IMERMAN ANGELS

Side Effects & Self Advocacy

Resource Guide

SUMMER 2025

VIRTUAL EVENT

Community Event Series

TUES SEPT 16 **6:00 PM CT**

Side Effects & Self Advocacy: Your Voice Matters, Your Power After Cancer

The cancer journey doesn’t end when treatment does. Survivors, caregivers and previvors alike often face ongoing challenges–from brain fog and word-finding issues to fatigue, emotional stress and navigating life after diagnosis.

For those living with cancer and those who love and support them, Dr. Gizelka David-West (see page 2) will share the importance of breaking the silence about side effects and how to speak up for your needs without guilt or fear.

During this FREE, virtual event, we'll discuss:

- Common myths and facts about discussing side effects with doctors
- Real-world strategies for self-advocacy in healthcare, at work and in everyday life
- Practical tools for communication, decision-making and accessing support systems

Whether you're a survivor, caregiver or previvor, this session offers tools, validation and connection because your voice matters, and your power after cancer is real.

REGISTER

See page 6 to learn about our November Community Event, Understanding Financial and Time Toxicity in Cancer Care

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How to Communicate With Your Doctor About Your Side Effects

For anyone impacted by cancer, communicating with your doctor – particularly when it comes to side effects and symptoms – is crucial. And yet, several common myths and fears can stand in the way. Gizelka David-West, MD, Director of Gynecologic Oncology at Northwell's Northern Westchester Hospital and Assistant Professor of OB-GYN at Zucker School of Medicine at Hofstra/Northwell, dispels these fears and provides tips on how to communicate with your medical team, better enabling you to receive the best possible care.

3 Common Myths

MYTH #1: It's all or nothing.

Patients might not want to tell their doctor about their side effects because they fear it's "all or nothing" – either they take the medication that helps treat their cancer or reduce recurrence risk and suffer with bad side effects, or they don't take the medicine at all and risk their cancer progressing or recurring.

REALITY

There are more than just two options, Dr. David-West says. Lowering the dose of a medication might be just as effective in treating the cancer while reducing the side effects. Other options may include maintaining the same dose but adding in other medications to help treat and manage side effects, or switching to a different medication that might be similarly effective but with fewer side effects, she explains. While the appropriate choice will depend on individual circumstances, an array of possibilities exist; talk to your doctor to determine the one that's right for you.

MYTH #2: Doctors are busy and I don't want to bother them.

When you experience a side effect, it's common to feel like you don't want to bother your doctor. As a patient, it can be hard to know how serious your concern is and if it's "serious enough" to warrant contacting your provider.

Gizelka David-West, MD;
Photo courtesy of Northwell Health

REALITY

"You're never bothering anyone within your care team," says Dr. David-West. "We are your care team for a reason – we're here to take care of you."

Your care team includes more than just your doctor; it also encompasses the other providers that work with them too, such as nurse practitioners, physician assistants and patient navigators. The doctor might not be the first point of contact when a patient reaches out to a medical practice, says Dr. David-West, but whoever is designated to receive patient questions and concerns will escalate it as necessary to the appropriate provider.

MYTH #3: Doctors know everything and patients should be passive.

In the old, paternalistic model of healthcare, doctors are on a pedestal and patients are just along for the ride, passively following doctors' orders and never questioning anything.

REALITY

Today, patient-centered care and shared decision-making, where doctors and patients work together to determine care plans based on clinical evidence while also considering patient preferences and values[1], are at the forefront. Doctors have extensive knowledge, training and expertise, but they're also human, Dr. David-West points out, and humans make mistakes.

Being an educated, informed patient is essential. Dr. David-West encourages patients to know what chemotherapy drugs they're receiving and how often; which tests, like blood work and imaging, they should be getting and when; and what to expect in terms of things like medication side effects and surgical recovery. And if your doctor doesn't explain this to you, ask.

3 Tips for Self-Advocacy

As a patient, there are things you can do to help your doctor best care for you. Dr. David-West shares a few of her favorite tips.

