



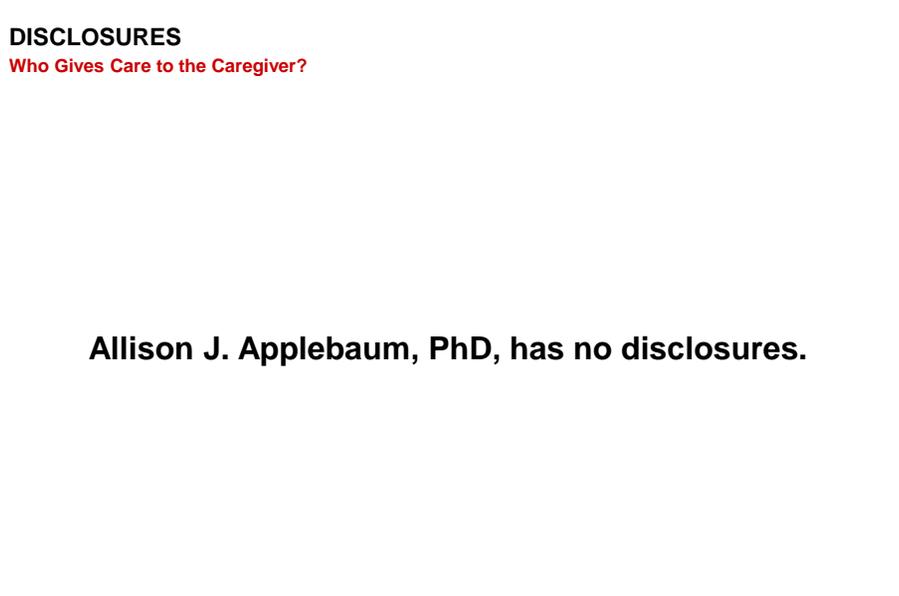
# WHO GIVES CARE TO THE CAREGIVER?

**Allison J. Applebaum, PhD**  
*Director, Caregivers Clinic*  
*Assistant Attending Psychologist*  
Department of Psychiatry and Behavioral Sciences  
Memorial Sloan Kettering  
Counseling Center  
New York, NY

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## DISCLOSURES

**Who Gives Care to the Caregiver?**

**Allison J. Applebaum, PhD, has no disclosures.**

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# Who Gives Care to the Caregiver

The Leukemia & Lymphoma Society

Wednesday, November 28, 2018

**Allison J. Applebaum, Ph.D**  
*Director, Caregivers Clinic*  
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Department of Psychiatry and Behavioral Sciences  
Memorial Sloan Kettering Cancer Center  
New York, NY



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## Who are Caregivers?



- Formal caregivers
- Informal caregivers (ICs)
- World Health Organization (WHO) estimates that ~8% of the global population is dependent on others for care:
  - 1/3 US households in 2017 had an IC
  - 65.7 million Americans, 4.6 million of whom provide care to patients with cancer
  - ICs are predominantly female and providing care to a parent, and over 1/3 provide care to two or more people



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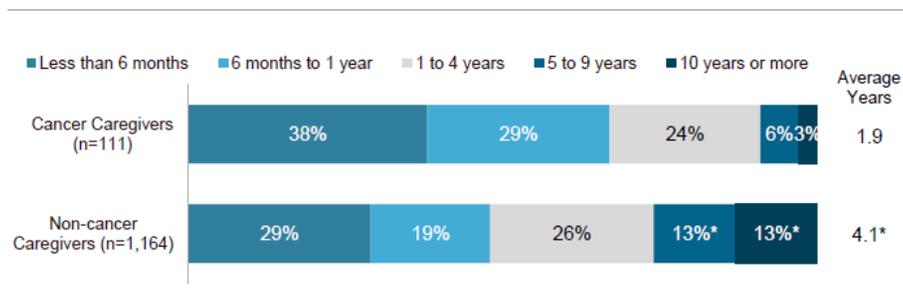
## What Do Caregivers Do?

