

WORDS OF WISDOM ON CAREGIVING FROM THE CONNER CREEK CANCER ACTION COUNCIL



CANCER INSTITUTE

Wayne State University

OFFICE OF COMMUNITY OUTREACH
AND ENGAGEMENT



PREPARED BY
CONNER CREEK CANCER ACTION COUNCIL, DETROIT
MICHIGAN CANCER HEALTHLINK

LOOK INSIDE



2023-2024

CAREGIVER RESOURCE GUIDE

PREPARED BY
CONNER CREEK CANCER ACTION COUNCIL, DETROIT
MICHIGAN CANCER HEALTHLINK

TABLE OF CONTENTS

OUR STORY 2

MEET OUR COUNCIL 3

CUES FOR CANCER
CAREGIVERS 4

FINANCIAL CONSIDERATIONS 6

FINANCIAL RESOURCES 7

CANCER INFORMATION
RESOURCES 09

LOCAL CANCER-SPECIFIC
RESOURCES 10

CANCER-RELATED GLOSSARY 12

FREQUENTLY ASKED
QUESTIONS 13

ACKNOWLEDGEMENTS 20

2023-2024





OUR STORY

In 2016, the **Detroit Conner Creek Cancer Action Council (CAC)** was established on the Northeast side of Detroit. This group was made up of cancer survivors, caregivers and advocates from the Detroit Conner Creek community.

After meeting for 18 months and learning about cancer and its impact on the community, early on the Conner Creek CAC indicated that there should be a resource for cancer caregivers, to provide information from a community perspective. Focus groups were conducted with cancer survivors and caregivers to give further direction to this effort. Much of what was learned from those experiences has helped to form the framework of this guide.

We hope this guide helps cancer caregivers to think about how important their role is in the life and well-being of their cancer survivor. This booklet is designed to assist with the complexities of the healthcare system and accompany you on your caregiving journey.

What is a cancer caregiver?

A cancer caregiver is the individual who cares for a person affected by cancer. Often, caregivers are spouses, partners, parents, or adults. The caregiver plays a key role in the patient's overall care. Caregivers must be reliable in providing quality caregiving support which serves crucial to the overall well-being of the cancer patient.

What does a caregiver do?

As a caregiver, you may serve as a health aid at home while being an emotional pillar. You may feed, dress, and bathe the person touched by cancer. You may help decide their daily schedules, manage insurance, and transportation. You may be an assistant, manager, and housekeeper. You may fully have to take over the duties of the person with cancer. Caregivers responsibilities and roles change based on the needs of the patient.

MEET OUR COUNCIL

The Conner Creek Cancer Action Council (CAC) was the first CAC established in 2016 under Michigan Cancer HealthLink in partnership with the Voices of Detroit Initiative (VODI); no longer active.



Anitta Orr
Conner Creek CAC
member



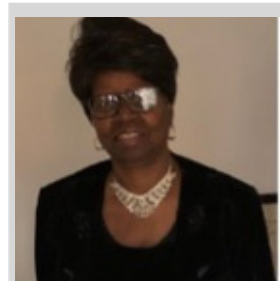
Clare Carlisle
Conner Creek CAC
member



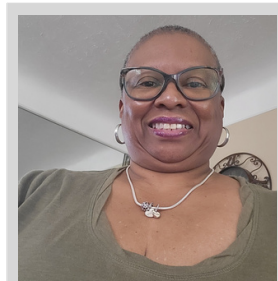
Deborah Anderson
Conner Creek CAC
member



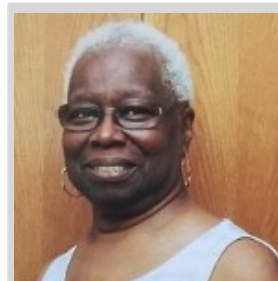
Deborah Hill
Conner Creek CAC
member



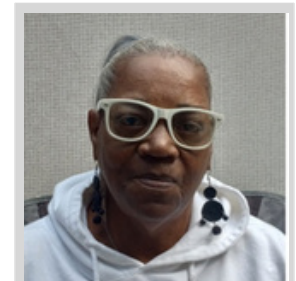
Delouris Simpson
Conner Creek CAC
member, deceased



