

**WELCOME & INTRODUCTIONS**  
*Insight into Caregiving*

Welcome to LLS Community  
 We are a community of blood cancer patients, survivors and caregivers.  
 We're here to support you, give you trusted information and resources,  
 and help you feel connected. No one should have to face a blood cancer  
 diagnosis alone.



To join LLS Community, visit [www.LLS.org/community](http://www.LLS.org/community).

*Program will begin shortly*

**BEATING CANCER IS IN OUR BLOOD.**



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 CANCER  
 IS IN  
 OUR BLOOD.**

**INSIGHT INTO  
 CAREGIVING**

**Richard Dickens, MS, LCSW-R**  
 Director of Client Advocacy  
 CancerCare  
 New York, NY



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 **A WORD FROM A CAREGIVER**  
*Insight into Caregiving*

“When I couldn’t sleep, I composed haiku—my way of counting sheep.”



Sharon Saltzman

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 **DISCLOSURES**  
*Insight into Caregiving*

**Richard Dickens, MS, LCSW-R has no disclosures.**

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**Insight Into Caregiving**  
Richard Dickens, MS, LCSW-R

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**CAREGIVERS**  
**The Unsung Heroes**



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## Who Is A Caregiver?



The person who most often helps the person with cancer and is not paid to do so. In most cases, the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, co-workers, or neighbors may fill this role. The caregiver has a key role in the patient's care. Good, reliable caregiver support is crucial to the physical and emotional well being of people with cancer.

**American Cancer Society**

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## By The Numbers



The number of individuals currently providing care for patients is startling: recent US national estimates of cancer caregivers range from 2.8-6.1 million adult individuals. <sup>(1,2)</sup>

Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, with 32% providing 41 or more hours of care weekly, the equivalent of a full-time job. <sup>(3)</sup>

Since supporting a person with cancer can be particularly, demanding, they devote nearly 50% more hours per week for providing care than those caring for people dealing with non-cancer diagnosis. <sup>(4,5)</sup>

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# Your Role As A Caregiver



- Going grocery shopping and preparing meals
- Assist with personal hygiene and changing clothes
- Assisting with using the bathroom
- Cleaning & Laundry
- Keeping track of finances
- Driving a loved one to appointments and treatment
- Providing emotional support
- Reminding them to take medication and adhere to the treatment plan
- Communicating with members of the treatment team
- Taking notes during medical appointments
- Communicating with friends and family

Leukemia & Lymphoma Society

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Image: Heather McKean

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# LONG DISTANCE CAREGIVING



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## CHALLENGES & OPPORTUNITIES

- Feelings of guilt: not doing enough because they aren't physically present. 1) Remind yourself you're doing the best you could. 2) Be realistic, the original behavioral ideals you set for yourself may be too high. 3) Acknowledge and honor your right to protect your self-interests. <sup>(6)</sup>
- Remember that guilt is a byproduct of loving someone and not wanting them to suffer.
- Financial strain: feeling they "should" help out more since they are not physically present; can lead to difficulties in managing one's finances. Establishing boundaries, especially within chronic conditions.

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## CONTINUED

- Resentment: “why me?” built-up feelings of frustration by you or by your family. Before these thoughts overwhelm you break the overall caregiving tasks into smaller parts and decide what you are capable of doing.
- Uncertainty: of emotional and practical challenges that a cancer diagnosis brings. Ex: Worrying how the PWC is doing since you’re not there to witness it and help.
- Frustration: navigating things from afar can come with new challenges. Identify a task you’re good at: finance, advocacy, health care, etc. and reinforce that challenges also present opportunities.

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# PHYSICAL, SOCIAL & EMOTIONAL CHALLENGES FOR CAREGIVERS

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Put your oxygen mask on yourself before you help anyone else!

