

BUILD YOUR OWN REFERRAL GUIDE OF RESOURCES AND SUPPORTIVE SERVICES FOR BREAST CANCER PATIENTS

A resource developed by the Michigan Department of Health
and Human Services and Facing Our Risk of Cancer
Empowered.

PURPOSE OF THIS GUIDE AND TOOLKIT

This guide was developed by FORCE and the Michigan Department of Health and Human Services. We developed this information based on results of a survey of genetic counselors and oncology nurse navigators who indicated that lack of local programs or providers can be a barrier to the referral of breast cancer patients to support services.

This guide is for health care professionals who provide care and supportive services to breast cancer survivors and women living with metastatic breast cancer. It will help you compile your own personalized referral toolkit of commonly requested experts, programs and services for patient referrals in your area.

Where appropriate, we provide links to information on national guidelines for referrals (note that some websites, like the National Comprehensive Cancer Network, require you to create a profile and log in). We include links to tools to find a practitioner in your area. When available, we also link to tools to find telemedicine experts and other resources.

If you have difficulty identifying a particular expert or service in your area, you may contact the closest comprehensive cancer center to see if they have specialists or referral recommendations.

- [National Cancer Institute \(NCI\)-Designated Cancer Centers](#)
- [National Comprehensive Cancer Network \(NCCN\) member institutions](#)
- [The Commission on Cancer \(CoC\) accredited centers](#)

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HOW TO PREPARE & CREATE YOUR TOOLKIT

We recommend using the resources provided in this document and spending two to three hours over the next month to assemble your personal toolkit. For each category, identify professionals or services in your area or via telehealth that address your patients' most frequently cited concerns or requested resources. Once you have compiled your resources, we recommend that you speak with your colleagues and members of professional organizations to share or learn of new resources to include. Update your toolkit periodically to ensure that the resources are still available and to add new ones.

LIST OF EXPERTISE & SERVICES

This toolkit covers the following programs and services:

- [Clinical trials](#) p. 4
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CLINICAL TRIALS

GUIDELINES:

Although there are no specific national guidelines regarding patient participation in clinical trials, several national organizations, including the National Comprehensive Cancer Network (NCCN) and the National Cancer Institute (NCI), have issued statements about the importance of clinical trial referral.

“NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.” – National Comprehensive Cancer Network

“We believe that clinicians should present the option to participate in clinical trials to their patients so that they can make informed decisions about trial participation together. Clinicians should not make this decision for their patients.” – National Cancer Institute

REFERRING PATIENTS TO CLINICAL TRIALS:

You are in a unique situation to help patients find clinical trials for which they are eligible. Numerous resources facilitate finding breast cancer prevention, detection, treatment and quality-of-life clinical trials. Having an available list of clinical trials in each category can help you refer patients who are interested in enrolling. When referring patients, it may be helpful to provide education on the purpose of clinical trials to improve patient health literacy and reduce fear.

- [Clinicaltrials.gov](https://www.clinicaltrials.gov) allows you to plug in the type and stage of cancer and filter by location.
- FORCE’s Research Search and Enroll Tool allows you to search for:
 - [Breast cancer treatment clinical trials](#) by stage, mutation and tumor biomarkers.
 - [Breast cancer prevention clinical trials.](#)
 - [Quality-of-life clinical trials.](#)
 - [Breastcancertrials.org](https://www.breastcancertrials.org) and [Metastatic Trial Search.](#)

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EXERCISE AND PHYSICAL ACTIVITY

GUIDELINES:

The National Comprehensive Cancer Network has [recommendations for exercise and physical activity](#), including recommendations for resistance exercise and stretching, for cancer survivors as part of their survivorship guidelines. The American College of Sports Medicine also has [published guidelines](#) for cancer prevention and people in treatment.

REFERRING PATIENTS TO EXERCISE PROGRAMS:

The YMCA offers exercise classes, including all levels of fitness programs. The YMCA also offers financial assistance for those who need it. You can [locate a YMCA by zip code](#). Select YMCA locations partner with [Livestrong for the Livestrong at the Y](#) program, specifically designed to improve fitness in cancer survivors.

