This guide is a compilation of services, programs and tools available across the country to help CoC-accredited organizations meet Standards 3.1, 3.2 and 3.3. The guide is comprised of local, regional and national resources from Alliance member organizations.

To view the CoC Standards visit:
https://www.facs.org/quality%20programs/cancer/coc/standards

Contact: Julie Taylor (jtaylor@cancersupportcommunity.org)

THE ALLIANCE FOR QUALITY PSYCHOSOCIAL CANCER CARE

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This Resource Guide provides tools and/or programs that are available to CoC-accredited institutions. For each Standard, resources are categorized according to programs that are available nationally, local programs that may serve as an example or best practice, and other services for patients that are available nationally.

The Alliance is a coalition committed to implementing recommendations of the IOM Report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. The Alliance vision is “To ensure psychosocial care is integrated into the medical standard of care for people with cancer.”

- Academy of Psychosomatic Medicine
- American Cancer Society
- American Childhood Cancer Organization
- American Psychiatric Association
- American Psychosocial Oncology Society
- American Psychosomatic Society
- American Society of Clinical Oncology
- Association of Pediatric Oncology Social Workers
- American Society for Radiation Oncology
- Association of Community Cancer Centers
- Association of Oncology Social Work
- Bladder Cancer Advocacy Network
- CancerCare
- Cancer Legal Resource Center
- Cancer Support Community
- Center for Communication in Medicine
- City of Hope National Medical Center
- Dana Farber Cancer Institute
- Free to Breathe
- Kidney Cancer Association
- International Psycho-oncology Society
- Mattie Miracle Cancer Foundation
- National Coalition for Cancer Survivorship
- National Association of Social Workers
- Robert H. Lurie Comprehensive Cancer Center of Northwestern University
- The University of Texas MD Anderson Cancer Center
- University of California Irvine Chao Comprehensive Cancer Center
- University Hospitals Seidman Cancer Center
- Yale Comprehensive Cancer Center
Standard 3.1: Patient Navigation Process

A patient navigation process, driven by a community needs assessment, is established to address health care disparities and barriers to care for patients. Resources to address identified barriers may be provided either on-site or by referral to community-based or national organizations. The navigation process is evaluated, documented, and reported to the cancer committee annually. The patient navigation process is modified or enhanced each year to address additional barriers identified by the community needs assessment.

NATIONALLY AVAILABLE PROGRAMS

American Cancer Society

National Cancer Information Center: Staff are available 24/7, 365 days a year to provide referrals to resources available from community-based and national organizations. CoC-accredited hospitals and patients can contact the National Cancer Information Center to locate local resources and can request information about their diagnosis and treatment options. Healthcare providers and patients can also access the Society’s website, cancer.org, to search for resources available in their zip code, city, or state.

Contact:
1-800-227-2345
www.cancer.org
http://www.cancer.org/treatment/supportprogramsservices/app/resource-search


Contact:

Additional Information:
In 2010, ACS hosted the National Patient Navigation Leadership Summit, gathering cancer clinicians, researchers, practicing public health experts, funders, and patient navigators to develop a national consensus on common outcomes of patient navigation. The goal of the Summit was to develop and propose core metrics for navigation programs to measure the impact on individuals and populations across the disease continuum. This article describes the Summit and outlines the need for such an endeavor in the effort to support the growth and sustainability of patient navigation.
Standard 3.1: Patient Navigation Process

American Childhood Cancer Organization

Childhood Cancer Patient Navigation Services, including a list of Children’s Oncology Group certified treating institutions, comprehensive manual of childhood cancer organizations and resources, information on clinical trial phases, emotional support, referral to local ACCO family support programs and referral to ACCO’s online Inspire Community

Contact:
855-858-2226 (ACCO)
http://www.acco.org/Information/Support/PsychologicalEmotional.aspx
https://www.inspire.com/groups/american-childhood-cancer-organization/

ACCO offers a comprehensive list of resources, tools, support networks, and specialized programs to help children and families cope with the medical, emotional, and psychological repercussions of childhood cancer. These resources include a book that helps parents navigate palliative care needs, educational needs of their children as well as journals to help families track treatment information.
http://www.acco.org/we-can-help/

Additional Information:
Online, phone and email patient navigation to assist the family whose child is diagnosed with cancer. Navigation services include referrals to ACCO local affiliate programs, ACCO’s Inspire community and other childhood cancer resources. Navigation also includes disease specific information, cancer treatment and clinical trial terminology, as well as assistance with identification of open therapeutic clinical trials.

Association of Community Cancer Centers

Cancer Care Patient Navigation: A Call to Action: The Association of Community Cancer Centers (ACCC) offers resources and tools for cancer programs interested in creating, implementing, and sustaining patient navigation programs. ACCC provides an online resource which will help to: 1) identify barriers to access to care that patient navigation can address; 2) increase successful implementation of patient navigation services; 3) refine staffing models; and 4) establish effective metrics for measuring patient navigation services internally and for benchmarking patient navigation services against other community cancer centers. Components include:
• Cancer Care Patient Navigation: A continuing education activity
• Cancer Care Patient Navigation: A practical guide for community cancer centers
• ACCC Guidelines: Cancer Care Patient Navigation
• Cancer Care Patient Navigation: Tools for community cancer centers

Contact:
www.accc-cancer.org/patientnavigation
Standard 3.1: Patient Navigation Process

Cancer Support Community

**CSC Local Affiliate Network:** CSC has an international network of more than 50 local affiliates and 100 satellite locations that provide support groups, educational workshops and health and wellness classes to all people impacted by cancer. All CSC programs are provided to patients, survivors, caregivers and family members free of charge. To find an affiliate in your community, visit [www.http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-CSC-Affiliate](http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-CSC-Affiliate)

**Contact:**
Sara Goldberger, LCSW-R
sara@cancersupportcommunity.org
646-600-7565

**Toll-Free Cancer Support Helpline:** CSC’s toll-free Cancer Support Helpline is open Mon-Fri 9 am- 9 pm Eastern. It is staffed by licensed mental health professionals who can provide emotional support, education about the social and emotional aspects of living with cancer, information about community resources to anyone touched by cancer. Spanish speaking counselors are available.

**Contact:** 1-888-793-9355

**Online Support Services:** CSC offers online support through The Living Room, a forum where people affected by cancer can connect with others 24/7. The Living Room offers discussion boards moderated by licensed mental health professionals on topics like breast cancer, living life after treatment or caregiving. Users can create a secure personal website to stay connected to friends and family.

**See more at:** [http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.FjgCVnBB.dpuf](http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.FjgCVnBB.dpuf)

The Mattie Miracle Cancer Foundation

The MATTIE MIRACLE CANCER FOUNDATION is a 501(c)(3) tax-exempt public charity. The organization was founded by Victoria Sardi-Brown and Peter Brown, in loving memory of their seven-year-old son, Mattie. The Mattie Miracle Cancer Foundation is dedicated to increasing childhood cancer awareness, education, advocacy, research and psychosocial support services to children, their families, and medical personnel. Children and their families are supported throughout the cancer treatment journey, to ensure access to quality psychosocial and mental health care, and to enable children to cope with cancer so they can lead happy and productive lives.
Standard 3.1: Patient Navigation Process

Additional Information:
Mattie Miracle is committed to ensure that children with cancer and their families have access to a minimum level of psychosocial care from the time of diagnosis, through survivorship, or end of life and bereavement care. As such, the Foundation had the vision for the creation of psychosocial standards and has financially supported the development of the Psychosocial Standards of Care for Children with Cancer and their Families. To learn more about these Standards and the implementation process, please visit: www.mattiemiracle.com/standards

Contact:
Victoria Sardi-Brown, Ph.D., LPC
vicki@mattiemiracle.com
www.mattiemiracle.com
202-549-8036

National Cancer Institute

Navigation Assessment Tool: This tool, developed by members of the former NCI Community Cancer Centers Program (now the Community Oncology Research Program), is used to help build or advance a navigation program based on criteria discussed in each category. Each category represents a component of navigation that should be present in any program. The levels of the tool provide a way to advance from the minimum to a benchmark status.

