

CLL SOCIETY

Smart Patients Get Smart Care™

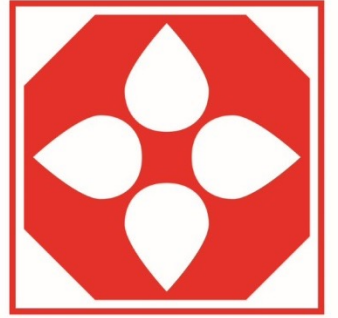
Giving Care to the Caregiver

November 1, 2021

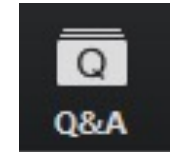
10:00 AM PT, 11:00 AM
MT, 12:00 PM CT, 1:00
PM ET

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
- Please complete the short survey emailed after the event. Your response will help CLL Society plan future events
- The virtual event is being recorded and will be available on our website
- Closed captions are available. If you want to turn them on or off, go to Live Transcript and Show Subtitle or Hide Subtitle



CLL SOCIETY

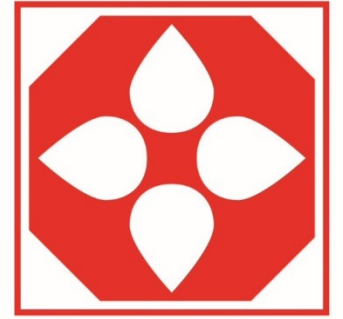


Show Subtitle
View Full Transcript
Subtitle Settings...



Live Transcript

This program was made
possible by grant support
from



CLL SOCIETY



Speakers



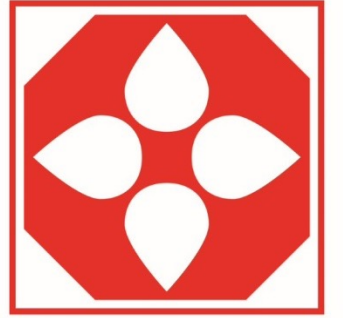
Welcome & Moderator: Patricia Koffman
Co-Founder and Communications Director
CLL Society



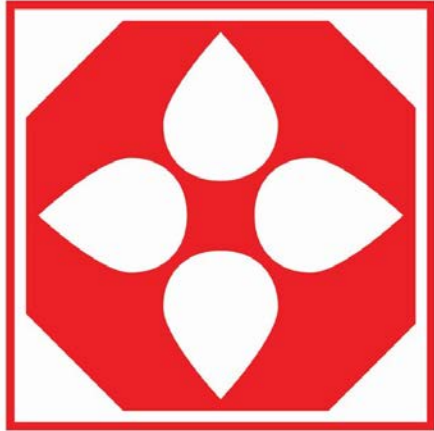
Introduction & Moderator: Brian Koffman, MDCM
(retired), MS Ed
Executive Vice President and Chief Medical Officer
CLL Society



Speaker: Allison J. Applebaum, PhD
Associate Attending Psychologist
Memorial Sloan Kettering Cancer Center



CLL SOCIETY



CLL SOCIETY

Smart Patients Get Smart Care™

Giving Care to the Caregiver

Allison J. Applebaum, Ph.D.
Associate Attending Psychologist
Director, Caregivers Clinic
Memorial Sloan Kettering Cancer Center

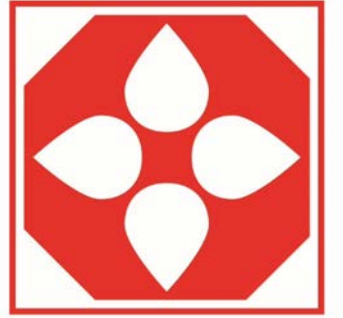
November 1, 2021



Memorial Sloan Kettering
Cancer Center

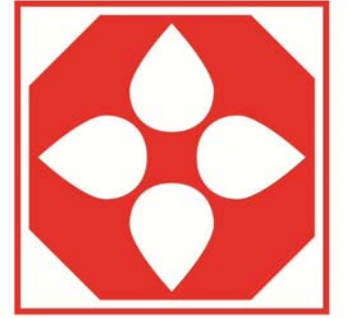
Disclosures

- Blue Note Therapeutics, Inc.



