



ALLIANCE FOR QUALITY
PSYCHOSOCIAL **CANCER CARE**

A RESOURCE GUIDE FOR COC-ACCREDITED FACILITIES: MEETING THE COMMISSION ON CANCER PATIENT-CENTERED STANDARDS

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.

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THE ALLIANCE FOR QUALITY PSYCHOSOCIAL CANCER CARE

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ALLIANCE FOR QUALITY PSYCHOSOCIAL CANCER CARE

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 Academy of Pain Management
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
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
The LIVESTRONG Foundation
Leukemia and Lymphoma Society
Lung Cancer Alliance
National Coalition for Cancer Survivorship
National Association of Social Workers
National Patient Advocate Foundation
Robert H. Lurie Comprehensive Cancer Center of
Northwestern University
Society for Behavioral Medicine
University of California Irvine Chao
Comprehensive Cancer Center
University Hospitals Seidman Cancer Center
Yale Cancer Center



ALLIANCE FOR QUALITY PSYCHOSOCIAL CANCER CARE

*Meeting the Commission on Cancer Patient-Centered Standards
A Resource Guide for CoC-Accredited Facilities*

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>

Cancer Supplement – National Patient Navigation Leadership Summit (NPNSL): Measuring the Impact and Potential of Patient Navigation

Contact:

<http://onlinelibrary.wiley.com/doi/10.1002/cncr.v117.15s/issuetoc>

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.

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/>

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

Cancer Support Community

CSC Local Affiliate Network: CSC has a national 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:

Vicki Kennedy, LCSW

Vicki@cancersupportcommunity.org

202-650-5379

National Toll-Free Cancer Support Helpline: CSC's toll-free Cancer Support Helpline is open Mon-Fri 9 am- 8 pm Eastern. It is staffed by trained counselors who can provide emotional support, education and information about community resources to anyone touched by cancer.

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 a full suite of services including online cancer support groups and discussion boards led by licensed mental health professionals on topics like breast cancer, living life after treatment or caregiving. Online cancer support groups are real-time groups that meet online in a chat room for 90 minutes each week and are facilitated by professionals specially trained in the issues faced by those affected by cancer. Groups are offered for people with different types of cancer, caregivers and those dealing with bereavement.

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

The LIVESTRONG Foundation

LIVESTRONG Cancer Navigation Services assist with providing referrals to in house programs -- Emotional Support, to connect clients with support groups, and counseling services; and **LIVESTRONG Fertility**, to help explore fertility preservation options with clients. **LIVESTRONG** also provides referrals to partner organizations who can help address: financial, insurance, debt crisis, and workplace concerns; clinical trial information; peer mentor matching; and health literacy to help understand medical reports and results.

Contact:

855-220-7777

<http://www.livestrong.org/we-can-help/navigation-services/>

Additional Information:

Free online, phone, or in-person patient navigation for anyone affected by cancer. Services are Monday – Friday, 9am – 5pm CST. **LIVESTRONG** Cancer Navigation Services can also provide referrals to **LIVESTRONG** Foundation partner organizations including:

- Imerman Angels for peer-to-peer support
- Navigate Cancer Foundation for help answering medical questions and understanding reports
- CureLauncher for clinical trial matching
- Patient Advocate Foundation for financial assistance, workplace concerns, and insurance issues.

Navigators also work with clients to identify local and online resources for the client, which can help meet their needs. Note, **LIVESTRONG** Cancer Navigation Services do not provide specific information about the cancer or recommendations on institutions where patients should receive care.

National Cancer Institute, National Community Cancer Centers Program

Navigation Assessment Tool: This tool 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.

Contact:

<http://ncccp.cancer.gov/about/reports-and-tools.htm>

Standard 3.1: Patient Navigation Process

ADDITIONAL PATIENT NAVIGATION SERVICES AND RESOURCES FOR PATIENTS AVAILABLE NATIONALLY

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.cancercares.org

CancerCare Financial Assistance Programs: <http://www.cancercares.org/financial>

CancerCare Co-Payment Assistance Foundation: <http://www.cancercares.org/copayfoundation>

CancerCare publications: <http://www.cancercares.org/publications>

Connect Education Workshops Teleconference/webcasts: www.cancercares.org/connect

Podcasts: www.cancercares.org/podcasts

Cancer Legal Resource Center

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, insurance agents, and accountants can provide additional assistance. There is also an intake form available online.

