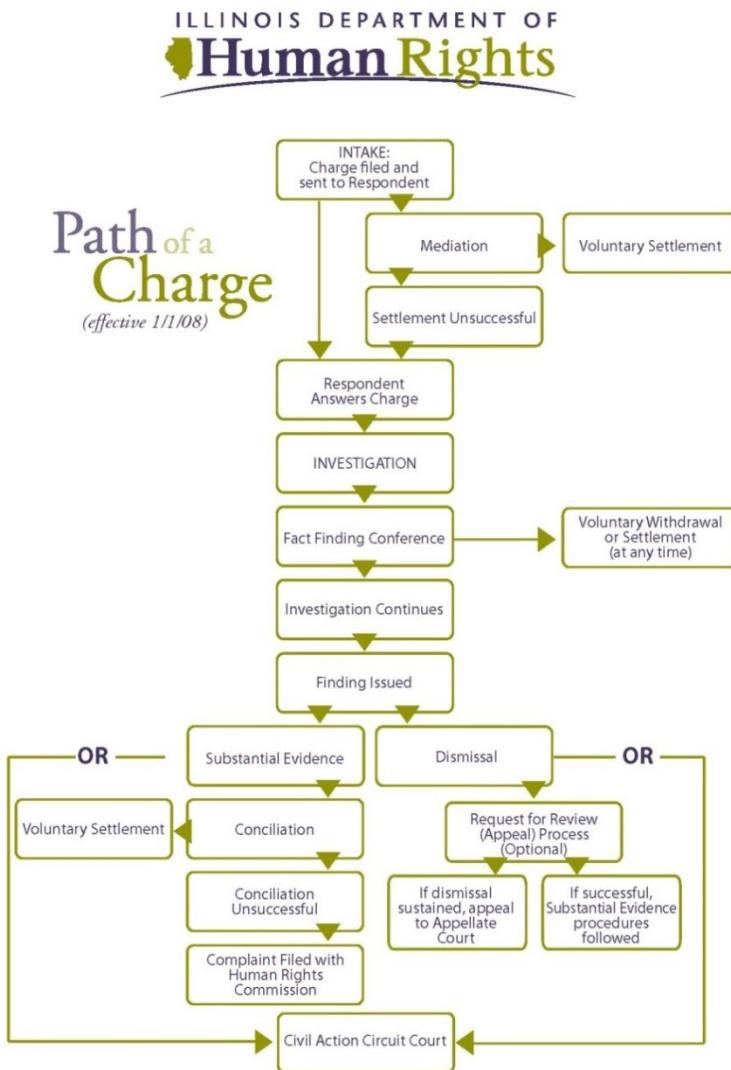
#### C. Discrimination Complaint Process

If you feel that you have been discriminated against because of your cancer diagnosis or other disability, then you may consider filing a complaint. The first step is to determine if your claim is covered by the IHRA and/or the ADA. If it is covered by the IHRA alone, or both the IHRA and the ADA, you must file a complaint with the State of Illinois first. Complete the Illinois Employment Complaint Information Sheet (available in the Appendix or online at [www2.illinois.gov/dhr/FilingaCharge/Documents/CIS\\_Empl.pdf](http://www2.illinois.gov/dhr/FilingaCharge/Documents/CIS_Empl.pdf)). Submit the completed

---

<sup>24</sup> 775 ILSC 5/2

Information Sheet to the Illinois Department of Human Rights. If the IDHR determines that your allegations are covered under the IHRA, they will draft and send you a “charge” for you to sign and return to them. The flow chart below, from the Illinois Department of Human Rights outlines the process of a discrimination complaint in Illinois.



If your claim is also covered under the ADA and you wish to file both complaints, you must use the administrative compliant procedures established by the Equal Employment Opportunity Commission (EEOC). You may also contact the EEOC and file a “Charge of Discrimination.” You can file this charge at:

Equal Employment Opportunity Commission ~ Chicago District Office  
 500 West Madison Street, Suite 2000  
 Chicago, Illinois 60661

While the office accepts walk-ins, they suggest that if you are going to file charges of discrimination, that you call (800) 669-4000 to schedule an interview between 8:30 a.m. and 3:30 p.m. on Monday through Friday. If you have a disability that makes it difficult to attend an in-person interview, you may request a telephone interview.

The EEOC may suggest that you complete mediation before they launch an official investigation. Both you and your employer must agree to mediation, which is when an independent third party attempts to resolve the issues. Participating in the EEOC's mediation program is free, voluntary, and confidential. There may be several benefits to mediation, including avoiding a potentially costly lawsuit and perhaps even retaining your employment. If you are unable to resolve the issues through mediation, the EEOC will investigate your charge of discrimination to determine if there is "reasonable cause" to believe that you were discriminated against. If reasonable cause is found, the EEOC will attempt to resolve the issue with your employer. If they are unable to resolve the issue, the EEOC will file suit against your employer on your behalf. If, however, the EEOC does not find discrimination, or if the EEOC decides not to pursue the suit, they will issue you a "right to sue" letter. This letter will provide you with the ability to sue your employer in federal court.

If you choose to pursue a lawsuit against your employer in federal court you may want to consider hiring a lawyer that specializes in employment matters. To find an attorney, you can use the attorney referral service at the McHenry County Bar Association ([www.mchenrycountybarassoc.org](http://www.mchenrycountybarassoc.org)), contact the National Cancer Legal Services Network ([www.NCLSN.org](http://www.NCLSN.org)), or if you have an income below 125% of the FPL you may be able to receive assistance through Prairie State Legal Services, Inc. ([www.pslegal.org](http://www.pslegal.org)). For more information on finding legal assistance, visit <https://triagecancer.org/QuickGuide-LegalAssistance>.

There are some very important deadlines to keep in mind if you are considering filing a discrimination claim under the Illinois Fair Employment law or the ADA action:

Action	Deadline	Contact
Filing your Illinois Employment Complaint Information Sheet (available in the Appendix)	180 days of date discrimination occurred	IL Department of Human Rights Chicago Office 100 W. Randolph Street, 10th Floor, Intake Unit Chicago, IL 60601 (312) 814-6200 <a href="http://www.illinois.gov/dhr">www.illinois.gov/dhr</a>
Filing your charge of discrimination with EEOC	180 days of date discrimination occurred	Equal Employment Opportunity Commission 500 West Madison Street, Suite 2000 Chicago, Illinois 60661 (800) 669-4000 <a href="http://www.eeoc.gov">www.eeoc.gov</a>

Filing Claim in Court	90 days from receiving “right to sue” letter	Hire an attorney ( <i>See legal section in Resources</i> )
-----------------------	--	--

For general information about the ADA please visit [www.eeoc.gov](http://www.eeoc.gov). For more information about the IHRA please visit [www.illinois.gov/dhr](http://www.illinois.gov/dhr). Additionally, you can visit <https://triagecancer.org/employment> and access the following resources:

- Quick Guide to the Americans with Disabilities Act (ADA)
- Quick Guide to Reasonable Accommodations
- Checklist: Reasonable Accommodations
- Quick Guide to Disclosure, Privacy, & Medical Certification Forms
- Quick Guide to “Chemo Brain”
- Video: How to Deal with Side Effects at Work

#### *Remember Chris?*

Chris is 24 years old and is a childhood cancer survivor. He is very excited about graduating from college in a few weeks. Chris has some trouble with mild depression, fatigue, anxiety, and memory problems, so he was taking a lighter load each semester, setting back his graduation date. He is ready to start looking for a job and is concerned about how to enter the job market with a history of cancer and his ongoing health issues. He is wondering if he has to disclose his medical history and if people will still hire him if he does.

#### *What Options Does Chris Have?*

- Under the ADA, Chris does not have to disclose his cancer or the specifics about this medical history.
- If he decides to request a reasonable accommodation from a future employer, he may need to complete a medical certification form for his employer.
- Some reasonable accommodations he may want to think about requesting include additional breaks or use of a tape recorder. For ideas of additional reasonable accommodations Chris could contact the Job Accommodation Network ([www.askJAN.org](http://www.askJAN.org)).
- While Chris is looking for a job that offers health insurance coverage, he may be able to stay on his parents' health insurance plan until he is 26 years old.
- If Chris ages out of his parents plan before finding a job, he may elect COBRA coverage for 36 months, or purchase a new plan in the State Health Insurance Marketplace.

## Taking Time off Work

### *Meet James*

James was diagnosed with stage III prostate cancer. He is a full-time administrator for a large company. James is married with three kids and he knows that he needs to work to pay his family's bills and his family has health insurance coverage through his employer. He isn't sure about whether or not he has any employee benefits, because he hasn't taken a vacation or sick day in five years. He is not sure of his treatment schedule yet, but his doctor told him that he will need surgery and mentioned something about chemotherapy and radiation. What can James do?

Whether you are the one who has been diagnosed with cancer or you are caring for a loved one, you may need to take time off work. While there are some laws that provide protections to take time off from work, many employers are more generous than what the law requires in their leave policies. It may be beneficial for you to check your employee contract, employee manual, or union contract, or talk to your human resources representative about your employer's specific leave policies.

### I. The Family and Medical Leave Act (FMLA)

The Family and Medical Leave Act (FMLA) is the federal law that may provide you with the right to take a total of twelve weeks of unpaid, but job and benefit protected leave per year to deal with your own serious medical condition or to take care of a child, parent, or spouse with a serious medical condition.<sup>25</sup>

#### **FMLA Eligibility**

- Employer has 50+ employees within 75 miles of your worksite
- Employee has worked a total of 12 months for employer, and 1,250 hours in 12 months before leave

#### *FMLA Covered Employers*

In order to be eligible to take FMLA leave, you must work for a public employer of any size (e.g., federal, state, and local governments) or a private employer with 50 or more employees who work within a 75-mile radius of your work site.

You can determine if your employer is eligible by adding up the number of employees that the employer had during 20 or more calendar workweeks in either

<sup>25</sup> The Family and Medical Leave Act of 1993, 29 U.S.C. §2601

the current or preceding calendar year. The 20 workweeks do not have to be consecutive. Any employee whose name appears on the employer's payroll will be considered employed each working day of the calendar week, and must be counted whether or not any compensation was received for the week. If you work in a "branch" of a larger company (e.g., chain restaurant, retail store, bank branch), you may count any employee that works for your company within 75 miles of your work site towards the 50 employee requirement. The 75 miles is determined by "using surface transportation over public streets, roads, highways, and waterways, by the shortest route from the facility where the employee requesting leave is employed."<sup>26</sup>

#### *FMLA Eligible Employees*

In addition to working for a large enough employer, you must have worked for your employer long enough. The FMLA requires that you work for your employer for at least 12 months, and that you have worked 1,250 hours (slightly more than part-time). The 12 months do not need to be consecutive, only cumulative. The FMLA allows you to go back seven years to determine your work history. This means that as long as you have worked for that employer for a total of 12 months or more in the last seven years, and that you have worked 1,250 hours during the last 12 months that you worked for the employer, then you are eligible to take FMLA leave.

Here are some different ways that you can meet the 1,250 hours requirement:

- Work 24 hours per week for 52 weeks in a row
- Work 40 hours per week for 31 weeks in a year
- Work over 104 hours each month for 12 months in a row

If you are unsure of your employer's or your eligibility under the FMLA, you may want to use the U.S. Department of Labor's online Family and Medical Leave Act Advisor found at:

[www.webapps.dol.gov/elaws/whd/fmla/overview.aspx](http://www.webapps.dol.gov/elaws/whd/fmla/overview.aspx).

#### *Amount of Medical Leave*

If you work for a covered employer and you are an eligible employee, the FMLA entitles you to take up to 12 weeks of unpaid leave per year to deal with your own serious medical condition or to care for a seriously ill child, parent, or spouse. Leave may be taken all at once, or in shorter periods of time if it is medically necessary. For example, you are able to take 12 weeks off in a row to recover for surgery or you may want to take every Friday off for your chemotherapy appointments.

---

<sup>26</sup> 29 C.F.R. §825.111(b)

You are entitled to 12 weeks of leave per 12-month period. There are different ways to calculate the 12-month period; however, the employer must choose one of the following ways and apply it to all employees. The four ways to calculate the 12-month period are:

- A calendar year
- The 12-month period based on the date when an employee first begins FMLA leave
- The 12-month period measured backwards from the date an employee uses FMLA
- Any other fixed 12-month period (e.g., fiscal year, employee hiring date, etc.)

If the employer doesn't specify one of the four options above, then the option that is most favorable to the employee is automatically utilized.

If you are a part time employee, but otherwise are eligible to take FMLA leave, your amount of leave is pro-rated. For example, if you work 24 hours a week and take six hours of leave, you will be considered to have used one-quarter of a week of leave.

#### *Job & Benefit Protections*

FMLA leave is job protected, meaning that when you return from leave, generally you must be reinstated into the same or equivalent position which you had when you took time off. An equivalent position is going to be one with equivalent pay, benefits, responsibilities, and other conditions of employment. There are a few exceptions when an employer will not be required to reinstate you:

- If you provide your employer with notice that you do not plan to return to work;
- If your position was eliminated while you were out on leave;
- If you would have been terminated for a legitimate reason (e.g., misconduct);
- If you were a highly paid “key employee” and your leave would cause substantial economic injury to the business; or
- If you are unable to return to work after exhausting your allotted FMLA leave.

