



The Financial Side of Cancer

How Do I Afford My Treatment

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Overview

- What is health insurance?
- What do I need to know to navigate my insurance and advocate for myself
 - Key terms
- What if I can't work
 - Disability options
 - FMLA
 - ADA protections
- Where can I get more help?
 - Co-pay assistance

Newsflash: Being Sick Isn't Cheap

- **68%** of personal bankruptcies in the US are the result of medical debt.
- **78%** of those declaring personal bankruptcy due to medical debt were INSURED (Woolhandler, et.al. American Journal of Medicine, 2009).
- **One out of four** cancer patients avoids filling prescriptions due to cost and **42 %** of cancer patients express a significant or catastrophic financial burden (The Oncologist, 2013).
- 11 of the 12 cancer drugs approved by the FDA in 2012 **cost over \$100,000 per year.**

Being Sick Isn't Cheap

- **55%** of cancer patients surveyed said the stress of dealing with costs negatively affects their ability to focus on their recovery (Association of Oncology Social Work).
- **But only 36%** of patients have discussed the cost of treatment with their oncologist and only half of patients surveyed feel comfortable speaking with health professionals about financial issues (Association of Oncology Social Work).
 - **16%** of patients and caregivers report that they believe their oncologists give a lot of thought to the financial implications of the treatment they prescribe (Association of Oncology Social Work).
 - **58%** of patients reported being distressed about their finances during treatment, but only **25%** of those younger than 64 said their care team never considered their financial situation during treatment planning; **34%** said it was only "sometimes" considered. (CancerCare)

Costs influence care, health & well-being

- Many respondents used care-altering strategies to reduce costs:
 - **29%** said they skipped doctors' appointments;
 - **38%** postponed or did not fill drug prescriptions;
 - **34%** skipped doses;
 - **30%** ordered medications online from sources outside the US; and
 - **31%** cut oral medications in half.
- Respondents use life-style altering strategies to reduce costs:
 - **One-third** of respondents ages 25 to 54 reported cutting back on groceries and transportation; and/or borrowed money;
 - **One-quarter** applied for financial assistance;
 - 21% missed a utility bill payment;
 - 17% missed a rent or mortgage payment.
- The average monthly out-of-pocket spending for treatment-related expenses among non-elderly respondents was \$1,112, nearly twice as much as those 65 and older (CancerCare).

- Financial protection against medical expenses if you have an accident or major illness.
- Insurance is a contract between you (the insured) and the insurance company.
- Typically, the provider of the service submits a claim to the insurance company (the payer) for the services provided.
- With some plans or services, the patient will pay out of pocket for the visit/procedure, submit supporting documentation to the insurance company for the claim and then be reimbursed for the expense.

What is Health Insurance?

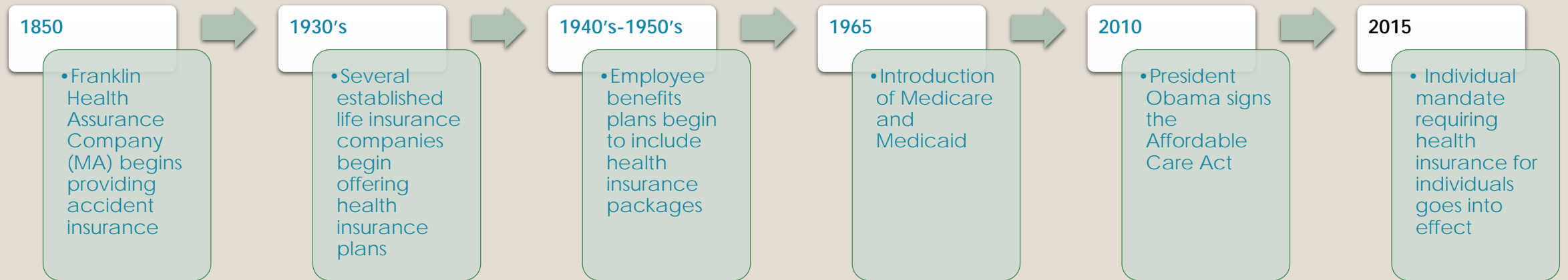


Why Should I Have Health Insurance?

