

# Caregiving In Cancer

### Resource Guide

**FALL 2024** 

### **Community Event Series**



### National Family Caregivers Month

NOVEMBER

Thank you to all the incredible caregivers who support and care for their loved ones.

### Stand By Me: Lessons Learned as a Family Caregiver and a Caregiving Scientist

Dr. Allison Applebaum will explore four important lessons she's learned from her career in caregiving science and her experience as a family caregiver: (1) caregivers are responsible for conveying patients' personhood, for telling their story and making it matter to those who are providing medical care; (2) caregivers are critical members of the healthcare team and have responsibilities ranging from performing medical and nursing tasks, to case management, to healthcare communication; (3) emotions are messengers, and negative emotions experienced by caregivers can teach us how to live life more fully and authentically; and (4) despite suffering, caregiving provides us with an opportunity to connect to meaning and purpose.

Attendees will leave the talk feeling empowered and with concrete tools and strategies they can use to navigate caregiving successfully.

Read more about our guest speaker and this topic on page 2.

REGISTER





# A Closer Look at Dr. Applebaum

#### Dr. Applebaum Bio

Dr. Allison Applebaum is a caregiving scientist, writer, researcher, speaker, and advocate. She was the Founding Director of the Caregivers Clinic at Memorial Sloan Kettering Cancer Center. The Caregivers Clinic was the first of its kind to provide targeted psychosocial support to caregivers of patients receiving cancer care at MSK. Dr. Applebaum works with healthcare systems worldwide to develop similar support programs for caregivers, to draw attention to the unique needs of caregivers across various illnesses and care settings, and to implement systems-level changes that facilitate support and integrate caregivers more formally into the healthcare team. She is also the author of the recently published narrative nonfiction book, Stand By Me: A Guide to Navigating Modern, Meaningful Caregiving (Simon Element, 2024).

#### Dr. Applebaum Q + A:

### How and why did you become involved in the professional caregiving space?

When I began my postdoctoral fellowship in psychooncology in 2010, I was initially supporting patients with advanced, life-limiting cancers. I realized quickly, however, that there was a significant gap in support services available for their family caregivers – their parents, partners, children, siblings and friends – despite the fact that healthcare was already depending on caregivers to shoulder tremendous responsibilities, and the distress and burden of caregivers had been very well documented in the scientific literature. So, a year later in 2011, I founded the Caregivers Clinic at Memorial Sloan Kettering Cancer Center (MSK), whose mission is to assure that no caregiver experiencing significant distress as a result of their critical role goes unidentified and deprived of necessary psychosocial services.

### Describe how psychosocial support has evolved in the last decade or so?

When I began working in psycho-oncology, psychosocial care for patients with cancer was becoming a standard of care, and support services for patients were being developed in cancer centers across the country. At that time, however, psychosocial support was rarely offered to family caregivers. Today, distress screening for patients with cancer has become a standard of



DR. ALLISON APPLEBAUM

care, and my hope is that in the not-too-distant future, such screening for caregivers will as well. Psychosocial services for caregivers like the Caregivers Clinic at MSK are now being replicated, and colleagues and I are working to ensure that within the next decade, every cancer center will offer comprehensive psychosocial support to family caregivers, as well as patients.

### How does caregiver support fit into the continuum of care for cancer fighters?

I see family caregiver support as a key element of cancer care, as care for the patient with cancer includes attending to the needs of the family facing cancer. Ideally, as soon as patients begin their treatment, family caregiver(s) should be identified, screened for distress and triaged to appropriate levels of support. When caregivers feel supported and their psychosocial needs are met, they are better able to take care of patients, which means that ultimately, support for caregivers is support for patients with cancer.