FMLA leave is also benefit protected. If your employer pays for a portion or all of your health insurance coverage, they must continue to do so while you are out on leave (i.e., they cannot force you to elect COBRA during your FMLA leave). However, that rule only applies to health insurance, not disability or life insurance or any other employer sponsored benefit. Once you return from leave, all benefits that you received prior to your leave must be reinstated.

An employer is not permitted to retaliate or discriminate against you because you took FMLA leave.

### *Serious Medical Condition*

FMLA leave is available to take care of your own serious health condition, to take care of a child, parent, or spouse with a serious health condition, to care for a newborn child following birth, or for the adoption or fostering of a child. A serious health condition is an “illness, injury, impairment, or physical or mental condition that involves inpatient care or continuing treatment by a health care provider.” You can satisfy the “continuing treatment” test by showing:

- A period of incapacity of more than three consecutive, full calendar days plus treatment by a health care provider twice, or once with a continuing regimen of treatment;
- Any period of incapacity related to pregnancy or for prenatal care;
- Any period of incapacity or treatment for a chronic serious health condition;
- A period of incapacity for permanent or long-term conditions for which treatment may not be effective; or
- Any period of incapacity to receive and/or recover from multiple treatments or surgery.<sup>27</sup>

The regulations specify that if an employee asserts a serious health condition under the requirement of a “period of incapacity of more than three consecutive, full calendar days and any subsequent treatment or period of incapacity relating to the same condition,” the employee’s first treatment visit (or only visit, if coupled with a regimen of continuing treatment) must take place within seven days of the first day of incapacity. Cancer typically qualifies as a serious health condition under the FMLA.

The FMLA also allows you to take leave for “chronic serious health conditions.” A chronic serious health condition is one that:

- Requires “periodic visits” for treatment by a health care provider or nurse (e.g., twice or more times a year);
- Continues over an extended period of time; and
- May cause episodic rather than continuing periods of incapacity.

---

<sup>27</sup> [www.dol.gov/whd/fmla/finalrule/NonMilitaryFAQs.htm](http://www.dol.gov/whd/fmla/finalrule/NonMilitaryFAQs.htm)

## **II. Illinois State Leave Law**

Illinois does not require employers to provide employees with sick leave benefits, either paid or unpaid. However, if the employer does offer sick leave to its employees, they must allow that employee to take time off to act as a caregiver to their child, spouse, sibling, parent, mother-in-law, father-in-law, grandchild, grandparent or stepparent.<sup>28</sup>

## **III. When FMLA or State Leave is Exhausted**

You may be able to use the FMLA and ADA together to receive additional leave time as a reasonable accommodation. For example, if you have taken your 12 weeks of FMLA time, you may ask your employer for some additional time off as a reasonable accommodation.

Generally, the employer must grant this additional leave if it is for a definite period of time (e.g., 2 weeks) and it is not an undue burden on the employer. Recently the Seventh Circuit Court of Appeals, which covers Wisconsin, Illinois, and Indiana, said that employers do not need to provide “multi-month leaves” as a reasonable accommodation.<sup>29</sup> Meaning in Illinois, you likely will not be able to ask for more than one month off as a reasonable accommodation. If you are requesting additional leave as a reasonable accommodation, you will need to follow the steps and suggestions outlined in the previous chapter. For more information, you can also download the Triage Cancer Quick Guide to How the FMLA Works with Other Benefits at <https://triagecancer.org/QuickGuide-FMLA-OtherBenefits>.

## **IV. Medical Certification**

If you ask for a reasonable accommodation or FMLA leave, your employer has the right to ask you for medical certification that you do indeed have a disability under the ADA (or state fair employment law) or a serious medical condition under the FMLA. It is important to communicate with your health care team if you wish to keep your exact diagnosis confidential from your employer, because medical certification forms may request information that will disclose your diagnosis. For example, there may be a space for your doctor to write in your diagnosis or it may just have a space for the health care provider who is completing the form to include their type of practice or medical specialty. What this means practically is that if you are trying to keep the details of your diagnosis confidential, you may not want to have an oncologist complete the form. Fortunately, there are many types of health care professionals that are able to complete these forms (e.g., primary care physician, clinical social workers, etc.) Please keep in mind that employers are not permitted to ask for copies of your medical records

---

<sup>28</sup> Public Act 99-0841. Effective January 1, 2017.

<sup>29</sup> *Golden v. Indianapolis Housing Agency*, Case No. 17-1359 (Oct. 17, 2017 7th Cir.)

or put your medical information in your employee file. There may be limited instances when your employer is able to contact your health care provider. Under the FMLA, your employer may only contact your health care provider to “authenticate” and “clarify” the information provided on a medical certification form. Authentication means that the employer can verify that your health care provider actually signed the paperwork and that it was not forged. Clarification means that the employer can ask questions of the health care provider, because they cannot read the handwriting or there is something else confusing about the medical certification form. Employers cannot ask for additional information from your health care provider. Under the ADA, your employer may be able to contact your health care provider, but only with your express permission. Please see the Medical Certification Chart in the Appendix for an outline of what is and is not permissible for medical certification forms under the ADA and FMLA.

For more information, download Triage Cancer’s Quick Guide to Privacy, Disclosure, and Medical Certification at <https://triagecancer.org/quickguide-disclosure>.

#### V. Filing a Complaint under FMLA

The federal agency responsible for enforcing the FMLA is the U.S. Department of Labor’s (DOL) Wage and Hour Division. If you feel that your rights under the FMLA have been violated, you may file a complaint with the DOL; however, unlike with the ADA, it is not necessary to do so before bringing a lawsuit in federal court. If you would like to file a claim, contact the local office of the U.S. Department of Labor Wage and Hour Division, Chicago District Office located at 230 S. Dearborn Street, Room 412, Chicago, IL 60604-1591 (<https://www.dol.gov/whd/>).

### *Remember James?*

James was diagnosed with stage III prostate cancer. He is a full-time administrator for a large company. James is married with three kids and he knows that he needs to work to pay his family's bills and his family has health insurance coverage through his employer. He isn't sure about whether or not he has any employee benefits, because he hasn't taken a vacation or sick day in five years. He is not sure of his treatment schedule yet, but his doctor told him that he will need surgery and mentioned something about chemotherapy and radiation.

### *What can James do?*

- James could check his employer's policies to determine what employee benefits he is entitled to (e.g., paid sick days, disability insurance, etc.)
- James may be eligible for 12 weeks of FMLA leave if his company has at least 50 employees. He has worked there at least five years and because he hasn't taken a sick or vacation day in five years, he has probably worked 1,250 hours in the last 12 months
- If for some reason James will not be able to return to work after 12 weeks of FMLA leave, then he may be able to ask for additional time off as a reasonable accommodation under the ADA; however, he may need to elect COBRA to keep his health insurance coverage during that extended leave time
- If James chooses to leave his job to focus on treatment and recovery, he should explore all of his options for health insurance coverage. (See section on Health Insurance)

## Disability Insurance

### *Meet Hannah*

Hannah, a 35-year-old nurse, is suffering from depression and memory problems after going through treatment for brain cancer. Her memory problems are so severe she is no longer capable of working. She knows that she will likely never return to nursing, but does not know if she would be able to do another type of job eventually. She is concerned about how she is going to pay her bills after her savings are exhausted.

If you are unable to work or you take unpaid medical leave due to your cancer diagnosis, you may be forced to find alternative sources of income. One option may be to utilize disability insurance.

### I. Disability Insurance Basics

Disability Insurance is insurance that provides employees with some income (typically 50-70% of your salary) while they are unable to work due to a medical condition. Illinoisans may have access to individual, employer sponsored, and federal disability insurance plans. An individual plan is one that you purchase directly from an insurance company. An employer sponsored plan is one that your employer provides you with as part of your employee benefits package. Both individual and employer sponsored plans can be short-term (typically 6 months – 1 year) or long-term (typically longer than 1 year).

Keep in mind that each type of disability insurance has a different definition of “disability.” Even if you have completed treatment, you may be experiencing side effects from treatment or have other medical conditions that are keeping you from being able to work. If you have one of these plans, you may be entitled to some retroactive benefits, if you are already back at work. Even if you have completed treatment, you may be able to get reimbursed for things that you paid for while in treatment. Contact your insurance company or your employer’s human resources representative for more information.

#### A. Federal Disability Insurance Programs

There are also two federal long-term disability programs: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). While these programs are slightly different,

both of are administered by the Social Security Administration (SSA) and are based on your inability to work due to a long-term (at least one year) disability.

### *Social Security Disability Insurance (SSDI)*

Social Security Disability Insurance pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid into the Social Security Retirement System through Social Security taxes.

In order to be insured, and, therefore, eligible for this program, you must have enough "credits." Generally, individuals over 31 will need 40 credits, 20 of which were earned in the 10 years immediately before your disability begins. In 2019, you will earn one credit for each \$1,360 of wages or self-employment income. When you've earned \$5,440, you've earned your four credits for the year.

However, if you become disabled before you are 24 years old, you may qualify for SSDI if you have earned six credits in the three-year period ending when your disability starts. If you become disabled between the ages of 24 and 31, you may be eligible for SSDI benefits if you have credit for working half the time between age 21 and the time you become disabled. For example, if you become disabled at age 27, you would need credit for 3 years of work (12 credits) out of the past 6 years (between ages 21 and 27).<sup>30</sup>

In addition to working enough in the past, you must also meet the Social Security Act's definition of a disability,<sup>31</sup> which means that:

- I. You cannot do work that you did before because of your disability;
- II. You cannot adjust to other work because of your disability; and
- III. Your disability is expected to last for at least one year or result in death.

The SSA uses a five step process to determine if you have a disability.

1. Are you working, and your earnings average more than \$1,220 a month (in 2019 for non-blind individuals)?

If yes, you will not be deemed disabled for SSDI. If no, proceed to step 2.

2. Is your medical condition "severe"?

If yes, proceed to step 3. If no, you will not be deemed disabled.

---

<sup>30</sup> [www.ssa.gov/dibplan/](http://www.ssa.gov/dibplan/)

<sup>31</sup> 42 U.S.C. 423 Sec 223(d)(1)

3. Is your medical condition found in the list of disabling conditions/impairments?

If yes, then you are deemed disabled. If no, then the SSA will look at the severity of the conditions. If the SSA deems the condition severe enough, you are deemed disabled. If the SSA does not deem the condition severe enough, proceed to step 4.

4. Can you do the work you did previously?

If yes, you will not be deemed disabled. If no, proceed to step 5.

5. Can you do any other type of work?

If yes, you will not be deemed disabled. If no, you will be deemed disabled.

If your claim is approved, then you will begin to receive a check in the mail, starting the sixth full month after the date your disability was determined to have begun. When thinking about when you will actually start receiving payments, there are a few different dates to keep in mind:

- **Disability onset date (DOD).** Once your claim is approved, you will receive a letter with a date of “disability onset.” This is the date that SSA believes your disability began. It is important to recognize that for an individual with cancer, the DOD is not usually the diagnosis date, but the date that treatment begins, because it is usually needing to receive treatment or side effects from treatment that keep an individual from working.
- **Application date.** This is the date on which you filed an application with the SSA.
- **Waiting period.** SSDI requires a five-month waiting period before you will be entitled to receive SSDI benefits. The waiting period begins the first month after the month of the DOD.
- **Date of entitlement.** This is the first month after the five-month waiting period when you are entitled to receive benefits.
- **Approval date.** This is the date the SSA actually approves an individual’s application.

It is imperative to understand these dates in order to accurately assess when you will begin receiving benefits, and how much you will get paid, because the SSA does provide for SSDI back payments and retroactive payments.

#### *Back Pay versus Retroactive Pay*

The application and approval process for Social Security disability benefits can take several months. To compensate for the time that an individual should have received benefits, the SSA allows for back payments. Back payments cover the time between the end of a five-month waiting period and the date when the SSA approves the individual’s application.

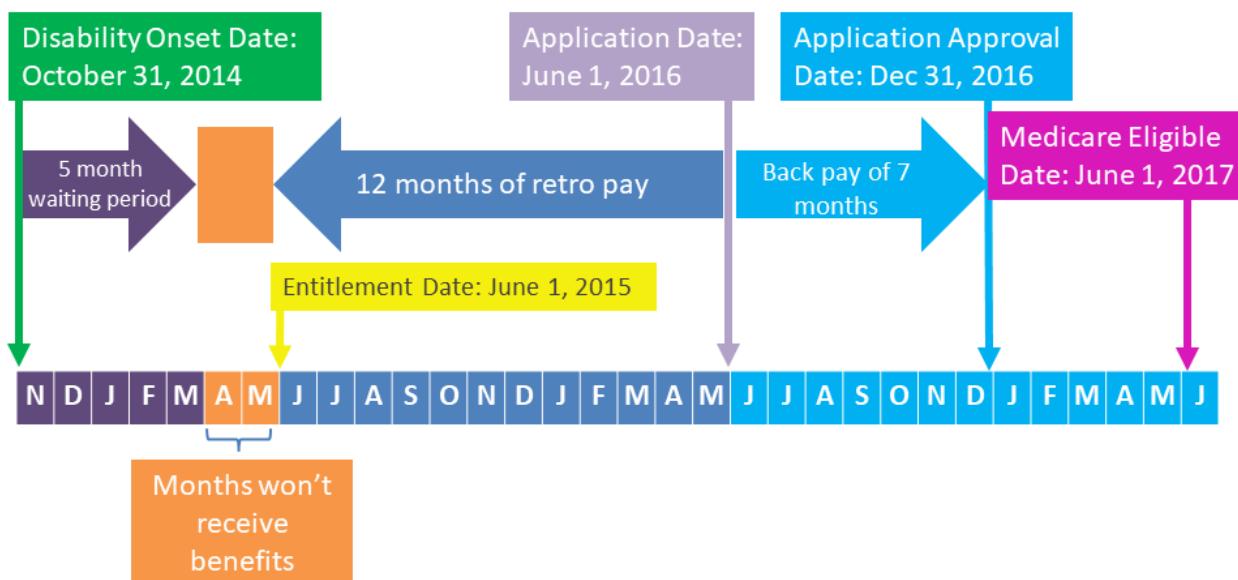
The SSA also understands that individuals may not apply for SSDI benefits until long after their disability began. Therefore, the SSA also provides retroactive payments. Retroactive payments cover up to 12 months from the date of application back to the date of disability onset. Only SSDI applicants are eligible for retroactive benefits; SSI applicants are not.