CLL SOCIETY

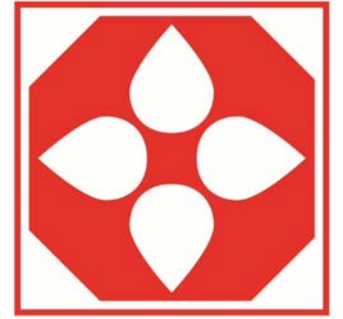
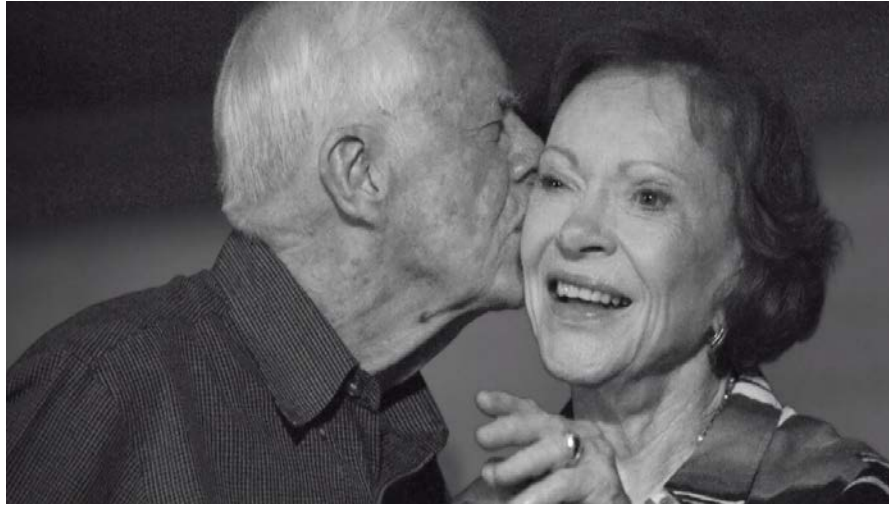
Overview of Talk



CLL SOCIETY

- 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:



CLL SOCIETY

*“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.”*

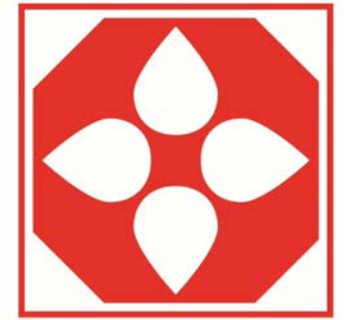
For Some Caregivers, Trauma Lingers

How Getting High Made Me a Better Caregiver

By Tom Huth

April 16, 2016

75, Taking Care of Mom, 'We Did Not Think She Would Live This Long'



CLL SOCIETY

Caregiving Is Hard Enough. Isolation Can Make It Unbearable.

Caregiver, Plus M.D. or R.N.

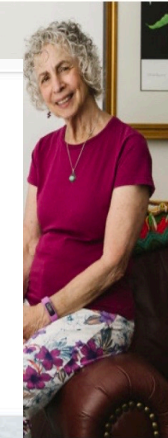


Caregivers Sometimes Must Sacrifice Their Careers



June 15, 2017

Will Suffer Medicaid Cuts



el, 99, and her
York Times



Training Needed Care Is Lacking

Marcy Sherman-Lewis, 99, and her husband, David Rinehart, 93, both of whom have Alzheimer's disease.

By Paula Span



Joyce Hesselberth

By Paula Span

Dec. 4, 2015

Her supervisors empathized. They knew why Marcy Sherman-Lewis, a customer service agent, was missing workdays:

apartment in
mother, Ivana,
mia. Jeenah

Gina Rinehart, 103, and her husband, David Rinehart, 93, both of whom have Alzheimer's disease.

By Paula Span

March 10, 2017

By Judith Graham

"H" from Chicago, I heard you when you

means providing
ork Times

case: "family

help to a
bor, assisting
ag, cooking,
Makela for The

THE TI
When Me
Lea Squ

Nicholas
challenge
learned i
stress. F

By Cath

Oct. 4, 2012

July 28, 2

"This k

herself. "It's nowhere near

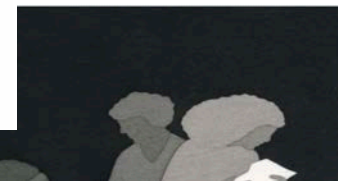
Antonio Fuentes, 28, a Medicaid managed care patient who has cerebral palsy and cannot speak, requires a home attendant. Reynaldo Leal for The Texas Tribune

By Becca Aaronson

The abrupt exodus of thousands of South Texas Medicaid patients from one

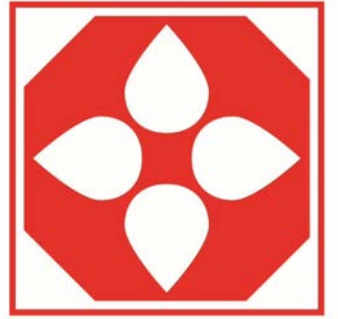
"Ladysitting: My Year With Nana

choice but to
lives around a loved



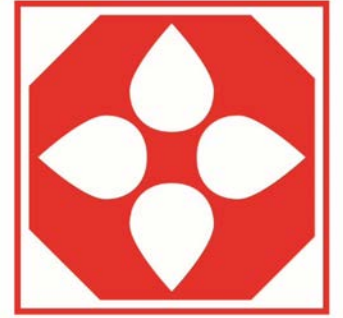
Who are Caregivers?