Stand By Me: A Guide to Navigating Modern, Meaningful Caregiving

**VIEW BOOK** 

# Caregiving In Cancer Resources

DESCRIPTION	LINK
CancerCare - Caregiver Resources and Support Groups	Watch
A Caregiver Toolkit For Cancer Centers And Staff	Read
Supporter's Roadmap - Not Quite A Caregiver	Read
Helping You And Your Loved One with Nutrition	Read
Courageous Parents Network - Caring For A Child	Read
Caring For Your Loved One with Cancer	<u>Listen</u>
Cancer Risk Assessment Tool	Read
Things Caregivers Need To Know When Their Loved One Dies	Read
Love Your Caregiving Life Podcast	Listen
Advice And Support For The Caregivers Featuring Dr. Allison Applebaum	Listen
Caregiver Virtual Trainings	Watch
Hospice And Community Care Caregiver Training	Watch
Cancer Caregivers Need Care Themselves	Watch
Supporting Caregivers When It Comes To Work - Laws That Protect	Watch
What Can Caregivers and Family Expect	Read
A Practical Guide to Cancer Rights For Caregivers (Triage Cancer)	Read
Caregiving Webinar (Triage Cancer)	<u>Watch</u>
Bright Spot Network: Parenting With Cancer	Watch
From Resentment To Relief: Advocating For Your Needs As A Cancer Caregiver	Listen
Coping With Your Loved One's Metastatic Triple Negative Breast Cancer	Listen
Navigate Financial And Legal Tools For Family Caregivers	Read
Care Partner Support Home Page - Patient Empowerment Network	Read
Bright Spot Network's Virtual Support Groups	Read

# Caregiving In Cancer Events

\*All events listed are offered virtually unless noted otherwise

DESCRIPTION	DATE/TIME	LINK
Navigating Caregiver Rights At Work, Etc.	10/25 & 10/26	Register
ZERO Plus One Prostate Cancer Caregiver Retreat / In Person - Chicago	10/26 - 10/27	Register
For Caregivers: Coping With The Stresses Of Caregiving When Your Loved One Has Triple Negative Breast Cancer	11/13 12:30p CT	Register
Supporting A Partner During Cancer Treatment	11/13 at 6p CT	Register
Casual Chat For Sarcoma Caregivers	3rd Tuesday of every odd month, 4p CT	Register
Navigating Caregiving For Adult Children With Cancer As An Older Adult With CancerCare	11/19 at 12p CT	Register
Kidney Cancer Support Groups	Last Tuesday of each month at 6p CT	Register
Caregiver Support In Illinois	2nd and 3rd Tuesday of every month at 6:30p CT	Register
Private Soul Care Workshops (Hope for Stomach Cancer)	1st and 3rd Thursday of every month at 6:30p CT	Register
AnCan Stage 3 & 4 Virtual Cancer Care Partners Group	1st and 3rd Tuesdays of every month at 7p CT	Register
Family And Friends Weekly Support Group	Every Tuesday (weekly) at 5p CT	Register
Teal Cares Network - Ovarian Cancer Caregivers Support Group	Every 1st Tuesday of every month at 6:30p CT	Register
2024 Fall Bladder Cancer Summit For Patients And Families / In Person - Philadelphia, PA	10/25 & 10/26	Register



Imerman Angels has helped me channel my grief and keep moving forward. I have this good feeling when I'm helping someone because I didn't have something like this before, and building this sense of community with others has helped me a lot.

# Partner Spotlight



Mission: The Cocktails & Caregivers Foundation provides support, resources and a sense of community for individuals caring for a loved one facing long-term sickness, disability or terminal illness.

**About:** Caregiving can be a lonely job. Cocktails & Caregivers is a community

of people who "get it." Nominate a caregiver and they'll take it from there. Send care packages and cards to remind the people you love, they aren't alone.

**History:** Cocktails & Chemo started as a blog; a place where Joe and Amanda Clark would share their personal account as a young couple facing a deadly disease. Joe was diagnosed with colon cancer when he was 28 years old and just two months before the couple would wed. They blogged about their accounts as they faced chemotherapy instead of a honeymoon and through the birth of their daughter, Mira Joey. When Joe died in 2014, Amanda felt a calling to recognize other caregivers like herself in her late husband's honor. In 2021, that message expanded beyond her story to serving caregivers everywhere the name changed to Cocktails & Caregivers, creating a place where an underserved group can find support without the stigma.

LEARN MORE



Caregiving is hard and exhausting. There is a lot of pressure, mourning, sadness, guilt and a whole lot of fear. That said, I really did have a closer relationship with my partner. We talked through everything; he trusted me with decision-making and he was able to support me in the ways he was able to. There's so much responsibility and physical exhaustion that when your partner passes, one of the feelings often left unspoken is relief. Relief is usually not considered one of the stages of grief and people feel guilty for feeling it, but it's very much part of the process. People should know it's okay to have those feelings and all the other emotions they experience."