The process of determining these dates and eligibility for benefits is often confusing in real life and is best explained through example:

- Isabelle applied for disability benefits on June 1, 2016, due to her cancer diagnosis. The SSA deemed her DOD was October 31, 2014. Isabelle's waiting period was from November 1, 2014, to March 31, 2015. Her date of entitlement was June 1, 2015. However, her application was not approved until December 31, 2016.
- Isabelle is entitled to retroactive payments for the time between her entitlement date backwards to when the waiting period ended. However, since retroactive payments are capped at 12 months, she will only receive payment for the months of June 1, 2015–May 31, 2016. Therefore, for April and May 2015, she will not receive any benefits. Isabelle will also receive back pay for the six months from June 1, 2016, when the application was submitted, to December 31, 2016, when the application was actually approved. She would also become eligible to receive Medicare benefits on June 1, 2017—25 months after her date of entitlement.

The following figure illustrates Isabelle's SSDI timing:

## SSDI Timing Example



The amount that you will receive each month is based on your lifetime average earnings covered by Social Security. You can get an estimate of this amount by creating a *mySocialSecurity* Account at <https://www.ssa.gov/myaccount/>.

#### *Practical Tips for the Application Process*

Applying for Social Security disability benefits can be time consuming and daunting. However, there are a few practical steps you can take to improve your chances of being approved for benefits, as follows:

- **Submit sufficient information about health care providers.** You do not need to submit copies of their medical records; however, you should list all health care professionals, hospitals, clinics, and other facilities where you received treatment, even if tangentially related to their cancer diagnosis. For example, an individual may see a psychiatrist to cope with the anxiety experienced during cancer treatment. That individual should include the psychiatrist's name and contact information in the application for disability benefits, even though the psychiatrist did not treat the individual for cancer. The SSA will contact the health care providers listed in the application to gather medical information, including medical records.
- **Avoid mistakes and omissions in the application itself.** Make sure that everything is spelled correctly (e.g., diagnoses, medications, names of health care providers and facilities, etc.). Additionally, answer all of the questions posed in the application, with as much detail as possible. If a field is not applicable to you, it is best to include a notation like "N/A" so DDS does not assume it was left blank by mistake.
- **Do not work and earn more than the SGA amount at the time of application.** If you do continue to work and makes more than the SGA threshold, the application will be denied.

You may apply for SSDI benefits online at [www.ssa.gov/applyfordisability](http://www.ssa.gov/applyfordisability), or by calling (800) 772-1213, to make an appointment to file a disability claim at your local Social Security office or to set up an appointment for someone to take your claim over the telephone. The disability claims interview typically lasts about one hour.

#### *Supplemental Security Income (SSI)*

Unlike SSDI, Supplemental Security Income provides individuals with disability benefits based on financial need rather than previous work history. Eligibility will be determined based on an income and asset test and if you fit into one of three categories: 65 years old or older; blind; or disabled.

The SSA will look at the total amount of income that you have, including: wages, Social Security benefits, pensions, interest on accounts, food, and shelter. The amount of income you can receive each month and still get SSI depends partly on where you live.

The SSA will not consider the following items when looking at your income:

- The first \$20 a month of most income you receive;
- The first \$65 a month you earn from working and half the amount over \$65;
- Supplemental Nutrition Assistance Program (SNAP) benefits,
- Shelter assistance you receive from non-profit organizations; and
- Most home energy assistance.

An individual must have less than \$2,000 worth of assets or resources and a couple may have no more than \$3,000 worth of assets or resources in order to be eligible for SSI. Assets might include stocks, bonds, bank accounts, etc. However, the SSA does exempt some assets. For example, the SSA does not include the following when calculating your asset level:

- Your home and the land it is on;
- Life insurance policies worth less than \$1,500;
- Your car (usually);
- Burial plots for you and/or your immediate family; and
- Up to \$1,500 in burial funds for you and up to \$1,500 in burial funds for your spouse.

To apply for SSI, you can complete the majority of your application online at:

[www.ssa.gov/pgm/ssi.htm](http://www.ssa.gov/pgm/ssi.htm). You also can call the SSA at (800) 772-1213 to request an appointment to speak with an SSA representative. You will need to compile the following items to complete your application:

- Your Social Security card;
- Your birth certificate or other proof of your age;
- Proof of U.S. citizenship or eligible non-citizen status;
- Information about the home where you live, such as your mortgage or your lease;
- Payroll slips, bank books, insurance policies, burial fund records, and other information about your income and the things you own;
- Your checkbook or other papers that show your bank, credit union, or savings and loan account number; and
- If you are applying for SSI because you are disabled or blind, bring the names and contact information for the doctors, hospitals, and clinics that you utilize.

In 2019, the highest federal SSI payment is \$771 a month for a person and \$1,157 a month for a couple.

#### B. Illinois SSI Supplemental Payment

Illinois residents who are collecting SSI benefits may also be eligible for an additional payment from the state, called the state supplemental payment (SSP).<sup>32</sup> To determine if you are eligible for SSP, subtract your “monthly maintenance costs” from the amount you receive from SSI payment, plus any other income. If your monthly maintenance costs are more than what you bring in with SSI and other income, then you will receive an additional amount. The SSP is administered by the Illinois Department of Human Services (DHS).

#### C. Appealing a SSA Decision

Many people are discouraged because they are denied for Social Security benefits the first time they apply. It is estimated that around 70% of all applications are denied on the first round. You are able to appeal the SSA’s decision; however, you must do so in writing within 60 days of receiving denial letter (5 days after date on the letter). There are four levels of appeals:

- Request for Reconsideration
- Hearing by an Administrative Law Judge (Applicants who appeal to this level have a much better chance of getting their claim approved and you may want to consider hiring an attorney for this stage)
- Review by the Appeals Council
- Federal Court Review

Each level of appeal will delve into great detail about your medical condition and the severity of your disability. You may want to consider enlisting your health care team’s assistance in applying for and appealing a denial of SSA benefits.

If you need to appeal a SSDI or SSI determination, you may want to consider hiring an attorney. Social Security attorneys work on a contingency basis. This means that you can hire an attorney to help with appealing your decision, even if you do not have the money upfront to pay for their services. If they are able to win your appeal, they will take a percentage of your benefits. The law limits the amount that lawyers can charge you on contingency to 25% of the past-due benefits you are awarded, up to a maximum of \$6,000 except in extreme cases. To find an attorney, you can use the attorney referral service at the McHenry County Bar Association ([www.mchenrycountybarassoc.org](http://www.mchenrycountybarassoc.org)), the Lake County Bar Association, serving McHenry County

---

<sup>32</sup> 305 ILCS, section 5/3-1 *et seq.*

([www.lakebar.org](http://www.lakebar.org)), or contact the National Cancer Legal Services Network ([www.NCLSN.org](http://www.NCLSN.org)).

The Triage Cancer Quick Guide to Legal Assistance may also be useful:

<https://triagecancer.org/quickguide-legalassistance>.

The SSA has several tools online that you may find useful. If you are trying to determine if you are eligible for or applying for benefits, the disability planner at [www.ssa.gov/dibplan](http://www.ssa.gov/dibplan) may be helpful. If you are already collecting benefits or would like to keep track of your quarters of credit, you may want to create a "my Social Security Account" at [www.ssa.gov/myaccount](http://www.ssa.gov/myaccount).

For more information about disability insurance in general visit

<https://triagecancer.org/disability-insurance> and <https://cancerfinances.org>.

### *Remember Hannah?*

Hannah, a 35-year-old nurse, is suffering from depression and memory problems after going through treatment for brain cancer. Her memory problems are so severe she is no longer capable of working. She knows that she will likely never return to nursing, but does not know if she would be able to do another type of job eventually. She has some savings but is concerned about how she is going to pay her bills after that is exhausted.

### *What are Hannah's options?*

- Hannah should check her employee manual (if she has one) or speak to whomever deals with benefits at work to see if she is currently enrolled in any disability insurance policies through her employer.
- If Hannah cannot do ANY job, she may qualify for SSDI if she has worked for at least 40 quarters (20 in the last 10 years); is deemed to have a disability that is expected to last a year or longer or result in death; and is unable to work because of that disability.
- If Hannah cannot do ANY job, depending on how much Hannah has in savings, she may also qualify for SSI.
- Hannah may want to apply for both SSI and SSDI to help bridge the gap of the SSDI 5-month waiting period.

## Estate Planning

### *Meet Jim and Pam*

Jim and Pam have always talked about the fact that they should have a will and name a guardian for their two young children, but they never got around to completing an estate plan. Pam was diagnosed with colon cancer last week. The doctors do not know how she will respond to treatment, but have warned him that there may come a time when she is unable to verbalize her wishes or make medical decisions for herself. Are there steps that Jim and Pam can take now to protect themselves and their family?

There is a general misconception that only wealthy or older individuals need an estate plan. However, almost everyone can benefit from having even the most basic plan in place. Even if they have never considered creating an estate plan before, a cancer diagnosis can motivate individuals to prepare for the future in new ways.<sup>33</sup>

Estate planning can mean different things to different people. Perhaps the broadest definition is that it is the process to create a plan to ensure that individuals' wishes about the distribution of their property, their health care, and caring for their loved ones are carried out in the event of their incapacitation or death.

### I. Estate Planning Basics

In addition to having to discuss challenging topics, another reason estate planning can be daunting is that there are many unfamiliar terms used. Understanding the following terms can help demystify estate planning.

#### *Common Estate Planning Terms*

- **Administrator:** a person, or company, appointed by a court to manage an estate if no executor has been appointed or if the named executor or personal representative is unable or unwilling to serve
- **Assets:** everything a person owns (e.g., property, accounts, insurance policies, etc.)
- **Beneficiary:** a person who receives a benefit from a will, trust, or insurance policy
- **Bequest:** the property or money that is given in a will

---

<sup>33</sup> The American Bar Association, *LEGAL GUIDE FOR THE SERIOUSLY ILL* (2010); Michael A. Dalton & Thomas P. Langdon, *Estate Planning for Financial Planners* (5th ed. 2009).

- Decedent: a person who has died; generally used to describe the person who has written the will after he or she has passed away
- Executor: the person named in a will to carry out the terms of the will and to administer the decedent's estate; this person can also be known as a personal representative
- Grantor: the person who conveys ownership of property (e.g., the person writing a will).
- Intestacy: when someone dies without a will
- Probate: the court process that occurs after someone dies to deal with the distribution of property
- Testator: the person who has created a will
- Trustee: the person who is designated to administer and oversee a trust

It can be incredibly overwhelming to even start the process of estate planning, especially when you may also be coping with all of the other issues that can accompany a cancer diagnosis. Some big picture questions you can start with include:

- What do I own?
- How do I own it?
- What do I want to happen to what I own when I die?
- Are there people who I am legally responsible for?
- Are there people who I want to take care of?
- Who would I want to make medical and financial decisions for me if I am unable?

In order to effectively answer these questions, you will likely have to do some fact-finding or gathering of information about your estate.

### *What Is an Estate?*

An estate includes all of the property an individual owns at the time of death. The components of the estate may be wide-ranging. For example, in addition to a home and other real estate, an estate may include cars, furniture, jewelry, collections (e.g., baseball cards), and artwork. Bank accounts, stocks, bonds, securities, pensions, Social Security benefits, and life insurance policies are also part of an estate. Even payments owed to the individual, like a tax refund or an inheritance, are included in his or her estate. Digital property like online bank accounts, electronic devices, files and photos on the devices, e-mail accounts, social media accounts, blogs, and intellectual property are also considered part of an individual's estate. An individual's

debts are also part of the estate. Once you determine what you owe, you need to figure out if your family members would be responsible for paying your debts after they die. For example, adult children are generally not responsible for the unpaid medical bills of their parents.

Once you have determined what you own, it may also be useful to determine its value. Some items, like a car, may have a set value based on the model and age of the car. Some values, like those for real property, may fluctuate based on the market. Other items, like keepsakes or family heirlooms, may not have a large monetary value, but a substantial sentimental value. Gathering this information may help you devise a plan for how you want to distribute your property upon death.

