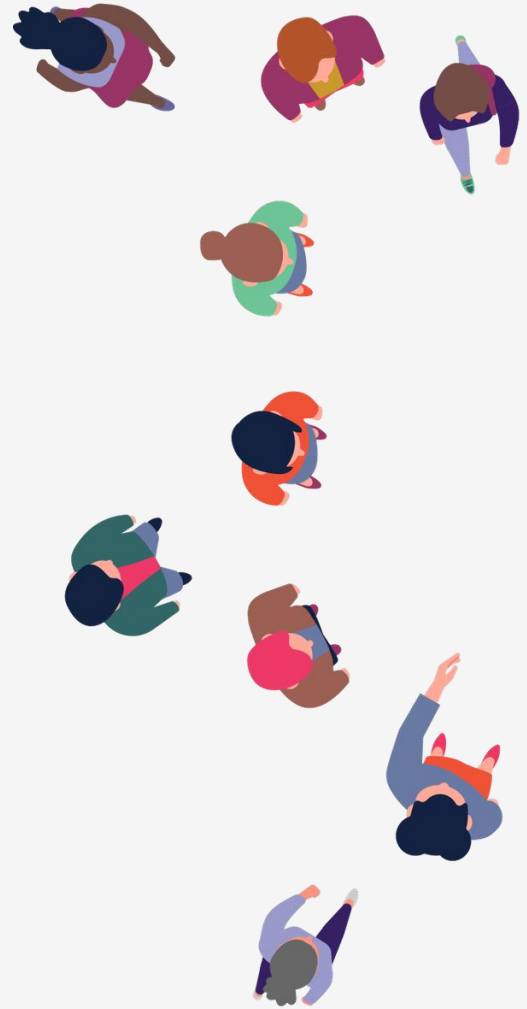


Caregiver care: What you need so you can give

Speaker: Celeste Vaughan-Briggs, LCSW



LBBC Fall Summit 2026

Caregiver care: What you need so you can give

L

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?



This Photo by Unknown author is licensed under [CC BY-NC](#).





Cancer Caregivers



Cancer care- Stories from CancerCare Clients



<https://www.cancercare.org/voice-of-cancercare/library>



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:

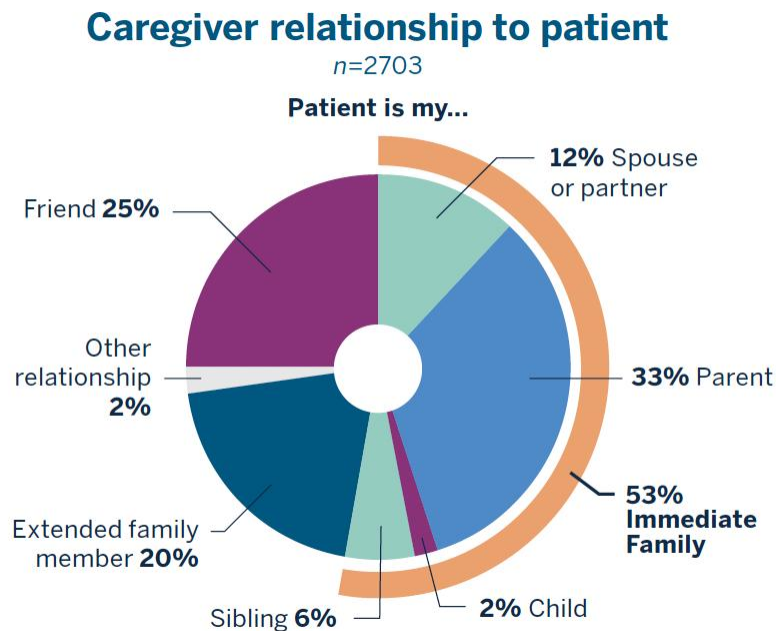
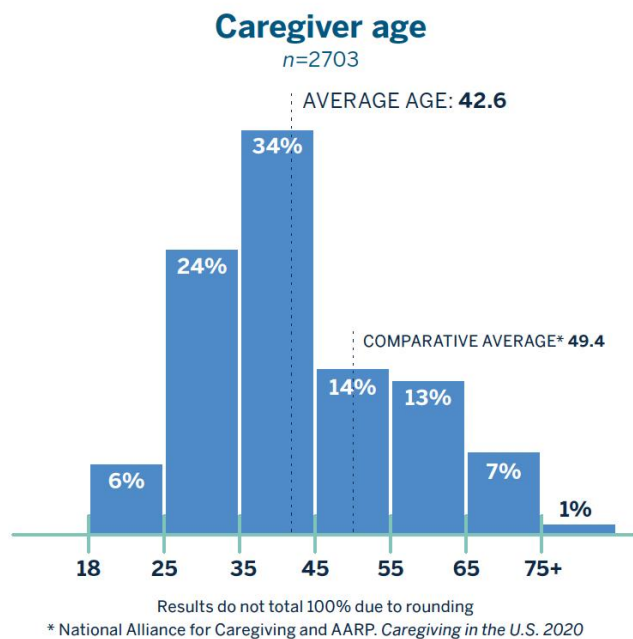
- 58% were women.
- 88% cared for a relative.
- 39% lived with the person being cared for.
- 50% reported high emotional stress related to caregiving.
- 25% reported high financial strain.
- 50% were employed while caregiving, working an average of 35 hours per week.
- 73% were involved in discussions 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]