- Accidents and sickness happen all the time.
- Medical debt is the number one cause of personal bankruptcy.
- Insurance helps us have access to networks of doctors and hospitals as a group and to negotiate lower costs with insurance companies.
- Health insurance acts to safeguard our quality of life, and physical and financial well-being.
- Because you **HAVE** to (the individual mandate).

How Did We Get Here?

A Brief History of Health Insurance in the US.



Private Plans

Employer/Union
Provided Plans

Types of
Insurance

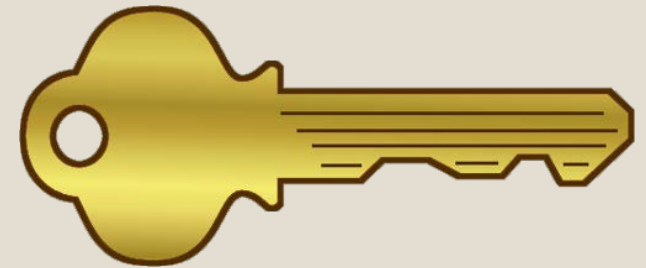
Government Provided
Plans

Medicare, Medicaid, Veterans, Tricare

Affordable Care
Act Plans

Key Considerations

- What is covered?
- What isn't covered?
- How much does it cost?
- What health care providers can I see?
- Where can I use my plan?



The Super Six:

Key Things About Your Coverage You **MUST** Know

- **Premium**-the monthly amount you pay for your insurance plan(s).
- **Deductible**-the amount of money you pay before your insurance starts to cover healthcare costs.
- **Cost Sharing** -The contribution you pay towards your health care costs out of your own pocket
 - Typically includes deductibles, coinsurance, and copayments, or similar charges.
 - Does not include premiums, balance billing amounts for non-network providers, or the cost of non-covered services.
- **Co-pay**- a fixed dollar amount you pay when you go for an appointment/procedure in addition to what the insurance company pays for the service. For example \$20 for office visit with primary care provider.
- **Coinsurance** -the cost sharing amount you pay as part of your coverage. For example if your plan covers at 80/20% your coinsurance is 20%.
- **MOOP**-the maximum out of pocket you pay during a benefit period; also called a stop-loss.

Other Important Things to Know

- **Benefit year**-A year of benefits coverage under an individual health insurance plan; can be based on calendar year (as with Medicare/ACA plans), fiscal year, or employment date.
- **Formulary**-A list of prescription drugs covered by a prescription drug plan; can include tiers and step therapies
- **Network**-The facilities, providers and suppliers your health insurer has contracted with to provide health care services.

Other Important Things to Know

- **Prior authorization**-Approval from a health plan that may be required before you get a service or fill a prescription in order for it to be covered by your plan.
- **Preauthorization/precertification/prior approval**-A decision by your health insurer or plan that a health care service, treatment plan, prescription drug or durable medical equipment is medically necessary.
- Your health insurance or plan may require preauthorization for certain services before you receive them, except in an emergency.
- Preauthorization isn't a promise your health insurance or plan will cover the cost.
- **Denial**-a refusal by an insurance company to honor a request by an individual (or his or her provider) to pay for health care services obtained/ordered/requested by a healthcare professional.
- **Appeal**-A request to the health insurer or plan to review a decision or a grievance again; can have multiple levels and be consumer and/or provider driven.

How Do I Figure Out My Insurance Coverage?

- KNOW YOUR PLAN.
 - What are the “pain points” with your current coverage?
 - Don’t throw away your explanation of benefits forms(EOB)!
- Use the Cancer Insurance Checklist to DO YOUR RESEARCH!
 - http://www.cancerinsurancechecklist.org/site/wp-content/uploads/2015/10/cancer_coverage_checklist_tabloid_dk-changes-03.pdf
- ASK FOR HELP!



BUT WHAT IF I CAN'T WORK?!

COPING WITH INCOME & RESOURCE CHANGES

- ❖ Disability Options
 - ❖ FMLA
- ❖ ADA Protections

Disability Options

Employer Provided

- Your employer MAY provide some short and/or long term disability coverage.
- Be mindful during open enrollment periods of your employers disability options.
- ST disability coverage is usually not the same amount of income as what you received when you were working.