#### *How Does an Individual Own Property?*

After you determine what you own and its worth, you need to determine how you own the property. There is more than one way to own property. Sometimes how you own property is determined at the moment you acquire the property and others will be based on law. The following are the three most common ways to own property:

- **Individual ownership.** This is property that an individual owns outright, to which no one else has a legal claim. For example, if Jim buys a car and only his name is on the title, he owns that car individually. Therefore, he can make decisions about who will own that car upon his death.
- **Joint ownership.** There are two different ways that one can own property jointly:
  - **Joint tenancy with right of survivorship.** With this type of ownership, all of the owners hold an equal right to the property and do not need the other owners' permission to access or utilize that property. For example, if Jim and Pam own a bank account in joint tenancy with right of survivorship, each one could spend money from that account without the other's permission. If Jim were to die, Pam would become the sole owner of the entire account without having to go through probate. Many married couples own their homes as joint tenants with right of survivorship, so their home would not go through probate.
  - **Tenancy in common.** With this type of joint ownership, each individual "tenant in common" owns a specific percentage of the property. Each is only free to withdraw/mortgage/sell his or her own portion of that property. When a tenant in common dies, his or her share of the property would pass to his or her beneficiaries and not to the surviving tenants in common. For example, Pam and Jim own an apartment building with four units as tenants in common, with each of them owning

50% of the building. When Jim dies, ownership of two of the units would transfer to his niece, as named in his will. Now Pam and Jim's niece own the apartment building as tenants in common.

- **By contract.** In some types of property like life insurance, retirement accounts, and living trusts, ownership is determined by the contract itself. With these types of property, the owner has full control over the property while alive, but after death, the property transfers to a beneficiary of the owner's choice. For example, Jim has a retirement account and Pam is the sole beneficiary listed. While he is alive, Jim has the full right to withdraw or add funds to that account as he sees fit. Upon his death, the balance of the account will go directly to Pam. Generally, all Pam will need to do is provide a death certificate to access the funds without going through probate.

The following table outlines property ownership considerations:

Ownership Type	Included in Will?	Probate Required?	Percentage of Ownership
Individual Ownership	Yes	Yes	100%
Joint Tenancy with Right of Survivorship	No	No	100%
Tenancy in Common	Yes	Yes	Established when property is acquired
By Contract	No	No	100%

Once you have more information about what you own and how you own it, you can better determine how to move forward with an estate plan.

## II. Creating an Estate Plan

### A. Decisions about Property and Final Wishes

As discussed above, there are different ways to own property. For property that is owned individually or as a tenant in common, it is up to the property holder to make a plan for what happens to that property when he or she dies. The two main estate planning tools to consider are a will and a trust.

## *Wills*

A will is a legal document that provides instructions for what you would like to have happen to your property upon death. A will is also the place where parents can name a guardian for minor children as well as provide other directions (e.g., wishes for a funeral).

### *Creating a Will*

Each state has different rules about how to create a valid will. In Illinois, to be valid, the will must be in writing, the testator be of “sound mind” and over the age of 18 (or an emancipated minor), the testator must sign the will, and the will must be signed by two uninterested witnesses, all in each other’s presence. To see the requirements to create a valid will in other states, please visit <https://triagecancer.org/estateplanning>.

There are several do-it-yourself options available for people who either have a relatively simple estate, or cannot afford an attorney. There are online services, books, and computer software that can cost anywhere between \$0 and \$200. Some local legal aid organizations hold periodic estate planning clinics. Consider contacting your local agency for more information. Creating a will can feel daunting and if individuals have an especially complicated estate they may want to consider hiring an estate planning attorney.

Other reasons that an individual may consider hiring an attorney include:

- Having an estate so large there are significant tax implications
- Complex plans for inheritance
- Complicated family structure
- Co-owning a small business and have questions as to the rights of surviving owners
- Wanting to make arrangements for long-term care of a beneficiary (e.g., an incapacitated adult child)
- Anticipating someone would contest the will on grounds of fraud, undue influence, or an individual’s capacity

The McHenry County Bar Association has a lawyer referral service to help you find a local attorney: <http://www.mchenrycountybarassoc.org/attorney-referral-service/>.

### *What to Include in a Will*

A will should include almost all of the property you own. The few exceptions include property for which, upon acquiring, a beneficiary was chosen (e.g., a life insurance policy) or property owned jointly with right of survivorship.

A will should also designate what should happen to any property that is acquired after the will is created. This can easily be done through a clause in a will called a “residuary clause,” which allows for any property owned at the time of death to be given to specific individuals. For example, Javier has a will with a residuary clause that designates any property not included in his will to go to his best friend Martin. Javier buys a vintage guitar after receiving his cancer diagnosis and then passes away before adding the guitar to his will; the residuary clause in his will means that Martin would receive the guitar.

### *Making Changes to a Will*

It is important to remember that wills can be revoked or changed at any time as long as the testator is of sound mind. A codicil is a legal document that amends, rather than replaces, a previously executed will, and can be used for minor changes. Minor changes might include adding or removing a particular gift (like a car an individual no longer owns) or updating the legal name of someone after a marriage who receives property granted by the will. Codicils must be executed in the same way that wills must be executed in that state. For example, because Illinois requires that the will be witnessed by two uninterested parties, the codicil must also be signed by two uninterested parties. On the other hand, revoking a current will and making a new one should be considered for major changes, such as completely removing a beneficiary or adding a new child as a beneficiary. Generally, if you decide to create a new will, it is wise to destroy all old wills as to avoid any confusion or doubt as to which is the valid will.

Once a will is created, it should be kept in a safe, but accessible location. The executor or a close loved one should be made aware of the location of the will and have access. For example, it can cause a problem for an executor if the only copy of a will is in a safe deposit box that only you can access. Regularly reviewing and updating a will in order to make necessary changes is an important part of estate planning.

### *Probate*

When an individual dies their estate must be probated. Probate is the process through which a court supervises the gathering and distribution of the decedent’s property.

In Illinois, there are two main ways that an estate is administered, either through the Illinois Small Estate Affidavit or through the formal in-court Illinois Probate Process. The Illinois Small

Estate Affidavit<sup>34</sup> is typically used when the estate has less than \$100,000.00 in assets, the estate does not contain real estate, no fighting is expected, and formal probate has not been initiated. Otherwise, the formal in-court probate is utilized. In both cases the estate must first pay the decedent's debts and funeral and estate administration expenses, then any remaining property is distributed according to the terms of the individual's will. The executor named in the will distributes property. The executor must be approved by the probate court before the executor has authority to handle the affairs of the estate and property distribution. If someone dies without a will, his or her property will be distributed according to the state's intestacy statute.

Intestacy laws vary greatly from state to state, the following chart illustrates Illinois' law of intestate succession.<sup>35</sup> Many people choose not to draft a will because they believe that their spouse will inherit all assets when they die. However, under Illinois' law, children (regardless of age) of a married person will receive half their estate when they die. This can cause practical problems, particularly if the children are very young and are unable to receive the inheritance until they are 18 years old.

If you die with:	Here is what happens:
children but no spouse	children inherit everything
spouse but no children or parents	spouse inherits everything
spouse and children from you and that spouse	spouse inherits 1/2 of your intestate property children inherit 1/2 of your intestate property
parents but no spouse or descendants	parents inherit everything
siblings but no spouse, descendants, or parents	siblings inherit everything

### *Non-Probate Transfers*

In some circumstances, individuals may choose to use a non-probate transfer to transfer ownership of property outside of the probate process in order to expedite the distribution of assets. There are several different types of non-probate transfers, and the tool used will depend on the type of asset being transferred:

- Payable-on-death accounts can be used to transfer money immediately upon death. The beneficiary must present the grantor's death certificate to the financial institution. The

<sup>34</sup> [https://www.cyberdriveillinois.com/publications/pdf\\_publications/rtopr31.pdf](https://www.cyberdriveillinois.com/publications/pdf_publications/rtopr31.pdf)

<sup>35</sup> 755 ILCS 5/2-1

financial institution then transfers legal ownership and full control of the money to the beneficiary.

- A “transfer-on-death deed (TOD),” is a way to transfer real property (e.g., a home) outside of probate, but maintain a life estate (i.e., control over the property while an individual is still alive). A TOD deed can also be useful for individuals who receive Medicaid and have had to leave their home for care on a permanent basis (e.g., nursing home or hospice). Typically, when that happens, the property is no longer considered the primary residence for the individual and the value cannot be counted against them for Medicaid eligibility. By executing a TOD deed, an individual can keep his or her interest in the property while alive, but also maintain Medicaid benefits. In some circumstances, this also protects the property from being sold, after one’s death, to repay the cost of Medicaid long-term care benefits that were received.

Other types of non-probate transfers include life insurance policies, deferred compensation plans, and pension plans. In these instances, the owner of the policy or account names a beneficiary. Upon an individual’s death, the beneficiary typically only needs to present a death certificate to gain access to the funds.

### *Trusts*

A trust is another tool for estate planning. Unlike wills that express your wishes for what will happen to your property after you die, a trust is a legal entity that will actually own the property. The person placing the property into the trust is known as the *grantor*. The person the grantor chooses to oversee the property in the trust is known as the *trustee*. Finally, the person who receives the benefit of the property in the trust is known as the *beneficiary*. Property that can be held in a trust includes land, buildings, bank accounts, stocks, artwork, cars, jewelry, and other personal property. To set up a trust, the grantor lists the purposes of the trust and makes the trust property available to the trustee. When property is put into a trust, legal ownership is transferred from the grantor to the trust itself. The trustee then has a legal responsibility to handle the property within the trust the way the grantor has specified in the written trust agreement.

People set up trusts for a variety of reasons and there are different types of trusts depending on an individual’s needs. The most common types of trusts are:

- **Living trust.** This type of trust is also referred to as an *inter vivos* trust. It is created while the individual is still alive and is generally revocable until one dies. The most common way to create these trusts is for the grantors to appoint themselves as trustees and as

long as they remain mentally competent, they can change or dissolve the trust at any time, for any reason. Typically, a living trust becomes irrevocable when the grantor dies.

- **Irrevocable trust.** Unlike a living trust, an irrevocable trust cannot be changed or revoked by the grantor once created by the grantor. These types of trusts may provide some tax benefits and protection from legal action or creditors. However, one should not create this type of trust lightly since they will no longer have full control over the property once established, even if they name themselves trustee.
- **Testamentary trust.** These types of trusts are established, in a will, to provide for individuals who need help managing their assets. These types of trusts do not go into effect until the grantor dies. Testamentary trusts can be especially useful to parents who have young children and want to provide for future education, health care, or general support. They may also be helpful in meeting ongoing expenses for dependent adults with special needs while safeguarding their government benefits (e.g., Medicaid).
- **Special needs trust.** Sometimes referred to as supplemental needs trusts, these trusts allow individuals with a disability to hold an unlimited amount of assets in a trust for their benefit. The advantage of these trusts is that assets included in the trust are not considered “countable assets” for certain government benefits that are based on certain income and resource levels (e.g., Supplemental Security Income or Medicaid). A special needs trust may supplement care the government provides. For example, the trust may pay for hours of home health care in addition to those paid for by Medicaid. There are very specific requirements<sup>36</sup> that must be met in order to establish a valid special needs trust, including:
  - The beneficiary must be younger than 65 at the time the trust is established
  - The trust is irrevocable
  - The trustee has sole and absolute discretion over the use of the trust funds for the sole benefit of the recipient of government benefits (i.e., the trustee cannot be required to pay the beneficiary directly from the trust)
  - The trust includes a provision that states that any funds remaining in the trust at the death of the beneficiary are available to reimburse the state for any Medicaid costs the beneficiary received

---

<sup>36</sup> Omnibus Budget Reconciliation Act of 1993 (42 U.S.C. § 1396p(d)).

Tax savings may be a benefit to establishing a trust. For example, a grantor may make annual tax-free gifts to trusts, in an amount allowed by law, to children or grandchildren. This practice reduces the taxable estate and so will help to save on taxes at the grantor's death. As a result, more of the grantor's assets will pass to the grantor's beneficiaries. Unlike a simple will, establishing a trust can be complicated and has serious implications because the grantor is giving up ownership of the property held in the trust. Therefore, it may be in an individual's best interest to hire an estate planning attorney who is well versed in the state's trust and tax laws to ensure that the trust is set up in the proper manner.

Once a trust is established, it is important to let relevant parties know of its existence and of the location of all pertinent documents. Many people opt to keep their trusts with the attorney who drafted the trust. In that case, the trustee should be given the contact information for the attorney, at a minimum.

## B. Decisions about Medical Care

There may come a time in an individual's cancer experience when he or she is unable to make medical or financial decisions. However, there are tools that can be used to ensure that their wishes are honored with respect to their medical care and financial affairs.

### *Advance Health Care Directives*

There may come a time when you are unable to express your wishes about your medical care. Fortunately, there are steps you can take to plan ahead in the event you become incapacitated. Generally speaking, an advance health care directive is a legal document in which individuals can provide written instructions, or state preferences, about their medical care should they become unable to communicate. Illinois law allows you to make four types of advance directives: a health care power of attorney; a living will; a mental health treatment preference declaration; and a Do-Not-Resuscitate (DNR)/Practitioner Orders For Life-Sustaining Treatment (POLST).