To view the abstract:

Contact:
https://ncorp.cancer.gov
Standard 3.1: Patient Navigation Process

ADDITIONAL PATIENT NAVIGATION SERVICES AND RESOURCES FOR PATIENTS AVAILABLE NATIONALLY

Bladder Cancer Advocacy Network (BCAN)

BCAN’s Survivor 2 Survivor program connects newly diagnosed patients with another survivor who has undergone similar treatment. The volunteer survivors provide their firsthand account of life with a bladder cancer diagnosis. To access the program, call 1-888-901-2226(BCAN), ext. 212, or email aspangler@bcan.org.

Contact:
1-888-901-2226 (BCAN) ext. 212
Email: aspangler@bcan.org

CancerCare

Professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved. Programs include counseling and support groups, education, financial assistance and practical help and are provided by professional oncology social workers at no charge. These counseling services are offered in English and Spanish with bilingual social workers as well as publications in Spanish.

Contact:
1-800-813-HOPE (4673)
www.cancercare.org
CancerCare Financial Assistance Programs: http://www.cancercare.org/financial
CancerCare Co-Payment Assistance Foundation: http://www.cancercarecopay.org
CancerCare publications: http://www.cancercare.org/publications
Connect Education Workshops Teleconferences/webcasts: www.cancercare.org/connect
Podcasts: www.cancercare.org/podcasts

Cancer Legal Resource Center

The Cancer Legal Resource Center (CLRC) provides free information, resources, and education about cancer-related legal questions to patients, survivors, caregivers, and health care professionals.

CLRC National Telephone Assistance Line: Callers can receive free and confidential information about laws and resources for their particular situation. Members of CLRC’s Professional Panel of attorneys can provide additional assistance. There is also an intake form available online. Services are available in English and Spanish, and a language line is used for callers who speak other languages.

Contact:
1-800-THE-CLRC (843-2572)
www.cancerlegalresources.org
Submit an intake online at www.clrcintake.org
CLRC Educational Materials: These helpful publications are available on the CLRC website free of charge in PDF format. Some materials may be available to order for a nominal charge.

- Patient Legal Handbook: This handbook is a resource for patients coping with cancer and provides valuable information about cancer-related legal issues from diagnosis through survivorship. This handbook is part of a project funded by Amgen’s Breakaway from Cancer partnership program to educate patients with cancer about cancer-related legal issues. (Also available in Spanish)
- Other materials covering topics including, but not limited to advance planning, employment, health insurance appeals, financial assistance, caregiver rights, and resources for children and young adults.

CLRC Webinars: Archived webinars covering a variety of cancer-related legal issues are available to watch for free on the CLRC website.

Contact:  
http://cancerlegalresources.org/publications-webinars/  
clr@drlcenter.org
Standard 3.2: Psychosocial Distress Screening

The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.

NATIONALLY AVAILABLE PROGRAMS

American Cancer Society

Distress in Patients with Cancer: A downloadable guide to help patients understand cancer-related distress and how they can get help and support. The guide includes a distress screening tool thermometer and self-assessment guide for patients.

Contact:
1-800-227-2345

Psychosexual Distress Screening in CoC Hospitals – September 22, 2014
A recording of a webinar hosted by the ACS that featured speakers from the ACS NCIC, CoC and the Cancer Support Community, who shared perspectives on the value of psychosocial distress screening in the delivery of patient-centered cancer care, and practical recommendations for integrating distress screening within CoC-accredited cancer programs.

http://youtu.be/vmMz9mt4gJM

American Psychosocial Oncology Society

The American Psychosocial Oncology Society has a growing number of resources available for professionals in the field of psychosocial oncology actively engaged in distress screening and management. They devote a portion of their website specifically to this topic providing a joint position statement from APOS, AOSW, and ONS on implementing distress screening. APOS has a series of webinars on the topic of distress screening for psychosocial professionals that have been recorded and are made publicly available. There are also links to other professional resources pertinent to distress screening.

The APOS Screening for Psychosocial Distress Program in Partnership with Yale School of Nursing
This is a two-year educational program designed to prepare cancer care clinicians to develop and implement a comprehensive distress screening program in their practice environments. Information on this program can be found at: http://www.apos-society.org/APOS/Distress_Screening_Program/Distress_Home.aspx

Contact:
1-434-293-5350
www.apos-society.org
Standard 3.2: Psychosocial Distress Screening

American Society of Clinical Oncology

Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation (Andersen BL, et. al.)
ASCO has established a process for adapting other organizations’ clinical practice guidelines. This article summarizes the results of that process and presents the practice recommendations adapted from the Pan-Canadian Guideline on Screening, Assessment and Care of Psychosocial Distress (Depression, Anxiety) in Adults with Cancer, which addressed the optimum screening, assessment, and psychosocial supportive care interventions for adults with cancer who are identified as experiencing symptoms of depression and/or anxiety.

www.jco.ascopubs.org/content/32/15/1605.long

Screening, Assessment, and Management of Fatigue in Adult Survivors of Cancer: An American Society of Clinical Oncology Clinical Practice Guideline Adaptation (Bower JE, et. al.)
This guideline presents screening, assessment, and treatment approaches for the management of adult cancer survivors who are experiencing symptoms of fatigue after completion of primary treatment.


Association of Community Cancer Centers

The Association of Community Cancer Centers’ Cancer Program Guidelines are designed to assist cancer programs in developing a comprehensive interdisciplinary program to meet the needs of cancer patients and their families. The guidelines include a section that addresses psychosocial oncology care and distress management services.

Contact:
www.accc-cancer.org/guidelines

CancerCare

PHQ-9 Screener: CancerCare utilizes the PHQ-9 to screen for distress: The PHQ-9 screener is used as well as clinical assessment by trained oncology social workers who staff CancerCare’s Counseling Line.

Contact:
1-800-813-HOPE (4673)

CancerCare Online and Telephone Support Groups: A range of support for people with cancer, available online and over the phone.

Contact:
http://www.cancercare.org/support_groups

CancerCare Counseling Services

Contact:
http://www.cancercare.org/counseling
**Standard 3.2: Psychosocial Distress Screening**

**Cancer Support Community**

**CancerSupportSource® (CSS) Distress Screening Program**: a comprehensive web-based computerized screening program with automated information and referrals to institutional and community resources. CSS is available through an annual license fee with support and consultation in setting up a comprehensive screening program, ongoing upgrades and enhancements, and availability of local and national CSC resources to assist screened patients. CancerSupportSource Distress Screening and Personal Support Care Planning is also available free of charge throughout Cancer Support Community affiliates nationwide and to patients who call the CSC Cancer Support Helpline. Helpline Counselors can assist patients who have online access to complete the screening program, develop a Personal Support Care Plan and access information and supportive resources.

**Contact:**
Cate O'Reilly, MSW
(858) 353-6430
cate.oreilly@patientplanningservices.com

**CSC Local Affiliate Network**: CSC has an international network of more than 50 local affiliates and 100 satellite locations that provide support groups, educational workshops and health and wellness classes to all people impacted by cancer. All CSC programs are provided to patients, survivors, caregivers and family members free of charge. To find an affiliate in your community, visit [www.http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-CSC-Affiliate](http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Find-a-Local-CSC-Affiliate)

**Contact:**
Sara Goldberger, LCSW-R
sara@cancersupportcommunity.org
646-600-7565

**Toll-Free Cancer Support Helpline**: CSC’s toll-free Cancer Support Helpline is open Mon-Fri 9 am- 9 pm Eastern. It is staffed by licensed mental health professionals who can provide emotional support, education about the social and emotional aspects of living with cancer, information about community resources to anyone touched by cancer. Spanish speaking counselors are available.

**Contact:** 1-888-793-9355

**Online Support Services**: CSC offers online support through The Living Room, a forum where people affected by cancer can connect with others 24/7. The Living Room offers discussion boards moderated by licensed mental health professionals on topics like breast cancer, living life after treatment or caregiving. Users can create a secure personal website to stay connected to friends and family.