1. Keep a detailed log of your side effects and symptoms — and a short summary.

Keeping track of your side effects will help your doctor know specifically what you're experiencing, but your provider likely won't have time to review 10 pages of notes during your appointment. To make the most of your time with your doctor, Dr. David-West recommends bringing your side effects log – but also jotting down a short summary of your biggest concerns, focusing on any serious side effects your doctor may have cautioned you about, as well as any side effects that are persisting or are getting worse.

2. Bring someone with you to your appointments if you can.

People might downplay or dismiss their own side effects, notes Dr. David-West. A caregiver, partner, family member or friend can point out when something is more serious than what a patient is relaying. For instance, they might share insights like their loved one's gait is unsteady after surgery, or their neuropathy is causing them to frequently drop things around the house.

3. Follow up if you don't hear back.

For non-urgent medical questions, healthcare practices tend to respond between 24 and 48 hours. But if you haven't heard back after two days, don't keep waiting – follow up, advises Dr. David-West. Doctors and their teams do their best to respond, but your message may have fallen through the cracks. If you are experiencing a medical emergency though, call 911 or go to the emergency room.

How Peer Mentoring Can Help

Peer mentors can't provide medical advice, but they can offer **support and encouragement** through the sometimes scary and intimidating process of advocating for yourself in the healthcare system. Below, three of our Mentor Angels share their tips and suggestions for **self-advocacy**.

> **"It is crucial to communicate effectively with your medical team! Keeping a list of questions and concerns was very helpful, as I found myself leaving appointments frustrated because I forgot to ask about something."**
>
> – Danny, Mentor Angel

> **"[Speaking] as an oncology nurse and cancer survivor, it is VERY important to advocate for yourself. Your providers don't know if you don't tell them if you are having issues with side effects. There are things they can do to help minimize your symptoms, but only if they know about them."**
>
> – Suzie, Mentor Angel

> **"Getting a Mentor was an important part of my advocacy. I found someone impartial, who has been through the diagnosis and who I could be open and honest with."**
>
> – Jamie, Mentor Angel

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[1] National Learning Consortium "Shared Decision-Making Fact Sheet," https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf

Side Effects & Self Advocacy Resources

DESCRIPTION	LINK
Parenting Through Cancer Side Effects	Read
Myelofibrosis Symptoms And Side Effects | Why Speaking Up Is Vital	Watch
Tips And Advice For Self Advocacy - Multiple Myeloma Leukemia	Watch
Tips And Advice For Self Advocacy - Acute Myeloid Leukemia	Watch
Advice For Myeloma Care Partners | Monitoring For CAR T-Cell Therapy Side Effects	Watch
What Myeloma Care Partners Should Know About Bispecific Antibody Side Effects	Watch
Follicular Lymphoma Care: Bispecific Antibody Side Effects And Precautions	Watch
Managing CLL Side Effects | Innovative Strategies And Approaches	Watch
Self-Advocacy In Myeloma Care | Advice From An Expert	Watch
Lung Cancer Care Decisions | Advice For Self Advocacy	Watch
Self-Advocacy: Advice For Being A Pro-Active MPN Patient	Watch
FLOURISH Program	Read
RESTORE Program	Read
Understanding Chemo Brain	Watch
Symptom Management	Watch
Lymphedema Management And Risk Mitigation	Watch
Kidney Cancer Association: Be Your Own Best Advocate	Watch
Kidney Cancer Association: Managing Treatment Side Effects	Watch
Kidney Cancer Association: Side Effect Management Video Library	Watch
Fight CRC Side Effects Booklet	Read
Fight CRC Beyond Blue - Building Your Team	Read
Understanding Neuropathy After Ovarian Cancer Treatment	Watch