Contact:

1-800-THE-CLRC (843-2572)

www.cancerlegalresourcecenter.org

Submit an intake online at www.clrcintake.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

<http://www.cancer.org/acs/groups/cid/documents/webcontent/002827-pdf.pdf>

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

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.

<http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2013.53.4495>

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.cancercares.org/support_groups

CancerCare Counseling Services

Contact:

<http://www.cancercares.org/services>

Cancer Support Community

CancerSupportSourceSM (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:

Vicki Kennedy, LCSW

Vicki@cancersupportcommunity.org

202-650-5379

CSC Local Affiliate Network: CSC has a national 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:

Vicki Kennedy, LCSW

Vicki@cancersupportcommunity.org

202-650-5379

National Toll-Free Cancer Support Helpline: CSC's TOLL-FREE Cancer Support Helpline[®] is open Mon-Fri 9 am- 8 pm ET. It is staffed by licensed mental health professionals specifically trained in psycho-oncology who can provide

information and referral, short-term cancer counseling, distress screening and support care planning as well as decision support counseling services.

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 a full suite of services including online cancer support groups and discussion boards led by licensed mental health professionals on topics like breast cancer, living life after treatment or caregiving. Online cancer support groups are real-time groups that meet online in a chat room for 90 minutes each week and are facilitated by professionals specially trained in the issues faced by those affected by cancer. Groups are offered for people with different types of cancer, caregivers and those dealing with bereavement.

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

Contact:

Sara Goldberger, LCSW

Sara@cancersupportcommunity.org

646-600-7565

For referrals or more information for all services: 1-888-793-9355.

The LIVESTRONG Foundation

LIVESTRONG Emotional Support: Emotional Support Navigation can be accessed in person, online, and over the phone by connecting with the LIVESTRONG Foundation at 855-220-7777. Services are available Monday – Friday, 9am – 5pm CST. Upon connecting with the Emotional Support Team, a psychosocial assessment of needs is conducted along with a distress scale measurement in order to connect anyone affected by cancer with the resources that can help reduce cancer-related stress and anxiety. LIVESTRONG Counselors also provide free, short-term supportive counseling, and can connect anyone with support groups and resources that can help improve coping skills.

Contact:

855-220-7777

<http://www.livestrong.org/we-can-help/navigation-services/>

National Cancer Institute

Distress Screening: GEM-Distress Measurement (DM): GEM-DM is 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

Contact:

Lynne Padgett, PhD

Padgettls@mail.nih.gov

<https://www.gem-beta.org/public/wsoverview.aspx?cat=8&wid=15&aid=0>

Psychosocial Assessment Tool, a self-assessment tool for community cancer programs. This tool is designed for community cancer programs to use as a self-assessment to evaluate and improve their psychosocial care services. The tool provides guidance and ensures that the psychosocial needs of cancer patients are met. Multidimensional, culturally informed psychosocial health screenings include: Emotional/Mental Health Needs (i.e., anxiety, depression, coping, sexuality); Practical Problems (i.e., concrete needs and illness-related concerns - financial, transportation, housing); Social Problems (i.e., lack of social support/resources, vocational impact, insurance); and Support Needs (i.e., personal, social, medical, spiritual).

Contact:

Lynne Padgett, PhD

Padgettls@mail.nih.gov

<http://ncccp.cancer.gov/about/reports-and-tools.htm>

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

http://www.phqscreeners.com/overview.aspx?Screeener=02_PHQ-9

**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. Through a cooperative agreement with the Centers for Disease Control, ACS is developing the infrastructure for The National Cancer Survivorship Resource Center (NCSRC), which will disseminate evidence-based information, guidance and resources to healthcare professionals and survivors

Patient Guide: *Life After Treatment: The Next Chapter in Your Survivorship Journey*. This downloadable guide helps people understand what life may be like after treatment and what they can do to stay as healthy as possible.