**See more at**: [http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.FigCVnBB.dpuf](http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.FigCVnBB.dpuf)

**Contact:**
Sara Goldberger, LCSW-R
Sara@cancersupportcommunity.org
646-600-7565
For referrals or more information for all services: 1-888-793-9355
Standard 3.2: Psychosocial Distress Screening

National Cancer Institute

Distress Screening: GEM-Distress Measurement (DM): GEM-DM is a project initiated by the NCI’s Behavioral Research Program, providing a mechanism to determine the use of measures in different contexts and elicit feedback from the research and practice communities. Subsequent work would build on the collaboration between research, practice and policy, to provide objective data to help researchers and clinicians make decisions about the ‘best’ measures of distress and to promote data harmonization.

Resources include:
- The ability to rate and comment on measures
- Download publicly available measures
- Links to documents reviewing measures, as well as Canadian guide to distress screening implementation

Contact:
Richard Moser, PhD
mosterr@mail.nih.gov


GEM Homepage:
https://www.gem-measures.org/Public/Home.aspx

GEM-DM Workspace:

NCI Community Oncology Research Program Psychosocial Assessment Tool
This tool is a self-assessment of capacity to deliver psychosocial care in the cancer center setting. Common uses include: annual program evaluation, strategic planning, and communication with administration. The tool is aligned with, but not restricted to, current Commission on Cancer distress screening standards. It provides a rubric for evaluation psychosocial care for cancer patients and survivors. It has been used in research, clinical and training programs to improve the delivery the psychosocial care.

https://ncorp.cancer.gov

Contact:
Julia Rowland, PhD
rowlandj@mail.nih.gov
Standard 3.2: Psychosocial Distress Screening

OTHER RESOURCES AND TOOL AVAILABLE NATIONALLY*

National Comprehensive Cancer Network® (NCCN®)

NCCN® Distress Thermometer Screening Tool, an initial single-question screening tool that identifies distress coming from any source, even if unrelated to cancer. The Distress Thermometer was developed to help patients determine their level of distress and for health care providers to determine the types of support services a patient may need. It can be filled out by the patient in the waiting room or with the help of a health care provider. The Distress Thermometer has been validated in many studies and has shown good sensitivity and specificity.

Contact:
215-690-0300
www.nccn.org

The Distress Thermometer can be found on page DIS-A of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management, available at:
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#distress

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Pfizer, Inc.

PHQ-9, The Patient Health Questionnaire (PHQ) is a self-administered screening and diagnostic tool for depression. The PHQ-9 offer clinicians a concise tool for mental health disorders, which have been field-tested in office practice. The screeners are quick and user-friendly, improving the recognition rate of depression and anxiety and facilitating diagnosis and treatment.

Contact:
questions@phqscreeners.com
www.phqscreeners.com

*NCCN and Pfizer, Inc. are not Alliance member organizations, but these tools are utilized by many organizations.
Standard 3.3: Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

NATIONALLY AVAILABLE PROGRAMS

American Cancer Society

ACS has multiple sources of information to assist patients and caregivers in transitioning from active treatment into survivorship and follow-up care.

Contact:
1-800-227-2345
Visit: http://www.cancer.org/treatment/survivorshipduringandaftertreatment/index

The National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaborative effort between the American Cancer Society, The George Washington University Cancer Institute, and the Centers for Disease Control and Prevention. Its goal is to shape the future of adult post-treatment cancer survivorship care and to improve the quality of life of cancer survivors as they transition from treatment to recovery. The Survivorship Center staff and more than 130 volunteer survivorship experts nationwide developed recommendations to address the gaps in adult post-treatment survivorship care resulting in the development of the resources listed in the link below for cancer survivors, caregivers, health care professionals, and the policy and advocacy community.

Contact:
Email: Survivorship@cancer.org
Visit: www.cancer.org/survivorshipcenter

In addition to the main link above, the Survivorship Center Resources include the following tools:

- **Tools for Cancer Survivors and Caregivers**

- **Tools for Healthcare Professionals**
**Standard 3.3: Survivorship Care Plan**

- **Cancer Survivorship E-Learning Series for Primary Care Providers**
  The National Cancer Survivorship Resource Center offers a free online continuing education program to educate primary care providers about cancer survivorship. The Cancer Survivorship E-Learning Series for Primary Care Providers features content on:
  - The role of clinical generalists and specialists in providing follow-up care to survivors of adult-onset cancers
  - How to manage long-term and late physical and psychosocial effects of cancer and its treatments
  - Survivorship care planning and care coordination

  The series is available at no cost and offers continuing education credits for physicians, physician assistants, nurse practitioners, and nurses. New content will be added on an ongoing basis. Each webinar is led by national experts and features a cancer survivor story.

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

**Survivorship Care Plans**
ACS provides brief descriptions and links to several care plans developed by different organizations.

Visit: [http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index](http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index)

**Implementing Survivor Care Plans in CoC-accredited Hospitals – November 11, 2014**
A recording of a webinar hosted by the ACS that featured speakers from the CoC, clinicians from CoC-accredited hospitals both large and small, and The Survivorship Center, who shared perspectives on the value of survivorship care plans as well as recommendations for implementing survivorship care plans in CoC-accredited programs, and sharing ACS and The Survivorship Center resources to support SCP implementation and survivorship programs.

Visit: [http://www.youtube.com/watch?v=x7a62fSOq_w&feature=youtu.be](http://www.youtube.com/watch?v=x7a62fSOq_w&feature=youtu.be)

**Information for Health Care Professionals**
A central repository for the cancer survivorship care guidelines, and the ACS cancer screening and nutrition and physical activity guidelines for cancer survivors that were leveraged in the cancer survivorship care guidelines. Pages feature a brief description of the cancer survivorship care guideline development process, links to the full CA article and CA Patient Page, guideline recommendations tables, The E-Learning Series, prescription for cancer information tool and life after treatment guide. The guidelines help inform key elements of survivorship care plans.

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

**Survivorship Videos**
This video series features content on survivorship care plans, nutrition and physical activity for cancer survivors, managing physical and emotional side effects, and cancer survivor stories.

Lifestyle Changes that Make a Difference: Nutrition and Physical Activity Guidelines for Cancer Survivors
This information for patients is based on the “ACS Nutrition and Physical Activity Guidelines for Survivors” developed by the Society and a panel of experts in nutrition, physical activity and cancer survivorship. This patient guide is meant to provide information they need to make informed choices food and physical activity.


Cancer Survivors Network
A peer-support online community for cancer survivors, families and friends including member pages, private and secure internal email, discussion boards, chat rooms, and free monthly newsletter.

Visit: http://csn.cancer.org/?_ga=1.93934804.83306453.1447016091

My LifeLine.org
A free social network that empowers cancer patients and caregivers to build an online support community of family and friends to foster connections, inspiration, and healing through free, personalized websites.

Visit: http://www.cancer.org/treatment/supportprogramsservices/onlinecommunities/mylifelineorg

American Childhood Cancer Organization
iCANcer, the first iPhone/iPod/iPad app designed to help both adult and childhood cancer patients, caregivers and survivors manage their cancer journey. iCANcer helps manage medical information by allowing you to graph lab results, log treatments and side effects, sync doctor appointment information with your calendar and access important cancer resources. iCANcer features:
• Password protected
• Exports medical information
• Graphs tests and lab trends over time
• Sorts current and past medications
• Organizes and syncs doctors’ appointments
• Stores questions to ask specialists
• Manages medical history
• E-mails your information to a new doctor

Contact:
Naomi Bartley (iCANcer creator and survivor)
hope4acure@gmail.com
http://www.acco.org/Information/Resources/iCANcer.aspx
American Society of Clinical Oncology

ASCO has developed a template for healthcare professionals to use when providing a survivorship care plan to patients who have completed curative cancer therapy. The survivorship care plan contains important information about treatment the patient received, their need for future checkups and cancer tests, the potential long-term late effects of the treatment they received, and ideas for ways survivors can improve their health. Links to the template and other survivorship care resources are found in the links below.

Contact:
http://www.asco.org/advocacy/asco-cancer-survivorship-compendium-provides-practical-practice-tools

ASCO Answers Guide to Cancer Survivorship
http://www.cancer.net/survivorship

Contact:
1-888-651-3038
contactus@cancer.net

Association of Community Cancer Centers

The Association of Community Cancer Centers provides resources for cancer programs interested in creating, implementing, and sustaining cancer survivorship programs.