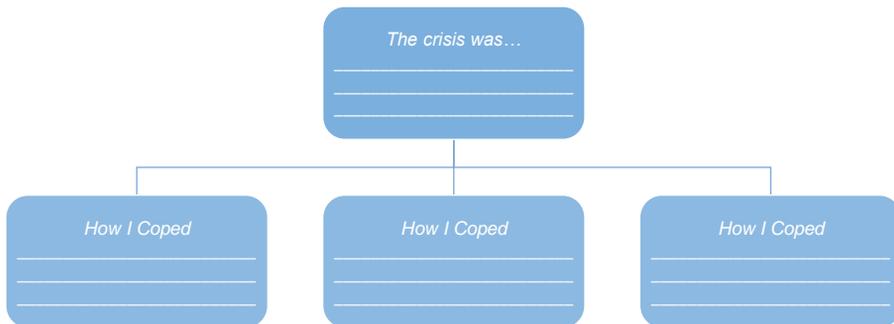


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## IDENTIFY YOUR COPING SKILLS



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# FDR

**“F”** are **Feelers**; those who you have a strong sense of fellowship with. Photo by [Artyom Kabajev](#) on [Unsplash](#)



**“D”** are **Doers**; those good at doing concrete tasks.



Image created by [Lélie Lesage](#).

**“R”** are **Researchers**; those with good understanding of technology and finding resources.

Photo by [Alvaro Reyes](#) on [Unsplash](#)



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My Cancer Circle is a service to support caregivers and people facing cancer. It is a simple online tool to help organize the community of people who want to help you. It coordinates their efforts to more efficiently support you and your loved one facing cancer by helping you:

Coordinate volunteer activities, including meals, transportation to medical appointments and other tasks

Provide a private space where community Members can offer words of support and encouragement. You can also post updates and information about your loved one

Schedule offers to give caregivers a break or to do something special for them

Creating your own personalized My Cancer Circle website is easy. Here's how it works:

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# THE GIFT OF GIVING

To be a caregiver is to know the gift of giving includes:  
sacrifice, responsibility, compassion, love, devotion.

To reach out to others for help allows them to share in  
the burden and experience the gift of giving.

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# SELF CARE FOR CAREGIVERS

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A Caregiver's Bill of Rights I have the right..

To take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of my relative.

To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.

To get angry, be depressed, and express other difficult feelings occasionally.

To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

To \_\_\_\_\_  
(Add you own statement of rights to this list. Read the list to yourself every day.)

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

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Trusted Information. Better Care.

**Caregiver Self Assessment Questionnaire**

The Caregiver Health Self Assessment Questionnaire was originally developed and tested by the American Medical Association, <https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire>. The questionnaire can help caregivers look at their own behavior and health risks. With their healthcare provider's help, this questionnaire can also help caregivers make decisions that may benefit both the caregiver and the older person. In turn, the questionnaire can help healthcare providers to identify and provide preventive services to an at-risk population which may be hidden. It may also improve communication and enhance the healthcare provider-caregiver health partnership. This questionnaire is meant to serve as a guide only. Be sure to speak to your healthcare provider about any concerns you may have about the questionnaire or your results.

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## It begins with the breath

“The single most effective  
relaxation technique I know  
conscious regulation of breath.”

