

**Breakout session**

**LIVING BEYOND  
BREAST CANCER®**

# Caregiver care

What you need so you can give

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SIDNEY KIMMEL COMPREHENSIVE CANCER CENTER CONSORTIUM

# Caregiver Care: What You Need So You Can Give

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# What We Will Cover Today

- 1. Who is a Caregiver? — Definitions & Demographics
- 2. What Caregivers Do — Roles and Responsibilities
- 3. What Makes Cancer Caregiving Unique
- 4. The Physical, Emotional & Financial Toll
- 5. Risk Factors for Caregiver Burden
- 6. The Other Side: Post-Traumatic Growth
- 7. Managing Emotions & Relationships
- 8. Coping Strategies That Work
- 9. Evidence-Based Support & Interventions
- 10. Practical Tools & Resources

# Defining the Informal Caregiver

An informal caregiver provides unpaid care and support to someone with cancer. They may be:

- Spouse or partner
- Adult son or daughter
- Sibling
- Parent
- Close friend or neighbor

Caregiving involves significant time and energy — often for months or years — and is physically, emotionally, and financially demanding.

# The Scale of Cancer Caregiving in America

**53M+**

Adults providing  
unpaid care in the U.S.

**~45%**

Increase in caregivers  
since 2015

**35 hrs**

Average hours/week  
cancer caregiver works

**\$450B**

Annual estimated value  
of unpaid caregiving

By 2030, 20% of the U.S. population will be over 65, accounting for ~70% of cancer cases. Demand for caregivers will grow.

## Who Provides Care:

- Average caregiver age: 51 years
- Most caregivers are women (61%)
- Most are spouses or partners (66%)
- 36% rate their own health as fair to poor

# The Many Roles of a Cancer Caregiver

## Physical & Medical Tasks

- Bathing, dressing, meal preparation (ADLs)
- Making phone calls, housework, transportation (IADLs)
- Administering injections or tube feedings
- Wound and catheter care
- Monitoring treatment side effects
- Medication management

## Emotional & Logistical Tasks

- Emotional support and active listening
- Coordinating care across providers
- Managing finances and insurance
- Communicating with the medical team
- Advocacy with family and friends
- Research and decision support

**Caregivers are irreplaceable members of the healthcare team.**

# What Makes Cancer Caregiving Unique

- Cancer caregivers spend more hours per day than those caring for other chronic illnesses
- Care is highly skilled — hospital-level tasks are now done at home
- Rapid health changes are common and unpredictable
- Multi-modal therapies create varied side effects
- Fear of recurrence is ever-present
- Out-of-pocket expenses are significant
- Caregiving can be intense but episodic, creating difficult transitions

# The Physical, Emotional & Financial Toll

64%

Report high  
levels of stress

42-47%

Screen positive for  
anxiety or depression

>50%

Struggling  
financially

- Isolation and loneliness are significantly more common
- Sleep disturbances and fatigue are nearly universal
- Caregivers often neglect their own preventive health care
- Older caregivers face increased mortality risk
- Feeling you have no choice worsens mental and physical outcomes

# Who Is at Greatest Risk for High Caregiver Burden?

## Caregiver Factors

- Poor caregiver health status
- Being a spouse or partner of patient
- Being female
  
- Older age of patient (associated with greater fragility)
- Having fewer social supports
- Feeling one has 'no choice' in caregiving

## Patient Factors

- High patient symptom burden
- Patient requiring help with ADLs
- High chemotherapy toxicity risk (high CARG score)
  
- Caregiver's own high distress scores

*Note: Caregiver distress often exceeds patient distress scores.*

# The Full Spectrum of Caregiver Emotions

## **Sadness & Grief**

Loss of your loved one's health, loss of your prior life and routines

## **Fear & Anxiety**

About the future, recurrence, treatment decisions, and 'what comes next'

## **Anger**

At the disease, at family members, at yourself, at the unfairness of it all

## **Loneliness**

Feeling unseen, unsupported, or unable to share your full burden

## **Guilt**

Feeling you aren't doing enough, or being healthy while they are not

## **Love & Devotion**

A profound commitment that drives you forward even in difficult moments

# Cancer and the Family Unit

- Cancer affects every family member differently and at different speeds
- Family members may not reach the same emotional stage together — that is normal
- Existing family conflicts rarely resolve on their own during illness
- Caregivers may feel caught between the patient, family, and medical team
- Children in the household also experience stress and may need separate support

# Post-Traumatic Growth: Finding Meaning Amid Difficulty

Post-traumatic growth (PTG) refers to positive changes that emerge from struggling with highly challenging circumstances. Many caregivers experience genuine transformation.