Side Effects & Self Advocacy Resources

DESCRIPTION	LINK
Menopause After Ovarian Cancer: Ways To Manage Symptoms	Watch
Manging Side Effects Of Head And Neck Cancers	Read
NCCS Self Advocacy - A Cancer Survivor's Guide	Read
NCCS Becoming A Self Advocate	Read
Self-Advocacy - Taking Charge Of Your Metastatic Cancer Experience	Watch
Pain And Sleep Management Strategies (Pancreatic Cancer)	Watch
Pain Management, Nutrition And Exercise (Pancreatic Cancer)	Watch
Coping With "Chemo-Brain"	Watch
Immunotherapy Side Effects	Watch
Managing Side Effects In Bladder Cancer Treatment	Watch
Changing The Odds Through Self Advocacy	Watch
The Importance Of Healthcare Self Advocacy	Watch
Being Your Own Best Advocate	Listen

> Being understood is very important because I can’t really talk about important details, such as chemo side effects and the fear and depression I may be feeling to friends and family. They try to be understanding but they can’t truly comprehend or even handle all of the information. I am grateful to my mentor and Imerman Angels for their help.
>
> – Cathy, Support Seeker, Pancreatic cancer

Side Effects & Self Advocacy Events

**All events listed are offered virtually unless noted otherwise*

DESCRIPTION	DATE/TIME	LINK
Overcoming The Challenges Of Swallowing Problems	August 18, 6-7 pm CT	Register
Practicing Mindfulness With Zentangles - Twistshop Program	August 21 at 6:30 pm CT	Register
Side Effects & Self Advocacy: Your Voice Matters, Your Power After Cancer	September 16th, 6-7 pm CT	Register
Understanding Financial and Time Toxicity in Cancer Care	November 12th, 6-7:30 pm CT	Register
ZERO+1 Prostate Cancer Caregiver Retreat	In person - Atlanta, GA Nov 15th-16th	Register

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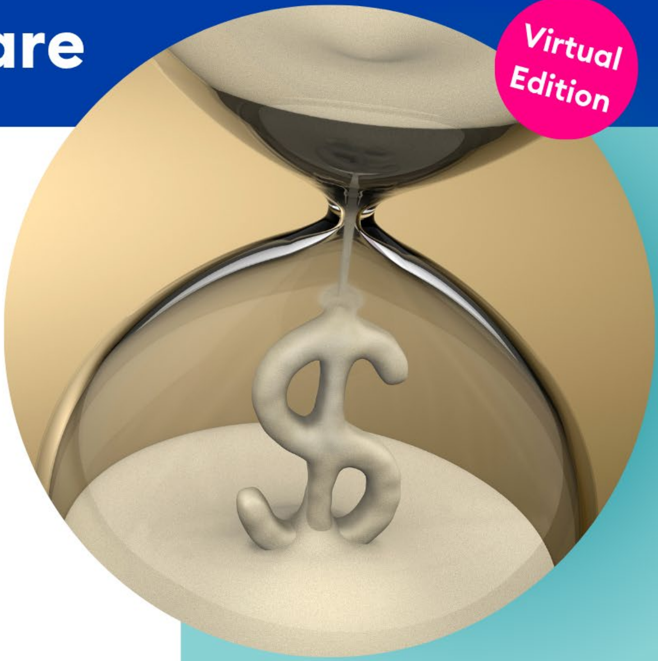
Understanding Financial and Time Toxicity in Cancer Care



Virtual Edition

Community Event Series

WEDS NOV 12 **6:00 PM CT**

This webinar will explore the concepts of financial and time toxicity often experienced by individuals coping with cancer and their caregivers. We will discuss how treatment-related costs, insurance barriers, lost income, and the demands on time contribute to stress and can impact health outcomes. We will cover tips and strategies to address these challenges and, hopefully, minimize their impact.

IN PARTNERSHIP WITH:

TRIAGE CANCER

PRESENTED BY:
Monica Fawzy Bryant, Esq.