The American College of Sports Medicine has a “ProFinder” search tool that allows you to [locate certified fitness professionals](#) by location and specialty.

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FATIGUE

GUIDELINES:

The National Comprehensive Cancer Network has [recommendations for fatigue assessment and management](#). Cancer fatigue can have multiple causes, including physical causes (e.g., sleep disturbances, hormonal side effects of cancer or treatment), so it's important that any patient who experiences fatigue talks to their doctor about the symptom.

REFERRING PATIENTS EXPERIENCING CANCER FATIGUE:

It's most important to assure that patients report fatigue to their oncologist or primary care provider to rule out an underlying cause. Some larger cancer centers have multidisciplinary fatigue clinics. Depending on the cause of the fatigue, referrals may also include:

- Exercise programs.
- Integrative medicine.
- Menopause interventions.
- Mental health services.
- Nutrition.
- Palliative care.
- Cancer centers with dedicated fatigue clinic.

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FERTILITY PRESERVATION

GUIDELINES:

The National Comprehensive Cancer Network has recommendations for fertility preservation as part of its [guidelines for adolescents and young adults](#). These guidelines state that addressing fertility as well as sexual health and function should be an essential part of managing people who are diagnosed with cancer and who are at risk for infertility or sexual dysfunction due to cancer treatments. Ideally, this conversation should occur before treatment starts.

REFERRING PATIENTS FOR FERTILITY PRESERVATION:

The Oncofertility Consortium at Michigan State University maintains [a database](#) of centers that focus on fertility preservation for people with cancer.

Livestrong has [a listing of 450 sites](#) that offer fertility preservation options for people diagnosed with cancer. Financial assistance may be available to make the cost of fertility preservation affordable for more patients. Refer patients to those programs as needed.

[Additional resources for fertility preservation](#)

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FINANCIAL RESOURCES

REFERRING PATIENTS FOR FINANCIAL ASSISTANCE:

- Patient Advocate Foundation has a comprehensive financial [resource database](#) with listings that are searchable by state.
- [Cancer Care](#) has limited financial assistance for treatment-related costs. Individuals who are undergoing cancer treatment and are below 250% of the Federal Poverty Level are eligible.
- [Susan G. Komen Treatment Assistance Program](#) or 1-877 GO KOMEN (465-6636).
- Pharmaceutical assistance programs may optimize insurance and help the patient. Cancer centers may have a social worker or financial counselor to assist patients with reducing the cost of cancer care.

[Additional resources for financial assistance](#)

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GENETICS

GUIDELINES:

The National Comprehensive Cancer Network has guidelines for genetic counseling and testing for people diagnosed with cancer. The NCCN has separate guidelines for [breast, ovarian and pancreatic cancer](#) and [colorectal cancer](#). The NCCN recommends genetic counseling with a medical professional with expertise in cancer genetics before and after genetic testing.

REFERRING PATIENTS FOR GENETIC COUNSELING AND TESTING:

- The National Society of Genetic Counselors (NSGC) has a database of [genetic counselors](#) that is searchable by expertise and location and identifies genetic counselors that provide telemedical services.
- [InformedDNA](#) offers genetic counseling via telephone with board-certified genetic counselors.
- The [Genetic Support Foundation](#) provides telemedicine genetic counseling services.

[Additional resources for genetics](#)

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INTEGRATIVE MEDICINE

GUIDELINES:

The Society for Integrative Oncology [clinical practice guidelines](#) on the evidence-based use of integrative therapies during and after breast cancer treatment. The most recent guidelines (2017) include the following recommendations:

- Meditation, relaxation, yoga, massage, and music therapy are recommended for depression/mood disorders.
- Meditation and yoga are recommended to improve quality of life.
- Acupressure and acupuncture are recommended for reducing chemotherapy-induced nausea and vomiting.