Cancer Care Survey



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.^[1] 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



Communication challenges

- Logistical
 - Help with Doctor's visits, medications, hospital/rehab stays
 - Help with ADL's
 - Transportation
 - Nutrition
 - Finances
 - Treatment related
 - Non medical
- Psychological/Emotional
 - Worry about disease
 - Worry about side effects
 - Impact on interpersonal relationships
 - Impact on work, school, etc
 - 'Difficult conversations'- Advanced Directives, Wills, POA, End of Life wishes/care



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?



[This Photo](#) by Unknown Author is licensed under [CC BY-SA](#)

Skills Building Exercise

Index cards and Pens will be distributed

Side 1

- Can I we have a conversation today?
- This is what I need you to know about how I feel physically today...
- This is what I need you to know how I feel emotionally today...
- I feel ____ about asking for and/or receiving help
- What else do you want to communicate to your caregiver?

Side 2

- I will try my best to hear what I need to hear from you today
- I am listening to what you have to say. But this is what I need you to know....
- I hear that is how you are feeling, this is how I am feeling today...
- I feel ____ about when we have a conversation about helping with ...
- What else do you need to say to your caree?

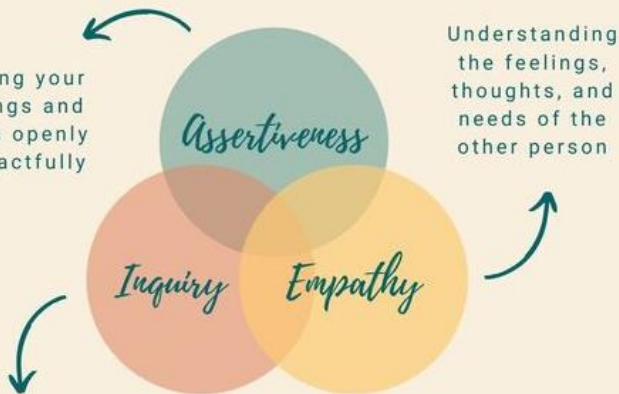


Communication Keys

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

@ppiascienceofhappiness

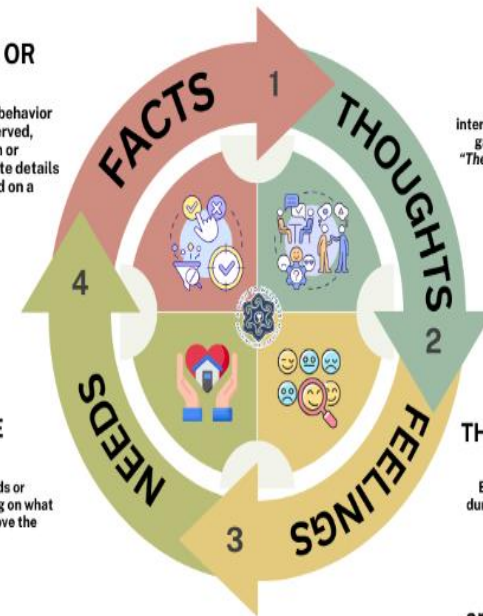
COUPLES COMMUNICATION WORKSHEET: THE FEEDBACK WHEEL

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.

apathetowellness.com



What helps

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



This Photo by Unknown Author is licensed under [CC BY-SA-NC](#)

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
- Susan G. Komen <https://www.komen.org/>
- Cancer Support Community <https://www.cancersupportcommunity.org/>
- Triage Cancer <https://triagecancer.org/>
- Metavivor <https://www.metavivor.org/>
- Innova Programs and virtual support www.lifewithcancer.org
- Support is Care <https://supportiscare.org/>
- CancerCare - support groups, individual counseling, resource <https://www.cancercare.org/caregiving>



PA Department of Aging resource: care needs checklist

Care Needs Worksheet

PA CareKit



This worksheet will help you and other family members determine what types of assistance your loved one needs.

Your Information

Your Name: _____ Date: _____

Loved One's Name: _____

Assessment

Assess the level of help or assistance needed to perform daily activities. Look into devices and technology that could help with these activities by visiting pa.gov/CareKit.

Activity	No Help	Some Help	Much Help	Notes
Bathing				
Dressing				
Grooming				
Toileting				
Eating				
Getting Out of Bed				
Getting Out of Chair				
Getting Out of Bath				
Walking				

Assess the level of help or assistance needed to perform more complicated skills.

Activity	No Help	Some Help	Much Help	Notes
Using the Telephone				
Shopping				
Transportation				
Money Management				
Laundry				
Light Cleaning				
Cooking				
Medication Management				



Pennsylvania Department of Aging | [Learn more at pa.gov/CareKit](http://pa.gov/CareKit) | 1

Care Needs Worksheet

PA CareKit



Assess the level of limitation or difficulty as the following activities affect your loved one's ability to function.

