



National Comprehensive
Cancer Network®

NCCN Digital Booklet of Patient Advocacy Resources



VIRTUAL PATIENT ADVOCACY SUMMIT: **Cancer Across the Lifespan**

The NCCN Digital Resource Booklet includes information from 25 patient advocacy organizations on their age-specific programs and resources.

This Booklet was developed in conjunction with The National Comprehensive Cancer Network's® (NCCN®) *Virtual Patient Advocacy Summit: Cancer Across the Lifespan* held on December 10, 2020.

To view a broader list of advocacy and support groups on the NCCN website, visit nccn.org/patients/advocacy/default.aspx.

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The Anal Cancer Foundation

The Anal Cancer Foundation is dedicated to ending anal cancer and improving the lives of those affected by it. The Anal Cancer Foundation (ACF) is dedicated to ending anal cancer and improving the lives of those affected by it. ACF achieves its mission through advocacy, education, research, and patient support.

URL: analcancerfoundation.org



Peer to Peer Support Program

Age Groups Served: Young Adults, Adults, Older Adults

A critical goal for ACF is that every person and family diagnosed with anal cancer knows they are not alone. ACF's Peer to Peer Support Program is a free service that matches anal cancer thrivers (our word for survivors) and caregivers with volunteers who have been through anal cancer.

ACF volunteers listen and help thrivers through their cancer journey by providing mentorship and sharing their own experiences. From newly diagnosed, to in-treatment, to post-treatment, to post post-treatment, connections are available for anyone at any age and any point in their cancer experience. Once a new participant is matched with a volunteer, ACF follows the pairing closely, providing resources, answering questions, and ensuring the match is working well.

Please contact connect@analcancerfoundation.org for more information and to be paired with someone with a shared experience.

Phone: 646-593-7739

Email: connect@analcancerfoundation.org

Angel Flight East Angel Flight East provides free flights for children and adults in need of medical treatment far from home.

URL: <https://angelflighteast.org/>

Hope in Flight

Age Groups Served: Children, Adolescents, Young Adults, Adults, Older Adults

Through a network of volunteer pilots, Angel Flight East (AFE) bridges the gap between critical medical care and how to get there. AFE covers a 14 state footprint from Virginia to Ohio to Maine and links up with other volunteer pilot organizations for destinations outside of our footprint. Patients are required to be medically stable and ambulatory to board an aircraft. Once qualified, a patient can fly as often as needed and there is never a charge thanks to the generosity of our volunteer pilots.

URL: angelflighteast.org/passengers/request-a-flight/

Phone: 215-358-1900

Email: jessames@angelflighteast.org

Bag It Bag it educates, supports and empowers patients, families, and caregivers through patient education materials and resources that focuses on self-advocacy and survivorship throughout the continuum of care.

URL: bagitcancer.org/

The Bag It bag

Age groups served: Young Adults, Adults, Older Adults

The Bag It bag includes a guidebook and booklets with critical content from national cancer organizations. The booklets include information on questions to ask your doctor, how to cope with the emotional aspects, types of cancer treatments, common side effects, physical activity, and nutrition. My Companion Guidebook is a great way to organize all the paperwork and track medical information, personal and healthcare contacts, medications, side effects, and more. Bag It is available in English and Spanish.

URL: bagitcancer.org/the-bag/

Phone number: 520-575-9602

Email: info@bagitcancer.org



CANCER101 CANCER101's mission is to empower, inform and engage patients and their care partners to navigate their cancer care and partner with their health care team to make informed decisions.

URL: cancer101.org

Phone number: 646-638-2202

Email: info@cancer101.org



CANCER101 Planner “Roadmap to Wellness”

Age groups served: Young Adult, Adults, Older Adults

The CANCER101 Planner provides basics for people diagnosed with cancer and their care partners. The toolkit empowers patients and care partners to get informed, track key elements of their journey, navigate their care, and partner with their care team to make informed decisions. Disseminated at the point of care, through our partnerships with over 1,200 hospitals and community practices, the toolkit ignites a participatory relationship with the health care team. It provides the resources, tools and templates that patients need to take an active role in their condition, but also manage various aspects of life that may be affected by cancer. The CANCER101 Planner can also be personalized by tumor type, phase in their condition, personal profile and specific interests. The ten chapters include:

- myCANCER101: Where do I start? Personalization by cancer type
- myNavigator: Tips to help navigate healthcare
- myToolbox: Templates to document health history and prepare for appointments
- Questions to Ask My Health Care Team: Divided by phase in treatment
- Clinical Trials: Overview of clinical trials as a care option
- Medicine & Symptom Tracker: Important information, trackers and tips
- Managing the Costs of Care: Tips to manage costs, bills and insurance
- Mind, Body & Connections: Nutrition, mental health, fitness, relationships and more
- C101 Lifesavers: Support for the care/ support partner
- Resources: Additional resources and dictionary of terms

URL: cancer101.org/planner/

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CANCER101 *Prescription to Learn*[®]

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Age groups served: Young Adult, Adults, Older Adults

Prescription to Learn[®] is a trusted ecosystem that helps patients and care partners navigate health care from prevention through long-term thrivership. Known as the GPS to healthcare, Prescription to Learn[®] was designed to guide patients and care partners through the information overload they are often confronted with throughout the cancer journey. The goal is to provide access to the right resources at the right time, empowering them to make informed decisions. Patients and care partners can personalize resources by disease state, phase in journey, medium of choice and learning style. They can also rate resources, view ratings of patients, care partners and healthcare professionals, as well as fill information prescriptions prescribed by their clinician.



URL: prescription2learn.org/

Health Match

Age groups served: Young Adult, Adults, Older Adults

Health Match is the problem solver, created to provide a lifeline to patients and their care partners when they need it most by matching them to solutions based on the issue they need help with. We have worked with patients and their care partners to identify identified the main issues that they face from the time of screening through long-term survivorship. These issues include: Find a Doctor, Costs of Care, Manage Symptoms, Care Partner Support, I'm Feeling Alone, Legal Issues, Work Issues, Transportation & Lodging, Talking to Kids About Cancer/Childcare, I Need an Escape, Home/Chore Coordination & Self Image/Sexuality. We have mapped the tools, services, and solutions available to address these problems from trusted organizations, where patients and their care partners can access and rate these resources, as well as view the ratings of others.

URL: cancer101.org/health-match/

Learning Preference Barometer

Age groups served: Young Adult, Adults, Older Adults

The Learning Preference Barometer is a tool that helps address health literacy needs by helping patients and care partners determine their primary and secondary learning style so that education, as well as communication with the health care team can be personalized based on their preferences. The tool guides each person through a series of engaging and interactive questions that assess learning style, recognizing they might be multi-modal. They can also learn the best techniques to act upon information based on their learning style, and access resources we've curated by learning style.

URL: cancer101.org/health-match/

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CANCER101 *Health Tips*

continued

Age groups served: Young Adult, Adults, Older Adults

Health Tips is an infographic series of top health tips and hacks that we've co-designed with patients, care partners, and clinicians based on their stories. This series includes:

- Top 10 Things Every Patient Needs to Know
- Top 10 Tips to Avoid Medical Errors
- Top 10 Tips to Manage the Costs of Care
- What To Do During the Visit With Your Doctor
- Circle of Care: Do You Know Your Health Care Team?
- Our Love/Hate Relationship With Technology



URL: cancer101.org/health-tips/

Cancer Support Community

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.

URL: cancersupportcommunity.org

Phone number: 202.650.5369

Email: efranklin@cancersupportcommunity.org



What Do I Tell the Kids Book

Age groups served: Children, Adolescents, Young Adult, Adults, Older Adults

If you are a parent, or caring for a child and cancer is in your family, this booklet is meant to give you information about a child's general understanding of cancer, ways to talk to them about cancer, some common behaviors you may see in children, and ways to support your family through this experience.

URL: cancersupportcommunity.org/sites/default/files/d7/document/fsac_what_do_i_tell_the_kids.pdf

Frankly Speaking About Cancer: Caregivers booklet

Age groups served: Young Adult, Adults, Older Adults

Family members, spouses, partners, and friends who take on a caregiving role feel cancer's deep emotional impact. This booklet has information to help you be an effective caregiver, reduce stress, get support, and address your own needs.

URL: cancersupportcommunity.org/sites/default/files/migrated/pdf/caregivers_0.pdf

Frankly Speaking About Cancer: Tips for Managing and Budgeting Your Cancer Costs

Age groups served: Young Adult, Adults, Older Adults

Having open conversations about money and the cost of cancer care can help you become better informed about your options for help. This book is a starting place to learn how to talk about the financial side of cancer and where to go for help.