Contact:
http://www.accc-cancer.org/resources/cancerSurvivorship-Overview.asp to access resources.

CancerCare

Care plans tailored to patient and caregiver need and situation. Callers are sent tailored CancerCare materials to help meet their need. CancerCare works with an extensive array of collaborating organizations to best meet client need. These and many other cancer organizations are listed extensively in the CancerCare Helping Hand Financial Resource Guide.

Contact:
1-800-813-HOPE (4673)
http://www.cancercare.org/helpinghand
**Standard 3.3: Survivorship Care Plan**

**Free to Breathe (National Lung Cancer Partnership)**

**Personalized Care Plan:** A resource that helps patients record information on diagnosis, track treatment and appointments, monitor symptoms and more. The Care Plan may be downloaded from the link below.

**Contact:**
608-833-7905  
info@NationalLungCancerPartnership.org  
http://www.nationallungcancerpartnership.org/care-plan

**National Cancer Institute**

**Survivorship Care Planning:** The NCI Office of Cancer Survivorship provides information and resources for survivors and clinicians including links to care planning tools.

**More info:**  
http://cancercontrol.cancer.gov/ocs

**Follow-up Care After Cancer Fact Sheet (CIS):** The Fact Sheet about the importance of follow-up care and what it entails.

**More info:**  
http://www.cancer.gov/cancertopics/factsheet/Therapy/followup

**Office of Cancer Survivorship Resource on Care Planning:** The GEM-Care Planning Initiative (GEM-CP) (NCI/HCIRB): Health care policy and health information environment variables relevant to survivorship care planning (e.g., electronic and personal health records (EHRs and PHRs) are dynamic and change rapidly. The GEM-Care Planning Initiative (GEM-CP), a project initiated by the National Cancer Institute's Health Communication and Informatics Research Branch (HCIRB) and Office of Cancer Survivorship, is intended to build consensus in the survivorship community around high-priority process and outcome measures for use in studies of survivorship care planning. Increased use of shared measures will enable comparability across studies and facilitate expeditious identification of strategies to implement optimal care planning - or barriers to that planning - for cancer survivors.

**More info:**  

**Contact:**  
Richard Moser, PhD  
mosterr@mail.nih.gov

The National Cancer Institute and American Cancer Society have launched the mHealth resource, Springboard Beyond Cancer, which is designed to improve cancer survivor self-management. Springboard Beyond Cancer addresses more than 20 symptoms and health behaviors with a focus on identifying strategies and skills training to promote active self-management among cancer survivors as a means to lessen the impact of disease and treatment side-effects and improve quality of life. This new tool is intended to make it easier for those in- or post-treatment to access essential information to help them manage their symptoms, change health behaviors,
deal with stress, communicate effectively with their healthcare team, and seek support from friends, family members, and employers.

The mobile-optimized website draws from existing information from Cancer.org & Cancer.gov, clinical literature related to survivorship and health behavior interventions, and more than a decade of mHealth experience.

More info:
https://Smokefree.gov/springboard/
http://pressroom.cancer.org/SpringboardLaunch

National Coalition for Cancer Survivorship

Journey Forward: Journey Forward’s Survivorship Care Plan Builder is a free software program designed to assist oncology professionals in quickly creating custom Survivorship Care Plans. It leverages cancer-specific templates to create a unique Care Plan for each patient, which can be printed, emailed or stored electronically. Journey Forward’s Survivorship Care Plan Builder can accept exported information from select cancer registry programs, eliminating much of the time and effort that typically goes into preparing a care plan.

More info:
www.journeyforward.org
http://www.canceradvocacy.org/partnerships/journey-forward/
http://www.canceradvocacy.org/nccs-resources/

For inquiries and comments about the Journey Forward initiative: info@JourneyForward.org
For technical support for the Survivorship Care Plan Builder or the Medical History Builder: info@nearspace.com
707-636-5900 (9AM-5PM, PST/PDT)

Additional Information:
The Survivorship Care Plan Builder generates care plans that reflect the guidance of both the Institute of Medicine (IOM) and ASCO, and include:

- contact information for the care team for facilitating the coordination of care
- information on diagnosis and staging
- a treatment summary
- a follow up care schedule
- a psycho-social assessment
- information on managing symptoms and what to watch for or expect

Journey Forward offers additional resources online at JourneyForward.org, including an online Survivorship Library and My Care Plan, a patient-oriented survivorship care planning tool.
Standard 3.3: Survivorship Care Plan

ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES

Alliance for Quality Psychosocial Cancer Care

The Alliance has created a searchable database of local, state and national resources for psychosocial care services. The Database includes resources to address range of social and emotional needs of cancer patients and families.

Contact:
Julie Taylor
jtaylor@cancersupportcommunity.org
jtaylor@wholecancerpatient.org
www.wholecancerpatient.org

American Cancer Society

The American Cancer Society offers a number of local programs and services to help people with cancer and their loved ones understand cancer, manage their lives through treatment and recovery, and find the emotional support they need.

More info:
Patients and providers can locate services in their community at:
http://www.cancer.org/treatment/supportprogramsservices/app/resource-search

I Can Cope Online: I Can Cope® is a free online educational program for people facing cancer and their families and friends. The program is comprised of self-paced classes that can be taken any time, day or night. Take as few or as many classes as you like. Many topics are offered such as information about cancer, managing treatments and side effects, healthy eating during and after treatment, communicating with family and friends, finding resources, and more.

More info:
http://www.cancer.org/icancope

Contact:
1-800-227-2345

Links to Survivorship Care Plans available from other national organizations:
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/survivorshipcareplans/index

Links include:
• What’s Next? Life After Cancer Treatment
• Journey Forward
• Prescription for Living
• ASCO Cancer Treatment Summaries
• LIVESTRONG Care Plan
American Psychosocial Oncology Society

The American Psychosocial Oncology Society promotes ongoing professional educational opportunities for healthcare professionals engaged in psychosocial care and research for individuals affected by cancer via its website. APOS has a webinar series for professionals and provides resources relevant to clinical practice guidelines and quality care standards for psychosocial care. The tailored webinars are interactive and provides timely information on fellowship opportunities to benefit early career professionals and other employment opportunities for those in later stages of professional growth and development. APOS hosts an annual conference for healthcare professionals engaged in advancing the science and practice of psychosocial oncology.

A section of the APOS website is devoted to highlighting resources for support available to patients and those affected by cancer. Through their website APOS provides essential information about the field of psychosocial oncology and links to resources, programs, and support that may ease the cancer journey.

APOS toll-free HELPLINE
A national resource to help people with cancer and their caregivers find emotional support in their own communities. This referral program is part of the Cancer Support Helpline (affiliated with the Cancer Support Community) and connects cancer patients, their caregivers and advocacy organizations, with psychiatrists, psychologists, nurses, social workers, and counselors skilled in the management of cancer-related distress.

Contact:
1-866-276-7443 (1-866-APOS-4-HELP)

Resources for People Affected by Cancer
The APOS website has a number of practical and tailored resources for educational and clinical needs of cancer patients and their families relating to:

- Coping
- Survivorship
- Navigation
- End of Life
- Talking with your doctor
- Resources and Links
- General Information on Cancer

Links:
- [Resources for Specific Cancers](#)
- [Coping and Financial Resources](#)
- [Pediatric Cancer Resources](#)
- [Young Adult Cancer Resources](#)
- [Peer Support Programs](#)
Standard 3.3: Survivorship Care Plan

ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES

Be The Match®/ National Marrow Donor Program®

Be The Match® is dedicated to helping patients, caregivers and families navigate the transplant process. We are available to offer one-on-one professional guidance and education by answering questions, sharing resources, and providing support. Our goal is to help patients, caregivers and their families learn about transplant as a treatment option, prepare for transplant and plan for life after transplant. Patient educational resources and services are free and available to all transplant patients (related, unrelated and autologous). Be The Match offers Spanish bilingual staff and translated materials in a number of languages.

Contact:
Patient Services
1-888-999-6743
Email: patientinfo@nmdp.org
www.BeTheMatch.org/patient
www.BeTheMatchClinical.org (for healthcare professionals)

CancerCare

Professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones and the bereaved. Programs include counseling and support groups, education, financial assistance and practical help and are provided by professional oncology social workers at no charge. These counseling services are offered in English and Spanish with bilingual social workers as well as publications in Spanish.