### *Health Care Power of Attorney*

This document is where you can name an agent to make medical decisions if you are ever unable to express your wishes in the future. You can name an agent and an alternate agent in the event that one of them cannot be reached. However, it is never recommended to appoint co-agents. The rational for this is that having two people with equal decision-making power

could lead to great conflict and confusion, thereby thwarting the very reason most people establish advance directives.

### *Living Will*

Living wills are often confused with power of attorneys for health care. Unlike a power of attorney for health care, a living will allows you to express your wishes about medical care but typically does not name an agent. In Illinois, a living will only applies to life-prolonging procedures (not routine care) for an individual who has a terminal condition. A terminal condition is defined as an “incurable and irreversible condition such that death is imminent and the application of any death delaying procedures serves only to prolong the dying process.”<sup>37</sup> It is not uncommon to have both an advance health care directive and a living will.

### *Mental Health Treatment Preference Declaration*

This document allows you to make decisions in advance about the types of mental health treatment you might receive, including: psychotropic medication, electroconvulsive therapy, and short-term (up to 17 days) admission to a treatment facility. For more information, visit <https://www2.illinois.gov/sites/gac/forms/documents/dmhtform.pdf>.

### *Do-Not-Resuscitate (DNR)/Practitioner Orders For Life-Sustaining Treatment (POLST)*

A DNR order is an advance directive written by a physician that tells medical professionals not to resuscitate an individual who goes into cardiac or respiratory distress.<sup>38</sup> A DNR is used only when an individual decides that is what they want and they should work with their health care team to complete the form. A practitioner order for life-sustaining treatment (POLST) is a medical order completed by a seriously ill individual and signed by a physician. POLST forms include directions about using CPR to revive a person who has stopped breathing or whose heart has stopped beating. In addition, these forms may include instructions about other types of treatment, including antibiotics, artificial nutrition, hydration, mechanical ventilation, emergency transport, and placement in the intensive care unit of a hospital.

In some states these are different forms. However, in Illinois, the forms are combined and there is one DNR/POLST form that can be completed. To download the DNR/POLST form for completion, visit <http://www.idph.state.il.us/public/books/dnrform.pdf>.

<sup>37</sup> <http://www.dph.illinois.gov/topics-services/health-care-regulation/nursing-homes/advance-directives>

<sup>38</sup> U.S. National Library of Medicine, MedlinePlus, *Do-Not-Resuscitate Order*, <https://www.nlm.nih.gov/medlineplus/ency/patientinstructions/000473.htm> (last visited Jan. 8, 2018).

To ensure that a DNR/POLST form is honored, copies should be placed in an individual's medical file and perhaps even carried on the individual's person or posted in a prominent location where the individual is likely to be (e.g., on the nightstand in the bedroom or on a fridge in the kitchen).

### *C. Decisions about Finances*

If individuals are incapacitated, even for a short period of time, there may also be a need to have someone who can handle nonmedical decisions.

#### *Power of Attorney for Property*

A power of attorney for property is a legal document where you (the principal) names a trusted adult (the agent) who is authorized to make financial decisions on your behalf. Some of the duties that the principal can grant an agent may include depositing or withdrawing funds from a bank account, or handling the principal's personal matters, such as receiving mail, making travel arrangements, or dealing with a health insurance company.

A power of attorney for property can be very useful in situations where a cancer diagnosis or side effects of treatment might lead to incapacitation. By having a power of attorney for property in place, the need for a court-appointed guardian to make financial decisions for the incapacitated individual is eliminated.

A properly created power of attorney for property can save caregivers considerable time and frustration. However, it is important to remember that this document will likely grant a large amount of decision-making power to an agent. Therefore, principals must be careful to create clearly defined conditions for the power of attorney for property. Where an agent is untrustworthy or a document fails to carefully articulate the principal's needs and desires, the power of attorney for property can be abused. To guard against misuse of the power, the principal must choose his or her agent or agents with great care. Often when people think about who to choose as their agent, they only think about family members. However, if you are having a hard time finding a trusted family member to act as an agent, it may be useful to think outside of the family to a trusted friend or business partner. You may also appoint both an agent and an alternate agent in the event that one is unavailable. However, just like with powers of attorney for health care, it is never recommended to appoint co-agents. Having two or more agents with equal power could lead to conflict and confusion. Finally, as a precautionary measure, you should be sure to include any desired restrictions in the document

itself. For example, you could only want the agent to have the power to write checks out of one bank account. While it is true that a power of attorney for property potentially gives an agent great power, it can also provide great peace of mind and security for an individual coping with cancer who may, at some point, become incapacitated.

Power of Attorneys for Property can be drafted with an attorney, or you can complete the Illinois Short Form. To download the Power of Attorney for Property Short Form for completion, visit [https://www2.illinois.gov/aging/protectionadvocacy/documents/poa\\_property.pdf](https://www2.illinois.gov/aging/protectionadvocacy/documents/poa_property.pdf)

#### D. Practical Matters

##### *Digital Afterlife*

Thinking about an individual's e-mail and social media accounts may seem trivial when dealing with a cancer diagnosis. However, in this day and age, when so much of an individual's life may take place in the electronic space, it can be useful to think about how they want to handle these accounts and create a digital estate plan. The process of creating a digital estate plan is similar to that of creating a will. You should start by collecting information about what you own digitally. That may include:

- Information or data that is stored electronically (e.g., in the cloud, on thumb drive, etc.)
- Online accounts, such as e-mail, digital voicemail, social media, shopping, photo and video sharing, music, video gaming, online storage, rewards, etc.
- Domain names, blogs, and websites owned
- Intellectual property (e.g., copyrighted materials, trademarks, etc.)

In creating a list or catalog of digital assets, you should also document the login and password information for each account. There are password managing services with a master password that can be shared, or the information can simply be written down in a safe place, accessible to the executor of the estate. Executors should also be made aware of your wishes about how each asset should be handled. For example, should accounts be closed, how should any monetary value be dealt with (e.g., rewards that can be turned in for merchandise), or if assets will continue to generate income (e.g., a copyrighted song), who will receive that income?

When thinking specifically about dealing with social media after death, each platform has a different process. For example, Facebook and Instagram gives users the option to elect whether they would like their accounts to be memorialized or permanently deleted when they die. Memorialized accounts will allow a user's friends to continue posting, and all of the existing

content remains. Facebook also allows users to name a “legacy contact” who is authorized to manage the account after the user dies. Upon the user’s death, the legacy contact should complete the online form and submit a death certificate. Twitter and LinkedIn require that the user’s agent notify the platform of the death and request that the account be deactivated.

It is important to go through each platform’s terms of service to determine the proper procedure for dealing with the account. Agents should not automatically log on to another user’s account to delete it, as that may be a legal violation.

Various e-mail platforms also have procedures to deal with an individual’s accounts after death. For example, Gmail, Outlook, and Yahoo have strict procedures to allow the authorized representative of the deceased person to access the content of an e-mail account. Gmail also gives users the option to set an “inactive account manager,” wherein after a set amount of inactivity an account is either shared or deleted.

Another significant area of personal property that can live in a digital account is music (e.g., iTunes). Apple specifically states that there is no right of survivorship for an AppleID, and upon a user’s death, the account, and all content within, will be deleted. So if music is being stored in an iTunes account, individuals may want to make sure to have an electronic backup that they can share with their beneficiaries.

It may seem inconsequential to think about social media, music, and shopping accounts in the big picture of estate planning. However, planning ahead can simplify the process for loved ones, and ensure that all assets are accounted for and protected.

### *Funeral Arrangements*

A sometimes overlooked aspect of estate planning includes making funeral and/or burial arrangements in advance. By planning ahead, you can help avoid putting loved ones in the position of making additional decisions during a difficult time of loss. Some questions an individual can start with are:

- Where and how do I want to be laid to rest (burial, cremation, burial at sea, etc.)?
- Are there cultural and religious customs that I would like to abide by?
- Do my loved ones have any preferences?
- Do I want a memorial service, a wake, or some other type of celebration of my life?
- Do I need to buy funeral insurance to help pay for these expenses in the future?

Funeral arrangements can be expensive, so you may also want to consider how to cover these costs. There are three main cost categories in funeral planning: costs related to the funeral home, the cemetery, and the grave marker. These costs can range from \$3,000 to \$15,000, and can vary greatly depending on where individuals live and what they choose.

Some individuals may also consider cremation. Cremation can be less expensive, averaging around \$3,200 plus the cost of an urn, which starts at \$20. Some funeral homes and cemeteries will not accept credit cards or payment plans, but require payment in cash and up front. Some funeral homes and cemeteries will allow individuals to set up a payment plan, if they chose to preplan a funeral. There are several options to purchase funeral or “final expense” insurance, to cover the cost of expenses.

Tools exist to help you preplan and document their wishes around funeral planning. For more information, visit <https://triagecancer.org/estateplanning>.

### *Legacy Planning*

Another idea that may appeal to individuals coping with cancer is legacy planning. This is a way to communicate with loved ones throughout their lives. For example, individuals can leave videos, cards, letters, and presents for milestones in the lives of their loved ones, such as birthdays, graduations, and weddings. MyWonderfulLife.com is a practical resource on funeral and legacy planning.

### *Storing Documents*

As discussed throughout this chapter, once an estate plan is completed, it is critical for people involved to know of the plan’s existence and to have access. Documents should be kept organized and account information listed clearly. Triage Cancer’s “Financial Big Picture” document is one way to organize this information (<http://triagecancer.org/FinancialBigPicture>). Saving documents outside of the home can also be useful if an individual is traveling and experiences a medical emergency, or in the event of disaster (e.g., fire, earthquake, flood).

One option is to save electronic copies of the documents on an online drive or cloud storage. There are free services (e.g., Google Drive, iCloud, Dropbox) as well as paid options (e.g., Everplans, Master Lock Vault) that can be accessed from any computer. If those options seem too complicated, another option may be to simply e-mail the documents to yourself. Anyone can sign up for a free e-mail address from providers like Gmail, Yahoo, or Microsoft. These e-

mail accounts can be accessed on any computer or mobile device around the world that has Internet access. Individuals may also consider giving the passwords to those accounts to their agents for easy access.

If you choose to keep these documents in a safe deposit box, you should be sure that the executor of your estate also has access to the box. If the documents are kept in a home safe, be sure your executor or a loved one has the code or key. An estate plan that cannot be found or accessed is effectively the same thing as not having a plan.

Estate planning can be daunting, emotional, difficult, and yet rewarding. When individuals are coping with cancer, they may find great comfort in exercising some control at a time when much feels out of their control. Open dialogue with one's loved ones and health care team about the realities of health care and what is most appropriate for you is encouraged. No one should feel that they are alone in this process. There are many resources out there to help you and your family establish a comprehensive and cohesive estate plan.

#### *Remember Jim and Pam?*

Jim and Pam have always talked about the fact that they should have a will and name a guardian for their two young children, but they never got around to completing an estate plan. Pam was diagnosed with colon cancer last week. The doctors do not know how she will respond to treatment, but have warned him that there may come a time when she is unable to verbalize her wishes or make medical decisions for herself. Are there steps that Jim and Pam can take now to protect themselves and their family?

#### *What are their options?*

- Jim and Pam should both draft wills that designate people to receive their property and a guardian for their minor children.
- They may also want to consider creating a trust to benefit their children.
- They may also want to take stock of their digital assets and consider preplanning their funerals.
- During the estate planning process, they should speak openly and honestly about what kind of health care treatment each one of them wants if they ever become incapable of making their own health care decisions, as well as complete advance health care directives and a Power of Attorney for Property.

## **Other Financial Tips**

When you have a history of cancer, which may have kept you from working for a period of time, which may have left you with medical bills that have affected your credit, and which may continue to pose a financial burden for you, it can seem overwhelming to find your way out of that maze. However, there may be steps you can take to build a foundation for a healthy financial future.

### ***Consider your Current Financial Picture***

Even if you had a financial plan prior to your cancer diagnosis, it can be helpful to review where you are financially after completing treatment. Figuring out what your financial picture looks like can help you decide which of the steps below you should take, if any. It can also help you identify priorities (e.g., do you need to find a job, do you have a stack of bills that you have been too afraid to open, or are you ready to start thinking about building your savings or contributing to a retirement plan?). Figuring out what your next steps might be is entirely personal to your situation.

To get a clear picture of your situation, consider these questions:

- What is the current status of your finances?
- Were you able to keep working through treatment or did you need to take time off? How did that affect your financial situation?
- Now that you are finished with treatment, are you back at work, able to go back to the same job or type of work, or because of side effects do you need to look for another career path?
- Do you have a stable income?
- What are your recurring and potential expenses?
- What assets do you have? These can include homes, savings bonds, retirement plans, etc. Some of these may be assets that can help you to access cash if necessary (e.g., 401K retirement plans or life insurance policies that you can withdraw money from early because of a serious medical condition).
- What secured and unsecured debt do you have? Secured debt includes things such as a car loan or home mortgage. Unsecured debt includes student loans, personal loans, and credit card debt.

### *Know Your Credit Score*

If you have already had a challenging financial picture, then you may be less concerned about a drop in your credit score from working with a debt solutions agency or filing for bankruptcy. However, it is important to learn about your credit score and to check your credit report. You can do so at [www.creditscorequiz.org](http://www.creditscorequiz.org). Your credit may be checked when you rent an apartment, lease or buy a car, buy a home, or even get cable television. In addition, some employers conduct background checks that include looking at your credit score or full report.