URL: cancersupportcommunity.org/sites/default/files/migrated/pdf/tips_for_managing_and_budgeting_your_cancer_costs.pdf

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Cancer Support Community

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Frankly Speaking About Cancer: Eating Well During Cancer Treatment

Age groups served: Young Adult, Adults, Older Adults

This booklet addresses how cancer patients can cope with common eating problems faced during treatment, like nausea or mouth sores. It also features recipes to help with common problems. Check out our recipe videos here: [youtube.com/watch?v=-G_McalWgXI&list=PLZkuZ-dO4OByLtB7figYPC2iE6x-XKN0Qp](https://www.youtube.com/watch?v=-G_McalWgXI&list=PLZkuZ-dO4OByLtB7figYPC2iE6x-XKN0Qp)

URL: cancersupportcommunity.org/sites/default/files/migrated/pdf/fsac_nutrition_during_treatment.pdf

Frankly Speaking About Cancer: Making Treatment Decisions

Age groups served: Young Adult, Adults, Older Adults

Making treatment decisions about your cancer may seem like a very complicated problem. But, it can be broken down into smaller “bites,” a series of decisions that you make at different points, from diagnosis through the end of your treatment.

URL: cancersupportcommunity.org/sites/default/files/migrated/pdf/making_treatment_decisions_2018.pdf

Cancer Experience Registry

Age groups served: Young Adult, Adults, Older Adults

The Cancer Experience Registry is an opportunity for any adult touched by cancer to share their experience so that others may learn. This online survey captures several parts of the patient and caregiver experience including physical, emotional, social, practical, and financial aspects of cancer. Doctors, nurses, researchers, policymakers, and others in the health care field use the findings in this report to help improve the cancer care journey.

URL: cancersupportcommunity.org/2020CancerExperienceRegistryReport

CLL Society

CLL Society is a patient–centric, physician–curated nonprofit organization focused on patient education, support, research, and advocacy. Dedicated to addressing the unmet needs of the CLL and related blood cancer communities, we explain the rapidly changing therapeutic landscape and the importance of clinical trials, support and build patient networks, engage in research and educate providers and patients. We believe SMART PATIENTS GET SMART CARE™. Learn more at cllsociety.org.

CLL-Specific Patient Support Groups

Age groups served: Young Adults, Adults, Older Adults

The CLL Society recognizes that not all patient needs can be addressed online so we felt it was critical to develop face-to-face Patient Support Groups focused specifically on chronic lymphocytic leukemia (CLL) led by volunteers in regions/cities where there is interest. Whether patients are newly-diagnosed or have lived with CLL for years, CLL Society will provide up-to-date information and support for all who attend meetings. The groups will provide mutual support, learning opportunities, patient-friendly, physician-reviewed monthly updates, as well as offering the opportunity to discuss anxieties and concerns with others.

URL: cllsociety.org/cll-specific-patient-support-groups/

CLL Society Expert Access™ Program

Age groups served: Young Adults, Adults, Older Adults

Free, online 2nd opinion consultation with a CLL expert physician. Personalized advice based on medical records and patients' questions. We believe that access to CLL expert care is critical for every patient to receive his or her best possible care. Access to a CLL expert provides proven survival and outcomes advantage. In other words, those with a CLL expert as part of their team, live longer than those without this advantage. This program offers patients access to CLL expertise through a HIPAA compliant online video consultation.

URL: cllsociety.org/cll-society-expert-access/

Debbie's Dream Foundation: Curing Stomach Cancer

Debbie's Dream Foundation: Curing Stomach Cancer is a 501(c)(3) non-profit organization dedicated to raising awareness about stomach cancer, advancing funding for research, and providing education and support internationally to patients, families, and caregivers. DDF seeks as its ultimate goal to make the cure for stomach cancer a reality.

URL: debbiesdream.org



Patient Resource and Education Program (PREP)

Age Groups Served: Young Adults, Adults, Older Adults

Through our PREP program, we offer many resources to the stomach cancer community through educational material, online content, educational events, monthly support groups, and mentoring services.