Contact:

1-800-227-2345

<http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-033352.pdf>

The National Cancer Survivorship Resource Center

The National Cancer Survivorship Resource Center (The Survivorship Center) is a collaboration between the American Cancer Society and The George Washington University Cancer Institute, funded by the Centers for Disease Control and Prevention. Its goal is to shape the future of post-treatment cancer survivorship care and to improve the quality of life of cancer survivors. The Survivorship Center staff and more than 100 volunteer survivorship experts nationwide developed the tools listed in the link below for cancer survivors, caregivers, health care professionals, and the policy and advocacy community.

Contact:

<http://www.survivorshipcancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/index>

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

- **Tools for Cancer Survivors and Caregivers**

<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforcancersurvivorsandcaregivers/index>

- **Tools for Healthcare Professionals**

<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index>

- **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>

Survivorship Care Plans

ACS provides brief descriptions and links to a number of care plans developed by different organizations.

<http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index>

Survivorship Videos: The video series includes videos on about nutrition and physical activity, managing side effects, and survivor stories.

<http://www.cancer.org/treatment/survivorshipduringandaftertreatment/survivorship-videos>

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.

<http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-037186.pdf>

Patient Page from CA: A Cancer Journal for Clinicians: Prostate cancer survivorship guidelines

Survivorship guidelines are advice from the American Cancer Society to help doctors, nurses, and other professionals take care of cancer survivors who have finished their cancer treatments. The survivorship guidelines presented here address issues that can occur in men after the treatment of prostate cancer.

<http://onlinelibrary.wiley.com/doi/10.3322/caac.21236/pdf>

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 will be listed extensively in the CancerCare Helping Hand Directory soon to be published.

Contact:

1-800-813-HOPE (4673)

Cancer Support Community and the LIVESTRONG Foundation

Cancer Transitions: Moving Beyond Treatment®, a 6-week, evidence-based program for survivors of any cancer diagnosis who have completed treatment. This program is targeted to those who have completed their treatment within the last 24 months; however, Cancer Transitions may benefit survivors at any time in their survivorship beyond 24 months. The program covers the benefits of exercise, nutrition, emotional support, and medical management including survivor care planning—core issues for cancer survivors. As part of the program, participants are assisted in completing a survivor care plan in collaboration with their healthcare team.

Contact:

Julie Taylor

jtaylor@cancersupportcommunity.org

<http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Cancer-Survivorship/Cancer-Transitions/About-Cancer-Transitions.html#sthash.qN70e2no.dpuf>

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>

The LIVESTRONG Foundation

LIVESTRONG Care Plan, a free online survivorship care plan that can be individualized based on the answers clients provide in a brief questionnaire. Clients can fill this out on their own, together with their healthcare provider, or with the help of their healthcare team.

Contact:

855-220-7777

<http://www.livestrongcareplan.org>

Additional Information:

The **LIVESTRONG** Care Plan program is designed for survivors of adult cancers. In order to develop the most accurate plan of care, clients may need to talk to their oncology team to have some details of their cancer therapy available:

- Type of cancer
- If you received radiation therapy, what type of cancer was this done for?
- If you received chemotherapy, what medications were received?
- If you underwent surgery, what procedures were done?

The care plan is meant for clients to review and discuss with their healthcare team (both oncology and primary care). Keep in mind that every case is different and the risks of some side effects vary based on the actual dose of radiation or chemotherapy that were received or the techniques that were used to administer these therapies. It is very important to review the plan of care with the oncology team to further clarify any risk.

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/HCIIRB): 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 (HCIIRB) 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:

<https://www.gem-beta.org/public/wsoverview.aspx?cat=8&wid=6&aid=0>

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 SurvivorCare Program

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)

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.

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.

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

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:

Allison Harvey, MPH

Allison@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:

Amna Baig, MPH

amna@cancersupportcommunity.org

www.cancerexperienceregistry.org

The Living Room® offers a full suite of CSC services online such as real-time professionally facilitated cancer support groups. The Living Room® also provides live chats with an oncology social worker, discussion boards on topics like Breast Cancer, Living Life After Treatment or Caregiving, and a way for patients and caregivers to create their own personal webpage.

