Managing the Challenges of Caregiving after Transplant

Celebrating a Second Chance at Life Survivorship Symposium

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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 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

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

Building a Support Team

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

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“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.”

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 – llsls.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* nbmtlink.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
• Family Caregiver Alliance - caregiver.org/resource/caregiver-college-video-series

References

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!