URL: debbiesdream.org

Phone: 855-475-1200

Email: programs@debbiesdream.org

EC Aware

EC Aware (formerly ECAA) is a non-profit comprised of all volunteers working to raise awareness of a deadly cancer that is little known among the general population. Our mission is to provide outreach for esophageal cancer patients, caregivers, and survivors; to increase public awareness of this disease; and to offer education and information in a supportive environment.

URL: ec-aware.org

EC Aware Website

Age groups served: Adults, Older Adults

Our website offers easy-to-read information on esophageal cancer – descriptions of the disease, its diagnosis, staging, treatments, and other factors. Our goal is to create a community of survivors, patients and caregivers that together can provide support and information while also increasing awareness of the disease. Information and support are critical in helping patients understand their diagnosis and treatment options.

Esophageal cancer is growing rapidly, with an average of diagnosed people being men over the age of 55; however, the age bracket is decreasing. When patients are diagnosed, we strongly recommend they seek guideline concordant care and join our online support groups. We have a collective social media page for patients, caregivers, and survivors, and individual pages for peer-to-peer support.

Family Reach

Family Reach is a national organization dedicated to eradicating the financial barriers that accompany a cancer diagnosis. We work with patients and healthcare professionals at more than 400 top-tier hospitals and cancer centers, striving to reach more families before they hit critical financial breaking points. Through our solutions-oriented Financial Treatment Program, nationwide events, strategic partnerships, and generous community support, we disrupt how cancer financially affects families.

URL: familyreach.org



Financial Treatment Program

Age Groups Served: Children, Adolescents, Young Adults, Adults

The Financial Treatment Program offers support services to help patients and caregivers overcome the financial side effects of a cancer diagnosis. It's never too soon to apply - we believe financial treatment should start as soon as cancer treatment does.

URL: familyreach.org/ftp/#FTP_Overview

Phone: 973-394-1411

Fight Colorectal Cancer (Fight CRC)

Fight Colorectal Cancer (Fight CRC) is the leading patient-empowerment and advocacy organization in the United States, providing balanced and objective information on colon and rectal cancer research, treatment, and policy. We are relentless champions of hope, focused on funding promising, high-impact research endeavors, while equipping advocates to influence legislation and policy for the collective good.

URL: fightcolorectalcancer.org

Biomarked

Age groups served: Young Adults, Adults, Older Adults

Biomarked is a series of educational resources for colon and rectal cancer patients. These resources include webinars, landing pages, fact sheets, and mini-magazines and are meant to inform patients and healthcare providers of the importance and availability of biomarker testing to improve patient treatment outcomes.

URL: fightcolorectalcancer.org/biomarked

Skin Toxicity Resources

Age groups served: Young Adults, Adults, Older Adults

Skin Toxicity, also known as Chemo Rash, is a common side effect for colorectal cancer patients. Certain kinds of cancer treatments, particularly Epidermal Growth Factor Receptor (EGFR) inhibitors, can cause a skin rash and other skin changes for colorectal cancer patients. Skin toxicity can manifest as a skin rash, itching and cracking, fingernail, and toenail irritation, dry skin, and sensitivity to the sun are common side effects. Fight CRC has developed resources for those experiencing skin toxicity, including video interviews with patients and providers, a mini magazine, and a fact sheet.

URL: fightcolorectalcancer.org/resources/skin-toxicity-resources/

Foundation for Women's Cancer

The Foundation for Women's Cancer (FWC) is a 501 (c)(3) nonprofit organization dedicated to supporting research, education and public awareness of gynecologic cancers. FWC is the official foundation of the Society of Gynecologic Oncology.

URL: foundationforwomenscancer.org



FWC Cancer Education

Age Groups Served: Young Adults, Adults, Older Adults

FWC Cancer Education is a comprehensive set of educational courses designed to support patients and caregivers that answers the question, “what do I need to know?” for a cancer journey. From the basics of “what is cancer?” to understanding treatments, clinical trials and how genetics play a role, to lifestyle discussions on sexual health and nutrition, these courses meet you where you are to answer the questions you might have. Available in self-study and live or recorded webinar formats, these courses are available for you when you need them. Additional downloadable resources are also a part of each course.

URL: foundationforwomenscancer.org/events-courses/upcoming-education-courses

Phone: (312) 578-1439

Email: FWCinfo@sgo.org

Kidney Cancer Association

2020 marks the Kidney Cancer Association's 30th anniversary! Founded in 1990 by a small but committed group of patients and doctors in Chicago, we're celebrating huge milestones and advances in research, in kidney cancer care and treatment, and in advocacy.