- 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



CLL SOCIETY

What Do the 53 Million U.S. Caregivers Do?

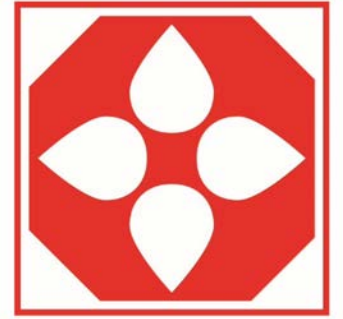


CLL SOCIETY

- 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*

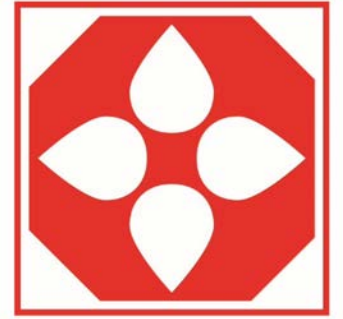
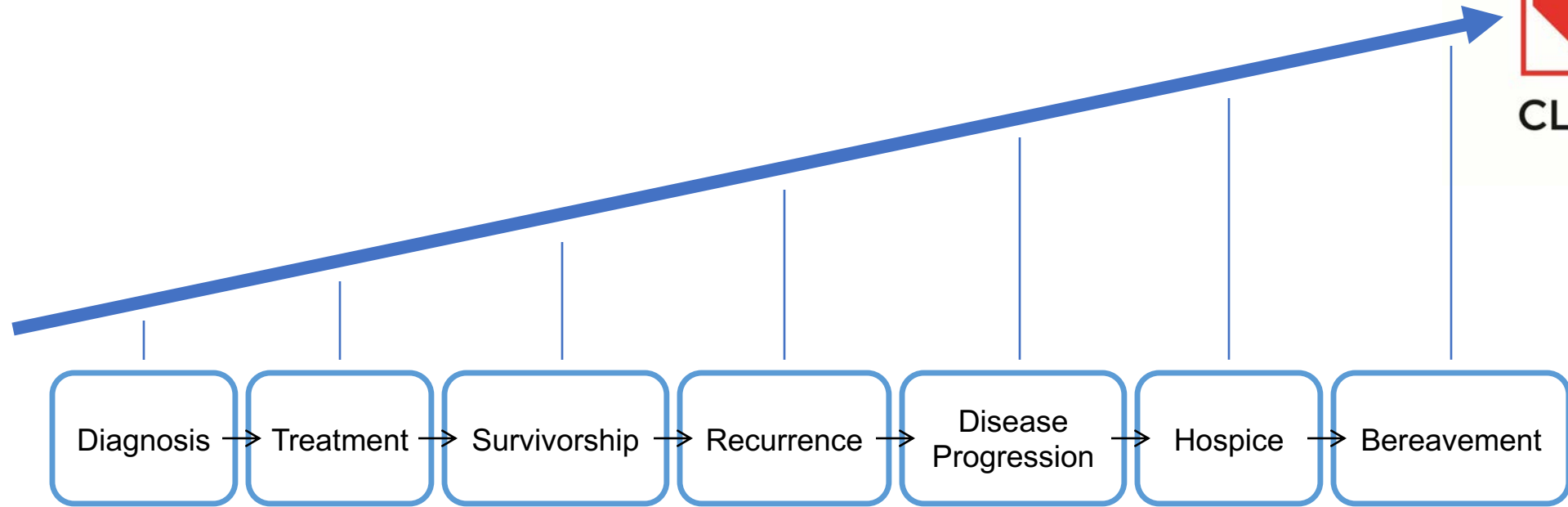
Caregiver Burden