Contact:
1-800-813-HOPE (4673) www.cancercare.org
CancerCare Financial Assistance Programs: http://www.cancercare.org/financial
CancerCare Co-Payment Assistance Foundation: http://www.cancercare.org/copay.org
CancerCare publications: http://www.cancercare.org/publications
Connect Education Workshops Teleconferences/webcasts: www.cancercare.org/connect
Podcasts: www.cancercare.org/podcasts

Cancer Legal Resource Center

The Cancer Legal Resource Center (CLRC) provides free information, resources, and education about cancer-related legal questions to patients, survivors, caregivers, and health care professionals.

CLRC National Telephone Assistance Line: Callers can receive free and confidential information about laws and resources for their particular situation. Members of CLRC’s Professional Panel of attorneys can provide additional assistance. There is also an intake form available online. Services are available in English and Spanish, and a language line is used for callers who speak other languages.

Contact:
1-800-THE-CLRC (843-2572)
www.cancerlegalresources.org
Submit an intake online at www.clrcintake.org

CLRC Educational Materials: These helpful publications are available on the CLRC website free of charge in PDF format. Some materials may be available to order for a nominal charge.
- Patient Legal Handbook: This handbook is a resource for patients coping with cancer and provides valuable information about cancer-related legal issues from diagnosis through survivorship. This handbook is part of a project funded by Amgen's Breakaway from Cancer partnership program to educate patients with cancer about cancer-related legal issues. (Also available in Spanish)
- Other materials covering topics including, but not limited to advance planning, employment, health insurance appeals, financial assistance, caregiver rights, and resources for children and young adults.

CLRC Webinars: Archived webinars covering a variety of cancer-related legal issues are available to watch for free on the CLRC website.

Contact:
http://cancerlegalresources.org/publications-webinars/
clr@drlcenter.org

Cancer Support Community

Frankly Speaking About Cancer, a free cancer education series, providing sound medical and psychological information for cancer patients and their loved ones on general cancer topics as well as specific cancer types. These education materials provide easy to understand Information about cancer through a variety of means (print, online and in-person programs), and are free to patients and loved ones. The information is reviewed by medical experts including oncologists, nurses, social workers, and patient advocacy groups and even patients and caregivers.

Contact:
workshops@cancersupportcommunity.org
http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer/What-is-FSAC.html#sthash.t1E2oolW.dpuf

Cancer Experience Registry: The Cancer Experience Registry is an online initiative designed to help us better understand the social and emotional needs of people living with cancer so that we and others can develop new resources that give support to the millions of people living with cancer every day. The Cancer Experience Registry will collect information about the experiences of people who have volunteered to share their cancer journey in a survey and will connect them to a network of support and resources.

Contact:
Jameese Johnson, MPH, CPH
jameese@cancersupportcommunity.org
www.cancerexperienceregistry.org
**Standard 3.3: Survivorship Care Plan**

**ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES**

**Toll-Free Cancer Support Helpline:** CSC’s toll-free Cancer Support Helpline is open Mon-Fri 9 am-9 pm Eastern. It is staffed by licensed mental health professionals who can provide emotional support, education about the social and emotional aspects of living with cancer, information about community resources to anyone touched by cancer. Spanish speaking counselors are available.

**Contact:** 1-888-793-9355
http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Cancer-Support-Helpline.html#sthash.CXC0vZC6.dpuf

**Online Support Services:** CSC offers online support through The Living Room, a forum where people affected by cancer can connect with others 24/7. The Living Room offers discussion boards moderated by licensed mental health professionals on topics like breast cancer, living life after treatment or caregiving. Users can create a secure personal website to stay connected to friends and family.

**See more at:** http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.FjgCVnBB.dpuf

**Contact:**
1-888-793-9355
Sara Goldberger, LCSW-R
sara@cancersupportcommunity.org
1-646-600-7565

**Center for Communication in Medicine**

**Difficult Conversations Video/Workbook: Finding a Path Through Illness:** Clear communication about needs and concerns is critical to helping patients secure both appropriate medical care and emotional support. The Difficult Conversations Workbook uses video of fellow patients’ reflections as a framework for guided writing exercises designed to help patients communicate his/her hopes and goals for treatment and beyond. FREE access to workbook available at www.speaksooner.org.

**Contact:**
Bernard Bandman, PhD
(802) 442-5800
b.bandman@communicationinmedicine.org

**SpeakSooner**
www.speaksooner.org
The Center for Communication in Medicine (CCM) recently launched SpeakSooner initiative in Vermont with the Difficult Conversations Toolkit as its centerpiece. The toolkit (video and workbook) serves as a guide to help patients and families identify their needs, values and priorities in preparing for discussions with healthcare providers about treatment choices and quality of life concerns, including identifying psychosocial and spiritual needs and resources.

The aim of the toolkit is to: empower patients to actively engage in timely and frank discussions in making decisions about care; help family and caregivers express concerns and secure the supports they need; and engage healthcare professionals to communicate honestly and compassionately about risks and benefits of treatment options and quality of life issues—sooner rather than later.
Standard 3.3: Survivorship Care Plan

ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES

The just released Institute of Medicine report on Improving Quality and Honoring Individual Preferences Near End of Life recommends that community-based organizations, "encourage meaningful dialogue among individuals and their families and caregivers, clergy and clinicians about values, care goals, and preferences related to advanced serious illness."

CCM’s toolkit is being used in the Rutland, VT Medical Center’s cancer center, in-patient palliative care service and hospice. In addition, the SpeakSooner initiative offers community programs aimed at educating the public about the toolkit’s use in decisions about care and securing supports. Physicians, nurses, psychologists, social workers and clergy are introducing the toolkit to patients and caregivers with much success.

Contact:
Bernard Bandman, PhD
(802) 442-5800
b.bandman@communicationinmedicine.org

Children’s Oncology Group

The Children’s Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world’s largest organization devoted exclusively to childhood and adolescent cancer research. The COG unites more than 9,000 experts in childhood cancer at more than 200 leading children’s hospitals, universities, and cancer centers across North America, Australia, New Zealand, and Europe in the fight against childhood cancer.

The Children’s Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers (COG LTFU Guidelines) are a resource for healthcare professionals who provide ongoing care to survivors of pediatric malignancies. The screening recommendations in these guidelines are appropriate for asymptomatic survivors of childhood, adolescent, or young adult cancer presenting for routine exposure-based medical follow-up. More extensive evaluations are presumed, as clinically indicated, for survivors presenting with signs and symptoms suggesting illness or organ dysfunction. A basic knowledge of ongoing issues related to the long-term follow-up needs of this patient population is assumed. Healthcare professionals who do not regularly care for survivors of pediatric malignancies are encouraged to consult with a pediatric oncology long-term follow-up center if any questions or concerns arise when reviewing or using these guidelines. A complementary set of patient education materials, known as "Health Links" accompany the guidelines in order to enhance patient follow-up visits and broaden the application of these guidelines. More detailed information regarding development and application of the COG LTFU Guidelines and related materials is available by accessing the documents below.

Although the information within the guidelines will certainly prove valuable to the survivors themselves, the only version currently available is targeted to healthcare professionals. Therefore, survivors who choose to review these guidelines are strongly encouraged to do so with the assistance of a healthcare professional knowledgeable about long-term follow-up care for survivors of childhood, adolescent, and young adult cancers.

http://www.survivorshipguidelines.org
**Standard 3.3: Survivorship Care Plan**

**ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES**

Free to Breathe (National Lung Cancer Partnership)

**Patient and Caregiver educational webinars:** Free to Breathe also refers patients requesting support services to CancerCare and Cancer Support Community which are included in this resource guide.

**Contact:**
608-833-7905  
info@NationalLungCancerPartnership.org  
http://www.nationallungcancerpartnership.org/lung-cancer-info/resources-for-patients-and-loved-ones/webinars

National Cancer Institute

**Facing Forward Series:** Information and guidance about post-treatment issues such as follow-up medical care, physical and emotional changes, changes in social relationships, and issues in the workplace.

