

NCCN Digital Booklet of Patient Advocacy Resources



PATIENT ADVOCACY SUMMIT: Navigating the Care Continuum from Screening through Survivorship

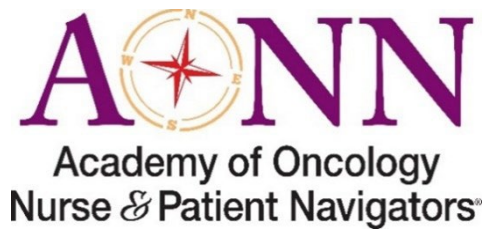
The NCCN Digital Resource Booklet includes information from 13 patient advocacy organizations on programs and resources to support people in navigating the cancer care continuum.

This Booklet was developed in conjunction with The National Comprehensive Cancer Network's® (NCCN®) Patient Advocacy Summit: Navigating the Care Continuum from Screening through Survivorship on December 5, 2023.

To view a broader list of advocacy and support groups on the NCCN website, visit [NCCN.org/patients/support-groups](https://www.nccn.org/patients/support-groups).

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Academy of Oncology Nurse & Patient Navigators (AONN+)

The Academy of Oncology Nurse & Patient Navigators (AONN+) is the largest national specialty organization dedicated to improving patient care and quality of life by defining, enhancing, and promoting the role of oncology nurse and patient navigators. Our organization of over 8,900 members was founded in May 2009 to provide a network for all professionals involved and interested in patient navigation and survivorship care services to better manage the complexities of the cancer care treatment continuum for their patients.

URL: www.aonnonline.org/

AONN+ Evidence-Based Navigation Metrics (as well as other tools & resources available on our website)

AONN+ is hard at work behind the scenes creating and developing innovative programming in collaboration with our industry and advocacy partners. Our goal is to provide a platform to further education, professional development, and resources for all navigators. Find government guidelines, downloadable references, educational media, and other invaluable resources to assist nurse navigators and patient navigators in the management of patient care. The creation of the standardized national metrics to measure programmatic success is vital to coordinating high-quality, team-based care and demonstrating the sustainability of navigation programs. It is imperative that oncology nurse and patient navigators understand that active participation in data collection, analytics, and reporting outcomes are not added responsibilities but are already a part of the professional role. The implications for navigation practices using quality navigation measures are that they are transformative, evaluate professional practice and care delivery, define oncology navigation practice and outcomes, and are necessary for sustainability of navigation.

URL: www.aonnonline.org/tools-and-resources

Phone number: 732-992-1532

Email: info@aonnonline.org



Association of Community Cancer Centers

Association of Community Cancer Centers (ACCC)

The Association of Community Cancer Centers (ACCC) is a powerful community of more than 34,000 multidisciplinary practitioners and 1,700 cancer programs and practices nationwide. ACCC provides resources on operations and management for programs and practices, reimbursement issues, policy and regulatory changes at the state and national levels, trends in cancer care, integrating new technologies and therapies, and more.

URL: www.accc-cancer.org/

Financial Advocacy Network

The Association of Community Cancer Centers (ACCC) is committed to building the confidence of oncology financial advocates, connecting them with much-needed solutions to improve the patient experience. Through the Financial Advocacy Network's tools and resources, ACCC empowers cancer programs and practices to proactively integrate financial health into the oncology care continuum and help patients gain access to high-quality care for a better quality of life. Resources include: Financial Advocacy Services Guidelines, Financial Advocacy Playbook, Financial Advocacy Boot Camp, Financial Advocacy Toolkit, Patient Assistance and Reimbursement Guide.

URL: www.accc-cancer.org/home/learn/financial-advocacy

Financial Advocacy Services Guidelines

Newly released by the ACCC Financial Advocacy Network, Financial Advocacy Services Guidelines serve as a framework for oncology financial advocacy programs. These guidelines were created using a collaborative, consensus-based process to promote and guide the implementation of critical financial advocacy services in cancer programs and practices across the nation.

URL: www.accc-cancer.org/home/learn/financial-advocacy/guidelines

Prior Authorization Clinic

ACCC is developed an educational program that fosters discussions on how to ease provider burden and ensure the best quality care for the patient when dealing with the utilization management technique known as prior authorization. Resources include: Six-part on-demand webinar series, titled: "Proactive Interventions for the Prior Authorization Process." Five one-pagers on different areas on oncology and two infographics around prior authorizations.