- Instrumental support
  - Activities of daily living (ADL)
- Emotional support
- On average, ICs provide care for 8.3 hours/day, for 13.7 months
- 1/3 ICs provide care for 5+ years
- Annual economic value of caregiving in the U.S. was recently estimated at \$375 billion

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## Caregiver Experience in Cancer Care

Figure 3: Duration of Care



Caregiving in the U.S., 2016; [www.caregiving.org](http://www.caregiving.org)

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## Caregiver Experience in Cancer Care

Figure 5: Hours of Care per Week

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Fewer than 9 hours	32%	47%*
9 to 20 hours	24%	21%
21 to 40 hours	13%	19%
41 or more hours	32%	22%
<i>Average hours of care provided per week</i>	<b>32.9*</b>	23.9

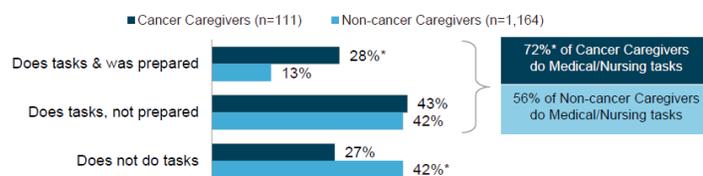
Caregiving in the U.S., 2016; [www.caregiving.org](http://www.caregiving.org)

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## Caregiver Experience in Cancer Care

Figure 8: Performance of and Preparation for Doing Medical/Nursing Tasks



Caregiving in the U.S., 2016; [www.caregiving.org](http://www.caregiving.org)

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## Caregiver Burden

### Caregiver Strain and Burden

*Caregiver strain and burden* encompasses the difficulties assuming and functioning in the caregiver role, as well as associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources. Caregivers experience differing challenges during different phases of the cancer trajectory that can significantly impact their functioning and quality of life.

Demands exceed resources

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## Caregiver Burden

- Multi-dimensional
  - Psychological
    - Anxiety
    - Depression
  - Physical/Medical
    - Cardiovascular disease
    - Poor immune functioning
    - Fatigue/sleep difficulties
    - Higher rates mortality
  - Financial
  - Temporal
  - Existential



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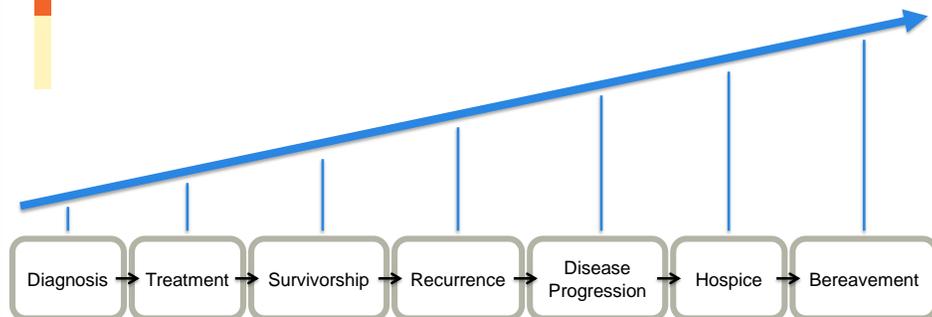
## Existential Distress

- Multi-dimensional
  - Hopelessness
  - Powerlessness
  - Questions about identity
  - Feeling like a burden to others
  - Decreased sense of meaning and purpose
  - Guilt
  - Death anxiety



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## Distress Across the Caregiving Trajectory



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## Cancer Caregivers *are* Cancer Survivors

- NCI (2013) definition of Cancer Survivor:

*“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. **Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.**”*



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## During survivorship, caregivers are at **greater** risk for **distress** than patients

- Caregivers of long term cancer survivors report significant health problems, including heart disease, hypertension and arthritis.
- Caregivers report lower QOL and receiving less social support than do patients.
- Fear of recurrence is *equal* if not *greater* among caregivers than patients.
- Navigating return to full-time employment and shifting family roles requires negotiation.