## Six Domains of Caregiver Post-Traumatic Growth:

1 Closer, more authentic relationships

2 Greater appreciation for life

3 Clarification of personal priorities

4 Increased empathy for others

5 Strengthened faith or spirituality

6 Improved health habits and self-awareness

*Higher PTG is associated with lower burden and reduced depression.*

# Managing Emotions: What the Evidence Tells Us

*Studies show caregivers who have balanced, proportional emotional responses fare better than those pressured to stay constantly optimistic.*

- You cannot control emotions — but you can control how you respond to them
- Feelings can be experienced without acting on them
- Suppressed emotions tend to resurface in harder-to-address forms
- Talking about distress often relieves it — listeners don't need answers
  
- Talking about fears does not worsen them — it defuses their power

# Staying Connected: Communication & Intimacy

## Communication

- Make time to talk about coping — not just medical updates
- Focus some conversations on topics other than cancer
- Identify shared stressors and problem-solve together
- Maintain normalcy and routine in your relationship
  
- Seek couples counseling or therapy if communication breaks down

## Sexuality & Intimacy

- Cancer treatment commonly affects intimacy through fatigue, pain, and body image changes
- Open communication about physical and emotional intimacy is essential
- Go slowly — there is no timeline for reestablishing physical closeness

# Warning Signs: When Caregiving Becomes a Crisis

Seek professional support if you experience any of the following:

## **Extreme, unrelenting fatigue**

not relieved by rest

## **Persistent sadness or emptiness**

feeling hopeless about the future

## **Persistent insomnia**

difficulty falling or staying asleep for weeks

## **Severe anxiety or panic attacks**

that interfere with daily functioning

## **Social withdrawal**

isolating yourself from friends and family

## **Loss of interest**

in activities previously enjoyed

## **Significant appetite change**

or unintentional weight loss/gain

## **Thoughts of harming yourself**

— if this occurs, seek help immediately

# Caring for Yourself Is Not Selfish – It Is Necessary

Research consistently shows that caregiver self-care improves not only the caregiver's health, but also the quality of care they provide to their loved one.

## Stay Active

Light exercise reduces fatigue and improves mood

## Prioritize Rest

Sleep deprivation magnifies all other stressors

## Stay Connected

Maintain contact with people outside caregiving

## Delegate Tasks

Assign specific tasks to others

## Mind-Body Practices

Mindfulness and relaxation techniques reduce distress

## Attend Your Own Appointments

Do not neglect your own health screenings

# Proven Coping Strategies for Cancer Caregivers

- Pace yourself — shift focus from worry to manageable tasks
- Set short-term goals for certainty when the future feels uncertain
- Compartmentalize — engage in non-cancer activities and relationships
  
- Be actively involved with the medical team — collaboration reduces distress
- Choose your support network carefully — avoid those who add distress
  
- Recall what helped with past stressors and apply it now

# The Caregiver Bill of Rights

*You have the right . . .*

- To take care of yourself — this gives you the capacity to care for others
  - To seek help from others, even if your loved one objects
  - To maintain your own life and identity outside the caregiving role
  - To feel and express difficult emotions — they are all valid
  - To take pride in what you are doing and recognize the courage it takes
- 
- To expect that healthcare systems support caregivers, not just patients

— Adapted from Jo Horne, *Caregiving: Helping an Aging Loved One*

# How to Ask for Help (And Let Others Give It)

- Give people specific tasks — vague offers rarely lead to help
- Create a system for updates: group text, CaringBridge, or phone tree
  
- Accept practical help: cooking, errands, transportation, childcare
- Divide caregiving tasks among family — no one should bear it alone
- Ask about home health aides, respite care, and community programs

# Key Transition Points: When Caregivers Need Extra Support

Each of the following transitions is associated with heightened caregiver distress and should prompt re-evaluation of support needs:

- Initial diagnosis and genetic testing
- Cancer recurrence
- Starting or stopping treatment
- Changes in treatment plan (especially to palliative intent)
- Hospitalizations and procedures
- Discharge from hospital to home with new care responsibilities
- Abnormal scan results or surveillance appointments
- Transition to hospice and end-of-life care

# Trusted Resources for Cancer Caregivers

## National Alliance for Caregiving

[caregiving.org](https://caregiving.org)

Research, advocacy, and support resources for all family caregivers

## Family Caregiver Alliance

[caregiver.org](https://caregiver.org)

Fact sheets, online education, and state-by-state service navigator

## Cancer Support Community

[cancersupportcommunity.org](https://cancersupportcommunity.org)

Free support groups, education, and the Cancer Support Source distress screening tool

## CancerCare

[cancercares.org](https://cancercares.org)

Free counseling, support groups, and financial assistance for patients and caregivers

## AARP Caregiving Hub

[aarp.org/caregiving](https://aarp.org/caregiving)

Practical tools including the Caregiving Resource Center and local support finder

## National Cancer Institute

[cancer.gov](https://cancer.gov)

Evidence-based information on cancer treatments, clinical trials, and caregiver guidance

## NAMI (National Alliance on Mental Illness)

[nami.org](https://nami.org)

Mental health support, helpline, and resources for caregivers experiencing depression or anxiety

## Area Agencies on Aging

[eldercare.acl.gov](https://eldercare.acl.gov)

Connect to local services: meals, transportation, respite care, and more

Living Beyond Breast Cancer | [lbbc.org](https://lbbc.org) | Education, support, and community for people affected by breast cancer

# Key Takeaways

1

## **You Are Not Alone:**

Millions of people are walking this path. Your feelings and struggles are normal and recognized.

2

## **Self-Care Is Care:**

Looking after your own health, emotions, and relationships is not indulgent — it makes you a better caregiver.

3

## **Burden Is Real and Measurable:**

Caregiver distress can be screened, identified, and treated. Ask your care team for support.

4

## **Evidence-Based Help Exists:**

Counseling, skills training, and structured interventions have demonstrated benefit for caregivers.

5

## **Growth Is Possible:**

Many caregivers discover new meaning, deeper relationships, and personal strength through this experience.

*"Caring for the caregiver is not separate from cancer care — it is cancer care."*

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