URL: www.accc-cancer.org/home/learn/financial-advocacy/prior-authorization-clinic



CANCERcare[®]

CancerCare

CancerCare is the leading national organization dedicated to providing free, professional support services including resource navigation, counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer.

URL: www.cancercares.org

CancerCare Support Services

CancerCare's Resource Navigation services are provided by professional resource navigators and oncology social workers to help address health disparities and overcome other barriers to care. Professional oncology social workers are also able to provide free emotional and other forms of practical support for people with cancer, caregivers and those who are bereaved.

URL: www.cancercares.org

Phone number: 800-813-HOPE (4673)

Email: info@cancercares.org



Cancer and Careers

Cancer and Careers empowers and educates people with cancer to thrive in their workplace, by providing expert advice, interactive tools and educational events.

URL: www.cancerandcareers.org

Resume Review Service

This service offers free, personalized feedback on your resume from one of our professional career coaches.

URL: www.cancerandcareers.org/resume_reviews/new

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

Balancing Work & Cancer Webinars

Cancer and Careers' Balancing Work & Cancer Webinar Series offers sessions related to the challenges of balancing work and cancer. All webinars are free to attend.

URL: www.cancerandcareers.org/en/community/events/webinars

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

Publications

Our library of publications, available in English and Spanish, provides a tangible, easy to digest opportunity to deliver key information to Patients, Survivors and Healthcare Professionals.

They can be ordered or downloaded from our website.

URL: www.cancerandcareers.org/publication_orders/new

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

Educational Videos

An archive of Cancer and Careers' videos, including webinar recordings, survivor stories, How-To instruction, conference highlights and more.

URL: www.cancerandcareers.org/en/community/videos

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

Collective Diary

Online forum where patients and survivors can share their experiences and what worked/didn't work – can be helpful if you're looking for a similar situation.

URL: www.cancerandcareers.org/diary

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

Ask a Career Coach

Individuals can submit a question to a career coach or, what many also find helpful, go through previously asked/answered questions.

URL: www.cancerandcareers.org/career-coach

Phone number: 646-929-8032

Email: cancerandcareers@cew.org

www.cancerandcareers.org

Available in English and Spanish our website offers hundreds of articles on all the issues related to the world of work and cancer.

URL: www.cancerandcareers.org

Phone number: 646-929-8032

Email: cancerandcareers@cew.org



Cancer Support Community (CSC)

The Cancer Support Community is a global nonprofit that uplifts and strengthens people impacted by cancer. We are dedicated to fostering a community where people find connection, compassion, and knowledge. We provide professionally led support and navigation services, along with social connections and award-winning education – when, where, and how impacted individuals prefer throughout their cancer experience. These resources are available at 190 Cancer Support Community, Gilda's Club, and healthcare partner locations as well as online and over the phone – all at no cost. We amplify the voices of those impacted by cancer through research and advocacy and create solutions that break down barriers to care and close the healthcare gap for communities whose members are disproportionately affected by cancer.

Find a location near you: www.cancersupportcommunity.org/find-location-near-you

CSC uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care. Our vision is that everyone impacted by cancer receives the support they want and need throughout their experience.

URL: www.cancersupportcommunity.org

Phone number: 888-793-9355

Email: contacthelpline@cancersupportcommunity.org

CSC Cancer Policy Institute (CPI)

The CPI brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policy making.

URL: www.CancerSupportCommunity.org/cancer-policy-institute

Phone number: 888-793-9355

Email: CancerTransitions@CancerSupportCommunity.org

MyLifeLine

MyLifeLine® is here to help you easily connect to your community to reduce stress, anxiety, and isolation – and to transform your cancer experience. Our online community includes patients, survivors, caregivers, and loved ones impacted by cancer. Through discussion boards and private websites, cancer patients and caregivers can connect with their community and others like them to reduce stress, anxiety, and isolation.

URL: www.CancerSupportCommunity.org/mylifeline

Phone number: 888-793-9355

Email: contacthelpline@cancersupportcommunity.org

Cancer Support Helpline

Our Cancer Support Helpline is staffed by community navigators and resource specialists who have extensive experience in helping people affected by cancer. We provide guidance, resources, and support to cancer patients or their loved ones with a variety of needs – from getting information about cancer, identifying a local support group, or just finding someone who is willing to listen.