URL: kidneycancer.org



KCA's Just Diagnosed Toolkit

Age Groups Served: Adults, Older Adults

The Just Diagnosed Toolkit is a critical resource for people newly diagnosed with kidney cancer and their families. The aim of the Toolkit is to help patients and their families make critical decisions about their care at a point when they are overwhelmed from just receiving a kidney cancer diagnosis.

URL: kidneycancer.org/just-diagnosed/

Phone: 1-800-544-3KCA

Email: patients@kidneycancer.org

The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society® (LLS) is a global leader in the fight against cancer by funding lifesaving blood cancer research around the world, providing free information and support services, and being the voice for all blood cancer patients seeking access to quality, affordable, coordinated care. The LLS mission: Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

URL: [LLS.org/PatientSupport](https://lls.org/PatientSupport)



Caring for Kids and Adolescents with Blood Cancer

Age Groups Served: Children, Adolescents

A workbook for the parent/guardian of a minor child (up to age 18) and includes information about caring for your child, treatment options, school, nutrition, financial and legal issues, and more. This Family Workbook includes a set of worksheets and activities and includes a tote, journal, pen and pill organizer.

URL: [LLS.org/FamilyWorkbook](https://lls.org/FamilyWorkbook)

Phone: 800-955-4572

Email: IRCpatient@lls.org

The Caregiver Workbook

Age Groups Served: Young Adults, Adults, Older Adults

A workbook for the caregiver of an adult patient and includes information about communicating as a caregiver, understanding blood cancers, caregiving during treatment, nutrition, financial and legal information, self-care and more. This Workbook includes a set of set of worksheets and includes a tote, journal, pen and pill organizer.

URL: [LLS.org/CaregiverWorkbook](https://lls.org/CaregiverWorkbook)

Phone: 800-955-4572

Email: IRCpatient@lls.org

Young Adults and Cancer

Age Groups Served: Young Adults

A short information material for young adults briefly describing topics that affect them during their cancer journey. Topics that are discussed include social media, sharing a diagnosis, mental health, sexuality and intimacy, fertility, parenting and work/school. The piece refers to the LLS website for more comprehensive information about each topic.

URL: [LLS.org/booklets](https://lls.org/booklets)

Phone: 800-955-4572

Email: IRCpatient@lls.org

LUNgevity Foundation

LUNgevity Foundation is the nation's leading lung cancer organization focused on improving outcomes for people with lung cancer through research, education, policy initiatives, and support and engagement for patients, survivors and caregivers. LUNgevity works tirelessly to advance research into early detection and more effective treatments, provide information and educational tools to empower patients and their caregivers, promote impactful public policy initiatives, and amplify the patient voice through research and engagement.



URL: lungevity.org

LUNgevity LifeLife

Age Groups Served: Adults, Older Adults

LifeLine is a peer-to-peer support program that matches lung cancer patients or caregivers with other lung cancer survivors or caregivers who have walked the lung cancer journey. These support mentors offer encouragement, advice, experience, and hope to those newly diagnosed and anyone needing additional support through a one-on-one personal connection by email or telephone.

LifeLine matches are based on factors including age, gender, and type of lung cancer. The Foundation is strategic and systematic when creating matches to ensure the matches will be beneficial, long-lasting, and caring.

LifeLine Partners can be a vital part of a newly diagnosed patients' support system and can help navigate through the logistics and emotions of a lung cancer diagnosis. As a current LifeLine mentee says, "[LifeLine] is just that: a lifeline. After reaching out to [my mentor] with news about my cancer, or everyday life, I know I am not alone."

URL: lungevity.org/lifeline

Phone: 312-407-6100

Email: info@lungevity.org

Lymphoma Research Foundation

The Lymphoma Research Foundation's mission is to eradicate lymphoma and serve those touched by this disease.

URL: lymphoma.org/aboutlymphoma/

Lymphoma Survivorship

Age Groups Served: Adolescents, Young Adults, Adults, Older Adults

The Lymphoma Survivorship factsheet provides information to survivors who are dealing with side effects of treatments, long term follow-up care, and the psychological impact of a cancer diagnosis. This factsheet provides information and resources for anyone interested in learning more.