State Disability

- Some states have state sponsored disability programs: CA, HI, NJ, NY, RI, & PR
- If you live in one of these states, your employer has paid in to the state disability fund. Short and long-term disability claims are managed by the state.
- Contact the state disability board ASAP when you are no longer able to work to initiate your disability claim.

Social Security Disability-SSDI

- You must have a documented work history to be eligible for SSDI.
- Your healthcare provider must attest that you will be out of work for at least 1 year as a result of your illness.
- There is a six month waiting period to begin receiving benefits.
- Your date of disability (i.e. the day you stop working as a result of your illness) is a key date.

The Family and Medical Leave Act of 1993 (FMLA)

- Permits employees to take unpaid, job protected, leave of absence time due to the *serious medical condition* of the employee or a family member - a spouse, parent, or child.
- Successful usage of FMLA is dependent on clear communication and teamwork between the employer, employee, and medical team.
- FMLA is intended to promote the work-life-family balance, enhance quality of life for employees and promote economic security and stability.
- FMLA helps employees feel like they do not have to choose between their jobs and their own well-being, or the well-being of a close relative who is coping with illness.

FMLA

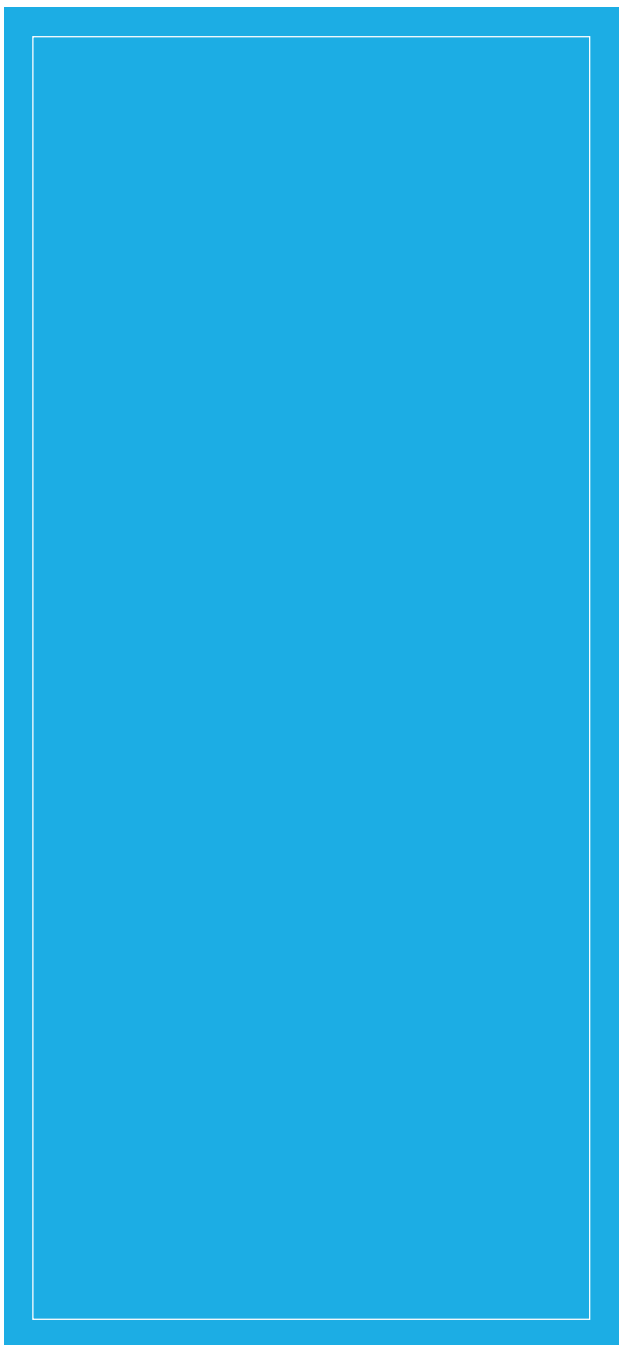
- FMLA covered time applies to both mental and physical illnesses of the individual/family member.
- Private employers with 50 or more employees and all public employers must offer FMLA to their employees who have worked at least 12 months and 1250 hours within the previous year (equivalent of 31.25 hours per week).
- A serious medical condition is a condition that results in an overnight stay in a hospital/extended care facility, and/or 3 days or more of incapacitation/inability to perform work tasks, and/or the need for ongoing medical care for the patient or family member for a chronic condition which results in incapacitation. Pregnant women and families who adopt a child are also covered under FMLA.



