

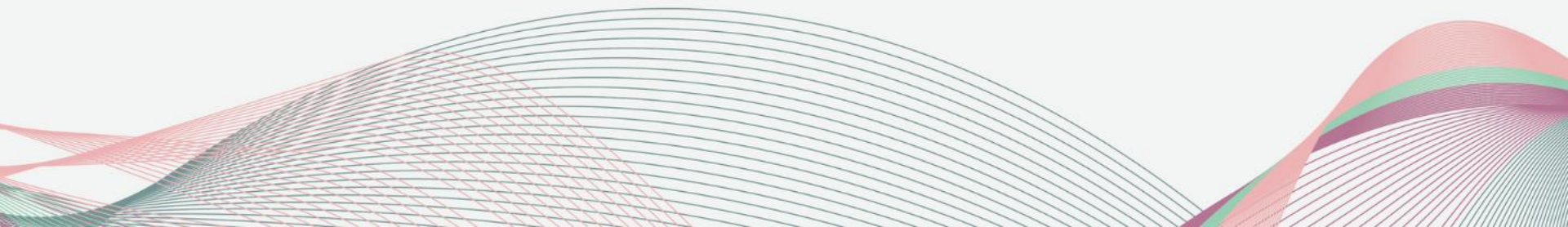
**Breakout session**

**LIVING BEYOND  
BREAST CANCER®**

# Talking together

Strengthening communication between people living with metastatic breast cancer and their loved ones

**Speaker:** Celeste Vaughan-Briggs, LCSW





LBBC Metastatic Breast Cancer Conference 2026  
Talking Together: Strengthening communication  
between people living with metastatic breast cancer  
and their loved ones



Celeste Vaughan-Briggs LCSW  
Program Manager- Breast and Cervical Cancer Screening  
Program  
Oncology Social Worker

# Agenda



Overview of Cancer, Cancer caregivers, Caregiver functions



Caregiver 'burden' / Caregiver stress



Communication challenges: activities



Resources

# Community Meeting:

How are you  
Feeling  
today?

What is your  
goal for today?

Who can you  
ask for Help?



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# Cancer Caregivers



# Who are Cancer caregivers?

## Who Are Informal Caregivers and What Roles Do They Play?

In 2016, the National Alliance for Caregiving reported an analysis of the survey responses of 111 caregivers who self-identified as providing care to a person with cancer.[3] The respondents were part of a much larger study that identified a representative sample of adult caregivers who provided unpaid care to an adult relative or friend in the 12 months preceding the time of the survey.

The following findings provide a snapshot of informal caregivers of people with cancer and the challenges they face:

- 58% were women.
- 88% cared for a relative.
- 39% lived with the person being cared for.
- 50% reported high emotional stress related to caregiving.
- 25% reported high financial strain.
- 50% were employed while caregiving, working an average of 35 hours per week.
- 73% were involved in discussions about care during hospitalization; however, only about half of these (54%) were asked what help was needed after discharge.
- 72% assisted with medical tasks.
- 43% reported needing help to manage emotional and physical stress.
- 40% wanted help making end-of-life decisions.
- 33% wanted help keeping their friend or relative safe at home.
- Caregiving for patients with cancer was noted to be episodic and lasted for approximately 2 years on average.

Caregiving is also relational.[4,5] In addition, there are important implications for the interconnectedness between patient and caregiver that the oncology clinician should be aware of, including the following:

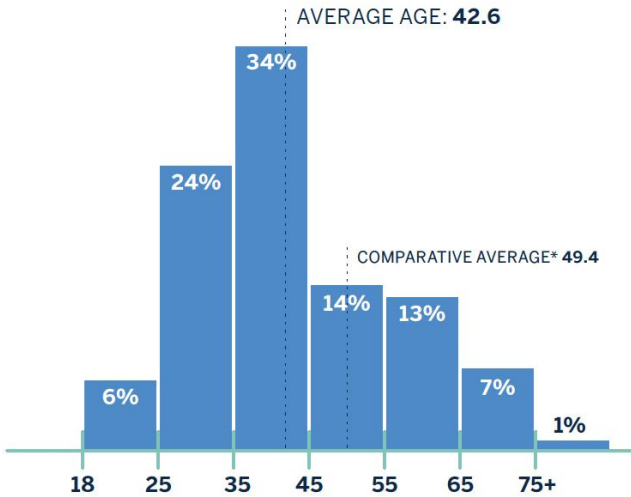
PDQ® Supportive and Palliative Care Editorial Board. PDQ Informal Caregivers in Cancer. Bethesda, MD: National Cancer Institute. Updated <03/12/2024>. Available at: <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>. Accessed <04/13/24>. [PMID: 26389284]

# Important facts and figures

- An estimated 2.8 million to 6.1 million adults in the U.S. provide unpaid support to someone close to them who has cancer.<sup>1</sup> These caregivers offer “practical and emotional support across the continuum of care,”<sup>2</sup> which includes aiding patients as they confront the many decisions to be made about their cancer treatment.
  - There are nearly two million new cases of cancer diagnosed each year,<sup>1</sup> and it is estimated that two-thirds of these people will have the support of caregivers.<sup>2</sup> Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, the equivalent of a full-time job,<sup>3</sup> and nearly 50% more hours per week than caregivers of
  - Caregivers are faced with information needs as soon as their loved one is diagnosed, when they immediately become immersed in helping to make medical choices for which they are ill prepared.
  - In 2020, more than 1 in 5 Americans (21.3%) had served as caregivers in the past 12 months—a percentage that has grown since 2015.<sup>22</sup>
- CancerCare. *Cancer Caregivers: National Research Report on Shared Treatment Decision-Making*. New York: CancerCare; 2022.

# Cancer Care Survey

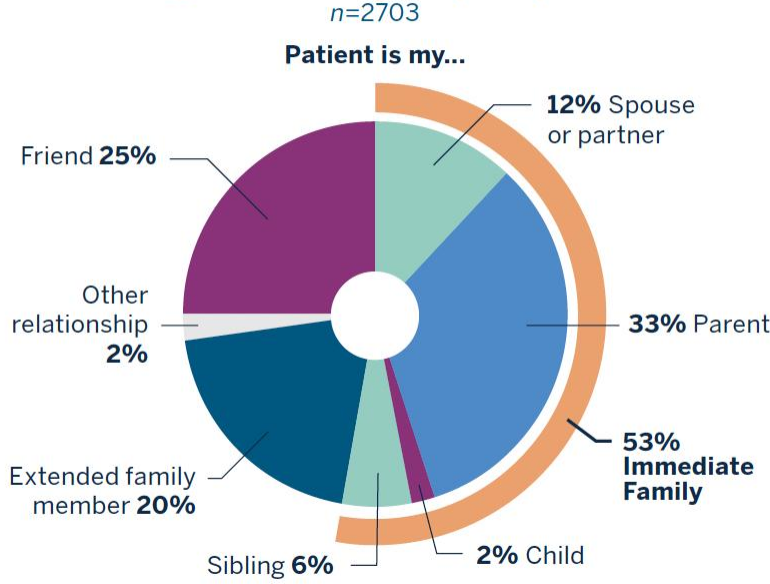
**Caregiver age**  
n=2703



Results do not total 100% due to rounding

\* National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*

**Caregiver relationship to patient**  
n=2703



CancerCare. *Cancer Caregivers: National Research Report on Shared Treatment Decision-Making*. New York: CancerCare; 2022.