The National Center for Complementary and Integrative Health (part of the National Institutes of Health) has a [page on state credentialing of integrative medicine experts](#).

REFERRING PATIENTS FOR INTEGRATIVE MEDICINE:

- The Society for Integrative Medicine has [a directory of integrative medicine experts](#) that is searchable by location and expertise.
- The National Certification Commission for Acupuncture and Oriental Medicine has a [searchable directory of licensed acupuncturists](#).

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LEGAL ISSUES

GUIDELINES:

People with cancer may benefit from legal services in several situations. No specific guidelines regarding referral for legal issues for patients are available, but several resources are available to assist patients.

REFERRING PATIENTS FOR LEGAL SERVICES:

- Triage Cancer has [a quick guide](#) for finding legal services.
- Triage Cancer also has [a state-by-state resource guide](#).
- The Cancer Legal Resource Center has [information and resources](#) on legal issues for people with cancer.

[Additional resources for legal issues](#)

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LGBTQ+ ISSUES

GUIDELINES:

The University of California San Francisco developed [cancer screening guidelines for transgender men and women](#). They have [guidelines for breast screening in transgender women](#) (including women with BRCA mutations) and [guidelines for breast screening in transgender men](#).

REFERRING LGBTQ+ PATIENTS FOR CARE:

The National LGBT Cancer Network has a database of [LGBT-friendly cancer screening centers](#) and [LGBT-friendly treatment centers](#).

[Additional resources for people who are LGBTQ+](#)

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LYMPHEDEMA

GUIDELINES:

The National Comprehensive Cancer Network has recommendations for lymphedema management as part of their [survivorship guidelines](#). In its earliest stages, lymphedema is reversible, so it's important that people are treated promptly.

REFERRING PATIENTS FOR LYMPHEDEMA SERVICES:

The Lymphology Association of North America (LANA) has a [lymphedema expert database](#) that allows you to search for specialists by location. The National Lymphedema Network also has a [database of lymphedema clinics](#).

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MENOPAUSE

GUIDELINES:

The National Comprehensive Cancer Network has recommendations for menopause management as part of their [survivorship guidelines](#). The North American Menopause Society (NAMS) has guidelines for the [management of genitourinary symptoms of menopause in women with breast cancer and women at high risk for cancer](#).

REFERRING PATIENTS TO MENOPAUSE EXPERTS:

The North American Menopause Society has a [database of menopause experts](#) that is searchable by location.

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MENTAL HEALTH

GUIDELINES:

The National Comprehensive Cancer Network has [recommendations for assessing and addressing distress for people with cancer](#).

REFERRING PATIENTS FOR MENTAL HEALTH SERVICES:

Numerous types of professionals may provide mental health services for cancer survivors and patients in treatment. These include:

- Psychiatrists.
- Psychologists.
- Social workers.
- Chaplains and Pastoral Care experts.

As a general approach to finding expertise for referral in your area, you may wish to start with the closest local [cancer center](#).

Other resources for finding mental health care professionals include:

- The Association of Oncology Social Workers has a [database to find a social worker](#) by location.
- The National Alliance on Mental Illness (NAMI) has [tips for finding a mental health professional](#).
- The Anxiety and Depression Association of America has a [database of licensed professionals who provide telehealth services](#).
- [Mental Health America](#) has a tool that walks patients through the steps of finding a mental health care professional based on their current needs.

[Additional resources for emotional and peer support](#)

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NUTRITION AND WEIGHT MANAGEMENT

GUIDELINES:

The National Comprehensive Cancer Network has recommendations for nutritional care for cancer survivors as part of their [survivorship guidelines](#). The National Center for Complementary and Integrative Health has a webpage, [“How Safe Is This Product or Practice?”](#) that discusses the safety of different supplements and vitamins for people in treatment.

REFERRING PATIENTS FOR NUTRITIONAL SERVICES:

The Academy of Nutrition and Dietetics has a [search tool](#) for finding experts by location and expertise (you can select oncology).