Each of the three national credit bureaus (Equifax, Experian, and TransUnion) is required to provide you with a free copy of your credit report once every twelve months, if you ask for it. To order a copy of your credit report, visit [www.annualcreditreport.com](http://www.annualcreditreport.com) or call 877-322-8228.

Once you receive your credit report, check to make sure that the information they have about you is correct. If not, you can ask the credit bureaus to fix the information. A credit bureau is permitted to report most accurate negative information for seven years and bankruptcy information for 10 years. To get more information about credit scores and reporting, please visit the Federal Trade Commission at [www.ftc.gov/credit](http://www.ftc.gov/credit).

### *Create a Budget for Your Current Situation*

After you have assessed your financial picture, create a budget that includes that new information, including any expenses you might have remaining related to your medical care. You may want to consider talking with a financial planner; to find one nearby, visit Financial Planning Association at [www.fpanet.org](http://www.fpanet.org). Financial planners work with people of all income levels so don't feel like you don't have enough money to utilize one. Consider contacting a consumer credit counseling agency, which can provide you with practical tools, such as financial calculators, budget worksheets, and other resources. They may also be able to help you negotiate payment plans or settlements with your creditors. As a consumer, you still have rights. Be aware that some debt solutions may negatively affect your credit score. You can find more information at [www.ftc.gov/bcp/edu/pubs/consumer/credit/cre19.shtm](http://www.ftc.gov/bcp/edu/pubs/consumer/credit/cre19.shtm) or the Consumer Credit Counseling Service of McHenry County, Inc., a local non-profit organization, may be able to help you. They can be reached at:

Consumer Credit Counseling of McHenry County  
400 Russel Court  
Woodstock, IL 60098  
(815) 338-5757 [www.illinoisccts.org](http://www.illinoisccts.org)

### *Take Steps to Rebuild your Credit Report*

It can be challenging to raise your credit score if it drops, but it is possible. Moreover, just because you have a low credit score does not mean that you cannot get credit. Each creditor sets their own standards and some may only look at your recent credit history. If your bill-paying history has improved, they may offer you credit. It may be worthwhile to contact potential creditors informally to discuss their credit standards. There are some ways to build a better credit report. For example, if you have one or more credit cards, make sure that the balances on each card are not more than 30% of your available credit on that card (e.g., if your card has a limit of \$5,000, try and keep the balance at no more than \$1,500). There are also some other ways to demonstrate fiscal responsibility, including:

- Filing your taxes. Even if you cannot pay the whole amount that is due, file your return and work out a payment plan with your state tax entity and the IRS.
- Paying down your bills with the highest interest rates first.
- Look into secured credit cards. These are credit cards that require you to put a certain amount of money into an account and they will give you a credit card with that spending limit. There are lots of credit card scams out there, so make sure that you go a reputable credit institution, such as a large bank or local credit union. Make sure to get all of the information before getting a secured card. Avoid cards with fees or ones that require you to buy insurance.
- Building your savings by paying yourself first each month, even if it is a small amount.

Retirement might seem far off in the future, but building your retirement assets is important, especially if you had to dip into your retirement plan while in treatment to help pay bills. If your employer matches your contributions to a 401k plan or another retirement plan, don't leave money on the table. Try to contribute the maximum amount to your plan that your employer will match.

### *Review your Medical Bills*

Medical bills may keep arriving long after your treatment is over. It is important to stay diligent and check that your bills are accurate, dispute them if there are problems, and if you believe a procedure or treatment should have been covered, and it wasn't, know that you have the right to appeal that decision (*See section above about appealing your insurance company's decision*).

If you have extensive bills, consider talking with a professional bill reviewer or medical claims organization (e.g., MedClaims Liaison [www.medclaimsliaison.com](http://www.medclaimsliaison.com)).

### *Contact your Creditors*

Talking with your creditors before they turn over your unpaid bills to collections agencies can help to protect your credit. If you can't make a payment, ask for more time. Check to see if they would be willing to negotiate a payment plan or accept a lower lump sum payment. This also applies to your landlord, student loan companies, and health care providers. However, be careful when considering paying medical bills by credit card. Most credit cards have high interest rates and you may end up spending more than necessary. It is also not recommended that you take out a loan on your home (e.g., a second mortgage or home equity line of credit) to pay your medical bills, because you then turn unsecured debt into secured debt and risk losing your home if you cannot make the payments. Some health care providers may be willing to discount your medical bill, so it can be worthwhile to ask.

Paying student loans might also be challenging for you. Some private student loan companies will allow you to change payment plans or postpone payments through a loan deferment or forbearance process. Federal student loans also have a system to forgive loans if you qualify as having a permanent and total disability or meet other criteria. Visit [www.studentaid.ed.gov/repay-loans/forgiveness-cancellation](http://www.studentaid.ed.gov/repay-loans/forgiveness-cancellation) or <https://cancerfinances.org> for more information.

### *Consider Financial Assistance Programs*

Even if the bulk of your cancer treatment is over, there may still be medications you need to help manage side-effects from treatment or other long term medical conditions that you may experience. Some financial assistance programs may help with medical expenses and some may help with insurance or other bills.

There are cancer specific and health care organizations that may provide financial assistance, such as the American Cancer Society, Patient Services Incorporated (PSI), Patient Advocate Foundation. In addition, The SAMFund ([www.SAMFund.org](http://www.SAMFund.org)) is a nonprofit organization that specifically provides young adult cancer survivors with a successful transition into their post-treatment life, by providing financial support through grants and scholarships.

Organizations such as NeedyMeds ([www.needymeds.org](http://www.needymeds.org)), Patient Access Network Foundation ([www.PANFoundation.org](http://www.PANFoundation.org)), and RxHope ([www.RxHope.org](http://www.RxHope.org)) may be able to help you pay for your prescription drugs. Additionally, many pharmaceutical companies have programs to provide people who are having financial difficulties with their medications.

As a cancer survivor, you may be eligible for certain scholarships to help pay for higher education. Several Divisions of the American Cancer Society ([www.cancer.org](http://www.cancer.org)) offer scholarships, as well as organizations such as Cancer for College ([www.cancerforcollege.org](http://www.cancerforcollege.org)) and the National Collegiate Cancer Foundation ([www.collegiatecancer.org](http://www.collegiatecancer.org)). To find an extensive list of scholarship opportunities, visit [www.finaid.org/scholarships/cancer.phtml](http://www.finaid.org/scholarships/cancer.phtml).

Your friends, family, neighbors, and co-workers may be sources of financial help. They may not realize that just because your treatment has ended you may still need financial assistance. Consider setting up an online fundraiser through a website such as GoFundMe or MyLifeLine, to raise money to help pay for medical bills or living expenses, while you are still getting back on your feet after treatment. However, before you set up an online fundraiser, consider all of the consequences of disclosing. More information can be found at <https://triagecancer.org/quickguide-disclosure>.

For more information about financial assistance options visit <https://CancerFinances.org> and choose “Financial Assistance.”

#### *Look at Your Insurance Portfolio for Potential Sources of Income*

There are different types of insurance coverage that you may currently have through your employer or that you purchased on your own, which can provide some financial assistance. Disability insurance is discussed in the section above, but also consider life or disease specific insurance (e.g., cancer insurance). Life insurance is insurance that you can purchase to provide a beneficiary of your choosing a preset amount of money in the event of your death. If you already have a life insurance policy and you need financial assistance, consider:

- Does your policy allow you to borrow money from the policy if you have a disability?
- Does your policy contain a waiver that pays your premiums for you while you are unable to work because of a disability?
- Could a viatical settlement be beneficial to you?
  - A viatical settlement is when you sell your life insurance policy to a third party, typically for less than the full policy amount. This may be a useful option because you get access to needed funds; however, your original beneficiary will not receive anything from the life insurance policy.

#### *Consider Talking to a Bankruptcy Attorney*

If you have already worked with a credit counseling agency and you still are unable to pay or negotiate a payment plan for your medical or other bills, you may want to talk with a bankruptcy attorney. It is critical to become informed about the bankruptcy process and its

effects on your credit report. Also, there are rules that make it more difficult to completely eliminate medical debt through the bankruptcy process than it has been in the past. Triage Cancer has a Quick Guide to Bankruptcy available at <https://triagecancer.org/quickguide-bankruptcy> that may be a good starting point. The American Bar Association also has a Guide to Credit & Bankruptcy that can be purchased at [www.americanbar.org](http://www.americanbar.org), or at online bookstores such as [www.amazon.com](http://www.amazon.com) or [www.barnesandnoble.com](http://www.barnesandnoble.com). You can find a bankruptcy attorney by contacting the McHenry County Bar Association, or visit [www.lawhelp.org](http://www.lawhelp.org).

## **Conclusion**

This handbook only scratches the surface of the types of legal and practical issues that you may have to navigate. Please know that Triage Cancer has additional resources to help. Please visit <https://triagecancer.org> to explore our free in-person events, webinars, videos, partner organizations, and online resources.

## **Resources**

<b>Resource Category</b>	<b>Page</b>
Employment Rights & Job Search/Retraining Resources	85
Legal Rights, Navigation & Case Management Resources	88
Health Insurance Resources	90
Financial Assistance Resources	91
Food, Housing, & Other General Financial Assistance Programs	91
Low Cost Medical Care & Supplies Resources	94
Prescription Drug Help	95
Utility Assistance Programs	96
Resources for Children	97
Other Services	101
Support Groups	104

## **Employment Rights and Job Search/Retraining Resources**

### **Cancer and Careers**

**What:** Provides patients, employers, and healthcare providers with legal rights, job searches, and professional development.

**Resources:** Publications, educational videos, check lists, resource contacts, resume review services, and events.

[www.cancerandcareers.org](http://www.cancerandcareers.org)

Available in Spanish

### **Career One Stop**

**What:** Offers career exploration, job search, and training programs.

**Resources:** Self-assessments, resume, interview and networking aid, categorized job searches, and a local help database.

[www.careeronestop.org](http://www.careeronestop.org)

Available in Spanish

### **Department of Public Aid**

**What:** Assistance services for low-income families

**Resources:** Trainings, information, outreach, and referrals

512 Clay St. Woodstock, IL 60098

(815) 338-0234

[www.dhs.state.il.us](http://www.dhs.state.il.us)

### **Disability.gov**

**What:** Federal Government website with link for employees and job seekers with disabilities.

**Resources:** Federal Policy, Campaigning for disability employment, and benefits.

[www.dol.gov/odep/topics/disability](http://www.dol.gov/odep/topics/disability)

Available in Spanish

### **Easter Seals Disability Services**

**What:** Helps people with disabilities, older workers, and veterans find and hold meaningful employment.

**Resources:** Services, Assistive technology, and transportation. Training for employers projected for those with disabilities. Closest affiliate is located in DuPage, IL

830 South Addison Ave. Villa Park, IL 60181

<http://www.easterseals.com>

## **FlexJobs**

**What:** Job search resource for remote, part-time, freelance, and flexible jobs.  
[www.flexjobs.com](http://www.flexjobs.com)

## **Equal Employment Opportunity Commission (EEOC)**

**What:** Enforces federal law against job discrimination.  
**Resources:** “How to” file reports, FAQ, and policy publications  
500 W. Madison St. Suite 2000 Chicago, IL 60661  
[www.eeoc.gov](http://www.eeoc.gov)  
Publications Available in variety of languages. Closest affiliate located in Chicago

## **Illinois Department of Employment Securities**

**What:** Employment Services to Illinois residents and employers.  
**Resources:** Unemployment insurance and employment services.  
500 Russell Ct. Woodstock, IL 60098  
(866) 488-4016  
[www.ides.illinois.gov](http://www.ides.illinois.gov)

## **Illinois Work Net Center**

**What:** Online database and job search website.  
**Resources:** Job search, disability information, trainings.  
[www.illinoisworknet.com](http://www.illinoisworknet.com)  
Available in Spanish

## **Job Accommodation Network (JAN)**

**What:** Guidance on workplace accommodations and disability employment issues.  
**Resources:** Consultations online or over the phone, publications, and online tools for using accommodations.  
(800) 526-7234  
[Askjan.org](http://Askjan.org)

## **McHenry County Workforce Center (An affiliate of Illinois workNet)**

**What:** provides employment related services in McHenry County.  
**Resources:** Training, placement assistance, counseling, resume writing. Resource room with computers, a fax, and internet access.  
500 Russel Court an Illinois WorkNet Center Woodstock, IL 60098  
(815) 338-7100 ext. 2771 ~ [workforcecenterRR@yahoo.com](mailto:workforcecenterRR@yahoo.com)  
[www.mchenrycountyworkforce.com](http://www.mchenrycountyworkforce.com)

**National Center on Workforce and Disability**

**What:** Provides information on job training, technical assistance, and legal rights  
[www.onestops.info](http://www.onestops.info)

**Pioneer Center for Human Services**

**What:** Specialized program that matches the community's employment needs with individuals.  
**Resources:** Job search, skills training, application assistance, workplace problem and solutions.  
4031 W Dayton St. McHenry, IL 60050  
(815) 344-1230  
[www.pioneercenter.org](http://www.pioneercenter.org)

