



Managing the Challenges of Caregiving after Transplant

Celebrating a Second Chance at Life
Survivorship Symposium

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Sarah Cannon Cancer Institute at
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“There are four kinds of people:
those who will become caregivers,
those who are caregivers,
those who were caregivers,
and those who will need caregiving themselves.”

-Former First Lady Rosalyn Carter

Objectives

- Provide overview of caregiving for the BMT recipient
- Discuss caregiver distress and burnout
- Identify self-care strategies and ways to create healthy boundaries
- Share resources for more information & support

CarePARTNERing

- Words matter
- One-way vs. two-way
- Mutual cooperation and joint responsibilities
- Common goals



A Caregiver Defined

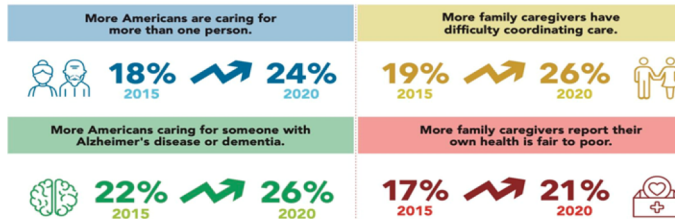
- A person who gives care to people who need help taking care of themselves.
- Caregivers are an extension of the cancer workforce.
- “Sandwich Generation”

CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

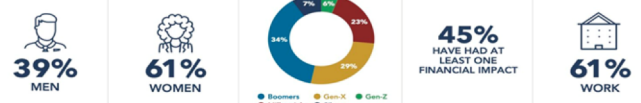


NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**



23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today's family caregivers?



AARP and National Alliance for Caregiving, 2021.

Caregiving for the Stem Cell Transplant Recipient

- Environment
- Physical Care
- Tracking
- Transportation
- Emotional Support
- Advocacy



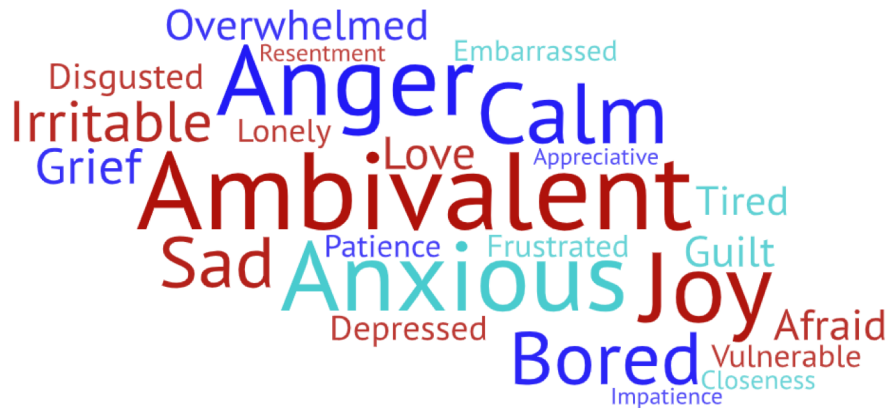
The Weight of Caregiving

Caregiving can have an affect on mental, emotional, and physical well-being.

- Caregivers have elevated risks for depression, anxiety, stress, and insomnia
- Caregivers often don't have time to process and deal with their own feelings and concerns due to the intense focus on the patient
- Caregivers often put themselves last and neglect self-care

As a result, "burn out" is common among caregivers

Common Emotions



Distress & Caregiving

Emotional:

- **Anxiety** → worry, fear, feeling overwhelmed, nervousness
- **Depression** → sadness, guilt, lack of interest, grief, crying
- **Anger** → irritability, yelling, being critical

Physical: poor sleep, headaches, muscle tension/soreness

Social: less contact with friends/family, fewer activities

Caregiver Burnout

- A state of physical and emotional exhaustion
- Can occur when caregivers do not receive the help/support they need and/or try to do more than able to on all levels
- Caused by demands on body, mind and emotions that allow one to neglect themselves due to focusing only on their loved one.



Signs of Burnout

Physical

Behavioral

Emotional

Cognitive

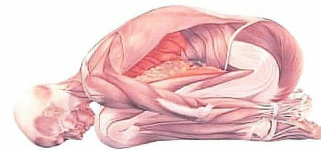


Preventing Burnout

- Build a team
- Self-care
- Seek counseling or peer support
- Self-compassion
- Communicate effectively
- Set healthy boundaries

DID YOU KNOW?

Doing this pose for 5 minutes a day...



It's super calming for the mind, It's great for your digestion, It elongates the lower back, It opens up the hips.

Building a Support Team

- Plan respite
- Process feelings/events
- Get organized and delegate
 - LotsaHelpingHands.com
 - MyLifeLine.org
 - CaringBridge.org



Lotsa Helping Hands
CREATE COMMUNITY



CARING
BRIDGE



CANCER SUPPORT
COMMUNITY
MYLIFELINE.ORG

Practicing Self-Care



Practicing Self-Care

- A prevalent topic, especially in relation to caregiver burnout
- Barriers
- Most understand importance, but struggle to find the time, energy, or opportunity to reconnect with enjoyment or relaxation
- Accept feelings, even when negative



Relax and Recharge

- Engage in activities for YOU
- Be physically active
- Read, journal, watch an uplifting series or movie
- Pay attention to nutrition
- Get creative
- Consider yoga or meditation
- Track your sleep



Counseling & Peer Support

- Local Oncology Social Worker or Psychologist
- Spiritual/Religious counselor
- BMT InfoNet:
 - Mental Health Provider Directory
 - Caring Connections Program
- Cancer Hope Network
- The LLS Community
- CancerCare
- Be the Match
 - Peer Connect
 - Patient Support Center



“Self-Compassion”

- What is self-compassion?
 - Self-kindness vs. Self-judgement
 - Common humanity vs. Isolation
 - Mindfulness vs. Over-identification
- What it isn't
 - It is not self-pity
 - It is not self-indulgence
 - It is not self-esteem
- Tips for Practice

“With self-compassion, we give ourselves the same kindness and care we'd give to a good friend.”