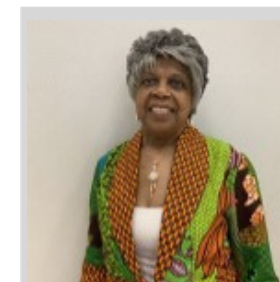
Diana Auston
Conner Creek CAC
member



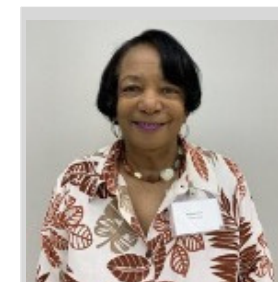
Elaine Stanley
Conner Creek CAC
member



Vera Bailey
Conner Creek CAC
member



Veronica Dozier
Conner Creek CAC
member



Vicky Gunn
Conner Creek CAC
member



Voncile Brown-Miller
Conner Creek CAC
Facilitator



Mikayla Harrison
Conner Creek CAC
Facilitator



"Nothing about us, without us, is for us." –
Tshilio Michael Masutha & William Rowland
1993

CUES FOR CAREGIVERS

PRACTICE SELF-CARE

- Eat well-balanced meals
- Meditate
- Exercise regularly
- Schedule alone time
- Socialize and maintain contact with others

DEVELOP & DOCUMENT A WRITTEN COORDINATED CAREGIVING PLAN

- Compile list of relevant professional resources
- Record or write down your patient's medication list including time, dosage, and frequency
- Record or write down a meal plan and notes on patient eating habits and note any side effects of medicine

BUILD A SUPPORT TEAM

- Ask for help
- Develop a list of possible helpers (relatives, friends, church, etc.)
- Schedule time for errands and other obligations

CANCER PATIENT RIGHTS

Patients with cancer have a right to their clinicians' best efforts as healers and as caring human beings. **They have a right to receive coordinated, timely care; to be listened to with compassion while receiving honest information; and to be guided with empathy through a dark place by a trusted expert partner.**



"God's timing is always perfect. Trust his delays. He's got you." – Tony Evans, Poet

CUES FOR CAREGIVERS

CONTINUED ...

CREATE A LIST OF PROFESSIONAL RESOURCES

- Doctor contact information
- Food preparation
- Delivery services- oxygen, meds, etc.
- Medical transportation services

There is space provided in the "Notes" section of this guide

BE READY TO BE AN ADVOCATE

- Compile as much relevant information as possible
- Ask for information regarding cancer type and treatment options
- Discuss prescribed treatments and medications
- Ask for training and instructions on administering treatments

COMMUNICATE WITH THE HEALTHCARE PROFESSIONALS

- Keep in contact with medical team to guide you through process
- Doctors are there to assist and guide so do not hesitate to ask

AFFIRMATION

I AM STRONG

I AM STRONG

I AM STRONG



FINANCIAL CONSIDERATIONS

When one takes on the responsibility of being a caregiver for a cancer patient there are many financial considerations that must be made. It is important that you familiarize yourself with all aspects of this important role and execute wise judgment in balancing your commitment to the patient as well as yourself.

There are three major considerations that must be made: employment, insurance, and finances.



MORE INFORMATION

Visit "*A Practical Guide to Cancer Rights for Caregivers*" at tragecancer.org/Guide-Caregiver

INSURANCE

- What insurance is available to cover the cost of medical care; disability insurance, social security, or social security disability insurance?
- Is the patient able to work?
- Is the caregiver working?
- How will the bills be paid?

FINANCE

- What legal documents do you need to consider: wills, trusts, advance healthcare directives, power of attorney?

EMPLOYMENT

- What insurance is available to cover the cost of medical care; disability insurance, social security, or social security disability insurance?
- Is the patient able to work?
- Is the caregiver working?
- How will the bills be paid?

Your relationship to the patient will determine if you are eligible for Family Medical Leave Act of 1993 (FMLA)

Check with your employer

FMLA is a labor law requiring covered employers to provide employees with job protected, unpaid leave for qualified medical and family reasons. Allows eligible employees to take up to 12 work weeks of unpaid leave during any 12 month period

<https://www.dol.gov/general/topic/benefits-leave/fmla>

FINANCIAL RESOURCES



NEW DAY FOUNDATION **Foundationforfamilies.org**

New Foundation provides financial assistance and emotional support to families affected by cancer. The foundation works to alleviate financial burdens, in addition to programs that include the Care Pack Program and the Hope for the Holidays; with both programs ensuring kids and families feel supported and loved amidst living with cancer.