# Caregiver Functions



# Functions of Caregivers

Assist in medical, financial, practical decision making

Providing physical care (often complex)

Providing emotional support

Navigating financial and insurance tasks

Navigating multiple complex systems: Medical, Social Services, employer benefits

# What does the research tell us about caregivers

## Physical impact

- Disrupted routines impacting health of patient, caregiver and other household members
- Sleep patterns impacted
- Nutrition
- New health issues
- Existing issues more symptomatic

## Emotional impact

- Distress
- Mental Health disorders new or previously diagnosed

## Relational impact

- Changing roles
- Unpredictability impacting existing structures/routines
- Communication changes

# What is ‘Caregiver Burden’

“The term **caregiver burden** describes a caregiver’s perceptions of the demands of caregiving and the resources available for addressing those demands. The Transactional Model of Stress and Coping is a useful framework for describing the relationships among caregiver demands, resources, burden, and the psychological consequences of being burdened.<sup>[1]</sup> From this perspective, a burden is perceived when the demands on the caregiver exceed the resources available to him or her. ”

- PDQ® Supportive and Palliative Care Editorial Board. PDQ Informal Caregivers in Cancer. Bethesda, MD: National Cancer Institute. Updated <03/12/2024>. Available at: <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>. Accessed <04/14/24>. [PMID: 26389284]

# Communication



# The context of the caregiving dynamics

- Patient and Caregiver life stage
  - Young Adult
  - Mid life (Sandwich generation)
  - Retirement age
- Relationship
  - Spouse
  - Parent
  - Adult child
  - Friend
- Other responsibilities/life areas
  - Career/work
  - Childcare
  - Eldercare
  - education
- Additional Important factors
  - Illness journey
    - From initial diagnosis to end of life
  - Personal and Community Networks for support
  - Impact of Identity on dynamic
    - Race
    - Gender
    - Class
    - Geographical region
    - Family History

# Two Buckets of Communication challenges: Logistical

## Time

Brief exercise:

To be done in your caregiving configuration. If your caregiver/caree is not present join into a group nearby

- Write down the 2-3 most important daily tasks you think are important for the other person in your dyad.
- Compare the lists
- Any surprises?



# Two Buckets of Communication challenges: Psychological/Emotional

## Communication during times of stress

- What is being said?
- What is the need/question?
- Who may have the information?
- Who should or should not be asked?
- How am I asking/being asked?
- How am I answering?
- Where are we?
- When is this information needed?
- When can I take a pause?



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## Two Buckets of Communication challenges: Psychological/Emotional

Ms. Smith is 68 year old living with MBC for the past 3 years. She lives was living alone after divorcing of her spouse and her two children: one son (34) and one daughter (27) moved out. Recently, she had a fall and required an orthopedic oncological specialist to put pins in her leg. She is out of the rehabilitation hospital and her children are home to help.

Ms. Smith has always been very independent and able to take care of her ADL's and the hospital and rehabilitation stay was very challenging.

There family is having a meeting to decide how to divide care. Her children are beginning to argue with each other.

Ms. Smith has important questions and input she would like to discuss about her care now and her worries/wishes about the future.

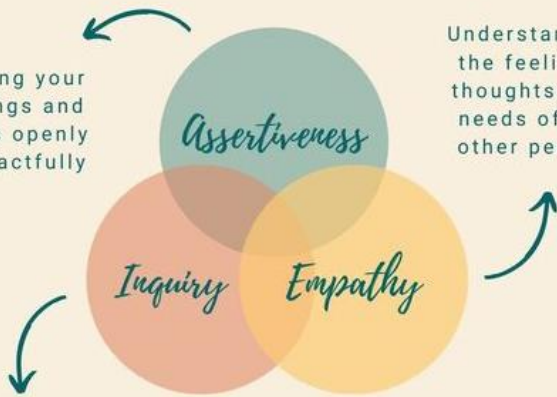
Discuss how might Ms. Smith guide this conversation with her children? How might Ms. Smiths son and daughter discuss next steps in a constructive way?

# Communication Keys

The three principles of

## Effective Communication

Sharing your feelings and needs openly and tactfully



Understanding the feelings, thoughts, and needs of the other person

Asking gentle, probing questions to find out more about the other person's feelings, thoughts, and needs

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## COUPLES COMMUNICATION WORKSHEET: THE FEEDBACK WHEEL

### WHAT I SAW OR HEARD

Describe the specific behavior or event that you observed, without interpretation or judgment. Use concrete details that could be captured on a video camera.