URL: lymphoma.org/wpcontent/uploads/2017/06/LRF_FACTSHEET_Lymphoma_Survivorship.pdf

Phone number: 800-500-9976

Email: helpline@lymphoma.org

Multiple Myeloma Research Foundation

The MMRF drives discoveries for new treatments, accelerates groundbreaking clinical trials and fuels the most robust data-driven initiatives in cancer research. Our goal is to find a cure for each and every patient diagnosed with multiple myeloma.

URL: themmrf.org



MMRF Patient Education Programs

Age Groups Served: Adults, Older Adults

The MMRF provides disease and resource information for multiple myeloma patients and their caregivers in the form of downloadable content, recorded webinars, short videos, and other virtual programming. Content is frequently added and updated to provide the most accurate and useful information.

URL: themmrf.org/resources/education-programs/

Phone number: 888-841-6673

Email: patientnavigator@themmrf.org

NormaLeah Ovarian Cancer Initiative

Our mission is to enrich lives through early detection education, patient support services and research funding for ovarian cancer – the silent killer of women. We help all cancer patients advocate for better outcomes.

URL: normaleah.org



sisterSTRONG

Age Groups Served: Young Adults, Adults, Older Adults

Ovarian cancer survivors have unique healthcare challenges and helping them thrive (not just survive) is part of our mission. Our sisterSTRONG program has many resources that can be shared with ovarian cancer patients and medical providers to make an ovarian cancer journey easier. Our programs include delivering Hugs&Hope packages to newly diagnosed patients, facilitating in-person and virtual gynecologic cancer support sessions, providing individualized support to those facing challenging situations, and connecting women impacted by this disease with others. Please reach out if we can help in any way. Our email is normaleah@normaleah.org.

Phone: 309.794.0009

Email: normaleah@normaleah.org

National Comprehensive Cancer Network

Through philanthropic support, the NCCN Foundation empowers people through knowledge and advances the mission of NCCN to improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives.

URL: [NCCN.org](https://www.nccn.org)



NCCN Guidelines for Patients®

Age Groups Served: Young Adults, Adults, Older Adults

The NCCN Guidelines for Patients present information from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) in an easy-to-learn format for people with cancer and those who support them. The patient guidelines are intended to:

- Put patients and providers on the same page with the same information
- Ensure that patients, no matter where they are treated, know what the experts agree is the standard of treatment and care
- Ensure patients are aware of all of their treatment and care choices
- Allow patients to self-advocate for their own best care

The NCCN Guidelines for Patients can be accessed online, on the NCCN Patient Guides app, and in print.

URL: [nccn.org/patients/guidelines/cancers.aspx](https://www.nccn.org/patients/guidelines/cancers.aspx)

Patient Advocate Foundation

Patient Advocate Foundation is a national 501 (c) (3) non-profit charity that provides direct services to patients with chronic, life threatening and debilitating diseases to help access care and treatment recommended by their doctor.

URL: patientadvocate.org

Phone: 757-528-4701

Email: amy.jeroy@patientadvocate.org



Making the Most of Your Insurance 365 Days a Year

Age Groups Served: Young Adults, Adults, Older Adults

This publication discusses tips in understanding insurance terminology, plan structures, how to read your explanation of benefits, and money saving tips to make the most of your insurance.

English: gateway.on24.com/wcc/eh/1258749/lp/2636787/making-the-most-of-your-insurance-365-days-a-year

Spanish: gateway.on24.com/wcc/eh/1258749/lp/2539057/making-the-most-of-your-insurance-365-days-a-year-spanish

Common Roadblocks to Care

Age Groups Served: Young Adults, Adults, Older Adults

Learn how to prevent and deal with the most common insurance-related hurdles including out of network doctors, medication barriers, losing insurance coverage and financial challenges resulting from insurance denials.

English: <https://gateway.on24.com/wcc/eh/1258749/lp/2467026/common-roadblocks-to-care>

Spanish: gateway.on24.com/wcc/eh/1258749/lp/2671856/common-roadblocks-to-care-spanish

Maintaining Eligibility for Insurance

Age Groups Served: Young Adults, Adults, Older Adults

Learn what protections and laws impact your insurance, COBRA, short and long-term disability benefits and federal disability, known as the Social Security Disability Insurance program.