**Contact:**
1-800-4-CANCER  

**Patient-Centered Communication in Cancer:** A monograph with lots of ‘how to’ tips based on the research evidence.

**Contact:**
http://appliedresearch.cancer.gov/areas/pcc/communication/monograph.html

**Grid Enabled Measures (GEM):** GEM is an electronic platform that hosts a number of workspaces with measurement tools that people can use (most in the public domain) to assess patient distress and the outcomes or impact of survivorship care planning processes.

**Contact:**

National Children's Cancer Society

The National Children's Cancer Society (NCCS) provides emotional, financial and educational support to children with cancer, their families and survivors.

Beyond the Cure Late Effects Assessment Tool  
http://www.thenccs.org/LEATT-info
Standard 3.3: Survivorship Care Plan

ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES

National Coalition for Cancer Survivorship

New Cancer Survival Toolbox©: A series of free, award-winning audio programs developed by leading cancer organizations to help people develop important skills to meet the challenges of their illness. These programs, created by cancer survivors and healthcare professionals, can be helpful to newly diagnosed individuals, family members and caregivers, as well as to anyone during all stages of their illness. The programs address scenarios for many topics and issues cancer patients/survivors face during their cancer journey. Each scenario is inspired by true stories of real cancer patients/survivors. The entire program is available for free download or mail order on the NCCS website and is available in English and Spanish.

Contact:
301-650-9127
info@canceradvocacy.org
http://www.canceradvocacy.org/resources/cancer-survival-toolbox/

Cancer Survival Toolbox – Hematologic Cancer Modules: An extension of the Award-winning Cancer Survival Toolbox, these additional audio programs address specific types of blood cancers. These programs, which were written by cancer survivors and healthcare professionals, can be helpful to individuals newly diagnosed, family members and caregivers, as well as to anyone at any other stage of the illness. All programs available free of charge on the NCCS website, iTunes, or by mail order. Titles in this series:
- Living with Non-Hodgkin Lymphoma (Available in English & Spanish)
- Living with Chronic Myelogenous Leukemia
- Living with Chronic Lymphocytic Leukemia
- Living with Blood and Marrow Transplant
- Living with Multiple Myeloma

Contact:
301-650-9127
info@canceradvocacy.org
http://www.canceradvocacy.org/resources/cancer-survival-toolbox/

Dying Well—The Final Stage of Survivorship is an informative, supportive, and reassuring program designed to teach you more about your choices and resources and what to expect during this last stage of survival. The program is recorded in both English and Spanish and is available for free download or by mail order on the NCCS website.

Contact:
301-650-9127
info@canceradvocacy.org
http://www.canceradvocacy.org/resources/cancer-survival-toolbox/special-topics/dying-well/

The Pocket Cancer Care Guide (iPhone App): An iPhone app designed to help with informed decisions about treatment. The Pocket Guide is for patients and their family, friends and loved ones to quickly and easily build lists of practical questions used to guide conversations between you and your doctor. Browse hundreds of questions in categories for each stage of your cancer diagnosis; build lists of questions to use when talking to your doctor; record and playback your doctor’s answers; create your own custom questions and add them to the
**Standard 3.3: Survivorship Care Plan**

**ADDITIONAL SURVIVORSHIP RESOURCES AND SERVICES**

app; explore the extensive glossary to learn more about medical terminology your doctor uses; link doctor appointments to your lists and automatically add it to your calendar.

**Contact:**
301-650-9127  
info@canceradvocacy.org  
http://www.canceradvocacy.org/resources/pocket-care-guide/

**Patient Education Booklets:** These helpful publications are available on the NCCS website free of charge in PDF format or through online order (nominal charge).

- **Teamwork: The Cancer Patient’s Guide to Talking with Your Doctor:** This booklet was developed by cancer survivors and health care professionals, addresses the need for good communication and provides a list of sound, practical questions that patients can use when talking with their doctor. Resource available in English and Spanish.

- **You Have the Right to Be Hopeful:** This booklet defines the many ways that hope can be present in a survivor’s life and offers a place for survivors to chronicle and reflect on their cancer journey. Resource available in English and Spanish.

- **Self-Advocacy: A Cancer Survivors Handbook:** Self-Advocacy focuses on self-training steps and tools to assist and empower individuals dealing with cancer. Resource available in English only.

**Contact:**
301-650-9127  
info@canceradvocacy.org  
http://www.canceradvocacy.org/nccs-resources/
Standard 3.1: Patient Navigation Process

A patient navigation process, driven by a community needs assessment, is established to address health care disparities and barriers to care for patients. Resources to address identified barriers may be provided either on-site or by referral to community-based or national organizations. The navigation process is evaluated, documented, and reported to the cancer committee annually. The patient navigation process is modified or enhanced each year to address additional barriers identified by the community needs assessment.

City of Hope

Patient Navigation Program: The Patient Navigation Program provides specialized assistance to vulnerable populations, addressing barriers to care identified through the institution’s community needs assessment. Patient navigators, clinical social workers, a patient resource specialist collaborate with members of the multidisciplinary team and partner with community-based organizations to ameliorate or eliminate barriers to care.

Patient Navigators provide personalized guidance, support and assistance to patients and their families. These trained professionals help patients and their families navigate complex health care systems and make use of the services that are needed to receive the best possible care.

Contact:
Annette Mercurio, MPH, MCHES
Director of Programs, Supportive Care Medicine
626-301-8926
http://www.cityofhope.org/biller-resource-center

Additional Information:
Navigator Role – Patient Care:

• Connects patients and families to resources and supportive care staff and services
• Eliminates or reduces barriers to medical and psychosocial care to ensure patient needs are met (appointments, insurance, financial)
• Enhances continuity of care and relationship with patients and families (get to “know” them well to better address their needs)
• Facilitates partnerships between the multidisciplinary team and patients and families, overcoming language/cultural barriers and enhancing communication
• Recognizes and helps patients alleviate stress and anxiety

Please note, these are best practices as shared by Alliance members. There are many other examples of best practices available in facilities and organizations across the country.
Standard 3.1: Patient Navigation Process
Best Practices

Navigator Role – SupportScreen Program:
- Generates and distributes daily list of patients to be screened in outpatient clinics
- Responds to SupportScreen generated referrals from patients requesting navigation assistance
- Maintains collaborative relationships with physicians, clinic managers and other staff with respect to the program
- Facilitates “in-service” training for new physicians, clinic managers, and other staff
- Identifies opportunities for improvement in SupportScreen processes and recommends enhancement/expansion plans

Norton Cancer Institute
(Norton has several locations serving the Greater Louisville, KY area)

Oncology Certified Nurse Navigators provide personalized education regarding cancer diagnosis, staging and treatment. Navigators facilitate timely communication among patients, caregivers and physicians. Navigators facilitate access to a multidisciplinary team based approach to care and transitioning care between physician’s offices and clinics. Navigators assist with identifying and addressing barriers to timely and appropriate treatment. They assist with connecting patients to the appropriate health care and community resources; including internal resources of art, music and massage therapy and nutritional counseling.

Norton provides referrals to national organizations for:
- Leukemia and Lymphoma Society Patient Assistance Program: www.lls.org
- American Cancer Society Support Services and Educational Resources: www.cancer.org
- National Cancer Institute Resources: www.cancer.gov
- National Brain Tumor Society Education Resources: www.braintumor.org

Contact:
Judy Fisher RN, OCN
Director
Community Resources and Support Services
Norton Cancer Institute
502-899-6867
Judy.fisher@nortonhealthcare.org

Mary Helen Davis, MD
Maryhelen.davis@nortonhealthcare.org
**Standard 3.1: Patient Navigation Process**

**Best Practices**

Robert H. Lurie Comprehensive Cancer Center at Northwestern University

**Lurie Cancer Center Navigators:** Patient navigators provide patients and their families with information about their diagnosis, treatment and available support services. Navigators serve as educators, advocates and guides before, during and after treatment as well as throughout survivorship. For more information, contact Dr. Pearman at tpearman@nm.org.