Gina R., Caregiver Support Seeker

# Additional Resources

#### **ADOLESCENTS AND YOUNG ADULTS (AYA) RESOURCES**

**Cactus Cancer Society** 

Inclusive Family Building
For Those Touched By
Cancer

The Scoop: Finances And Cancer - AYA Focused

The Scoop: Navigating
Careers And Cancer - AYA
Focused

The Scoop: Navigating
College And Cancer

Dating After A Cancer Diagnosis Podcast

Parenthood Options For Infertile Survivors

Camp Kesem

Young Adult Survivor/
Caregiver Retreats

Age Appropriate Family
Cancer Support Kit

#### **BILINGUAL RESOURCES**

Recursos En Español

**Prostate Care En Espanol** 

**Prostate Care En French** 

**Prostate Care In Shalom** 

Videos en Español On Radiation Therapy

Cancer Care en Español

Thyroid Cancer En Espanol

<u>Lidiar Con Los Efectos</u> Secundarios En El Trabajo

En Vivo: Amar Su Hígado

Kidney Cancer - Translated

Cómo Tomarse Tiempo Libre Con Goce De Sueldo

<u>Decisiones Sobre La</u> <u>Divulgación</u>

Opciones Cuando
Pierde Su Seguro Médico
Vinculado Al Trabajo

#### **CANCER-SPECIFIC RESOURCES**

Non-Small Cell Lung
Cancer: For Caregivers

For Caregivers: Practical
Tips for Coping With Your
Loved One's Chronic
Lymphocytic Leukemia
(CLL)

For Caregivers: Coping
With Your Loved One's
Metastatic Triple Negative
Breast Cancer

Understanding Caregiving
And Lymphoma

Kidney Cancer Unfiltered
As A Caregiver

Podcast: My Experiences
As A Bladder Cancer
Caregiver With Beáta
Baker

Testicular Cancer Foundation Summit Kidney Cancer Association
Caregiver Care Packs

Kidney Cancer Association
Kidney Cancer Unfiltered
Podcast

The Leukemia & Lymphoma Society Caregiver Support

Patient & Caregiver
Network

# Additional Resources

#### **CANCER-SPECIFIC RESOURCES** (con't)

Head & Neck Cancer
Alliance: Caregiver Needs
Webinar

What Care Partners Should
Know about Lymphoma

Bladder Cancer Basics:
Tips For Caregivers
Webinar

The Care Partner Toolkit:
CAR T-Cell Therapy

Bladder Cancer Basics:
Tips for Caregivers
Handbook

#### **GENETICS**

Understanding Genetic

Mutations & Biomarkers In

Ovarian Cancer)

Decoding Genetic Tests for Parents-To-Be

What If I Test Positive
For Genetic Mutations
- Should I Tell My

What is Genetic
Counseling and Genetic
Testing? What are
Previvors?

#### **RESEARCH & CLINICAL TRIALS**

Diet & Exercise May
Prevent Colorectal Cancer
Recurrence (Study)

Self-Perception and Intimacy After the Cancer Experience (Study)

Research Opportunity For Ovarian Cancer Patients

Counseling and Use of
Surrogacy Among Cancer
Survivors (CUSACS)

Why Prostate Cancer
Patients Should Consider
Participating in a Clinical
Trial

Understanding Clinical
Trials In Ovarian Cancer

Open Clinical Trials For Those Positive For The BRCA GENE

Participate In The Inherited Cancer Registry (ICARE)

Paid Research Study On Mindfulness And Social Support

American Cancer
Society: Black Women
+ Cancer Study

Paid Research Study For Those Diagnosed With Lynch Syndrome

Demystifying Clinical
Trials: A Comprehensive
Guide To The Science Of
Hope (Podcast)

**ProChange Previvor Trials** 

CURE - Caregivers As Vital

Members Of The Care

Team

Caregivers of Children w/Cancer 0-25 years old:





**Imerman Angels Grief ToolKit** 

A guide to coping and supporting the grief process.

**DOWNLOAD** 

List of helpful cancer related resources.

Request Brochures

Resource Page

**Shop Imerman Angels** 

### Become a Mentor Angel

Join our worldwide cancer support community as a Mentor Angel and provide personalized, one-on-one support for cancer fighters, survivors, previvors and caregivers.

**LEARN MORE** 



### Share your journey



Everyone has a story to tell. It only takes one story to inspire and provide hope to others. Whether it is a story of survivorship or your experience as a caregiver, others like you will find comfort in knowing they are not alone.

**SHARE YOUR STORY** 

# Connect with us

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