URL: www.cancersupportcommunity.org/cancer-support-helpline

Phone number: 888-793-9355

Email: contacthelpline@cancersupportcommunity.org

Cancer Transitions

The **Cancer Transitions: Moving Beyond Treatment**® program addresses many of the physical, social, and practical issues survivors may face as they transition into post-treatment cancer survivorship. This manualized program is designed to improve quality of life by focusing on lifestyle skills and prosocial support. Cancer Transitions is aimed at survivors of any cancer diagnosis who have completed active treatment within the last 24 months

URL: www.CancerSupportCommunity.org/cancer-transitions

Phone number: 888-793-9355

Email: CancerTransitions@CancerSupportCommunity.org

CSC Digital Platforms

With ONE platform, CSC offers multiple screening programs. Cancer Support Source for Patients and for Caregivers are two digital tools to screen for cancer-related distress. These are backed by research and scientifically validated screening and referral tools. Checking in is CSC's evidence-informed digital pediatric distress screener with optional EMR integration capabilities. The HRSN is a screening tool created by the Centers for Medicare & Medicaid Services (CMS) to help identify social needs that are impacting patients' health outcomes. CSC has developed a digital version.

URL: www.CancerSupportCommunity.org/cancer-policy-institute

Phone number: 888-793-9355

Email: Sales@CancerSupportCommunity.org



The Chrysalis Initiative

The Chrysalis Initiative exists to disrupt outcome disparities within breast cancer, so that every patient receives the care they deserve. By providing patients with mentoring and resource navigation and equipping Black women (and other disparate groups) with the opportunity and education to assess their breast cancer risk, we are closing the gap one story at a time.

URL: thechrysalisinitiative.org/

Phone number: 800-929-4979

Email: Info@thechrysalisinitiative.org

One-on-One Coaching

The Chrysalis Cancer Coaching Curriculum is designed to ensure a patient's knowledge of a comprehensive model for optimal cancer care.

One-on-One coaching informs and empowers patients throughout their treatment, helping them to feel confident and in charge by managing the worries and challenges specific to their experiences.

Through this social support and evidence-based information, Black women are given the tools they need to recognize bad practices in breast cancer healthcare and reimagine treatment and screening protocols for more equitable outcomes. This tailored relationship will help patients learn to advocate for equitable quality of care and, ultimately, better treatment outcomes. No more waiting on a biased system.

URL: thechrysalisinitiative.org/one-on-one-coaching/

BC Navi App

BC Navi equips Black women with breast cancer with the tools they need to recognize, share, and address gaps in healthcare.

Through BC Navi, patients with breast cancer can find and create reviews and ratings about the quality of care provided at healthcare centers in their area. These reviews will hold hospitals and doctors accountable and to a standard of transparency and equality.

This will help Black women with breast cancer know how to recognize, find, and share their experiences of informed and culturally competent care—as well as reveal where healthcare practices are falling short, both on a comprehensive and person-by-person basis. With this knowledge, patients can work together to make sure they are only choosing healthcare providers who will give them the quality of care they deserve.

URL: <https://thechrysalisinitiative.org/app/>

Virtual Learning Modules

The Virtual Learning Modules are a learning management system with program materials, including PowerPoint presentations, handouts, and interactive participant materials for the Chrysalis Cancer Curriculum.

Our online learning modules allow for ease of access and flexibility of schedule. Obtain the information you need at your convenience.

The learning modules are also customized based on your career and specific topics related to your breast cancer journey.

URL: thechrysalisinitiative.org/virtual-learning-module/

Equity Assessment

The Chrysalis Initiative's Equity Assessment, Tools and Improvement Plan provides evidence-based system-wide intervention and training for your cancer center or organization and ensures that your cancer care being administered addresses disparities within the cancer care continuum using a community-based participatory research approach. High-quality breast cancer care across the care continuum includes equity and reduces and, in some cases, eliminates disparities. How can you be sure that your cancer care delivery system is equitable, not only by intention but in demonstrated impact? What changes or improvements have to be made to reach your institutional principle of achieving equity in cancer care?

Are you a current healthcare provider serving Black women or other disparate groups? There might be blind spots and procedural issues that you are not aware of contributing to the inequities that your patients are experiencing. Either way, we can help with evidence-based solutions.

URL: thechrysalisinitiative.org/equity-assessment/

Provider Training and Education

The Chrysalis Cancer Curriculum Training for oncology nurse navigators and medical professionals within cancer teams on a comprehensive cancer model is designed to ensure that cancer care support teams are knowledgeable about all the aspects integral to optimal cancer care, including the unique needs of patients vulnerable to disparities.

Patients rely on their providers to ensure quality care. We want to make sure you have the tools and solutions to reduce disparities to help guide your patients through their breast cancer care.