MY MEDICARE MATTERS **mymedicarematters.org**

My Medicare Matters is a complete national education program that assists and guides medicare recipients to understand their medicare prescription drug coverage, assess their situation, understand the choices they have, compare plan options to make more informed decisions. This site features various coverages and costs, enrollment options, and lists varying assistance programs.

THE PINK FUND **pinkfund.org**

The Pink Fund is a non-profit breast cancer organization that will provide to breast cancer patients in active treatment 90-days of non-medical cost-of-living expenses; with the purpose being to allow those affected to heal, decrease stress levels, and return to the workplace. These expenses include housing, transportation, utilities, and insurance.





Expenses

Use the area below to plan and track costs related to insurance co-pays, medications, medical supplies, transportation, etc.

CANCER INFORMATION RESOURCES



AMERICAN CANCER SOCIETY

1-800-227-2345 | cancer.org

The American Cancer Society (ACS) offers an array of services to both patients and caregivers, specifically providing a diverse collection of information and resources that can benefit all people touched by cancer. The ACS provides the unique function to search for local clinical resources within your area featuring 24/7 cancer helplines, rides to treatment, support, and more in treatment & support.



CANCER.GOV

1-800-527-6266 | cancer.gov

Cancer.gov advances research in cancer control and population sciences to eliminate cancer and its consequences for all.



CANCER.NET

1-888-651-3038 | cancer.net

Cancer.net, the patient information website of the American Society of Clinical Oncology (ASCO), provides physician-approved information to assist patients and their families to make informed health care decisions. The website offers a diverse cancer guide providing basic information, navigating cancer care, coping, and financial considerations. This resource will help you make decisions based on your needs and cancer type.



LEUKEMIA & LYMPHOMA SOCIETY

1-800-955-4572 | lls.org

Leukemia & Lymphoma Society is the largest funder of cutting-edge research to advance blood cancer cures. The LLS mission is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families.

LOCAL CANCER-SPECIFIC RESOURCES



KARMANOS CANCER INSTITUTE

1-800-527-6266 | karmanos.org

Karmanos provides an interconnected system of care, within which you could find specialists, site locations, clinical trials, screening, request appointments, and more just from the top of the website. In addition, Karmanos includes information regarding the cancer we treat and support services.



GILDA'S CLUB METRO DETROIT

248-577-0800 | gildasclubdetroit.org

Gilda's Club Metro Detroit uplifts and strengthens people impacted by cancer by providing support, fostering compassionate communities, and breaking down barriers to care. Everyone impacted by cancer receives the support they want and need throughout their experience.



SISTERS NETWORK GREATER METROPOLITAN DETROIT

313-438-3639 | sistersnetworkgmdc.com

Sisters Network serves as one of the leading voices and only national African American breast cancer survivorship organization in the country. This network is committed to increasing local and national attention to the impacts of breast cancer within the African American community. Sisters Network hosts a plethora of programs relating to and advocating for breast cancer.

Important Contacts



GLOSSARY OF CANCER-RELATED TERMS

Benign

Not cancer; not malignant.

Biopsy

Removal of a sample of tissue or cell to see if cancer cells are present. There are several types of biopsies.

Carcinoma

A cancer that begins in the skin or the lining layer (epithelial cells) of organs.

Chemotherapy

The use of medicines to treat cancer. Chemotherapy may be given alone or with other treatments like surgery, radiation therapy, hormone therapy, targeted therapy, or immunotherapy. It can be given as an infusion, injection, or taken by mouth. Often called chemo.

Chronic

A reoccurring condition that lasts a long time.

Immunosuppression

When the immune system is weak. This condition may be present at birth, or it may be caused by cancer, or cancer treatments (such as chemotherapy and radiation). It leads to a greater risk of infection.

Immunotherapy

Treatments that use the body's immune system to fight cancer by boosting or changing how the immune system works so it can find and attack cancer cells.

In situ

In place; localized and confined to one area. Not considered cancer but can increase the risk of cancer developing later.

Malignant

Cancerous; dangerous or likely to cause death if untreated.

Prognosis

The likely course of a disease, including the chance for recovery or of the cancer coming back.

Radiotherapy

Treatment with high-energy particles or rays to destroy or damage cancer cells. The radiation is given by a machine outside the body (external radiation) or by radioactive materials placed in the tumor (brachytherapy or internal radiation). Radiation therapy can be used to shrink the cancer before surgery, to kill any remaining cancer cells after surgery, or as the main treatment.