REGISTER

Partner Spotlight

Patient Empowerment Network

The Patient Empowerment Network (PEN) is a non-profit organization whose mission is to fortify cancer patients and care partners with the knowledge and tools to boost their confidence, put them in control of their healthcare journey, and assist them in receiving the best, most personalized care available to ensure they have the best possible outcome.

PEN programs enhance patient health literacy to enable shared decision-making and provide informational and educational resources to empower patients and care partners at every step of their cancer journey.

LEARN MORE

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

Additional Resources

ADOLESCENTS AND YOUNG ADULTS (AYA) RESOURCES

Bright Spot Network
Dear Jack Foundation
Elephants And Tea
Young Survival Coalition
The Ahmad Butler Foundation
Stupid Cancer
The Cassie Hines Shoes Cancer Foundation

BILINGUAL RESOURCES

The Latino Cancer Institute
ALAS Wings
Latinas Contra Cáncer
Nueva Vida
Triage Cancer - Seguros, Empleo, Finanzas
Cancer Care
Chinese Community Cancer Information Center
New Hope Chinese Cancer Care Foundation - Translated

CANCER-SPECIFIC RESOURCES

National Ovarian Cancer Coalition
Leukemia & Lymphoma Society
Leukemia Research Foundation
National Brian Tumor Society
Bladder Cancer Advocacy Network
Kidney Cancer Association
The Paula Takacs Foundation For Sarcoma Research
American Lung Association
Hope For Stomach Cancer
Melanoma Action Coalition
Head & Neck Cancer Alliance
Male Breast Cancer Global Alliance
Learn Look Locate (Breast)
Melanoma Research Foundation
MPN Research Foundation
Sarcoma Alliance
Northwest Sarcoma Foundation
Blue Faery (Liver)
Colontown
Lary's Speakeasy

GENETICS

What Is Genetic Counseling And Genetic Testing ? What Are Previvors?
Decoding Genetic Tests for Parents-To-Be
What If I Test Positive For Genetic Mutations - Should I Tell My Family
Living LFS - Li-Fraumeni Syndrome
Alive And Kick'n - Lynch Syndrome
KRAS Kickers - KRAS Biomarker

Additional Resources

RESEARCH & CLINICAL TRIALS

- Participate In The Inherited Genetic Cancer Registry
- Latina breast cancer survivor -Together After Cancer
- Black Women And Cancer Study
- Organ transplant And Cancer Study
- Self-Perception And Intimacy After The Cancer Experience
- The Childhood Cancer Identity Project
- Open Clinical Trials Related to Hereditary Cancers
- A Healthy Diet And Exercise May Prevent Colorectal Cancer Recurrence

ADDITIONAL RESOURCES

- Pickles Group - Kids Supporting Kids
- Camp Kesem - A Child's Friend Through And Beyond A Parent's Cancer
- Cocktails & Caregivers
- Cancer Care - Free Professional Support Services And Information
- Twist Out Cancer - Creative Arts Programming
- National LGBT Cancer Network
- Triage Cancer - Insurance, Employment, Finances
- Cure Today - Online Magazine
- Worth The Wait - Fertility Treatments, Adoption, And Surrogacy
- Lazarex - Access To Care And Clinical Trials
- Alliance For Fertility Preservation
- Empowering Intimacy
- Team Maggie's Dream - Fertility Preservation
- Epic Experience - Adventure Camps
- Patient Empowerment Network - Education
- 3 Little Birds 4 Life

> I don't think you truly understand the caregiving aspect of cancer until you're immersed in it. [Doctors] don't really tell you a lot about the caregiving piece of it. I became a huge advocate for my husband's health care. I had to because no one else was. We caregivers help each other feel less alone.
>
> – Ginger, Caregiver Mentor Angel for Spouse, Penile cancer

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RESOURCES


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Grief Toolkit

A resource guide for our community to utilize when assisting others in managing their grief process.

Imerman Angels Grief ToolKit

A guide to coping and supporting the grief process.

DOWNLOAD

List of helpful cancer related resources.

Resource Page + Videos

Request Brochures

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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