- 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



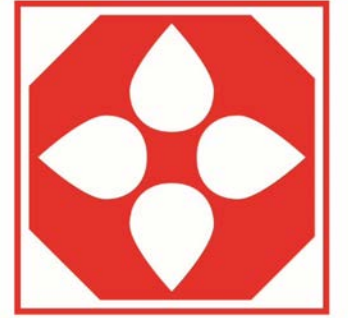
CLL SOCIETY

Distress Across the Cancer Caregiving Trajectory



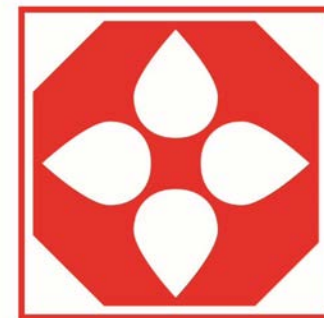
CLL SOCIETY

Worry among Caregivers



CLL SOCIETY

- 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



CLL SOCIETY

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

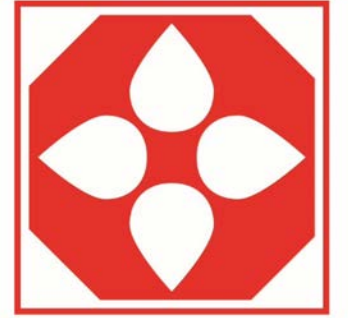
“He seems more out of breath, the cancer must be spreading...”

“The look on the doctor’s face meant...”

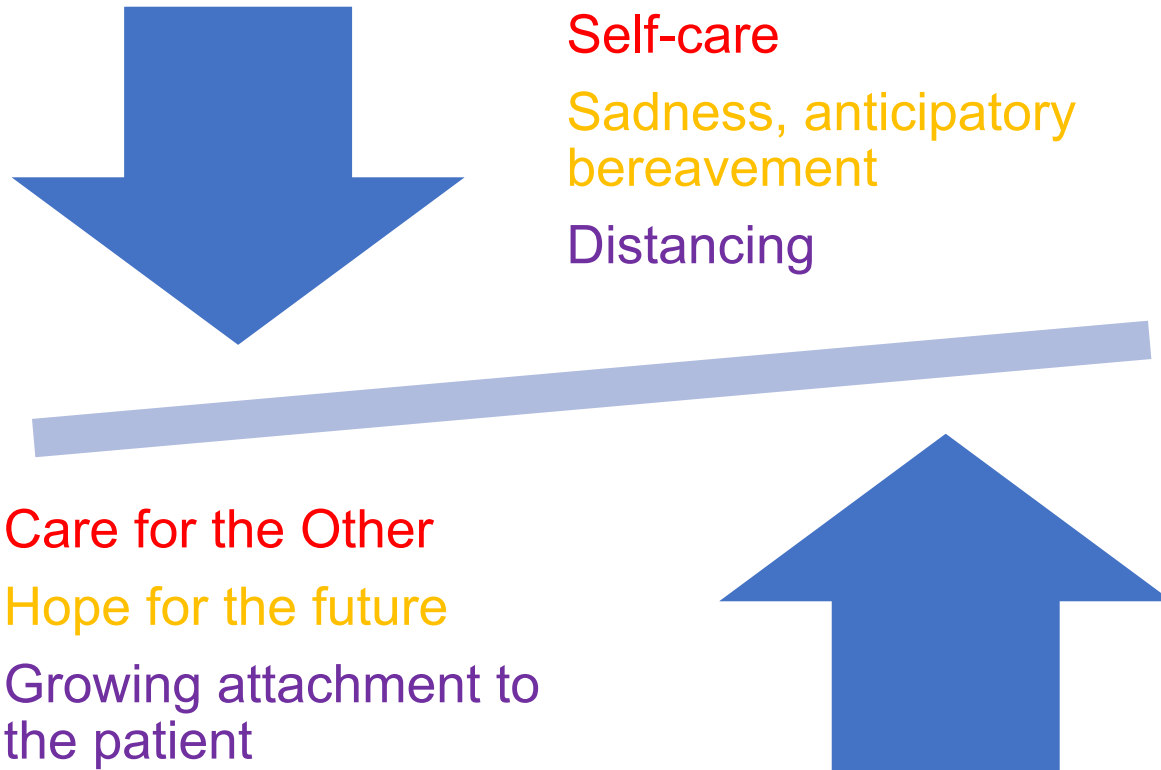
“My boss is going to fire me if I miss work again because of another family emergency...”