Kim et al., 2010, 2012; Lambert et al., 2012; Papastavrou et al., 2009.



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## During survivorship, caregivers are at ***greater*** risk for **psychopathology** than patients

- Baseline levels of anxiety and depression higher among caregivers than patients.
- Symptoms remained stable over 2 year survivorship period (4 groups modeled).
- Levels of anxiety and depression remained constant across time points from 6 months to 5 years post diagnosis.

Lambert et al., 2012



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## Institute of Medicine (IOM, 2008) “Retooling for an Aging America: Building the Health Care Workforce”

*Highlighted the responsibility of health care professionals to prepare caregivers for their role and the need to establish programs to assist them with managing their own stress that results from providing care.*



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## How to Get Help

- Recognize signs and symptoms of burden
- 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

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## Professional Support

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## Professional Support

- Many cancer centers have licensed clinical psychologists, social workers, and mental health professionals who specialize in supporting families facing cancer. Just ask!
- Phenomenal resources through organizations such as:
  - American Cancer Society
  - Cancer Support Community
  - CancerCare
  - The Leukemia & Lymphoma Society

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## Caregivers Clinic Memorial Sloan Kettering Cancer Center

Most frequent presenting complaints:

- Difficulty communicating with patients and/or healthcare professionals
  - Advanced Care Planning
  - Networks of silence
- Generalized Anxiety Disorder
- Insomnia and related distress
- Maintaining a balance between caregiving and self-care
- Guilt
- Existential distress, Death anxiety

**MR. WORRY**  
by Elspeth Langmuir



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*Palliative and Supportive Care*, page 1 of 22, 2012  
 © Cambridge University Press, 2012. 1479-0519/12/0000  
 doi:10.1017/S1479051912000064

#### REVIEW ARTICLE

### Care for the cancer caregiver: A systematic review

ALLISON J. APPLERBAUM, PH.D., AND WILLIAM BREITBART, M.D.  
 Memorial Sloan-Kettering Cancer Center, New York, New York

(Received April 1, 2012; Accepted April 16, 2012)

#### ABSTRACT

**Objective:** Informal caregivers (ICs) are relatives, friends, and partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to a patient with a life-threatening, incurable illness. The multidimensional burden that results from providing care to a patient with cancer is well documented, and as a result, a growing number of psychosocial interventions have been developed specifically to address this burden. The purpose of the present study was to characterize the state of the science of psychosocial interventions for informal cancer caregivers.

**Method:** A comprehensive systematic review of interventions for cancer caregivers was conducted via an electronic literature search of publications between 1980 and January 15, 2011. A final sample of 49 interventions was reviewed in detail.

**Results:** The interventions, which varied in terms of modality and patient population, fell into the following eight categories: psychoeducation, problem-solving, skills building interventions, supportive therapy, family/couples therapy, cognitive-behavioral therapy, interpersonal therapy, complementary and alternative medicine interventions, and existential therapy. Benefits and disadvantages of each of the categories are discussed, with special attention given to studies that produced null findings.

**Significance of results:** Shaped specific techniques, structured, goal-oriented, and time-limited interventions that are integrative appear to be the most feasible and offer the greatest benefits for ICs of cancer patients. Future studies are needed to examine the specific benefits and challenges of delivering interventions in alternative modalities (Internet, Skype) so that the needs of a greater number of ICs may be addressed.

**KEYWORDS:** Cancer caregivers, Caregiver burden, Psychosocial interventions

#### INTRODUCTION

There is growing recognition that comprehensive care for cancer patients involves attending to the psychosocial needs of their informal caregivers, as well as the various needs of the patients themselves (Breitbart & Alici, 2009). Informal caregivers (ICs) are defined as any relatives, friends, or partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to a

patient with a life-threatening, incurable illness (Hudson & Payne, 2009). In 2009, an estimated 65,700,000 people in the United States served as ICs for medically ill relatives, including 4,600,000 cancer patients (National Alliance for Caregiving, 2009). This number may be a reflection of the rising costs of healthcare, which have placed the responsibility of caring for the chronically medically ill – including cancer patients – on family caregivers (Panareta & McCordale, 2000). As the number of ICs will likely continue to rise in the future, special attention should be paid to the unique burden of ICs, not only for the benefit of the caregiver but also for that of the patient.