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PAIN MANAGEMENT

GUIDELINES:

The NCCN has guidelines for [pain assessment and management](#). The Michigan Department of Health and Human Services published a [Cancer Survivorship Rehabilitation and Pain Management](#) guide.

REFERRING PATIENTS FOR PAIN MANAGEMENT SERVICES:

Numerous types of professionals may provide management for pain depending on the cause. Patients should be encouraged to report their pain to their oncologist or primary care provider. Also, see these other sections:

- [Palliative care.](#)
- [Physical therapy.](#)
- [Integrative medicine.](#)

Patients with cancer pain may also benefit from a referral to a physiatrist, a physician who specializes in cancer rehabilitation medicine. Physiatrists may be found in larger health systems and may be able to address the source of pain after cancer.

As a general approach to finding expertise for referral in your area, you may wish to start with the closest local [cancer center](#).

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PALLIATIVE CARE AND HOSPICE

GUIDELINES:

The National Comprehensive Cancer Network has [guidelines for the referral of patients to palliative care](#). They suggest that all patients be screened for their palliative care needs at their initial visit and appropriate intervals. Patients/families and caregivers should be informed that palliative care is an important part of their care, regardless of the stage of disease or need for other therapies.

Palliative care focuses on symptom management. Patients may benefit even if they have early-stage cancer. Palliative care is often confused with hospice care. Hospice is a type of end-of-life palliative care. Palliative care is much broader and can address symptoms in combination with cancer treatment.

The [American Society of Clinical Oncologists](#) (ASCO) recommends that all patients with advanced cancer receive a palliative care plan within eight weeks of their diagnosis.

REFERRING PATIENTS FOR PALLIATIVE CARE SERVICES:

Palliative care specialists address a broad range of issues, including:

- Support for family members and caregivers.
- Pain and symptom management.
- Nutritional support.
- Emotional distress.
- Financial issues.
- End of life issues.

The following directories can help you find palliative care or hospice services:

- Check with your local cancer center about their palliative care referrals process.
- The Center to Advance Palliative Care has a [directory of palliative care programs](#) listed by location.
- The National Hospice and Palliative Care Organization has a [database of hospice providers](#) by location.

[Additional resources for palliative and hospice services](#)

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PHYSICAL THERAPY

GUIDELINES:

The NCCN [survivorship guidelines](#) include information on referral for physical therapy, including for post-radiation and post-surgery, lymphedema and pain. The Michigan Department of Health and Human Services published a [Cancer Survivorship Rehabilitation and Pain Management](#) guide.

REFERRING PATIENTS FOR PHYSICAL THERAPY:

The [American Physical Therapy Association \(APTA\)](#) has a directory of licensed physical therapists that is searchable by location. Patients should talk to their providers about a referral to physical therapy to facilitate payment for this treatment.

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SEXUAL HEALTH

GUIDELINES:

The National Comprehensive Cancer Network has recommendations for assessing and addressing sexual health and function as part of their guidelines for [adolescents and young adults](#) and their [survivorship guidelines](#). The guidelines state that addressing sexual health and function should be an essential part of managing people who are diagnosed with cancer and are at risk for sexual dysfunction due to cancer treatments.

REFERRING PATIENTS FOR SEXUAL HEALTH ISSUES:

The American Association of Sexuality Educators, Counselors and Therapists (AASECT) has a [directory of sexual health experts](#). Some providers are available for telemedical services.

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SMOKING CESSATION

GUIDELINES:

The NCCN has [guidelines for smoking cessation](#) for people diagnosed with cancer.

REFERRING PATIENTS FOR SMOKING CESSATION:

The Centers for Disease Prevention and Control (CDC) has a [directory of resources and smoking cessation quit-lines](#).

[Additional resources for smoking cessation](#)

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ADDITIONAL RESOURCES

CLINICAL TRIALS

The Michigan Department of Health and Human Services has a [handout on cancer clinical trials](#) that is designed for patients.