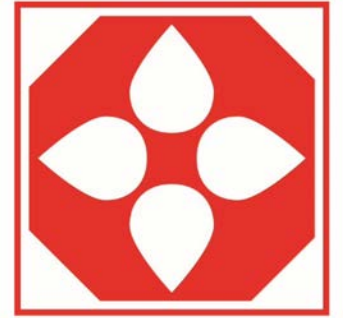
Core Conflicts among Caregivers



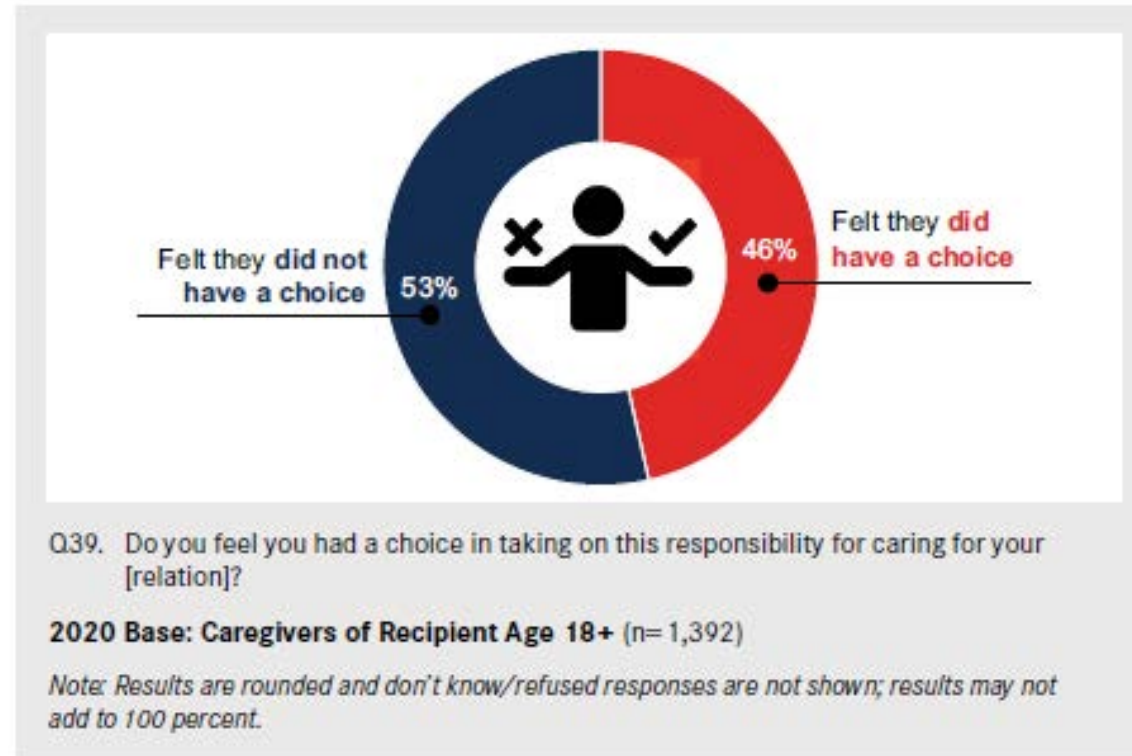
CLL SOCIETY

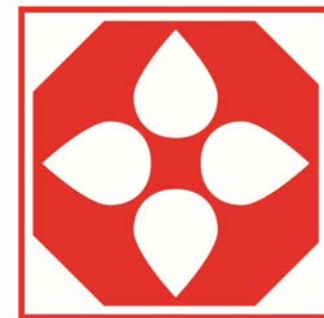


National Alliance for Caregiving/AARP, 2021



CLL SOCIETY

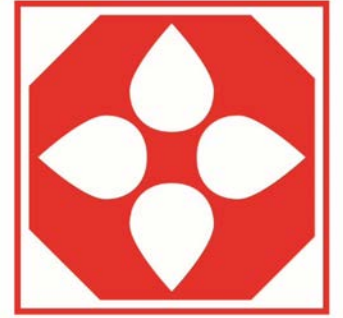




CLL SOCIETY

Self-Care

What is Self-Care?

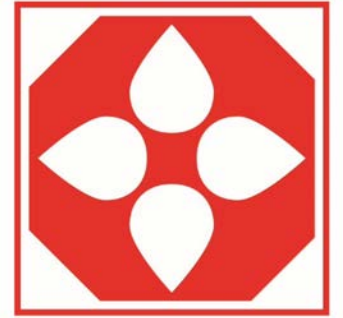


CLL SOCIETY

- 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.

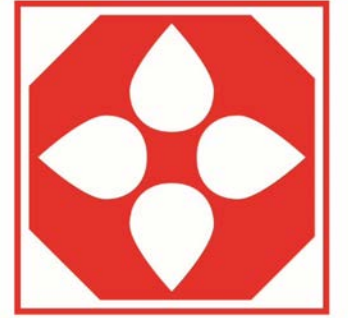
When is Self-Care Needed?