Remission

A period of time when the cancer is responding to treatment or is under control. In a complete remission, all the signs and symptoms of cancer go away, and cancer cells can't be found by any tests. In a partial remission, the cancer shrinks but doesn't completely go away. A remission might not mean the cancer is cured.

Secondary Cancer

A new, unrelated cancer that develops in people who have already had a different cancer. For example, if someone who has had breast cancer develops colorectal cancer. This is different from cancer coming back after treatment (recurrence).

Stage

The size of a cancer and if and where it has spread from the primary site. A clinical stage is based on results of the physical exam, biopsy and imaging tests. A pathologic stage is based on how the cells in the tissue samples from surgery or a biopsy look under a microscope.

Targeted Therapy

Treatment that uses drugs or other substances to identify and attack certain cancer cells. Targeted therapies tend to affect normal cells less and therefore cause fewer side effects than other cancer treatments.

Tumor

An abnormal growth of tissue. Tumors can be benign (not cancer) or malignant (cancer).

AFFIRMATION

I AM NEVER ALONE

I AM NEVER ALONE

I AM NEVER ALONE

Definitions are from the American Cancer Society Cancer Glossary <https://www.cancer.org/cancer/understanding-cancer/glossary.html>.

FREQUENTLY ASKED QUESTIONS CAREGIVERS HAVE ABOUT CANCER

What is cancer?

Cancer is used to describe the 100+ diseases that involve abnormal cell growth with the potential to spread to other parts of the body. Cells are the tiny, individualized building blocks that form our bodies and cancer originates in the cells of our organs, blood and bones. The most common types of cancer include breast, lung, prostate, colon and skin. Causes, symptoms and treatments can be very different for each type of cancer and even for each individual diagnosed.

What causes cancer?

The causes of cancer are complex and are still being studied today. Known contributing factors include: genetics, certain viruses and exposure to radiation, cigarettes, the sun, and toxic chemicals.

*For more information on cancer and its causes, go to:
<https://www.cancer.org/cancer/risk-prevention.html>

AFFIRMATION

**I AM GRATEFUL I AM ABLE TO TAKE
CARE OF OTHERS**

**I AM GRATEFUL I AM ABLE TO
TAKE CARE OF OTHERS**

**I AM GRATEFUL I AM ABLE TO TAKE
CARE OF OTHERS**

FREQUENTLY ASKED QUESTIONS CAREGIVERS HAVE ABOUT CANCER

Why do people with the same cancer get different treatment and have different problems?

Cancer is not a single disease, but a group of diseases that have different causes, characteristics, and outcomes. Even people who have the same type of cancer may have different treatments and problems because of various factors, such as:

- stage and grade of cancer
- other diseases (diabetes, heart disease)
- personal preferences regarding treatment

What is cancer-related fatigue?

From the American Cancer Society, the fatigue that often comes with cancer is called cancer-related fatigue. It's very common. Between 80% and 100% of people with cancer report having fatigue. The fatigue felt by people with cancer is different from the fatigue of daily life and different from the tired feeling people might remember having before they had cancer.

People with cancer might describe it as feeling very weak, listless, drained, or "washed out" that may decrease for a while but then comes back.

How can I get the best care from my doctor?

Getting the best from your doctor requires effective communication and mutual trust. You should be able to share your health concerns and preferences with your doctor, and your doctor should be able to listen and provide you with clear and accurate information. Getting a second opinion can also help you feel more confident about your diagnosis and treatment plan.

*For more information on this and other common side effects, go to:
<https://www.cancer.org/cancer/managing-cancer/side-effects.html>



Journal Notes



Journal Notes

[illegible]

This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Spiritual Support

[illegible]

ACKNOWLEDGEMENTS

Thank You!

We would like to acknowledge the hard work and dedication of our Conner Creek Cancer Action Council (CAC) in bringing this caregiving guide to life. Through the contributions of each and every member it is our hope that this guide will improve the experience of caregivers. We would also like to thank Kendrick Villion for his contribution to the layout and formatting of the guide. Special thanks to the Karmanos Cancer Institute Office of Community Outreach & Engagement and the Cancer Action Council facilitators Voncile Brown-Miller, Kari Snyder, Asha Freeman, MPH, and Mikayla Harrison on their hard work for making this possible. We would also like to acknowledge the leadership of Dr. Hayley Thompson and Brittany Dowe for their community engagement efforts that helped to make this guide possible. Congratulations to the Conner Creek (CAC) on a job well done!