### WHAT I'D LIKE NOW

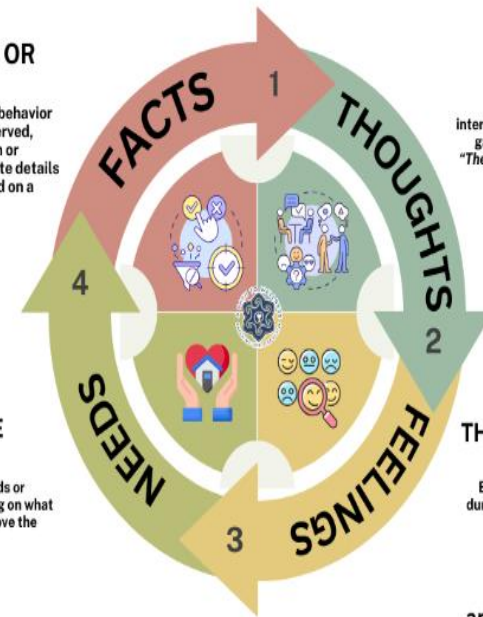
Communicate your needs or desires clearly, focusing on what could help heal or improve the situation.

### WHAT I MADE UP ABOUT THAT

Share your personal interpretation or the meaning you gave to the observed behavior. "The story my mind tells me is...".

### THIS IS HOW I FEEL ABOUT IT

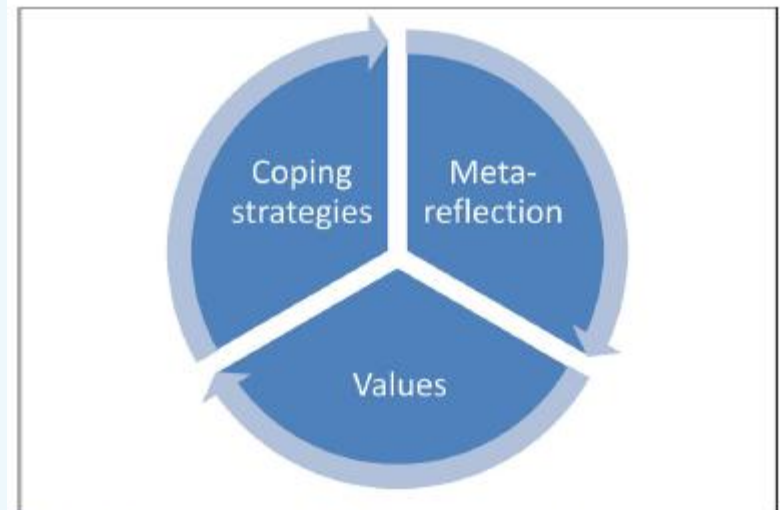
Express the emotions you felt during the event without mixing them with interpretations or accusations.



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# Resilience as a Therapeutic approach

- “Resilience is commonly referred to as the ability to recover or sustain well-being after an adverse life event, and represents a paradigm shift in psychology where there is increased focus on well-being and protective factors instead of solely on mental illness and risk factors.<sup>18</sup>”
- Coping Strategies- wide range of possibilities varying from acceptance to change strategies. Resilience being enhanced by being able to navigate and choose from different strategies based on context.
- Meta-reflection- “this ability to reflect on one’s thoughts and actions, in order to evaluate whether a given coping strategy is helpful for one’s situation, as well as whether it contributes to living a life based on what is important to the individual”.
- Valued living- ‘resilience is enhanced when a person is able to think and cope in ways that he or she finds meaningful and are aligned with what he or she finds valuable and important in life. .. Not based on the ability to use ‘good or ‘bad’ strategies, but rather on being able to flexibly choose strategies that can bring an outcome that is of value to the individual”



**Figure 1** Proposed central components of the resilience process: the meta-reflective skill of evaluating and choosing values-based coping strategies.

Genter P, Høeg BL, Hamre CJ, Andersen EAW, Dalton SO, Ribers B, Bidstrup PE. Protocol for 'Resilient Caregivers': a randomised trial of a resilience-based intervention for psychologically distressed partner caregivers of patients with cancer. *BMJ Open*. 2021 Nov 12;11(11):e048327. doi: 10.1136/bmjopen-2020-048327. PMID: 34772747; PMCID: PMC8593729.