FERTILITY PRESERVATION RESOURCES

- [Alliance for Fertility Preservation](#) – The exclusive focus of this organization is fertility preservation for cancer patients. This site is a resource for cancer patients who have a fertility risk presented by their cancer treatment.
- [American Society of Reproductive Medicine](#) – Has a section on its website dedicated to patient education including a [video on fertility preservation for cancer patients](#).
- [Save My Fertility](#) – Provides an online fertility preservation toolkit for patients with cancer and their providers.
- [Livestrong Fertility Program](#) – Provides reproductive information, resources and financial support to survivors whose cancer and/or treatment can cause fertility risks. This includes discounted fertility preservation services and free medications.
- [Team Maggie](#) – Provides financial assistance for preserving eggs and sperm to women and men with cancer who have been denied coverage by insurance.

FINANCIAL RESOURCES

- American Cancer Society – [“Understanding Health Insurance”](#) shares information about private and government insurance and other sources of financial help.
- [Benefits CheckUp](#) – Assists adults over age 55 with help to pay for prescription drugs, health care, utilities and other basic needs.
- [CancerCare](#) – Offers limited financial assistance for cancer-related costs and co-pays.
- [Cancer Financial Assistance Coalition](#) – A coalition of financial assistance organizations that works to eliminate financial challenges by educating patients on existing resources.
- [Cancer Insurance Checklist](#) – Assists those who have cancer, a history of cancer or are at risk for cancer with signing up for insurance using the Health Insurance Marketplace. In some circumstances, people can enroll even when the Marketplace is not open.
- [Co-Pay Relief Program](#) – [Patient Advocate Foundation](#) program provides direct financial assistance to insured patients to help pay for treatment. It assists with out-of-pocket costs that are not covered by insurance. It can be reached by calling 866-512-3861.
- [HealthWell Foundation](#) – Provides financial assistance for a variety of cancers.
- [Medicine Assistance Tool.org](#) – A search engine designed to help patients, caregivers and providers learn about resources that are available through biopharmaceutical programs.
- [NeedyMeds](#) – Provides information on pharmaceutical assistance programs.

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ADDITIONAL RESOURCES

FINANCIAL RESOURCES (cont.)

- [PAN Foundation](#) – Offers assistance programs for a variety of cancers.
- [RxAssist](#) – Aids with pharmaceutical company programs and other resources to help reduce medication costs.
- [RxHope](#) – A helping hand for people in need of medications. The organization serves as an advocate with patient assistance programs.

GENETICS

- [FORCE](#) – Focuses on hereditary cancers and provides support for people with an inherited mutation.
- [Sharsheret](#) – Provides education and support with a focus on Jewish women.

LEGAL RESOURCES

- [American Cancer Society](#) – Provides a guide on the Americans With Disabilities Act for people with cancer.
- [Disability Rights Legal Center](#) – Provides free legal assistance to people with a disability who experience discrimination.
- [Genetic Information Nondiscrimination Act](#) – GINA is a federal law that protects individuals from genetic discrimination in health insurance and employment.
- [Triage Cancer](#) – Offers resources including animated videos, quick guides and webinars to address legal and practical issues of caregiving.
- [Women’s Health and Cancer Rights Act of 1998](#) – WHCRA is a federal law that provides certain rights and protections to patients after a mastectomy. This law requires most health insurance plans that cover mastectomies to also cover breast reconstruction, prostheses and physical complications of all stages of mastectomy, including lymphedema.

LGBTQ+ SUPPORT

- [The National LGBTQIA+ Health Education Center](#) – Advances health equity for LGBTQIA+ people and the populations which may intersect with the LGBTQIA+ community.

MENOPAUSE

- [FORCE](#) has information and resources for women who experience young-onset menopause due to preventive surgery or treatment.
- [Hystersisters](#) provides support for people who have had gynecological surgery.
- The [North American Menopause Society](#) has a comprehensive website on menopause management.