Address correspondence and reprint requests to Allison J. Applerbaum, Department of Psychiatry and Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 441 Lexington Avenue, 7th Floor, New York, N.Y., 10017. E-mail: applerbaum@mskcc.org

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•Titles/abstracts of 2,199 articles reviewed,  
N=49 interventions included:

- 13 psychoeducation
- 10 supportive tx
- 10 problem-solving/skills building
- 8 family/couples tx
- 4 CBT/IPT
- 4 CAM/Sleep/Relaxation/Massage.

•88% delivered in person, 6% over the phone,  
6% combined in-person and telephone  
sessions.

•61% delivered to caregiver/patient dyad or  
family, 37% to individuals, 14% groups of  
caregivers.

•*Desire for caregiver-specific interventions*

•Successful interventions were time limited,  
flexibly administered, and integrative.

•*No interventions focused on existential  
distress, despite N=9 identifying this as an  
area that is critical for further study.*

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## Caregiver-Specific Interventions (2018)

- Cognitive Behavioral Therapy for Insomnia (CBT-I)
- Problem-Solving Therapy
- Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C)
- Emotion Regulation Therapy for Cancer Caregivers (ERT-C)
- Communication skills training programs



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# Self-Care



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## 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.



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## 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
  - Direct communication of depressive symptoms/suicidal ideation

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## 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

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Pleasure and Mastery Worksheet

Monday	_____	_____
	_____	_____
Tuesday	_____	_____
	_____	_____
Wednesday	_____	_____
	_____	_____
Thursday	_____	_____
	_____	_____
Friday	_____	_____
	_____	_____
Saturday	_____	_____
	_____	_____
Sunday	_____	_____
	_____	_____

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## Autogenic Relaxation Instructions

This exercise lowers physiological stress, increases blood flow, and decreases muscle tension through the repetition of simple words and phrases. The script below is one example of many variations. The script may be memorized or recorded on tape:

*My right arm is warm and heavy. My right arm is warm and heavy.*

*My left arm is warm and heavy. My left arm is warm and heavy.*

*My right arm and my left arm are warm and heavy. My right arm and my left arm are warm and heavy.*

*My forehead is calm and relaxed. My forehead is calm and relaxed.*

*My face is calm and relaxed. My face is calm and relaxed.*

*My entire head is calm and relaxed. My entire head is calm and relaxed.*

*My chest is warm and heavy. My chest is warm and heavy.*

*My stomach is calm and relaxed. My stomach is calm and relaxed.*

*My entire upper body is warm and heavy, calm and relaxed. My entire upper body is warm and heavy, calm and relaxed.*

*My right thigh is warm and heavy. My right thigh is warm and heavy.*

*My right lower leg is calm and relaxed. My right lower leg is calm and relaxed.*

*My left thigh is warm and heavy. My left thigh is warm and heavy.*

*My left lower leg is calm and relaxed. My left lower leg is calm and relaxed.*

*My entire right leg and my entire left leg are warm and heavy, calm and relaxed. My entire right leg and my entire left leg are warm and heavy, calm and relaxed.*

*My entire body is warm and heavy, calm and relaxed. My entire body is warm and heavy, calm and relaxed.*

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## Caregiving and Sleep Disturbance

Shaffer, 2017

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## What is Insomnia?