**SER Jobs for Progress National**

**What:** Senior Community Service Employment Program (SCSEP) offers part-time paid work training for low-income/unemployed seniors 55+ in government and non-profit skills. Available in Spanish and Russian.  
500 Russel Ct. Woodstock, IL 60098  
(224) 227-6422  
[www.ser-national.org](http://www.ser-national.org)

**The Work Site: Ticket to Work**

**What:** People receiving SSDI or SSI can obtain employment services, rehabilitation services, and more to achieve a vocational goal.  
(800) 772-1213  
[www.ssa.gov/work/](http://www.ssa.gov/work/)  
Available in multiple languages

**U.S. Department of Labor Wage & Hour Division**

**What:** Federal Government agency that oversees the Family and Medical Leave Act (FMLA):  
**Resources:** provides guidance, forms and fact sheets about taking medical leave  
230 S. Dearborn Street Room 412 Chicago, IL 60604  
(866) 487-9243  
[www.dol.gov/whd/fmla/](http://www.dol.gov/whd/fmla/)

## **Legal Rights, Navigation, and Case Management Resource**

### **American Association of People with Disabilities (AAPD)**

**What:** Website for disability-related news and information. Political and economic activist program information available,  
(800) 840-8844  
[www.aapd.com](http://www.aapd.com)

### **American Brain Tumor Association**

**What:** Organization that fund brain tumor research and provides educational and support services to people diagnosed with a brain tumor.  
8550 W. Bryn Mawr Suite 550 Chicago, IL 60631  
(337) 557-8750  
[info@abta.org](mailto:info@abta.org)  
[www.abta.org](http://www.abta.org)  
Care Line: (800) 886-2282

### **Illinois State Bar Association: Illinois Lawyer Finder**

**What:** Online tools to locate a local attorney. Phone consultations available to find an attorney for \$25 at 800-922-8757.  
(800) 922-8757  
[www.isba.org/public](http://www.isba.org/public)

### **Kane County Bar Association for Kane, DeKalb, Kendall, DuPage, Cook, Lake, McHenry, Will, and Winnebago counties**

(630) 762-1900  
[Kanecountybar.org/find-a-lawyer](http://Kanecountybar.org/find-a-lawyer)

### **Lake County Bar Association for Lake, McHenry, and Cook counties**

(847) 244-3143  
[lakecountylawyer.info/](http://lakecountylawyer.info/)

### **McHenry County Bar Association Lawyer Referral Service for McHenry County.**

(815) 338-9559  
[mchenrycountybar@gmail.com](mailto:mchenrycountybar@gmail.com)  
[www.mchenrycountybarassoc.org/](http://www.mchenrycountybarassoc.org/)

### **McHenry County State Attorney's Office**

**What:** Protects the rights and safety of McHenry County citizens and supports functions of county government.

2200 N. Seminary Ave. Suite C150 Woodstock, IL 60098

(815) 334-4159

<https://www.mchenrycountyil.gov/county-government/departments-j-z/state-s-attorney-s-office>

### **National Cancer Legal Services Network (NCSLN)**

**What:** Free legal services programs for cancer patients and their family and friends, health care providers, and attorneys.

**Resources:** Links to information and legal services

[www.nclsn.org](http://www.nclsn.org)

### **Patient Advocate Foundation (PAF)**

**What:** Provides case management services and publications on insurance and benefits

(800) 532-5274

[help@patientadvocate.org](mailto:help@patientadvocate.org)

[www.patientadvocate.org](http://www.patientadvocate.org)

Available in multiple languages

### **Prairie State Legal Services**

**What:** Free legal services for low-income persons and 60 and over who have serious civil legal problems.

**Resources:** Policy publications, self-help center links, and civil case legal assistance.

5320 West Elm Street McHenry, IL 60050

(815) 344-9113

[www.pslegal.org](http://www.pslegal.org)

### **Triage Cancer**

**What:** A non-profit organization that provides education on the legal and practical issues individuals coping with cancer face

**Resources:** Free publications, animated videos, educational blog, webinars, conferences, etc.

<https://triagecancer.org>

## **Health Insurance Resources**

### **Healthcare.gov**

**What:** Website for all healthcare options available

(800) 318-2596

[www.healthcare.gov](http://www.healthcare.gov)

Available in Spanish

### **Medicaid**

**What:** Illinois Department of Human Services Family Community Center in McHenry County

512 Clay Street Woodstock, IL 60098

(815) 338-0234

Application: [abe.illinois.gov/abe/access/](http://abe.illinois.gov/abe/access/)

### **Senior Health Insurance Program (SHIP)**

**What:** Free statewide health insurance counseling service for Medicare beneficiaries and their caregivers.

**Resources:** Health insurance publications and resources for Medicare

(800) 252-8966

[AGING.SHIP@illinois.gov](mailto:AGING.SHIP@illinois.gov)

[www.illinois.gov/aging/ship](http://www.illinois.gov/aging/ship)

### **Triage Cancer**

**What:** A non-profit organization that provides education on the legal and practical issues individuals coping with cancer face

**Resources:** Free publications, animated videos, educational blog, webinars, conferences, etc.

<https://triagecancer.org/healthinsurance>

### **U.S. Department of Labor**

**What:** Outlines information on the Consolidated Omnibus Budget Reconciliation Act (COBRA) for the continuation of health care coverage.

**Resources:** Frequently asked questions, healthcare opportunity links, and policy publications

[www.dol.gov/general/topic/health-plans/cobra](http://www.dol.gov/general/topic/health-plans/cobra)

Some Spanish publications available

## **Financial Assistance Resources**

Many programs are available that provide financial assistance with co-pays, healthcare, premiums, coinsurance, deductibles, and other expenses on a local, state and national level. In addition to the resources listed below, you may want to speak with your health care team for guidance or to view an up to date list visit <https://cancerfinances.org>.

### **Food, Housing, and Other General Financial Assistance Programs**

#### **Blessing Barn**

**What:** Provides basic life need supplies (clothes, household items etc.) to those in need

8310 Railroad St. Crystal Lake, IL 60012

(815) 382-0206

[jpiggott@blessingbarn.org](mailto:jpiggott@blessingbarn.org)

[www.blessingbarn.org](http://www.blessingbarn.org)

Open first Saturday of the month 9 am – 11 am

Interpreters available

#### **CancerCare**

**What:** Support for diagnosed patients receiving treatment and at or below the 150 percent federal poverty level.

**Resources:** Transportation, home care, childcare, and pain medication- funds not for rent, mortgages, utility payments or food

(800) 813-4673

[www.cancercare.org/financial](http://www.cancercare.org/financial)

Available in Spanish

#### **Catholic Charities USA - Chicago Office**

**What:** Provides emergency assistance for those undergoing major life crises.

**Resources:** Food and clothing supplies, other online resource connections.

721 N. LaSalle St., Chicago, IL 60654

(312) 655-7500

[catholiccharities.net](http://catholiccharities.net)

Available in Spanish. Closest affiliate is in Chicago, IL

**Cancer Financial Assistance Coalition (CFAC)**

**What:** A coalition of financial assistance organizations.

**Resources:** Database of organizations and advocating for cancer patients to participating organizations

Individually contact each organization

[www.cancerfac.org](http://www.cancerfac.org)

**Colon Cancer Alliance: Blue Hope Financial Assistance**

**What:** Provides financial assistance for colorectal cancer screening and treatment expenses for uninsured patients

(877) 422-2030

[www.ccalliance.org](http://www.ccalliance.org)

**Consumer Credit Counseling Services of Northern Illinois**

**What:** Credit and Debt counseling and education for anyone who needs financial assistance

**Resources:** Debt management program, house down payment assistance, and credit report analysis

400 Russel Ct. Woodstock, IL 60098

(815) 338-5757

[webmaster@illinoiscccs.org](mailto:webmaster@illinoiscccs.org)

[www.illinoiscccs.org](http://www.illinoiscccs.org)

**Direct Assistance Program**

**What:** Provide process to obtain emergency financial aid (Must live in Woodstock or within district #200)

**Resources:** Pace passes, gas, food, clothing, and some prescribed medications. Assist with rent, auto repairs, and shut off notices

Grace Lutheran Church 1300 Kishwaukee Rd. Woodstock, IL 60098

(815) 529-4370

[www.wacm.org](http://www.wacm.org)

**Leukemia & Lymphoma Society (LLS) Illinois Chapter**

**What:** Multiple financial programs available for blood cancer patients

**Resources:** Co-payment plans, travel expenses, and urgent needs

954 W. Washington Blvd Suite 305 Chicago, IL 60607

(800) 955-4572

[www.lls.org/support/financial-support](http://www.lls.org/support/financial-support)

Available in Spanish

### **McHenry County Housing Authority**

**What:** Assists low-income individuals with a variety of living necessities.

**Resources:** Emergency shelters, overdue rent & security deposits, home energy assistance, public housing assistance, and repair vouchers.

1108 N. Seminary Avenue (Route 47) Woodstock, Illinois, 60098

(815) 338-7752

[www.mchenrycountyhousing.org](http://www.mchenrycountyhousing.org)

### **McHenry County Food Pantries**

**What:** Provides free food for people of McHenry County

Crystal Lake: (815) 455-0961 Algonquin: (847) 854-1904 McHenry: (815) 344-4717 Woodstock: (815) 337-0375 (more online)

[www.needhelppayingbills.com/html/mchenry\\_county\\_food\\_pantry](http://www.needhelppayingbills.com/html/mchenry_county_food_pantry)

### **Meals on Wheels Association of America - Barrington Area Council on Aging**

**What:** Provide older adults who are low-income or have poor health with nutritious meals

6000 Garlands Lane, Suite 100 Barrington, IL 60010

(847) 381-5030

[info@bacoa.org](mailto:info@bacoa.org)

[www.bacoa.org](http://www.bacoa.org)

### **Mission4Maureen**

**What:** Financial assistance for brain tumor patients

(440) 840-6497

[info@mission4maureen.org](mailto:info@mission4maureen.org)

[www.mission4maureen.org](http://www.mission4maureen.org)

Apply Online

### **No Wooden Nickels**

**What:** Provides financial assistance for Illinois cancer patients.

**Resources:** Financial support on transportation, medical co-payments, meals, clothing, and labs, a scholarship program, and the adopt a family program

(888) 842-2654

[www.nowoodennickels.org](http://www.nowoodennickels.org)

Available in Spanish

**Surviving and Moving Forward: The SAMFund for Young Adult Survivors of Cancer**

**What:** Financial assistance for cancer survivors between the ages of 21 and 39.

(617) 938-3484

[grants@thesamfund.org](mailto:grants@thesamfund.org)

[www.thesamfund.org](http://www.thesamfund.org)

**The Pink Fund**

**What:** Assistance on cost-of-living bills during active treatment

(877) 234-7465

[info@thepinkfund.org](mailto:info@thepinkfund.org)

[www.pinkfund.org](http://www.pinkfund.org)

**Low Cost Medical Care and Supplies Resources****Community Health Partnership of Illinois**

**What:** Primary healthcare, insurance enrollments services, and patient assistance services for uninsured or underinsured

62 N. Ayer St. Suite A&B Harvard, IL 60033

(815) 943-4339

[www.CHPofIL.org](http://www.CHPofIL.org)

Available in Spanish

**Family Health Partnership Clinic**

**What:** Provides quality healthcare for uninsured and underinsured residents of McHenry County

401 Congress Parkway, Crystal Lake, IL. 60014

(779) 220-9300

[hpclinic.org](http://hpclinic.org)

Available in Spanish

**Illinois Breast and Cervical Cancer Program**

**What:** Free mammograms, breast exams, pelvic exams and Pap tests to uninsured women age 35-64.

Available in Spanish

### **McHenry Community Health Center**

**What:** affordable healthcare for publically insured, underinsured, and uninsured.

Resources: pediatric, adult medical, psychiatry, counseling, disease management, public benefit enrollment, and care management

3901 Mercy Cr. McHenry, IL 60050

(815) 363-9900

dmanjarrez@gefcc.org

GEFCC.org

Accepts most Medicaid insurance and offers sliding scale for eligible incomes

### **Prescription and Drug Help**

#### **CancerCare Co-Payment Assistance Foundation**

**What:** Co-payments for chemotherapy and targeted treatment drugs for patients up to 4 times the poverty level and receiving insurance to cover portion of expenses.

(866) 552-6729

information@cancercarecopay.org

[www.cancercare.org/copayfoundation](http://www.cancercare.org/copayfoundation)

Available in Spanish

#### **FamilyWize Card**

**What:** United Way of Greater McHenry County partnered with FamilyWize to distribute prescription discount cards for medications not covered by insurance. Save an average 45% on every prescription.