# What helps

- Is your glass half full or half empty?
- Whom can you share how your fears, frustrations, worries ?
- What works for you?



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# What helps

## Communication

- About diagnosis
- About changes in treatment, symptoms
- Fears and concerns

Cultivating and mindful participation in fulfilling activities ‘outside’ of cancer experience

Making and keeping connections with others who are supportive and nurturing

Seeking professional help when needed:

- Paid or non paid additional help at home
- Mundane tasks: cleaning, yardwork, laundry, cooking, etc

# What helps

Psychoeducation

Problem solving/skills building

Supportive therapy

Family/Couples therapy

Integrative/Complementary/Alternative therapy

- PDQ® Supportive and Palliative Care Editorial Board. PDQ Informal Caregivers in Cancer. Bethesda, MD: National Cancer Institute. Updated <MM/DD/YYYY>. Available at: <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>. Accessed <MM/DD/YYYY>. [PMID: 26389284]

# Resources

## Crisis Hotlines

- National Suicide Prevention Lifeline 800-273-8255, 988
- Crisis Text Line- US and Canada text HOME to 741741
- National Alliance on Mental Illness 800-950-NAMI

## Cancer specific resources

- American Cancer Society <https://www.cancer.org/>
- Living Beyond Breast Cancer [www.lbbc.org](http://www.lbbc.org)
- Susan G. Komen <https://www.komen.org/>
- Cancer Support Community <https://www.cancersupportcommunity.org/>
- Triage Cancer <https://trriagecancer.org/>
- Metavivor <https://www.metavivor.org/>
- Innova Programs and virtual support [www.lifewithcancer.org](http://www.lifewithcancer.org)

## Resources for children who have a parent or caregiver with cancer:

Pickles: support for children who have caregivers with cancer: <https://www.picklesgroup.org>

Camp Kesem: <https://www.kesem.org/>

BrightSpot Box art activities for children \* some have cost associated  
[Free art projects for kids – Bright Spot Network](#)

# Retreats and Wish Programs

- [Casting For Recovery](#) - Provides free fly fishing retreats for women of all ages with breast cancer
- [Image Reborn Renewal Retreats](#) - Free retreats designed to bring awareness to the emotional side of healing and wellbeing. Over a weekend retreat, women find comfort in connection and empowerment in learning the practice of self-care. Offers “Rest and Retreat,” “Active Retreat,” and “Adventure” trips. Currently offering trips for young survivors, MBC, and Latinx (Spanish speaking) survivors.
- [Little Pink Houses of Hope](#) - Weeklong retreats in various locations across the U.S. designed to help families build hope, nurture relationships, and find joy within a supportive community.
- [Leslie’s Week](#) - Family retreats for patients with metastatic breast cancer. Hosted at the DreamMore Resort in Tennessee. Accommodates 4-6 family members. Foundation covers accommodations but not transportation or meals. There are other single day events.
- [Mary’s Place by The Sea](#) - A place for women with cancer (not just breast cancer) to heal mind, body, and soul. Day retreats and two-night retreats available.
- [Send Me On Vacation](#) - A nonprofit organization that provides breast cancer survivors in need the opportunity to initiate the process of emotional healing through a vacation experience. Includes some international trips.

# Application based Options

Calm



•Headspace



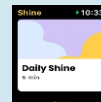
Mindfulness App



Stop Breathe & Think



Shine: Calm Anxiety & Stress



# Contact Information

Celeste Vaughan-Briggs LCSW

Program Manager, Breast and Cervical Cancer Screening Program

Oncology Social Worker

Sidney Kimmel Cancer Center at Jefferson

111 S. 11th Street Suite G301-Bodine Building

Philadelphia, PA 19107

215-955-5495 (p)

215-955-8965 (f)

267-432-1482 (m)

[JeffersonHealth.org/SKCC](https://JeffersonHealth.org/SKCC)

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