- 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



CLL SOCIETY

Self-Care Tips

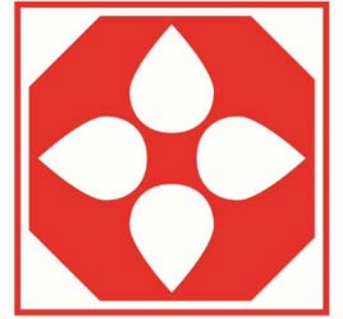


CLL SOCIETY

- 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

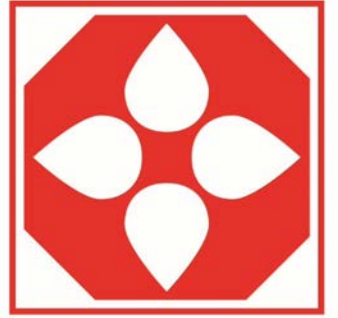
- Meditation
- Autogenic relaxation/progressive muscle relaxation
- Diaphragmatic breathing



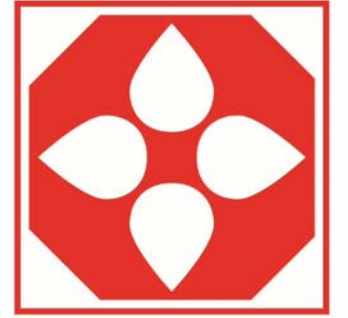
CLL SOCIETY

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

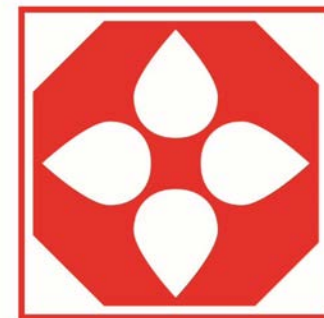


CLL SOCIETY



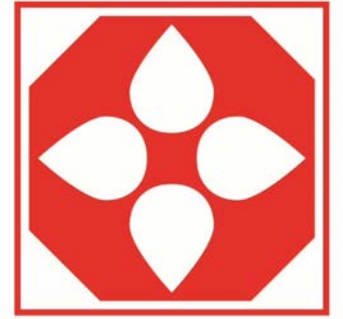
CLL SOCIETY

The Benefits of Being a Caregiver

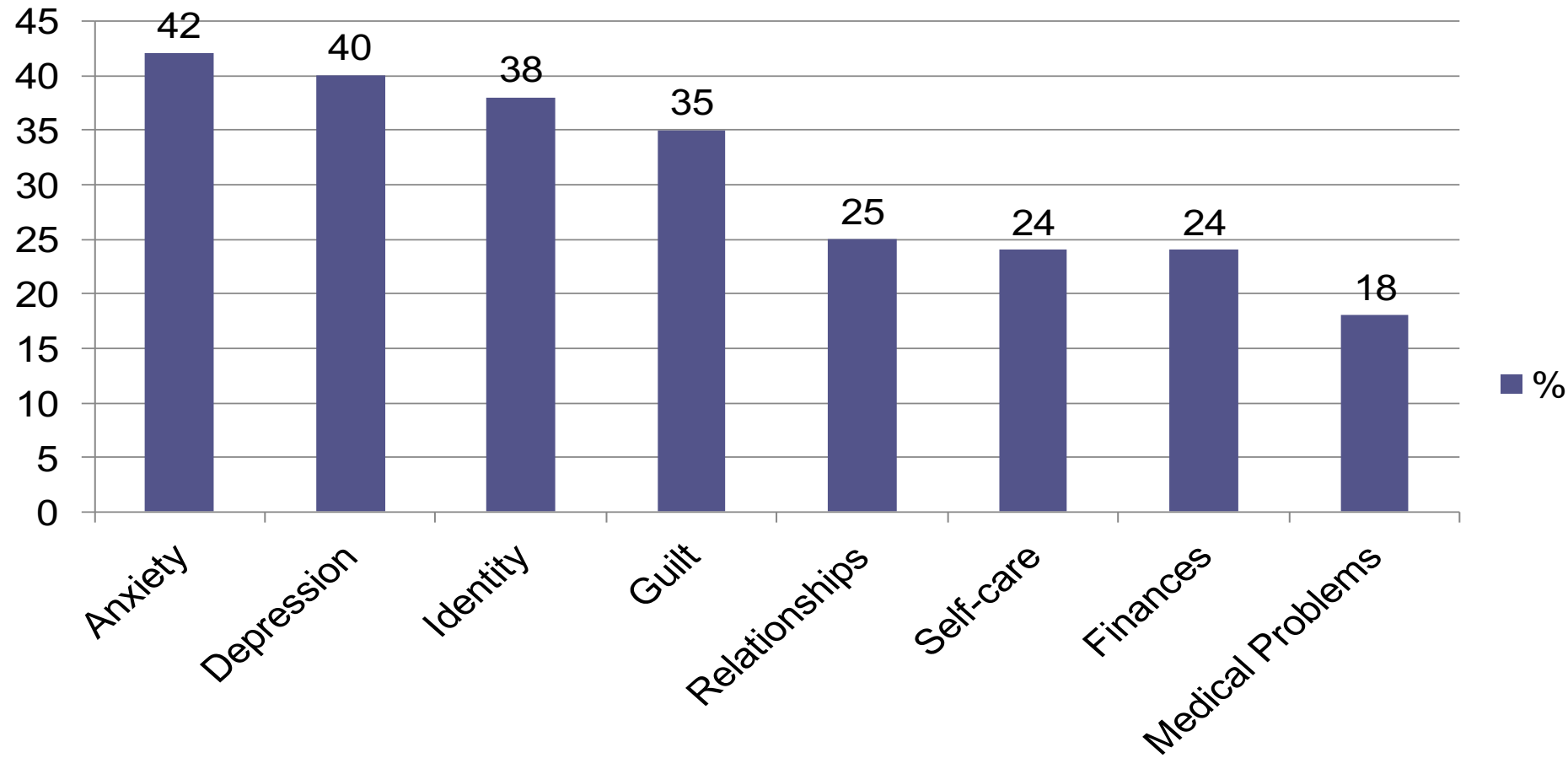


CLL SOCIETY

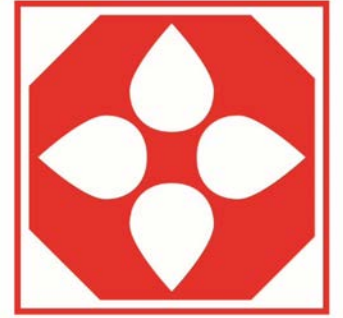
Challenges Faced by Caregivers



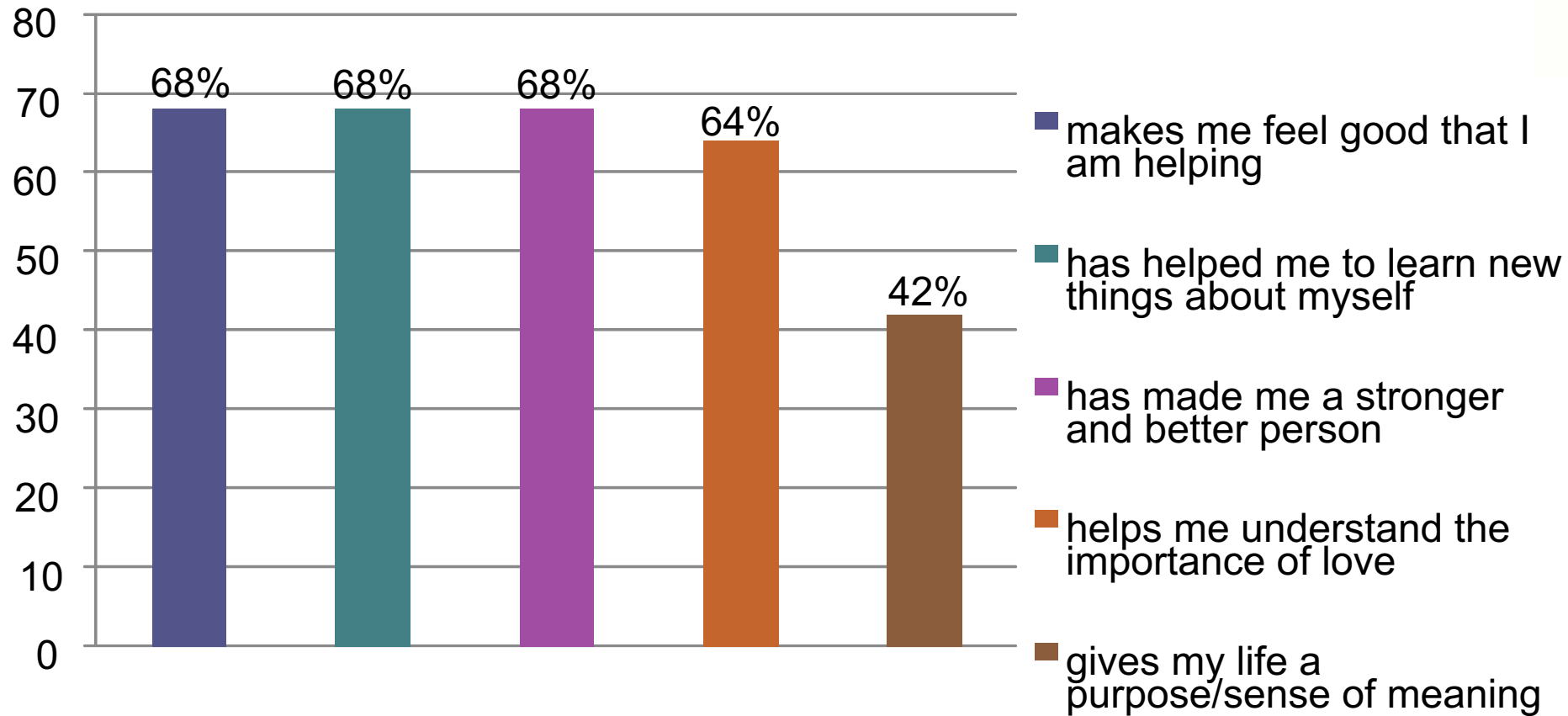
CLL SOCIETY