Contact:

Sara Goldberger, LCSW

sara@cancersupportcommunity.org

<http://www.cancersupportcommunity.org/MainMenu/Cancer-Support/Online-Support-Groups.html#sthash.nV4ulZeH.dpuf>

Cancer Support Helpline, a free professional service staffed by professional oncology social workers who locate local, regional and national resources for cancer-related needs as well as provide short-term counseling and ongoing support services. Helpline Counselors also provide treatment decision support counseling through Open to Options(SM) to assist patients in preparing a written Question List for an upcoming treatment decision. All services are also available in English and Spanish including: emotional support related to coping with cancer and its impact on family, work, relationships; web-based distress screening and assistance with family and end of life concerns.

Helpline available M-F, 9 am-8 pm EST.

Contact:

1-888-793-9355

Sara Goldberger, LCSW

sara@cancersupportcommunity.org

1-646-600-7565

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>

The LIVESTRONG Foundation

LIVESTRONG Self Navigation Tools: In addition to the direct service with Emotional Support Navigators, LIVESTRONG offers We Can Help self-navigation tools, where patients and loved ones can access information on resources, articles, and services offered by the LIVESTRONG Foundation. Through the online intake form that is available, clients can virtually access our services from anywhere simply by completing a form. Our Navigators then follow up with clients and connect them with resources that can help answer questions and provide support.

Contact:

1-855-220-7777

<http://www.livestrong.org/we-can-help/navigation-services/#tab3>

Lung Cancer Alliance

Lung Cancer HelpLine: The HelpLine is answered by trained and caring Master's level health professionals, and provides information and direction for anyone with questions and concerns about lung cancer.

Contact:

1-800-298-2436

Monday - Friday

9:00 a.m. to 5:00 p.m. Eastern Time

<http://www.lungcanceralliance.org/get-help-and-support/lca-services/lung-cancer-information-line.html>

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

<http://www.cancer.gov/cancertopics/coping/life-after-treatment>

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:

GEM homepage: <https://www.gem-beta.org/public/Home.aspx?cat=0>

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/product/the-cancer-survival-toolbox-dying-well-the-final-stage-of-survivorship/>

<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 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/>



BEST PRACTICES: EXAMPLES OF RESOURCES USED BY CANCER CENTERSⁱ

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: 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:

David Trejo

626-256-4673 ext. 63574

<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
- Recognizes and helps patients alleviate stress and anxiety

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

ⁱPlease 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.

Fox Chase Cancer Center

Fox Chase Cancer Center Partners Program: Breast Cancer Coordinators /Navigators Orientation Manual: This manual was created out of a need for nurses beginning the navigator position coming from various practice backgrounds. It is not a text book but rather resources available to assist with both program development as well as clinical aspects of breast cancer management. For more information, contact Elaine Sein.

Contact:

Elaine Sein

Elaine.sein@fccc.edu

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

Dr. Mary Helen Davis

Maryhelen.davis@nortonhealthcare.org

Robert H. Lurie Comprehensive Cancer Center at Northwestern University

American Cancer Society Navigators: The ACS Navigators program is available to other facilities. For more information, contact Dr. Wagner or ACS at www.cancer.org.

Contact:

Dr. Lynne Wagner

lwagner@northwestern.edu

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.

Contact:

Teresa Woodruff

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 CENTERS¹

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-Touch Screen Biopsychosocial Screening Tool: SupportScreen is a touch screen automated biopsychosocial screening program administered to cancer patients as part of the standard of clinical care at the City of Hope. 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. It was designed to run on simple network systems and to be easily adapted to a variety of settings including small clinical practices. The cost of the program depends on the number of licensed sites (not by patient or family member screened). 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.

Contact:

Richard Obenchain

626-256-4673 ext. 60629

info@SupportScreen.com

www.supportivecaretraining.com

email: screeningprograms@coh.org

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.

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

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. These tools are 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.

Contact:

Frank Penedo

Director of Cancer Control

fpenedo@northwestern.edu

University Hospitals Seidman Cancer Center

Adapted NCCN Distress Thermometer

Contact:

Kim Day

216-896-1758

ⁱPlease 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.