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ADDITIONAL RESOURCES

MENTAL HEALTH

- [Mental Health America](#) – Has a list of affiliates throughout the United States that offer support and resources for people who are affected by mental health issues.
- [American Cancer Society](#) – Provides information on types of psychosocial support services.
- [National Behavioral Health Network](#) – Provides information on the mental health impacts of a cancer diagnosis and how to manage them.
- [Cancer Hope Network](#) – Provides free one-on-one emotional peer support to adult cancer patients and their loved ones.
- [CancerCare](#) – Conducts online support groups that are led by oncology social workers using a password-protected message board format (not live chat).
- [Cancer Support Community](#) – Provides free social and emotional support for people who are impacted by cancer in an online format.

NUTRITION AND WEIGHT MANAGEMENT

- [Academy of Diet and Nutrition My Plate.](#)
- United States Department of Agriculture’s [Nutrition.gov](#) website.
- [American Institute for Cancer Research](#) – Provides information on healthy living for survivors, including infographics, quizzes and videos.
- Centers for Disease Control and Prevention (CDC) – [“Talk to Someone”](#) is an online resource for survivors. It discusses anxiety, alcohol, tobacco use, physical activity and nutrition.
- Cancer.Net provides education on healthy lifestyles:
 - [6 lifestyle changes](#) that can be made to improve cancer care.
 - [Healthy living after cancer.](#)

PALLIATIVE CARE AND HOSPICE SERVICES

- CancerCare – [Advance Care Planning: Be Prepared.](#)
- Cancer.Net – [Advanced Cancer Care Planning.](#)
- National Cancer Institute – [Coping with Advanced Cancer: Choices for Care Near the End of Life.](#)
- [American Cancer Society](#) – Provides next steps for individuals whose treatment is no longer working or has been stopped.
- [American Hospice Foundation](#) – Has a variety of articles on hospice including [16 Questions to Ask When Choosing a Hospice.](#)
- [National Cancer Institute](#) – Information on end-of-life care for people with cancer.

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ADDITIONAL RESOURCES

PALLIATIVE CARE AND HOSPICE SERVICES (cont.)

- [National Institute on Aging](#) – This booklet provides an overview of the issues often faced by people who care for someone nearing the end of life.
- [National Hospice and Palliative Care Foundation](#) – Provides a program called CaringInfo that shares free resources to help people make decisions about end-of-life care.

PEER SUPPORT

- [BreastCancer.org](#) – Has support message boards and information on breast cancer in English and Spanish.
- Facing Our Risk of Cancer Empowered (FORCE) is focused on hereditary cancers and people with an inherited mutation (such as BRCA1 and BRCA2, ATM CHEK2, PALB2, etc.) linked to cancer. Their [support programs](#) include a peer-matching and navigation program, message boards, and support groups.
- [LatinaSHARE](#) – Provides education resources in Spanish for women with breast or gynecologic cancer.
- [Living Beyond Breast Cancer \(LBBC\)](#) – Offers programs and services to help individuals whose lives have been impacted by breast cancer.
- [Metastatic Breast Cancer Network](#) – Provides a wide variety of information about living with metastatic breast cancer.
- [METAvivor](#) – Provides support, information and research focused on metastatic breast cancer.
- [National Native Network](#) – Works to decrease commercial tobacco use and cancer health disparities among members of American Indian and Alaska Native Tribes.
- [SHARE](#) – Provides education resources for women with breast or gynecologic cancer.
- [Sharsheret](#) – Provides education and support with a focus on Jewish women.
- [Sisters Network](#) – Focuses on breast cancer in the black community.
- [Tigerlily](#) – Provides support and inspiration for young women with breast cancer, especially women of color.
- [Young Survival Coalition](#) – Focuses on the unique needs of young women with breast cancer.

SMOKING CESSATION

- [Clearing the Air: Quit Smoking Today](#) – A booklet designed to support efforts to quit smoking at any stage in an individual's journey.

The Michigan Department of Health and Human Services and FORCE will not exclude from participation in, deny benefits of, or discriminate against any individual or group because of race, sex, religion, age, national origin, color, height, weight, marital status, partisan considerations, or a disability or genetic information that is unrelated to the person's eligibility.

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