FMLA

- An employee can take up to 12 weeks (60 work days or 480 work hours) of unpaid time per year under FMLA. This can be taken at one time or intermittently, meaning you can take time as needed with proper notice and planning with your employer.
 - For example, you receive chemotherapy on Thursdays, so you take Thursday and Friday under FMLA time and also have the weekend to recover. You then return to work as scheduled on Monday. You have used 2 days (16 hours) of FMLA time.
- If you have sick or vacation time, your employer should work with you on using this time with FMLA so that you have income.
 - Your employer should also facilitate usage of short and long term disability pay, in conjunction with FMLA, if this benefit is offered by your job.





ADA Protections

- Federal law-(there are also state disability protections)
- Provides individuals with disability protection against disabilities
- There are 5 Titles of the ADA
 - **Title 1: Employment**
 - Title 2: Public entities and transportation
 - Title 3: Public accommodations and commercial facilities
 - Title 4: Telecommunications
 - Title 5: Misc.

ADA: Title 1

- Who is eligible?
 - Private employers with 15 or more employees
 - State/local governments
- Be a “qualified individual”
- Have a disability under the ADA’s of disability definition
 - “A physical or mental impairment that substantially limits one or more major life activities.”
- Benefits
 - Protects the employee from discrimination
 - Reasonable accommodations

Using Reasonable Accommodations to KEEP Working

- What is a reasonable accommodation?
- Can include:
 - Modifying work space
 - Modifying work schedule
 - Use of technology
 - Changes to policies and procedures
 - Changes to job responsibilities
 - Change to another position



WHERE CAN I GET
HELP?

What is Co-Pay Assistance?

- Co-pay assistance is financial assistance for co-pays (patient responsibility) for patients WITH insurance—but whom we would consider to be UNDERINSURED (commercial/private/Medicare).
- Patients must meet BOTH diagnostic & financial criteria.
- Co-pay assistance covers costs of medication (oral and IV); some co-pay foundations also cover insurance premiums.
- Co-pay assistance typically does not cover co-pays for diagnostic imaging, labs, radiation, travel, lodging, or office visits.

What is Co-Pay Assistance

- For programs that do cover office visit co-pays (LLS and Cancer Care), office visits CAN be covered under Co-Pay assistance ONLY if the patient is receiving chemotherapy on the SAME DAY.
- Co-pay assistance DOES NOT apply to the uninsured.
- Co-pay assistance (private foundations) differs from co-pay cards (drug company sponsored).
- Co-pay assistance DOES NOT apply to treatments that are DENIED by the insurance company or experimental/off label uses of medications.

Co-Pay Assistance and WM



- The Leukemia and Lymphoma Society
 - Assistance is available up to \$7,500
 - You can reapply ANNUALLY (as long as funds remain available)
 - Use it or lose it
 - Currently closed; check frequently
 - Eligibility requirements:
 - Have a household income that is at or below 500% of the U.S. federal poverty guidelines as adjusted by the Cost of Living Index (COLI).
 - Be a U.S. citizen or permanent resident of the U.S. or Puerto Rico and be medically and financially qualified
 - Have medical insurance and/or prescription insurance
 - Have an LLS Co-Pay Assistance Program-covered blood cancer diagnosis confirmed by a doctor

https://www.lls.org/sites/default/files/National/USA/Pdf/Slides_Transcripts/2019_FPL_1.28.19.pdf

Co-Pay Assistance and WM



- Pan Foundation (1-866-316-7263)
 - Assistance is available up to \$5,000
 - Currently closed; check frequently
 - Eligibility requirements:
 - The patient must be getting treatment for Waldenstrom macroglobulinemia.
 - The patient must have Medicare health insurance that covers his or her qualifying medication or product.
 - The patient's medication or product must be listed on PAN's list of covered medications.
 - The patient's income must fall at or below 500% of the Federal Poverty Level.
 - The patient must reside and receive treatment in the United States or U.S. territories. (U.S. citizenship is not a requirement.)

