Giving Care to the Caregiver

November 1, 2021

10:00 AM PT, 11:00 AM MT, 12:00 PM CT, 1:00 PM ET
Housekeeping Notes

- The audience is muted
- Please direct your questions to CLL Society staff and speakers using the Q&A function (located at the bottom of your screen) at any time throughout the presentation
- Questions can only be seen by staff and speakers. We will do our best to answer as many questions as possible
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Speakers

Welcome & Moderator: Patricia Koffman
Co-Founder and Communications Director
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Introduction & Moderator: Brian Koffman, MDCM (retired), MS Ed
Executive Vice President and Chief Medical Officer
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Speaker: Allison J. Applebaum, PhD
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Disclosures

• Blue Note Therapeutics, Inc.
Overview of Talk

• Who are caregivers and why do they deserve our attention?

• What are the challenges faced by caregivers?

• Strategies to ensure caregiver wellbeing.

• The benefits of caregiving.
Former First Lady, Rosalynn Carter:

“There are only four kinds of people in the world: …those who have been caregivers, …those who are currently caregivers, …those who will be caregivers, …and those who will need caregivers.”
Who are Caregivers?

- Formal caregivers
- Informal caregivers

World Health Organization (WHO) estimates that ~8% of the global population is dependent on others for care:

- 1/3 US households in 2019 had a caregiver; ~2/3 during COVID-19 pandemic
- 53 million Americans, ~6 million of whom provide care to patients with cancer
- Caregivers are predominantly female and providing care to a parent, and over 1/3 provide care to two or more people
What Do the 53 Million U.S. Caregivers Do?

• Assist with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)

• Emotional support

• Nursing support
  • 72% of cancer caregivers and 56% of non-cancer caregivers perform medical/nursing tasks

• On average, caregivers provide care for 8.3 hours/day for 13.7 months; 22% provide care for 41+ hours/week

• Annual economic value of caregiving in the U.S. was recently estimated at $375 billion

• Caregivers are critical to our healthcare system
Caregiver Burden

• Multi-dimensional
  • Psychological
    • Anxiety
    • Depression
• Physical/Medical (19% report health is fair/poor)
  • Cardiovascular disease
  • Poor immune functioning
  • Fatigue/sleep difficulties
  • Higher rates of mortality
• Financial
• Temporal
• Existential
Distress Across the Cancer Caregiving Trajectory

- Diagnosis
- Treatment
- Survivorship
- Recurrence
- Disease Progression
- Hospice
- Bereavement
Worry among Caregivers

• Chronic worry and rumination commonly experienced by caregivers

• Among 398 caregivers seen in the Caregivers Clinic
  • 86 received initial diagnosis of Generalized Anxiety Disorder
  • 182 received initial diagnosis of adjustment disorder with anxious mood
“My boss is going to fire me if I miss work again because of another family emergency…”

“He seems more out of breath, the cancer must be spreading…”

“How am I going to raise my son as a single mother?”

“The look on the doctor’s face meant…”
Core Conflicts among Caregivers

Self-care
Sadness, anticipatory bereavement
Distancing

Care for the Other
Hope for the future
Growing attachment to the patient
Q39. Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don’t know/refused responses are not shown; results may not add to 100 percent.
Self-Care
What is Self-Care?

- Self-care is about being deliberate in taking time for yourself for the betterment of your mind, body and soul.

- Self-care is NOT about being selfish. It is about replenishing and refreshing your spirit in different ways.
When is Self-Care Needed?

• ALWAYS

• When burden is high:
  • No longer able to carry out responsibilities
  • Increased anger
  • More frequent medical problems
  • Poor health-related behaviors
  • Presence of thoughts that life is no longer worth living
Self-Care Tips

• Schedule self-care as you would a medical appointment or work meeting
• Integrate one self-care activity into every day, more on stressful days
• Take an honest look at your current coping strategies
• Think SMALL
• Make sure self-care activities are in line with good sleep hygiene
(Eventually) Experiencing Immediate Well-Being

• Meditation

• Autogenic relaxation/progressive muscle relaxation

• Diaphragmatic breathing
How to Get Help

• Activate support networks
  • Challenge yourself to ask for help
  • Support may come from unlikely sources

• Recognize what is meant by self-care
  • Guilt is a red flag
  • Self-care includes expressing emotions

• Ask the medical team to connect you with professional support
The Benefits of Being a Caregiver
Challenges Faced by Caregivers

- Anxiety: 42%
- Depression: 40%
- Identity: 38%
- Guilt: 35%
- Relationships: 25%
- Self-care: 24%
- Finances: 24%
- Medical Problems: 18%
Providing Care to a Loved One with Cancer

- 68% makes me feel good that I am helping
- 68% has helped me to learn new things about myself
- 68% has made me a stronger and better person
- 64% helps me understand the importance of love
- 42% gives my life a purpose/sense of meaning
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Thank You!
Audience Questions & Answers
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Thank You for Attending!

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Join us on December 2nd for a COVID-19 Webinar focused on Monoclonal Antibodies.

If you’re question was not answered, please feel free to email asktheexpert@cllsociety.org.

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