URL: thechrysalisinitiative.org/provider-training-education/



First Descents

First Descents provides free outdoor adventures to young adults impacted by cancer and Multiple Sclerosis.

First Descents offers young adults impacted by cancer and MS a free outdoor adventure experience designed to empower them to climb, paddle, and surf beyond their diagnosis, reclaim their lives, and connect with others doing the same. Programs take place across the US, and are open to the following communities:

Those Diagnosed with Cancer or Multiple Sclerosis

Young adults who were diagnosed with cancer or multiple sclerosis between the ages of 15-39 and who currently are between the ages of 18-45.

Caregivers

Caregivers for an individual with cancer or multiple sclerosis.

Caregiver applicants must have cared for an individual who qualifies for our programs (young adults impacted by MS or cancer between the ages of 18-45). Eligible individuals may have only ONE caregiver apply for our Programs.

Healthcare Providers

Oncology and multiple sclerosis healthcare providers who are currently between the ages of 18-45.

URL: firstdescents.org/

Phone number: 303-954-2490

Email: programs@firstdescents.org



IMERMAN ANGELS

Imerman Angels

We connect cancer fighters, survivors, previvors and caregivers to Mentor Angels, cancer confidantes with similar stories and experiences. Our unique matching process is done by real people, not a system with an algorithm.

URL: imermanangels.org/

Imerman Angels Grief Toolkit

The cancer experience is one that can be filled with grief and loss. Grief is a healthy response to the loss of something you love. It is a symbol of how much you cared and is part of the natural healing process to adjust to your new reality. Grief can become “complicated” when it is denied or avoided. As people impacted by cancer, you experience grief in a myriad of ways. Anticipatory grief, secondary grief and death-loss grief are all complicated issues our community confronts daily. Grieving for tangible things, such as life and body parts, and intangibles, such as body confidence and relationships, are real issues. This guide is a concise but a powerful tool to assist you in understanding, navigating and processing grief. Throughout the guide you will find prompts that give you quick reflection questions to assist you through this process.

URL: imermanangels.org/wp-content/uploads/2023/04/ia-grief-toolkit.pdf

Phone number: 877-274-5529

Email: Info@ImermanAngels.org



The Leukemia & Lymphoma Society

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

URL: www.lls.org

Survivorship Workbooks

The Survivorship Workbooks allow patients and caregivers to collect all the important information you or your loved one needs as they move through diagnosis and treatment into long-term management of a chronic blood cancer or begin post-treatment follow-up care. The workbook includes survivorship care plan worksheets; long-term and late effects information; healthy behavior recommendations; mental health exercises and information; and resources for planning for the future. There are three versions of the workbook: A Workbook for Adults, A Workbook for Young Adults and A Workbook for Children and Adolescents. AS with all resources provided by LLS, the workbooks are free of charge. For more information, patients/caregivers should contact the Information Resource Center at 800-955-4572, Monday through Friday, 9 a.m. to 9 p.m. ET.

URL: www.LLS.org/SurvivorshipWorkbook

Phone number: 800-955-4572



LUNGEvity Foundation

LUNGEvity Foundation transforms how people diagnosed with lung cancer live through research, education, advocacy, and support. LUNGEvity seeks to **empower patients to be active decision makers in their treatment process** through our extensive educational resources, online peer-to-peer support, and in-person survivorship programs. We provide a community of empowerment, support, and hope.

URL: www.lungevity.org

LUNGEvity Foundation Survivorship Resources

The LUNGEvity Foundation website offers a wide range of information, resources, and tools to help individuals impacted by lung cancer at any point along their journey, from pre-diagnosis through to survivorship, and to bereavement for caregivers. The materials on the website help individuals understand a diagnosis, know what questions to ask and when to ask them, and learn how to bridge the practical and emotional gaps in lung cancer survivorship. In addition to the resources and tools available, the website also welcomes users to the largest online and in-person network of support programs for people affected by lung cancer, all of which can be accessed through www.lungevity.org.

Navigation Resources: www.lungevity.org/for-patients-caregivers/navigating-your-diagnosis

Screening Support link: www.lungevity.org/for-patients-caregivers/lung-cancer-101

Support Services link: www.lungevity.org/for-patients-caregivers/support-services/peer-to-peer-mentoring/lifeline-support-partners

Survivor Resource Center: www.lungevity.org/for-patients-caregivers/survivor-resource-center

Caregiver Resource Center: www.lungevity.org/for-patients-caregivers/caregiver-resource-center

Helpful Resources: www.lungevity.org/for-patients-caregivers/caregiver-resource-center

Email: info@lungevity.org

Phone number: 240-454-3100 or 202-251-2382



**Tigerlily
Foundation**

Beauty. Strength. Transformation.