Providing Care to a Loved One with Cancer



CLL SOCIETY

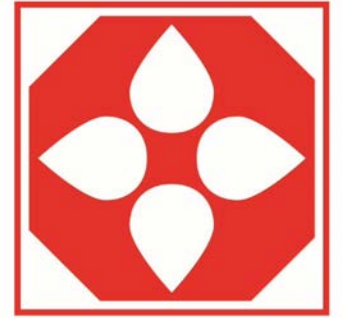


Acknowledgements

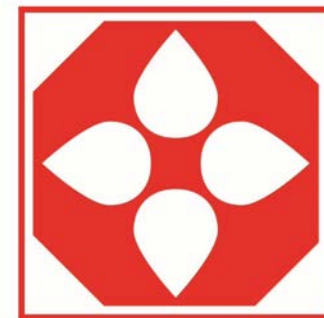
William Breitbart, M.D.
Wendy Lichtenthal, Ph.D.
Hayley Pessin, Ph.D.
Eli Diamond, MD.
Kelly Shaffer, Ph.D.
Noshin Haque, B.A.
Amanda Watsula, M.S.
Laura Polacek, M.A.
Kailey Roberts, Ph.D.
Aliza Panjwani, Ph.D.

Ruth McCorkle, PhD, RN, FAAN
Carol Farran, DNSc, RN, FAAN
Katherine Sharpe, MTS
Rachel Cannady, BS
Kara Buda, B.A.
Susan Holland, MPH
Leah Walsh, M.S.
Zeba Ahmed, M.A.
Douglas Mennin, Ph.D.
Michael Hoyt, Ph.D.

Dr. Applebaum's research is supported by the National Cancer Institute grants 1R01CA244185-01A1 and 1R01CA244172-01, American Cancer Society Grants PEP-21-041-01-PCSM and PEP 17-192-01-PCSM, the T.J. Martell Foundation, the Zickler Family Foundation, and the van Ameringen Foundation.