[www.familywize.org](http://www.familywize.org)

#### **NeedyMeds**

**What:** Helps locate assistance for medication and healthcare costs.

**Resources:** Database on prescription, coupon, transportation, and clinic resources

(800) 503-6897

info@needymeds.org

[www.needymeds.org](http://www.needymeds.org)

Available in Spanish

### **Patient Access Network (PAN) Foundation**

**What:** Provides medication and treatment expense support for patients

**Resources:** Co-payments, travel costs and premium costs.

(866) 316-7263

[info@panfoundation.org](mailto:info@panfoundation.org)

[www.panfoundation.org](http://www.panfoundation.org)

### **RxAssist**

**What:** Database of patient assistance programs, as well as practical tools, news, and articles to find free medications

[info@rxassist.org](mailto:info@rxassist.org)

[www.rxassist.org](http://www.rxassist.org)

### **RxHope**

**What:** Web-based patient assistance resource to determine eligibility for free or discounted drugs

[www.rxhope.com](http://www.rxhope.com)

### **GoodRx**

**What:** Helps find cheapest prescription in a geographic area.

[www.goodrx.com](http://www.goodrx.com)

### **Utility Assistance Programs**

Many gas, electric, water, and phone companies offer assistance programs. Contact your company before your fees become outstanding. Many companies are willing to create payment plans to accommodate and avoid shut-off notices. Your doctor or social worker can provide written letters describing why the assistance services are medically necessary. In emergencies, check with local helplines and social service agencies for possible one-time coverage.

### **H2O Help to Others Program**

**What:** Emergency assistance program created by Illinois American Water and Illinois' Salvation Army agencies to help provide supplemental funding to Illinois American Water customers. Local Salvation Army determines eligibility.

Crystal Lake Salvation Army 290 W. Crystal Lake Ave., Crystal Lake, IL 60014 (815-455-2769)

(800) 422-2782

[amwater.com/ilaw/customer-service-billing/customer-assistance-program](http://amwater.com/ilaw/customer-service-billing/customer-assistance-program)

### **Illinois Home Weatherization Assistance Program (IHWAP)**

**What:** Helps low income residents reduce energy costs by making their homes energy efficient.

Apply at McHenry County Housing Authority 1108 North Seminary Avenue P.O. Box 1109  
Woodstock, Illinois 60098-1109

[www.illinois.gov/dceo/CommunityServices/HomeWeatherization](http://www.illinois.gov/dceo/CommunityServices/HomeWeatherization)  
(815) 338-7752

### **Lifeline & Link-up Phone Assistance**

**What:** Helps pay for installation of telephone service and monthly charges for local phone service. Lifeline, a federal assistance program, offers up to \$10 off each month. Link-up, a state assistance program, offers up to a \$35 installation price.

[www.linkupillinois.org](http://www.linkupillinois.org)

Available in Spanish

### **Low Income Home Energy Assistance Program (LIHEAP)**

**What:** Helps eligible low-income households pay for home energy services, primarily in winter.

Apply at McHenry County Housing Authority 1108 North Seminary Avenue P.O. Box 1109  
Woodstock, Illinois 60098-1109

[www.illinois.gov/dceo/CommunityServices/UtilityBillAssistance](http://www.illinois.gov/dceo/CommunityServices/UtilityBillAssistance)  
(815) 338-7752

Online brochures available in Spanish

## **Resources for Children**

### **4-C-Community Coordinated Childcare**

**What:** Financial assistance to income eligible families seeking childcare

**Resources:** free childcare referrals and resource information

667 Ridgeview Dr. McHenry, IL 60050

(815) 758-8148 ex. 225

pamw@four-c.org

[www.four-c.org](http://www.four-c.org)

### **All Kids**

**What:** Complete health insurance for children that covers doctor visits, hospital stays, prescription drugs, vision care, dental care, and eyeglasses. Income requirements.

(866) 255-5437

[www.illinois.gov/hfs/MedicalPrograms/AllKids](http://www.illinois.gov/hfs/MedicalPrograms/AllKids)

Apply Online

### **Bear Necessities Pediatric Cancer Foundation**

**What:** Gifts/financial support for children (0-19) currently in treatment, living in the state of Illinois or being treated at one of the nine major Chicago area hospitals with pediatric oncology departments qualifies for our services.

(312) 214-1200 x25

[www.bearnecessities.org](http://www.bearnecessities.org)

### **Clayton Dabney Foundation for Kids with Cancer**

**What:** Provides low-income families, with children in the last stages of terminal cancer, assistance in providing last wishes, gifts, special events, family travel and financial assistance with household expenses.

(214) 261-2600

[www.claytondabney.org](http://www.claytondabney.org)

### **First Hand Foundation**

**What:** Provides low-income children with health-related needs treatment, equipment, displacement, or vehicle modification funding.

(816) 201-1569

[myfirsthand@cerner.com](mailto:myfirsthand@cerner.com)

[www.firsthandfoundation.org](http://www.firsthandfoundation.org)

**Friends4Michael Foundation**

**What:** Help cover specific non-medical costs related to a primary brain tumor diagnosis for families that have children 18 or under being treated in the United States.

(845) 401-8689

[assistance@friends4michael.org](mailto:assistance@friends4michael.org)

[www.friends4michael.org](http://www.friends4michael.org)

**Head Start - Community Action Agency for McHenry County**

**What:** Preschool program for children 3-5 and in low-income households

100 N. Benton Street Suite 3 Woodstock, 60098

(815) 338-8790

**It's All About Kids Foundation**

**What:** Helps McHenry County families who have a child diagnosed with cancer and are seeking financial assistance

(815) 482-1985

[www.itsallaboutkids.info](http://www.itsallaboutkids.info)

**National Children's Cancer Society**

**What:** Funds for transportation expenses such as mileage, airfare and lodging when a child needs to stay near the hospital for treatment or \$300 in emergency assistance.

(314) 241-1600

[www.thenccs.org](http://www.thenccs.org)

**St. Jude Children's Research Hospital**

**What:** Children's hospital that offers treatment protocols for pediatric brain tumors. All patients accepted are treated without regard to ability to pay - referrals made through doctor.

(901) 595-3300

[www.stjude.org](http://www.stjude.org)

Available in Spanish

**UIC Division of Specialized Care for Children**

**What:** Helps children (birth – 21) with special healthcare needs connect to services and resources. Eligibility determined by the Illinois Department of Healthcare and Family Services  
4302 N. Main St. Room 106 Rockford, IL 61103

(815) 987-7571

[dscc@uic.edu](mailto:dscc@uic.edu)

[www.dscc.uic.edu](http://www.dscc.uic.edu)

**United Healthcare Children's Foundation**

**What:** Helps children 16 and under gain access to health-related services not covered, or not fully covered, by their family's commercial health insurance plan

(855) 698-4223

[customerservice@uhccf.org](mailto:customerservice@uhccf.org)

[www.uhccf.org](http://www.uhccf.org)

## **Other Services**

### **Cancer Support Community - MyLifeLine.org**

**What:** Creates personal websites to allow people to easily get updates and offer support and encouragement to cancer patients.

(888) 793-9355

[support@mylifeline.org](mailto:support@mylifeline.org)

[www.mylifeline.org](http://www.mylifeline.org)

### **American Cancer Society Road to Recovery**

**What:** Provides transportation to and from treatment for people with cancer who do not have a ride or are unable to drive themselves

(800) 227-2345

[www.cancer.org](http://www.cancer.org)

Available in Spanish

### **CaringBridge**

**What:** Creates personal websites to allow people to easily get updates and offer support and encouragement to cancer patients.

(651) 789-2300

[www.caringbridge.org](http://www.caringbridge.org)

### **Cleaning for a Reason**

**What:** House cleaner services to provide free house cleaning to women, 19 years or older, battling any type of cancer

(877) 337-3348

[info@cleaningforareason.org](mailto:info@cleaningforareason.org)

[www.cleaningforareason.org](http://www.cleaningforareason.org)

### **Dental Lifeline Network**

**What:** Provides free, comprehensive dental treatment to people with disabilities, elderly or medically fragile

(888) 235.5826

[www.dentallifeline.org](http://www.dentallifeline.org)

### **Look Good Feel Better**

**What:** Free program for women in active cancer treatment in which cosmetologists teach women in active cancer treatment techniques. By appointment only.

(815) 344-8000

[www.centegra.org](http://www.centegra.org)

Centegra Sage Cancer Center, 4305 Medical Center Drive, McHenry, IL

(800) 3-ADVOCATE

[www.advocatehealth.com](http://www.advocatehealth.com)

### **McHenry County Crisis Program - 24 Hour Crisis Line Intervention**

**What:** Provides an opportunity for a person to talk about their problems and explore options.

Targeted referrals are given, linking the caller to appropriate service

(800) 892-8900

### **McHenry County 211**

**What:** Dialing 2-1-1 in McHenry County will connect you to a call center that will direct you to an appropriate social service agency or nonprofit organization

[www.findhelp211.org](http://www.findhelp211.org)

### **Pace Bus Dial-A-Ride - McHenry County**

**What:** Low cost transportation services for individuals with disabilities.

(800) 451-4599

[mcrider@co.mchenry.il.us](mailto:mcrider@co.mchenry.il.us)

[www.pacebus.com/sub/paratransit/sd\\_dial\\_a\\_ride](http://www.pacebus.com/sub/paratransit/sd_dial_a_ride)

Interpreters available upon request

### **Phil's Friends Care Packages**

**What:** Care Package with comforting items cancer patients need and enjoy. These Care Packages are then shipped and delivered in a decorated Phil's Friends box.

(224) 653-8315

[info@philsfriends.org](mailto:info@philsfriends.org)

[www.philsfriends.org](http://www.philsfriends.org)

### **Wig Program provided by American Cancer Society - McHenry County**

**What:** Free wigs to cancer patients.

(800) 227-2345

[www.cancer.org](http://www.cancer.org)

Centegra Hospital - Sage Cancer Center 4305 Medical Center Dr. McHenry, Illinois 60050

## **Support Groups**

### **Advocate Good Shepard Support Groups**

**What:** Emotional, social and educational support to those dealing with the cancer journey as patients, family members, caregivers and survivors.

**Resources:** Counseling Services, Social Work Services, Cancer Support Group, Breast Cancer Support Group, Melanoma Support Group, Polish Support Group, Bone Marrow Transplant Survivorship Group

(847) 723-5690

[www.advocatehealth.com/health-services/cancer-institute/support-wellness/cancer-survivorship-center](http://www.advocatehealth.com/health-services/cancer-institute/support-wellness/cancer-survivorship-center)

Cancer Survivorship Center 1999 Dempster St. Park Ridge, IL 60068

Available in Polish

### **American Cancer Society**

(800) 227-2345

[www.cancer.org](http://www.cancer.org)

Available in Spanish

### **Centegra Support Groups**

**What:** Emotional, social and educational support to those dealing with the cancer journey as patients, family members, caregivers and survivors.

**Resources:** Breast Cancer Survivor Group, Cancer Transitions, Caring for the Caregiver, Growing Together Through Cancer Transitions, Living with Grief, Young Ribbons-Breast Cancer Survivor Group

(815) 344-8000

[centegra.org/service/oncology/support/](http://centegra.org/service/oncology/support/)

### **The Cancer Transitions**

**What:** Program to help cancer survivors make the transition from active treatment to post-treatment care

(815) 759-4459

[centegra.org/event/cancer-transitions](http://centegra.org/event/cancer-transitions)

Centegra Sage Cancer Center, 4305 Medical Center Drive, McHenry, IL

### **Complementary Therapy**

**What:** offers a variety of these nondrug treatment options from music therapy and acupuncture to psychological support and yoga

(815) 356-6149

[centegra.org/service/oncology/support/](http://centegra.org/service/oncology/support/)

### **Independence Health & Therapy**

**What:** Provides support groups for caregivers

2028 N. Seminary Woodstock, IL 60098

(815) 338-3590

### **Mercy Breast Cancer Support Group**

**What:** Group for woman diagnosed with breast cancer, whether newly diagnosed or years into survivorship. You do not have to be a Mercyhealth patient.

(815) 971-1110

[www.mercyhealthsystem.org/service/cancer](http://www.mercyhealthsystem.org/service/cancer)

### **The Renewal Center: A Wellness Oasis for Cancer Survivors**

**What:** Counseling, education and connecting to help people deal with the emotional issues that comes with a diagnosis of cancer

620 Dakota St. Crystal Lake, 60014

(815) 382-5645

[centegracrisisservices.org/resource/renewal-center-wellness-oasis-cancer-survivors](http://centegracrisisservices.org/resource/renewal-center-wellness-oasis-cancer-survivors)

### **St. Peregrine Cancer Support**

**What:** Non-denominational support group that meets at 10:00 am the second Tuesday every month for cancer patients, survivors, family members and friends.

(815) 675-0140

[Stjohnsjohnsburg.org/st-peregrine-cancer-support](http://Stjohnsjohnsburg.org/st-peregrine-cancer-support)

Alternate meeting places between several Catholic Churches around Johnsburg, IL

### **Willow Creek Cancer Support Group**

**What:** Offers a large-group teaching, a devotional time, and small-group discussion, participants can experience joy, hope, and healing in this caring, Christ-centered community

67 Algonquin Rd South Barrington, IL 60010

(847) 765-5000

[www.willowcreek.org/en/care/relational-resources/cancer-support](http://www.willowcreek.org/en/care/relational-resources/cancer-support)

## **Appendix**

1. How Triage Cancer Can Help
2. Triage Cancer's Appeals Tracking Sheet
3. Illinois External Review Request Form
4. Medical Certification Chart – Explaining the Differences between FMLA and ADA
5. Department of Labor's Certification of Health Care Provider for Employee's Serious Health Condition (Family and Medical Leave Act)
6. Department of Labor's Certification of Health Care Provider for Family Member's Serious Health Condition (Family and Medical Leave Act)