Self-compassion, Kristen Neff, self-compassion.org 2021

Communication Tips

- Self Awareness
- Mindfulness of Other
- Groundedness
- Non-anxious Presence
- Curiosity
- Compassion
- Response Flexibility

Naming

Understanding

Respecting

Supporting

Exploring

Back & Arnold, 2014; Krimshtein et al., 2011
Anderson et al., 2016

Boundary Setting

Set Realistic
Goals

Reach Out For
Help

Process Feelings

Engage Loved One in Decision
Making

Keep Written
Calendar/Schedule

Evaluate Tasks and Only Complete Ones That Your Loved One is
Not Able to Complete

Caregiving Bill of Rights

I have the right :

- To take care of myself
- To seek help from others
- To maintain facets of my own life that do not include the person I care for
- To get angry or depressed

Caregiving Bill of Rights

- To reject any attempt to manipulate me
 - To receive consideration, affection, forgiveness and acceptance
- To take pride in what I am accomplishing
- To protect my individuality and my right to make a life for myself

— Jo Horne, author of *Caregiving: Helping an Aging Loved One*

Ending the Caregiving Role

- Support during Survivorship
- Create New Goals for YOU
- Meaning Making - process of gaining understanding of life events, relationships and yourself
- Giving Back



Resources – Websites

Cancer Specific

- The Leukemia and Lymphoma Society – lls.org/support-resources/caregiver-support
- International Myeloma Foundation – myeloma.org/resources-support/caregiver-resources
- Lymphoma Support Network – lymphoma.org/resources/supportservices/lsn

Stem Cell Transplant Specific

- BMT InfoNet – bmtinfonet.org/caregivers
- Be the Match – bethematch.org/caregiver
- National Bone Marrow Transplant Link – nbmtlink.org

Caregiving Specific

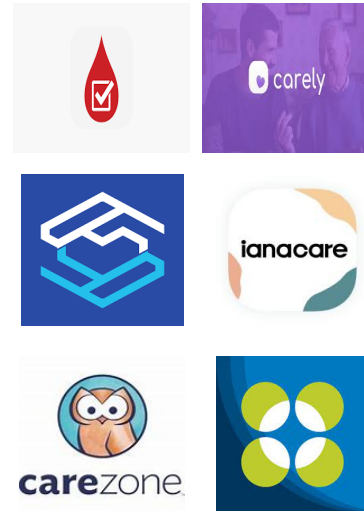
- Family Caregiving Alliance – caregiver.org
- Caregiver Action Network – caregiveraction.org

Resources – Websites

- Eldercare Locator (for your local Area Agency on Aging) – eldercare.acl.gov/Public/Index.aspx
- Caring Bridge – caringbridge.org
- Lotsa Helping Hands – lotsahelpinghands.com
- Caring – caring.com
- CaringInfo – National Hospice and Palliative Care Organization Program - caringinfo.org
- Share the Care – sharethecare.org

Resources – Apps

- LLS Health Manager App
- Carely – Family Caring App
- CareZone
- Ianacare – Caregiving Support
- Caring Village
- Medisafe – Medication Reminders
- My Be the Match – Post-Transplant Tracking



Resources – Books

- *The Sudden Caregiver: A Roadmap for Resilient Caregiving* – Karen Warner Schueler
- *Passages in Caregiving: Turning Chaos into Confidence* – Gail Sheehy
- *The Caregivers Toolbox* – Carolyn Hartley and Peter Wong
- *The Caregivers Guidebook: Your Resource for Successfully Navigating Life as a Caregiver* – Barbara Stewart
- *Self-Compassion: The Proven Power of Being Kind to Yourself* – Dr. Kristen Neff
- *Caregiver's Guide for Bone Marrow/Stem Cell Transplant*
nbmlink.org/product/caregivers-guide-for-bone-marrowstem-cell-transplant

Resources – Podcasts & Video Series

Podcasts

- “Caregiving Secrets” – *Apple podcast series*
- “How We Got Here” – *caregiving.com*
- “Marrow Masters” - *nbmtLINK*
- “Bloodline” - *Leukemia and Lymphoma Society*

Video Series

- American Cancer Society - [cancer.org/treatment/caregivers/caregiver-support-videos.html](https://www.cancer.org/treatment/caregivers/caregiver-support-videos.html)
- Family Caregiver Alliance - [caregiver.org/resource/caregiver-college-video-series](https://www.caregiver.org/resource/caregiver-college-video-series)

References

- Cleveland Clinic. 2020. Caregiver Burnout. Retrieved from <https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout>.
- Family Caregiver Alliance, Donna Schempp, LCSW. 2014. Emotional Side of Caregiving. Retrieved from <https://www.caregiver.org/resource/emotional-side-caregiving/>.
- National Alliance for Caregiving. 2021. Caregiving in the United States; 2020 report. Retrieved from <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>
- National Cancer Institute. 2021. Informal Caregivers in Cancer. Retrieved from <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq>.
- Northouse, L., et al. 2012. The Impact of Caregiving on the Psychosocial Well-Being of Family Caregivers and Cancer Patients. *Seminars in Oncology Nursing*, 28 (4).



Questions?



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Let Us Know How BMT InfoNet Can Help YOU!



Visit our website: bmtinfonet.org

Email us: help@bmtinfonet.org

Give us call: 888-597-7674

We're here to help every step of the way!