English: gateway.on24.com/wcc/eh/1258749/lp/2336891/maintaining-eligibility-for-insurance

Spanish: gateway.on24.com/wcc/eh/1258749/lp/2539059/maintaining-eligibility-for-insurance-spanish

Finding & Selecting Insurance

Age Groups Served: Young Adults, Adults, Older Adults

Choosing the right health insurance plan is so important. This guide will help you understand key insurance words, where to find options, essential health benefits, enrollment tips and more.

English: gateway.on24.com/wcc/eh/1258749/lp/2336645/finding-selecting-insurance

Spanish: gateway.on24.com/wcc/eh/1258749/lp/2539058/finding-selecting-insurance-spanish

PALTOWN

PALTOWN creates disease-specific communities like COLONTOWN, providing access to information about treatment options, clinical trials, and all aspects of the patient and caregiver experiences. We train patients and caregivers to become community leaders and peer educators.

URL: paltown.org



COLONTOWN

Age groups served: Adolescents, Young Adults, Adults

COLONTOWN, an online community for colorectal cancer patients and caregivers, offers more than 120 “neighborhoods,” along with a central Downtown group for all its 5400 members. These smaller groups focus on specific aspects of the patient and caregiver experience. We have groups for the teen-aged children of patients, for parents who are patients, for patients diagnosed under 40, and for patients diagnosed in their 40s. All our groups are led by trained volunteers living that experience. In addition to the age-based groups, we have groups for stages, treatment options, clinical trials, caregivers, and local “crews” all over the US and around the world. Join COLONTOWN, and “find your people” in a place where hope meets science.

URL: colontown.org/colontown-neighborhoods/

Phone number: 410-849-9660

Email: contact@paltown.org

The PAN Foundation

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications.

URL: panfoundation.org/



PAN Foundation Disease Funds

Age groups served: Young Adults, Adults, Older Adults

The PAN Foundation offers nearly 70 disease-specific assistance programs. These assistance programs help patients pay for their out-of-pocket costs, such as deductibles, co-pays and coinsurance, and health insurance premiums.

URL: panfoundation.org/find-disease-fund/

Phone number: 1-866-316-7263

Email: info@panfoundation.org

Patient Empowerment Network

The Patient Empowerment Network (PEN) supports patients through every step of their cancer journey. Through free online resources, we educate, then ACTIVATE cancer patients and care partners to attain the most current and personalized care available. Start here to achieve better cancer care as an empowered patient.

URL: www.powerfulpatients.org



Digitally Empowered™

Age Groups Served: Older Adults

Only 12 percent of US adults are proficient in obtaining and understanding the basic health information and services needed to make health-related decisions¹. One of the biggest hurdles to learning about health and health care decisions is the ability to access and use technology.

In collaboration with advocacy and healthcare partners, digital sherpa™ workshops are conducted across the country in treatment rooms, community centers, and support groups. PEN is now thrilled to be able to reach even more people through Digitally Empowered™ which offers the foundational components of the original, in-person digital sherpa™ program in a virtual format.

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Patient Empowerment Network continued



Patient Empowerment Network developed the Digitally Empowered™ program to help cancer patients and their care partners become more tech-savvy. Through a series of fun and easy-to-follow video modules, coupled with resource guides, PEN aims to help patients utilize technology to their advantage as they navigate their cancer journey. Course objectives include:

- How to Access the Internet
- Identifying credible resources and websites
- How to Use Telemedicine
- The Benefits of your Patient Portal
- Using Social Media to Connect and Learn
- Navigating your Health with Mobile Devices
- Apps for Convenience and Fun
- And more!

The Digitally Empowered™ online platform serves to help further reduce health and geographic inequities by helping participants acquire the technical skills necessary to access valuable online healthcare resources, regardless of their location, and without facing health risks from 1:1 contact if they are immunocompromised.

Reference: Kutner, M., Greenberg, E., Jin, Y., and Paulsen, C. (2006). *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483)*. U.S. Department of Education. Washington, DC: National Center for Education Statistics.

URL: iamdigitallyempowered.org

Email: contact@powerfulpatients.org

Redefined Courage Foundation, Inc

We seek to give 'HOPE' to women nationwide to support them in their healing from breast surgery.