- Rule of 3s:
  - $\geq 30$  minutes: fall asleep, waking in night, before alarm
  - $\geq 3$  nights per week
  - $\geq 3$  months

... despite adequate opportunity

... & distress / impairment

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## Insomnia Treatment

Today's date	Example: 4/5/11							
1. What time did you get into bed?	10:15 pm.							
2. What time did you try to go to sleep?	11:30 pm.							
3. How long did it take you to fall asleep?	55 mins.							
4. How many times did you wake up, not counting your final awakening?	3 times							
5. In total, how long did these awakenings last?	1 hour 10 mins.							
6. What time was your final awakening?	6:35 a.m.							
7. What time did you get out of bed for the day?	7:20 a.m.							
8. How would you rate the quality of your sleep?	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good

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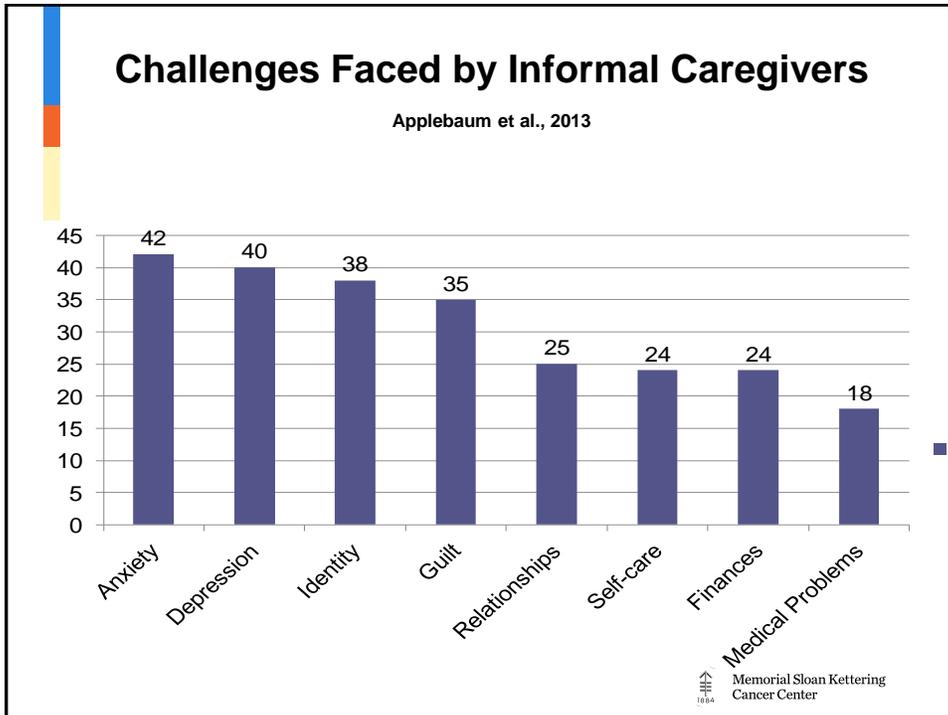


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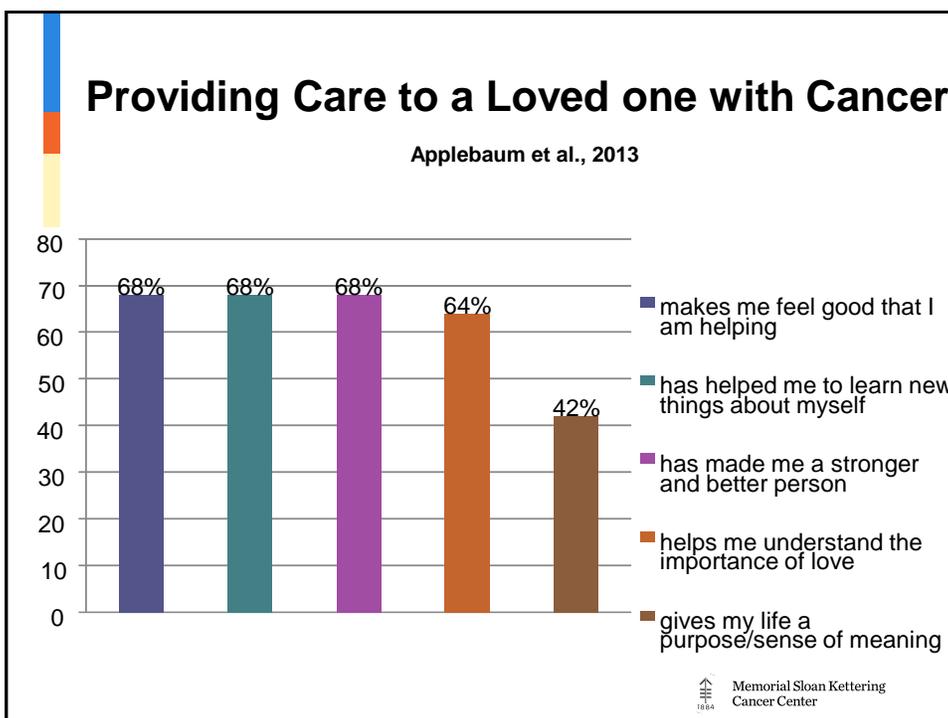
## The Benefits of Being a Caregiver