<https://panfoundation.org/index.php/en/patients/assistance-programs/waldenstrom-macroglobulinemia>

Percentages Over 2019 Poverty Guidelines

Family Size	100%	133%	150%	200%	250%	300%	400%	500%
1	\$12,490	\$16,612	\$18,735	\$24,980	\$31,225	\$37,470	\$49,960	\$62,450
2	\$16,910	\$22,490	\$25,365	\$33,820	\$42,275	\$50,730	\$67,640	\$84,550
3	\$21,330	\$28,369	\$31,995	\$42,660	\$53,325	\$63,990	\$85,320	\$106,650
4	\$25,750	\$34,248	\$38,625	\$51,500	\$64,375	\$77,250	\$103,000	\$128,750
5	\$30,170	\$40,126	\$45,255	\$60,340	\$75,425	\$90,510	\$120,680	\$150,850
6	\$34,590	\$46,005	\$51,885	\$69,180	\$86,475	\$103,770	\$138,360	\$172,950
7	\$39,010	\$51,883	\$58,515	\$78,020	\$97,525	\$117,030	\$156,040	\$195,050
8	\$43,430	\$57,762	\$65,145	\$86,860	\$108,575	\$130,290	\$173,720	\$217,150
For each additional family member	\$4,420	\$5,879	\$6,630	\$8,840	\$11,050	\$13,260	\$17,680	\$22,100

Targeted Therapies and WM

- Need help with your co-pays?
 - Apply for co-pay assistance
 - Need more support or don't have Rx coverage?
 - For the uninsured (including those who have exhausted insurance coverage)
 - Johnson and Johnson Assistance Foundation
 - Contact pharmaceutical manufacturer
 - Imbruvica (You&i support program: 877-877-3536)
<https://www.imbruvica.com/patient-support/access-support>
 - Rituxin: Genentech offers co-pay cards for commercially insured
<https://www.genentech-access.com/hcp/brands/rituxan/rituxan-nhl-cll/find-patient-assistance/co-pay-cards.html>

Other Sources of Assistance

- Medicine Assistance Tool <https://medicineassistancetool.org/>
- NeedyMeds <https://www.needymeds.org/>
- Rx Relief Pharmacy Discount Card <https://www.rxreliefcard.com/>
- RxAssist <https://www.rxassist.org/>
- RxOutreach <https://rxoutreach.org/>
- Xubex <https://www.xubex.com/>
- \$4 Generic Programs-Target, Wal-mart, local grocery store chains

Other Sources of Pharma Assistance

- Medicare Part D Recipients
 - Low Income Subsidy- “Extra Help” Extra Help is a federal program that helps pay for some to most of the out-of-pocket costs of Medicare prescription drug coverage. It is also known as the Part D Low-Income Subsidy (LIS).
 - Pays for your Part D premium up to a [state-specific benchmark amount](#)
 - [Lowers the cost of your prescription drugs](#)
 - Gives you a [Special Enrollment Period \(SEP\)](#) once per calendar quarter during the first nine months of the year to enroll in a Part D plan or to switch between plans (You cannot use the Extra Help SEP during the fourth calendar quarter of the year (October through December). You should use [Fall Open Enrollment](#) during this time to make prescription drug coverage changes.)
 - Eliminates any [Part D late enrollment penalty](#) you may have incurred if you delayed Part D enrollment
- State based prescription drug assistance for the elderly and/or disabled

Key Take-aways

- Get to know your insurance plan-**intimately**.
- Write everything down when dealing with your insurance company, a denial/appeal, disputed charge...including EVERYONE you talk to.
- Ask for help!
- Get creative.
- Use fundraising and crowdsourcing to help achieve specific fundraising goals.
- Thank foundations and individuals for their help!
- Give back: pay forward.



QUESTIONS?

Resources

- www.oncolink.org
- www.medicare.gov
- www.healthcare.gov
- Health Insurance Explained Video
 - http://kff.org/health-reform/video/health-insurance-explained-youtoons/?utm_source=kff&utm_medium=tile&utm_content=home&utm_campaign=consumer
- Health Insurance Quiz
 - http://kff.org/quiz/health-insurance-quiz/?utm_source=kff&utm_medium=tile&utm_content=home&utm_campaign=consumer
- Cancer Insurance Checklist
 - http://www.cancerinsurancechecklist.org/site/wp-content/uploads/2013/09/cancer_insurance_checklist.pdf

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