*Dr. Andrew Weil*

*Image: Allie*

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# Existence and Choice

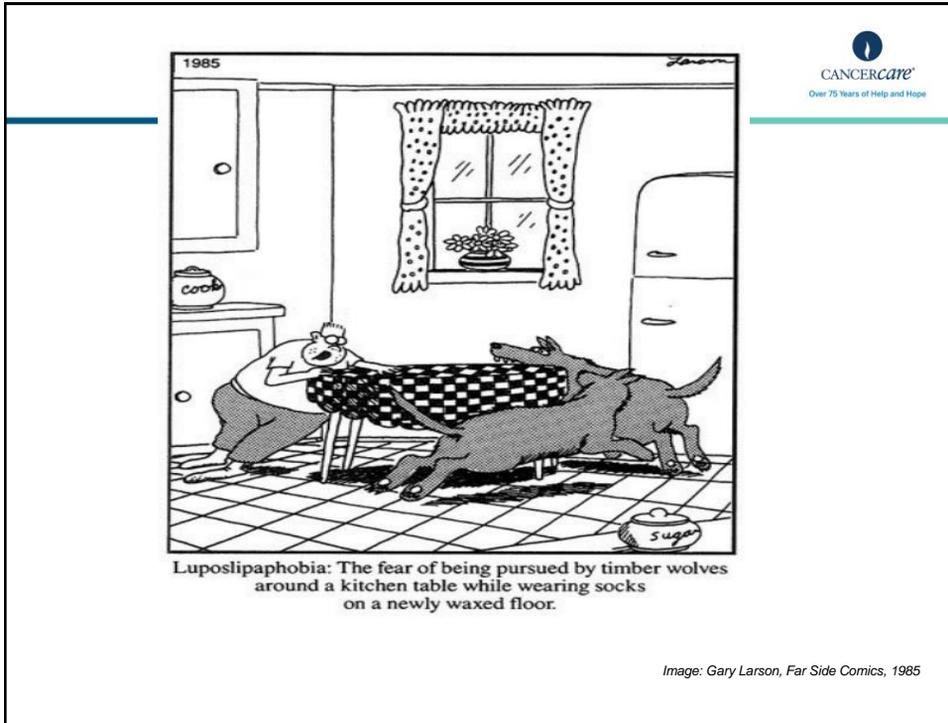
**“Grief is a process, but recovery is a choice.”**

*Choice always exists, even in the bleakest situation.*

**“Don’t forget to laugh!”**

*Finding your inner strength when it feels lost.*

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## Can You Imagine?

Can You Imagine?  
For example, what the trees do  
not only in lightening storms  
or the watery dark of a summer's night  
or under the white nets of winter  
but now, and now, and now – whenever  
we're not looking. Surely you can't imagine  
they don't dance, from the root up, wishing  
to travel a little, not cramped so much as wanting  
a better view, or more sun, or just as avidly  
more shade – surely you can't imagine they just  
stand there loving every  
minute of it, the birds or the emptiness, the dark rings  
of the years slowly and without a sound  
thickening, and nothing different unless the wind,  
and then only in its own mood, comes  
to visit, surely you can't imagine  
patience, and happiness, like that. By Mary Oliver

Photo by: charlotte hutson wrenn 2010

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## References

- 1 National Alliance for Caregiving: Cancer Caregiving in the U.S., An intense, episodic and challenging care experience. 2016. [www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport\\_FINAL\\_June-17-2016.pdf](http://www.caregiving.org/wp-content/uploads/2016/06/CancerCaregivingReport_FINAL_June-17-2016.pdf)
- 2 National Cancer Institute: Health Information National Trends Survey 5, Cycle 1. 2017, <https://hints.cancer.gov/data/survey-instrument.aspx>
- 3 The Caregiver Factor: Understanding the Medical Journey \_Caregiver\_Report.pdf of the Caregiver and their Information and Support Needs, Rx4Ggood; (2018) [http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G\\_Caregiver\\_Report.pdf](http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G_Caregiver_Report.pdf)
- 4 Care for the Cancer Caregiver. The ASCO Post; (2018) <https://www.ascopost.com/issues/September-25-2018/care-for-the-caregiver>
- 5 J. Clin Oncol 34, 2016 (suppl 26S; abstr 4) <https://meetinglibrary.asco.org/record/136381/abstract>
- 6 Seltzer, Leon, F., 9 Ways to Talk Yourself Out of Unnecessary Guilt. Psychology Today, (June 11, 2016). <https://www.psychologytoday.com/us/blog/evolution-the-self/201506/9-ways-talk-yourself-out-unnecessary-guilt>



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## Q&A SESSION

Insight into Caregiving

- **Ask a question by phone:**
  - Press star (\*) then the number 1 on your keypad.
- **Ask a question by web:**
  - Click “Ask a question”
  - Type your question
  - Click “Submit”

Due to time constraints, we can only take one question per person. Once you’ve asked your question, the operator will transfer you back into the audience line.