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**“Marriage is just as effective as chemotherapy.”**  
-Rebecca Johnson, M.D.

**Cancer caregivers are the next generation of cancer patients.**



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**WE TREAT PEOPLE WITHOUT CANCER, TOO.**

It's a helpless feeling to find out someone you love has cancer. Friends and family are often hit just as hard as the person diagnosed. That's why we offer caregiver support services to help people deal with this difficult situation while knowing their loved one is being taken care of. At Memorial Sloan Kettering, we're here for everyone affected by cancer, whether they're our patient, or a caregiver. Learn more at [MSKCC.ORG/MORESCIENCE](http://MSKCC.ORG/MORESCIENCE)

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SCIENCE.  
LESS  
FEAR.**



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MANHATTAN · BROOKLYN · LONG ISLAND · WESTCHESTER COUNTY · BASKING RIDGE, NJ  
In-network with most health plans. Ask about financial assistance.



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***Thank You!***



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**QUESTION & ANSWER SESSION**

**BEATING CANCER IS IN OUR BLOOD.**



LEUKEMIA &  
LYMPHOMA  
SOCIETY

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## LLS EDUCATION & SUPPORT RESOURCES

- Information Specialists**

Master's level oncology professionals, available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.

  - EMAIL: [infocenter@LLS.org](mailto:infocenter@LLS.org)
  - TOLL-FREE PHONE: 1-800-955-4572
- Free Education Booklets:**
  - [www.LLS.org/booklets](http://www.LLS.org/booklets)
- Free Telephone/Web Programs:**
  - [www.LLS.org/programs](http://www.LLS.org/programs)
- Live, weekly Online Chats:**
  - [www.LLS.org/chat](http://www.LLS.org/chat)




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LEUKEMIA & LYMPHOMA SOCIETY

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## LLS EDUCATION & SUPPORT RESOURCES

- 
  - LLS Podcast, *The Bloodline with LLS***

Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: [www.thebloodline.org](http://www.thebloodline.org)
- Education Videos**

Free education videos about survivorship, treatment, disease updates and other topics: [www.LLS.org/educationvideos](http://www.LLS.org/educationvideos)
- Patti Robinson Kaufmann First Connection Program**

Peer-to-peer program that matches newly diagnosed patients and their families: [www.LLS.org/firstconnection](http://www.LLS.org/firstconnection)
- Free Nutrition Consults**

Telephone and email consultations with a Registered Dietitian: [www.LLS.org/nutrition](http://www.LLS.org/nutrition)
- What to Ask**

Questions to ask your treatment team: [www.LLS.org/whattoask](http://www.LLS.org/whattoask)
- LLS Community**

Join the community of blood cancer patients, survivors and caregivers: [www.LLS.org/community](http://www.LLS.org/community)
- Other Support Resources**

Blogs, support groups, financial assistance and more: [www.LLS.org/support](http://www.LLS.org/support)



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**THANK YOU**

We have one goal: A world without blood cancers



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