URL: redefinedcourage.com/

HOPE (Post-operative shirt)

Age groups served: Young Adults, Adults

'HOPE' is a post operative shirt gifted to women nationwide that are healing from breast surgery-elective or required. This shirt is soft, cotton easily washable, button up shirt with (4) pockets inside to hold drain bulbs. This shirt is free except for a minimal shipping and handling fee.

URL: redefinedcourage.com/postopshirtrequest

Phone number: 919-263-4396

Email: hello@redefinedcourage.com



SHARE Cancer Support

SHARE is a national nonprofit that supports, educates, and empowers women affected by breast, ovarian, uterine or metastatic breast cancer, with a special focus on medically underserved communities. All of our services are provided in both English and Spanish, including national helplines, support groups, expert-led educational programs, community outreach, online communities, corporate education, local advocacy opportunities, caregiver support, and survivor-patient navigation.

URL: sharecancersupport.org



Share Helplines

Age Groups Served: Young Adults, Adults, Older Adults

SHARE's Helplines are categorized by the type of cancer: breast, ovarian, uterine, and metastatic breast cancer. Our supportive network is made up of volunteers who have had the cancer type specific to that Helpline who DO know what it's like, who HAVE been there, and who CAN help. We also offer peer matching whereby a caller is matched with someone who has a similar diagnosis, treatment, and/or pharmaceutical history so questions can be answered by someone who has first hand experience. No one needs to go through cancer alone. Our volunteers can refer callers to support groups, educational programs and can share many resources for financial assistance, transportation, clinical trials, caregiver support, meal delivery, to name a few. Our Helplines operate 7 days a week from 9:30 am to 9:00 pm EST.

URL: sharecancersupport.org/breast-cancer/helpline/

Phone: 844-275-7427 (844-ASK- SHARE)

Email: helpline@sharecancersupport.org

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SHARE Cancer Support

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Young Women's Gyn Cancer Support Group

Age Groups Served: Young Adults

The Young Women's Gyn Cancer Support Group is designed for women diagnosed under age 40 with ovarian and/or uterine cancer. Join us as we share information and support each other through the particular challenges faced by young women diagnosed with cancer. Facilitated by trained survivor peers. This support group is available online and over the phone.

URL: sharecancersupport.org/young-womens-gyn-cancer-support-group/

Phone: 844-275-7427 (844-ASK- SHARE)

Triage Cancer

Triage Cancer is a national nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials, and resources.

URL: tragecancer.org/

Phone number: 424-258-4628

Email: info@tragecancer.org



Quick Guide to Health Insurance

Age Groups Served: Older Adults

This Quick Guide provides information about Medicare that allows you to understand your options and find coverage that is appropriate to you. This Quick Guide covers the different "Parts" of Medicare, different types of Medicare plans, Medicare Supplemental Plans, and things to consider when choosing a Medicare plan.

URL: tragecancer.org/QuickGuide-MedicareExtended

Quick Guide to Medicare Savings Programs

Age Groups Served: Older Adults

This Quick Guide provides useful information about Medicare Savings Programs, including the four different Medicare Savings Programs, the different income and resource limits of each program, what "resources" are considered under the Medicare Savings Programs, and options for getting help paying for Medicare's out-of-pocket prescription drug costs.

URL: tragecancer.org/quickguide-medicaresavings

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Triage Cancer

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Quick Guide to Crowdfunding

Age Groups Served: Young Adults, Adults, Older Adults

This Quick Guide provides practical information about using crowdfunding to help pay for medical care and other expenses, including the different crowdfunding platforms, important considerations around disclosure, taxes, and income-based programs, and potential solutions to the negative impacts that crowdfunding can have on someone's benefits.

URL: tragecancer.org/quickguide-crowdfunding



Quick Guide to Disclosure, Privacy, & Medical Certification Forms

Age Groups Served: Young Adults, Adults, Older Adults

This Quick Guide provides practical information on making disclosure decisions, the legal protections that exist, and making conscious disclosure decisions online, with family and friends, and at work.

URL: tragecancer.org/QuickGuide-Disclosure



National Comprehensive
Cancer Network®

For more information on the NCCN Oncology Policy Program,
please visit [NCCN.org/policy](https://www.nccn.org/policy) or contact:

Alyssa Schatz, MSW
Senior Director, Policy & Advocacy

Schatz@nccn.org

policy@nccn.org