**Contact:**
Timothy Pearman, PhD, ABPP
tpearman@nm.org

**The Oncofertility Consortium®** is a national, interdisciplinary initiative designed to explore the reproductive future of cancer survivors. The Oncofertility Consortium® addresses the complex health care and quality-of-life issues that concern young cancer patients whose fertility may be threatened by their disease or its treatment. The Consortium represents a nationwide, interdisciplinary, and interprofessional network of medical specialists, scientists, and scholars who are exploring the relationships between health, disease, survivorship and fertility preservation in young cancer patients. Their work and its findings may also extend to patients who have been diagnosed with other serious diseases and who must undergo fertility-threatening treatments.

www.myoncofertility.org

**Contact:**
Teresa Woodruff, PhD
tkw@northwestern.edu
www.oncofertility.northwestern.edu

University Hospitals Seidman Cancer Center (OH)

**Nurse Navigators** to assist patients prior to entry into our system assist them in gaining entry to needed services inside the cancer hospital and within the community.

**Community outreach** into minority populations to provide wellness teaching and screenings.

Every patient is screened for any barriers to care at their first visit and periodically thereafter.

Quick Guide to Ways We Can Help

Program Calendar

**Contact:**
Trish Gallagher
216-286-3805
BEST PRACTICES: EXAMPLES OF RESOURCES USED BY CANCER CENTERS

Standard 3.2: Psychosocial Distress Screening:

The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.

City of Hope

SupportScreen is an automated biopsychosocial screening program administered to cancer patients as part of the standard of clinical care at the City of Hope. SupportScreen was implemented in 2009; to date 30,000 screenings have been conducted using SupportScreen. SupportScreen has a < 1% refusal rate and is available in English, Spanish and Traditional Chinese.

SupportScreen covers the entire process of biopsychosocial screening—from initiation of patient responses to the generation of referrals and provision of educational information. It is a patient-friendly automated process that identifies, triages, and provides educational information all in real time. SupportScreen also facilitates patient, physician and multi-specialist communication and is used to maximize the effectiveness of clinical encounters and overall cancer care (see figure 1 below).

1 Please note, these are best practices as shared by Alliance members. There are many other examples of best practices available in facilities and organizations across the country.
Standard 3.2: Psychosocial Distress Screening
Best Practices

SupportScreen is flexible in real-time and highly customizable to meet the multiple needs of patients, family members and caregivers. SupportScreen has been tailored in a variety of ways at the City of Hope. Here are some examples how SupportScreen has been used to personalize the care of patients, family members and caregivers: 1) ICU SupportScreen-Family/Caregiver/Patient entered data: preferences and values, Advance Directives, ICU orientation and education, request a family goals of care meeting, biopsychosocial distress; 2) Couples clinics SupportScreen- Patients and partners entered data: Biopsychosocial distress screening, Metastatic specific questions, prognosis, relationship, role-specific satisfaction; 3) Pediatrics SupportScreen- Patients and parents entered: Biopsychosocial distress tailored by age: 8-12 and 13-20 (patients under 8 parent entered only); 4) Survivorship SupportScreen- Patients entered: biopsychosocial distress and symptom screening to populate survivorship care plan and 5) Pre-Anesthesia Testing Clinic SupportScreen- Patients entered: Post-operative nausea, Advance Directives, tobacco use, distress screening.

SupportScreen is integrated with most platforms and was designed to run on simple network systems to be easily adapted to a variety of settings including small clinical practices. SupportScreen has many unique features; here are some examples of the key features of SupportScreen: 1) Ability to easily modify content (includes triggers, triage, education materials and items) and implement immediately via web-based secure administration screen; 2) Easily integrated with EMR including discrete data, standard HL7 messages and PDF; 3) Real-time tailored educational materials printed in-clinic; 4) 3rd to 4th grade reading level; 5) Multiple questions types: branching, multi-select, dichotomous, Likert scale, open-ended; 6) Patient-friendly interface: touch screen, mouse and keyboard; 7) Real-time summary report triaged to MD, RN, MSW and other health care professionals ; 8) Real-time outputs: e-mail, print, text, EMR, PDF; 9) Prioritized concerns and specific assistance identified for the patient and health care team; 10) at home screening and 11) Valid and reliable content. SupportScreen has been licensed to many institutions (large and small) across the United States. The cost of the program depends on the number of licensed sites (not by patient or family member screened).

For program information please contact:
Annette Mercurio, MPH, MCHES
Director of Programs, Department of Supportive Care Medicine
City of Hope National Medical Center
e-mail: amercurio@coh.org

For licensing information please contact:

Quinn Montgomery, ClearVoice Health
e-mail: qmontgomery@clearvoicehealth.com
http://www.clearvoicehealth.com/aboutus/

In addition, to learn about a free NCI supported training program to teach health care professionals how to implement biopsychosocial screening visit our website www.supportivecaretraining.com or e-mail us at: Screeningprograms@coh.org.
**Standard 3.2: Psychosocial Distress Screening**
**Best Practices**

Fox Chase Cancer Center
Distress screening and supportive care for patients treated in the radiation oncology department and Polaris Dashboard. This FCCC standard operating procedure was developed to safeguard timing of assessment and referral to supportive care services based on level of distress of distress. The grid or cross walk is a utilization grid of supportive resources based on level of distress.

**Contact:**
Peg O'Grady, PhD
Peg.ogrady@fccc.edu
For other resources and support, contact:
1-800-FOX-CHASE (369-2427)
Support Groups: 215-278-2668

The University of Texas MD Anderson Cancer Center

The University of Texas MD Anderson’s Patient Needs Screening Policy is that patients are screened for multidisciplinary service needs by the Registered Nurse (RN), Physician, Physician Assistant (PA), or Advanced Practice Registered Nurse (APRN) at the following times in their care delivery: 1) when newly registered, 2) every 30 days thereafter, 3) every EC visit and, 4) every inpatient admission. Criteria have been established requiring referral to Social Work for elevated levels of distress (4 or greater).

In addition, the Distress Screening and Psychosocial Management algorithm outlines the process for psychosocial distress screening and lists/describes all clinical (consult required) and support services (no consult required) that will support the psychosocial needs of our patients. The algorithm was designed to align with our Patient Needs Assessment Policy (#CLN1167), identifying specified time points, along the continuum of care, to screen for distress.

On March 4, 2016, MD Anderson unveiled its new electronic health record which included NCCNs Distress Thermometer and Problem List and reporting infrastructure to monitor progress.

On April 26, 2016, MD Anderson received accreditation and commendation, from the Commission on Cancer, at the **Silver Level**, due in part to having met Standard 3.2 requirements.

**Contact:**
Karen Stepan, MPH, RN, MCHES
Program Manager, Psychosocial Oncology
kstepan@mdanderson.org
Standard 3.2: Psychosocial Distress Screening
Best Practices

Norton Cancer Institute

Distress screening is conducted at each of practice locations to ensure the timely assessment and referral of patients to appropriate supportive care. Patients have opportunity to receive support from a wide array of psychosocial services including social work, spiritual care, education/navigation, financial counseling, and behavioral health services. Behavioral oncology services are provided by an integrated team of mental health providers available to patients receiving care at Norton Cancer Institute. A multidisciplinary approach to care helps to facilitate more timely referrals to appropriate resources including management of psychological and emotional care needs.

Contact:
Elizabeth Archer-Nanda, DNP, APRN, PMHCNS-BC
Manager, Behavioral Oncology Program
Norton Cancer Institute
Norton Medical Plaza II, Suite 405
Louisville, KY 40207
(502)899-2673

PHQ-9 Distress Screener
Contact:
www.phqscreeners.com

Distress Thermometer: The Distress Thermometer was created by the National Comprehensive Cancer Network as a tool patients can use to talk to their health care team about their distress. It has a scale to indicate the level of distress. It also asks about the parts of life in which patients are having problems. The Distress Thermometer has been tested in many studies and found to work well. See page 10 of the Alliance Resource Guide for links to the Distress Thermometer.

Contact:
www.nccn.org

Robert H. Lurie Comprehensive Cancer Center at Northwestern University

NIH PROMIS Depression and Anxiety computer adaptive tests: PROMIS screening assessments are for fatigue, pain and physical function in addition to anxiety and depression. The NIH PROMIS tool is available nationally.