Activity	No Effect	Some Effect	Major Effect	Notes
Hearing				
Vision				
Orientation				
Thinking/Cognition				
Memory				
Decision-Making				
Grip/Dexterity				
Balance				
Strength				
Fatigue				
Bladder/Bowel Control				
Hypertension				
Breathing				
Diabetes				
Depression/Anxiety				
Arthritis/Osteo				
Cancer				
Physical Disability				
Other				

Assess which days of the week your loved one needs support with their care needs.

Day of the Week	Needs Support	AM	PM	Has Support	AM	PM	Notes
Monday							
Tuesday							
Wednesday							
Thursday							
Friday							
Saturday							
Sunday							

Source: www.claritylegalgroup.com

Paid for with Pennsylvania Taxpayer Dollars.



Pennsylvania Department of Aging | [Learn more at pa.gov/CareKit](http://pa.gov/CareKit) | 2

PA CareKit- Printable planning resources



PA Department of Aging <https://www.pa.gov/agencies/aging/pa-carekit/caregiving-resources/pa-carekit-printable-resources>



Jefferson Health | HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

Family Caregiver Alliance- Resources



TOP 17 RESOURCES FOR FAMILY CAREGIVERS

A list of caregiver favorites from Family Caregiver Alliance

Are you one of America's 48 million family caregivers? If so, you may have questions about care planning, your care recipient's health condition, daily care activities and more. Check out answers and guidance in these 17 resources* — some of our caregiver clients' favorite articles, fact sheets and videos.

DEMENTIA

- Caregiver's Guide to Understanding Dementia Behaviors [link](#)
- Dementia: Is This Dementia and What Does It Mean? [link](#)
- Ten Real-Life Strategies for Dementia Caregiving [link](#)

SELF-CARE

- Taking Care of You [link](#)
- Emotional Side of Caregiving [link](#)
- Caregiver Relaxation Exercises [link](#)

PLANNING FOR CARE

- Hiring In-Home Help [link](#)
- Caregiving at Home: A Guide to Community Resources [link](#)
- Residential Care Options: Housing Options [link](#)
- Hospital Discharge Planning [link](#)
- Pathways to Effective Communication for Healthcare Providers and Caregivers [link](#)
- Legal Planning for Incapacity [link](#)

DAILY CARE

- Incontinence Care [link](#)
- Caregiver College (video series) [link](#)
Covers the basics of everyday caregiving tasks related to personal care.
- Medication Management (video series) [link](#)
Gives guidance on all aspects of managing a care recipient's medications.
- Safe at Home (video series) [link](#)
Covers home safety matters when caring for those with dementia.
- Family Caregiving How-To (video series) [link](#)
Developed with Home Alone Alliance and AARP, this series covers specific medical/nursing tasks.

NEED MORE INFO?

- Search our extensive library of resources under [All Resources](#) on our website.
- Sign up for CareNav™, a free online dashboard (+ customized resources) for family caregivers.
- Need additional help? Contact us info@caregiver.org or 800.445.8106.

MULTIPLE LANGUAGES

- Many FCA resources, including some above, are available in Spanish, Vietnamese, Chinese, Tagalog, and/or Korean.

VISIT OUR WEBSITE, EMAIL, OR CALL TODAY.

www.caregiver.org | info@caregiver.org | 415.434.3388 | 800.445.8106

For more than 40 years, Family Caregiver Alliance has worked to improve the quality of life for family caregivers and their care

- Family Caregiver Alliance is national organization that has a variety of resources for both caree and caregiver

Family Caregivers Alliance <https://www.caregiver.org/resource/top-17-resources-for-family-caregivers/>



Caregiving specific resources

- Caregiver Action Network <https://www.caregiveraction.org/>
- Family Caregiver Alliance <https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/#tool-1>
- AARP Veteran and Military Families Caregivers Guide <https://www.aarp.org/content/dam/aarp/caregiving/pdf/aarp-veterans-caregiving-handbook.pdf>
- Pennsylvania Aging Care Kit- a tremendous resource with videos, interactive worksheets, Self care and caregiving resources.
 - <https://www.pa.gov/agencies/aging/pa-carekit>
- Pennsylvania Area Agencies on Aging <https://www.caregiver.org/connecting-caregivers/services-by-state/pennsylvania/>
- AARP resources for Caregivers <https://www.caregiver.org/resource/national-resources-for-family-caregivers/>
- Diverse Elders Coalition <https://diverseelders.org/>
- Meals on Wheels of America <https://www.mealsonwheelsamerica.org/find-meals-and-services/>
- Needy Meds <https://www.needymeds.org/>
- Well Spouse Association <https://wellspouse.org/>
- Roslyn Carter Institute for Caregivers <https://rosalynncarter.org/homepage-version-1-exygy/>



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



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

JeffersonHealth.org





This Photo by Unknown Author is licensed under [CC BY-SA-NC](#)



Jefferson Health

HOME OF SIDNEY KIMMEL MEDICAL COLLEGE

JeffersonHealth.org