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## LLS EDUCATION & SUPPORT RESOURCES

### HOW TO CONTACT US:

To contact an **Information Specialist** about disease, treatment and support information, resources and clinical trials:



Call: (800) 955-4572

Monday to Friday, 9 a.m. to 9 p.m. ET



Chat live online: [www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)

Monday to Friday, 10 a.m. to 7 p.m. ET



Email: [infocenter@LLS.org](mailto:infocenter@LLS.org)

All email messages are answered within one business day.



### CLINICAL TRIAL SUPPORT CENTER

Work one-on-one with an LLS Clinical Trial Nurse Navigator who will help you find clinical trials and personally assist you throughout the entire clinical-trial process.

[www.LLS.org/Navigation](http://www.LLS.org/Navigation)

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### NUTRITION CONSULTATIONS

Our registered dietitian has expertise in oncology nutrition and provides free one-on-one consultations by phone or email.

[www.LLS.org/consult](http://www.LLS.org/consult).



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## LLS EDUCATION & SUPPORT RESOURCES



ONLINE CHATS





**Online Chats**

Online Chats are free, live sessions, **moderated by oncology social workers**. To register for one of the chats below, or for more information, please visit [www.LLS.org/chat](http://www.LLS.org/chat).

**Education Videos**

View our free education videos on disease, treatment, and survivorship. To view all patient videos, please visit [www.LLS.org/EducationVideos](http://www.LLS.org/EducationVideos).

**Patient Podcast**

*The Bloodline with LLS* is here to remind you that after a diagnosis comes hope. To listen to an episode, please visit [www.thebloodline.org](http://www.thebloodline.org).

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## LLS EDUCATION & SUPPORT RESOURCES



877.557.2672

### Help With Finances

The Leukemia & Lymphoma Society (LLS) offers financial assistance\* to help individuals with blood cancer.

The **LLS Patient Aid** Program provides financial assistance to blood cancer patients in active treatment. Eligible patients will receive a \$100 stipend. Visit [www.LLS.org/PatientAid](http://www.LLS.org/PatientAid)

The **Urgent Need** Program, established in partnership with Moppie's Love, helps pediatric and young adult blood cancer patients, or adult blood cancer patients who are enrolled in clinical trials, with acute financial need. The program provides a \$500 grant to assist with non-medical expenses, including utilities, rent, mortgage, food, lodging, dental care, child care, elder care, and other essential needs. Visit [www.LLS.org/UrgentNeed](http://www.LLS.org/UrgentNeed)

The **Susan Lang Pay-It-Forward Patient Travel Assistance** Program provides blood cancer patients a \$500 grant to assist with transportation and lodging-related expenses. Visit [www.LLS.org/Travel](http://www.LLS.org/Travel)

The **Co-Pay Assistance** Program offers financial support toward the cost of insurance co-payments and/or insurance premiums for prescription drugs. Visit [www.LLS.org/Copay](http://www.LLS.org/Copay)

\*Funding for LLS's Co-pay Assistance Program is provided by pharmaceutical companies. Funding for other LLS financial assistance programs is provided by donations from individual donors, companies, and LLS campaigns.

The Leukemia & Lymphoma Society (LLS) offers the following financial assistance programs to help individuals with blood cancer: [www.LLS.org/Finances](http://www.LLS.org/Finances)



To order free materials: [www.LLS.org/booklets](http://www.LLS.org/booklets)

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**THANK YOU**

We have one goal: A world without blood cancers

 LEUKEMIA & LYMPHOMA SOCIETY