Contact:
David Cella, PhD
d-cella@northwestern.edu

NCCN Distress Thermometer: The Distress Thermometer was created by the National Comprehensive Cancer Network as a tool patients can use to talk to their health care team about their distress. It has a scale to indicate the level of distress. It also asks about the parts of life in which patients are having problems. The Distress Thermometer has been tested in many studies and found to work well. See page 10 of the Alliance Resource Guide for links to the Distress Thermometer.
**Standard 3.2: Psychosocial Distress Screening**

**Best Practices**

**Cancer Survivorship Institute:** Lurie Comprehensive Cancer Center offers specialty support programs and clinics to provide emotional and practical support for patients and their families during all stages of their care; from diagnosis through treatment, recovery, and long-term follow-up. These programs offer practical and supportive information to help survivors and caregivers cope with the shift in focus from treatment to recovery when caring for a loved one with cancer. The continuum of support services includes psychosocial support and education during and after completing primary treatment for their cancer, care plans that detail future follow-up, monitoring for late side effects of treatment, modifying lifestyle factors that can impact health outcomes, and tools to address physical and emotional concerns. The Institute's clinicians and social workers are trained to provide psychosocial and emotional support, nutrition counseling, fertility preservation, social work services, and healthcare system navigation. The following are examples of tailored and specialized clinics and programs that focus on the unique needs of different demographic groups.

Integrative Oncology services that combine conventional and complementary therapies to aid the healing process are provided by the Northwestern Integrative Medicine program. The therapeutic strategies engage the mind, body, spirit and community, and focus on lifestyle choices. Wellness plans may include functional nutrition, traditional Chinese medicine and acupuncture, relaxation, biofeedback, cognitive behavioral therapy, and massage therapies.

http://cancer.northwestern.edu/survivorship/

**Contact:**
Frank Penedo, PhD
Director of Cancer Control
fpenedo@northwestern.edu

University Hospitals Seidman Cancer Center

**Adapted NCCN Distress Thermometer**

**Contact:**
Kim Day
216-896-1758
Standard 3.3: Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment. The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

The University of Texas MD Anderson Cancer Center

Office of Cancer Survivorship
The mission of The University of Texas MD Anderson’s Cancer Survivorship Program is to address the outcomes of cancer and its therapy, and to improve cancer survivors’ health and quality of life, through integrated programs in patient care, research, prevention, and education.

Who are cancer survivors and what does cancer survivorship mean? The terms have different meanings to different people, and defining this growing population has stirred some controversy. The National Cancer Institute, Office of Cancer Survivorship, notes than an individual becomes a cancer survivor at the time of diagnosis through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience. MD Anderson’s Cancer Survivorship Program supports this definition. The definition is integrated into the institution’s current multidisciplinary care model and culminates in a novel multidisciplinary clinical approach that focuses on the care of long-term survivors.

The Office of Cancer Survivorship supports the Cancer Survivorship Program by:
- Collaborating with expert clinicians and researchers to promote survivorship as a distinct phase of the cancer care continuum
- Developing a database of core metrics to monitor our progress in improving cancer care and research
- Disseminating education and research about the problems and needs of cancer survivors and their caregivers to the public and professionals who treat cancer patients
- Collaborating with clinicians, researchers and other health professionals to establish a cancer survivorship research portfolio with common research agendas

Clinical Operations
To address survivorship as a distinct phase of care, multidisciplinary, disease-specific survivorship clinics were initiated at MD Anderson in 2008. Eleven adult survivorship clinics have launched, and the long-standing Childhood Cancers survivorship program has been aligned to this initiative. MD Anderson’s survivorship clinics follow clinical practice algorithms that outline best practices for a particular type of cancer or treatment site. These disease-specific algorithms have been developed for MD Anderson using a multidisciplinary approach. They take into account our patient population, services, structure and clinical practice.
**Standard 3.3: Survivorship Care Plan**

**Best Practices**

Survivorship Clinical Practice Algorithms

1. Currently, there are 47 disease-specific practice algorithms which outline eligibility criteria for transitioning a patient to survivor status and also include recommendations specific to each cancer survivor. New algorithms are under development for CML and CLL.

2. MD Anderson’s Survivorship Clinical Practice Algorithms are available on internet at [Cancer Survivorship Algorithms](#).

<table>
<thead>
<tr>
<th>Disease Site</th>
<th>Algorithms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gynecologic Oncology</td>
<td>4</td>
</tr>
<tr>
<td>Endocrine (Thyroid)</td>
<td>2</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>9</td>
</tr>
<tr>
<td>Breast</td>
<td>3</td>
</tr>
<tr>
<td>Head &amp; Neck</td>
<td>6</td>
</tr>
<tr>
<td>Stem Cell Transplant (Allogeneic)</td>
<td>9</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>3</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>5</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1</td>
</tr>
<tr>
<td>Thoracic</td>
<td>1</td>
</tr>
<tr>
<td>Leukemia</td>
<td>2</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>47</strong></td>
</tr>
</tbody>
</table>

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Robert H. Lurie Comprehensive Cancer Center at Northwestern University

A survivorship care plan (SCP) is a document that serves as a roadmap to understand future follow-up and expectations. It contains a treatment summary that highlights all the important information related to the diagnosis, including type of cancer, staging, surgical procedures performed and any treatment administered, for example chemotherapy, radiation or hormonal therapy. The survivorship care plan also contains details on follow-up, monitoring recommendations for the diagnosis itself as well as side effects or late effects of treatment, quality of life and overall health. The survivorship care plan is intended to educate individuals and to serve as a communication tool between your oncology doctors and primary health care team. At Lurie Comprehensive Cancer Center, SCPs will be available to all patients completing primary treatment starting January 1, 2015.
**Standard 3.3: Survivorship Care Plan**

**Best Practices**

**Cancer Survivorship Institute:** Lurie Comprehensive Cancer Center offers specialty support programs and clinics provide emotional and practical support for patients and their families during all stages of their care; from diagnosis through treatment, recovery, and long-term follow-up. These programs offer practical and supportive information to help survivors and caregivers cope with the shift in focus from treatment to recovery when caring for a loved one with cancer. The continuum of support services includes psychosocial support and education during and after completing primary treatment for their cancer, care plans that detail future follow-up, monitoring for late side effects of treatment, modifying lifestyle factors that can impact health outcomes, and tools to address physical and emotional concerns. The Institute’s clinicians and social workers are trained to provide psychosocial and emotional support, nutrition counseling, fertility preservation, social work services, and healthcare system navigation. The following are examples of tailored and specialized clinics and programs that focus on the unique needs of different demographic groups.

The Lynn Sage Breast Cancer Survivorship Program offers comprehensive care and management strategies for the unique challenges that women who are treated for breast cancer face as they transition to post-treatment survivorship care. These issues include hot flashes, osteoporosis, fatigue, weight gain, depression, anxiety, cognitive impairment, sexual dysfunction, neuropathy, fertility problems, and lymphedema.

The Survivors Taking Action & Responsibility (STAR) Program is a comprehensive, long-term follow-up program for adult survivors of pediatric cancer. The STAR Program follows survivors through adulthood focusing on their special medical and psychological needs. Effective integration between the Lurie Cancer Center and the Ann & Robert H. Lurie Children’s Hospital of Chicago STAR programs improves the care throughout a survivor’s lifetime.

The Senior Oncology Outcomes, Advocacy, and Research Program (SOAR) is a cancer survivorship program specifically tailored to meet the needs of older individuals. The focus of SOAR is to help improve their health-related quality of life and overall health outcomes. The Institute is in the planning and development stages of expanding specialty clinics in GI Oncology, Stem Cell Transplant, and Neuro-oncology.

Integrative Oncology services that combine conventional and complementary therapies to aid the healing process are provided by the Northwestern Integrative Medicine program. The therapeutic strategies engage the mind, body, spirit and community, and focus on lifestyle choices. Wellness plans may include functional nutrition, traditional Chinese medicine and acupuncture, relaxation, biofeedback, cognitive behavioral therapy, and massage therapies.

[http://cancer.northwestern.edu/survivorship/](http://cancer.northwestern.edu/survivorship/)

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*Please note, these are best practices as shared by Alliance members. There are many other examples of best practices available in facilities and organizations across the country.*