Tigerlily Foundation

Tigerlily Foundation is a national women's health and oncology organization providing education, awareness, advocacy and hands-on support to young women (15-45) – before, during and after cancer. Our Mission is to educate, advocate for, empower, and support young women, before, during and after cancer with a vision to end disparities – of age, stage and color, in our lifetime.

URL: www.tigerlilyfoundation.org/

Tigerlily Barrier Toolkits

Literacy, financial barriers, access, social, systemic, and other issues should not be determinants of life and health equity. Particularly as patients are impacted by COVID and post COVID pandemic repercussions, the pandemic has had and will continue to impact health within the healthcare and cancer care ecosystem. To ensure patients have the right resources at their fingertips, we have created barrier toolkits. We listened to our patients and created these for and with patients and caregivers.

URL: www.tigerlilyfoundation.org/barrier-toolkits/

Phone number: 1-888-580-6253

Email: info@tigerlilyfoundation.org

RAISE

Tigerlily Foundation has partnered with WiTT Forever to establish the RAISE platform. RAISE, which stands for Resources and Assistance for Support and Empowerment, is a platform that makes it easy for patients to get support without feeling as though they are burdening others. We understand that patients living with cancer and chronic disease often face challenges that lead to the need to make difficult decisions about paying for groceries, childcare or life-saving medical care. Individuals on the RAISE platform can list out the things they need help with – both financial and non-financial – and other people can view this list and claim items for which they're able to provide help. There is an inner circle facing side and a public facing side so a patient can get financial assistance from general donors and keep their more private needs—like picking up their child from school—to their inner circle of people they know and are in their lives. This platform is patient driven and will evolve as patients provide insights – we look forward to sharing enhancements and additional resources as the RAISE platform continues to grow!

URL: raise.tigerlilyfoundation.org/

Phone number: 1-888-580-6253

Email: info@tigerlilyfoundation.org



Patient Empowerment Network

Patient Empowerment Network (PEN) is a 501(c)(3) non-profit organization with a mission enhance patient health literacy to enable shared decision-making and provide informational and educational resources to empower patients and care partners at every step of their cancer journey.

URL: powerfulpatients.org/

Prostate Cancer Resources- Patient Empowerment Network

Prostate cancer is the most common cancer in men in the US, after skin cancer. Almost all prostate cancers are adenocarcinomas (cancers that begin in cells that make and release mucus and other fluids). Prostate cancer often has no early symptoms.

Prostate cancer usually grows very slowly. Finding and treating prostate cancer before symptoms occur may not improve health or help you live longer. Talk to your doctor about your risk of prostate cancer and whether you need screening tests. This site provides general information. Please talk to your own doctor to make healthcare decisions that are right for you.

URL: powerfulpatients.org/help-by-cancer-diagnosis/prostate-cancer/



Triage Cancer

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

URL: tragecancer.org

Practical Guide to Cancer Rights

Triage Cancer's comprehensive Cancer Rights Guides introduce you to the cancer rights law topics that most people encounter in some way after a cancer diagnosis. While these materials are designed for individuals diagnosed with cancer, caregivers, and health care professionals, they are helpful to anyone with a serious medical condition, or anyone who wants to learn about their rights.

URL: tragecancer.org/guide

Phone number: 424-258-4628

Email: info@tragecancer.org

Checklist to Avoid Financial Toxicity

Triage Cancer's Checklist to Avoid Financial Toxicity will help you reduce the potential short and long-term financial burden of a cancer diagnosis and treatment.

URL: tragecancer.org/Checklist-FinancialToxicity

Phone number: 424-258-4628

Email: info@tragecancer.org

CancerFinances.Org

This interactive tool is designed to help guide you through some key topics that may impact your financial situation. Whether you are newly diagnosed or many years past active treatment, this site can help. By answering a few questions, the tool will guide you to the information most relevant to you.

URL: tragecancer.org/cancerfinances-postcard

Phone number: 424-258-4628

Email: info@tragecancer.org



For more information on the NCCN Oncology Policy Program,
please visit [NCCN.org/policy](https://www.nccn.org/policy) or contact:
Taneal D. Carter, MS, MPA
Manager, Cancer Care Equity Program
carter@nccn.org