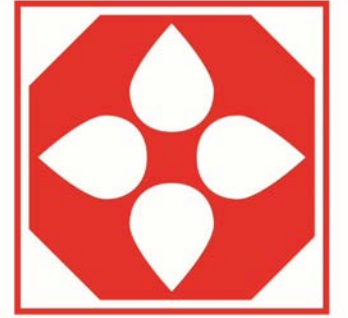


CLL SOCIETY



CLL SOCIETY

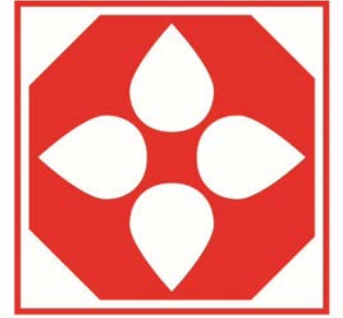
Thank You!



CLL SOCIETY

Audience Questions & Answers

This program was made
possible by grant support
from

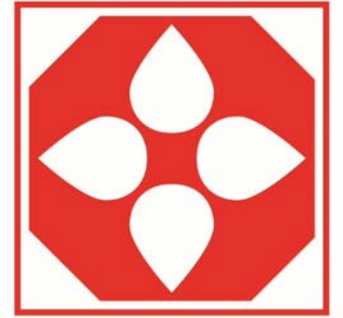


CLL SOCIETY



Thank You for Attending!

Please take a moment to complete our **post-event survey**, your feedback is important to us



CLL SOCIETY

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

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

CLL Society is invested in your long life. Please invest in
the long life of the CLL Society by supporting our work

cllsociety.org/donate-to-cll-society/