





SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA (CLL)

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Smart Health Psychology


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CLL Caregiver

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WELCOMING REMARKS
SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA

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The Leukemia & Lymphoma Society



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DISCLOSURES

SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYtic LEUKEMIA



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Marni Amsellem, Ph.D, have no significant financial interest



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Recognizing and Meeting your Needs as a Caregiver

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"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."**

-Rosalynn Carter, former US First Lady

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YOU as the caregiver

Identity as a caregiver

- In which ways does the term 'caregiver' resonate with you?
- What feels unique to you now in helping your loved one navigate CLL?

Things you know about being a caregiver (but are good to hear again and again)

- You are a caregiver regardless of how close you live to your loved one
- Being a caregiver does not mean you will have a reduced quality of life
- You have finite resources
 - Pace yourself
 - Take care of yourself



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Recognizing your needs as a caregiver

- Informational needs
- Emotional Support needs
- Practical needs
- Personal needs
 - We all have different needs.
 - How are your needs as a caregiver being met?
 - How might you better address your needs?
 - How might your needs change over time?



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Awareness of Caregiver Burden

Burden involves multiple dimensions:

- Emotional Distress (increased risk of anxiety and depression)
- Physical Health
- Financial
- Temporal

This highlights the importance of addressing distress and seeking support



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Managing the uncertainties of CLL

Chronic worry and rumination are commonly experienced by caregivers
How can you prepare yourself mentally for uncertainty? For treatment?

- Challenges of wait & see
- Adjusting between watch & wait vs. active treatment

Tips:

Acknowledge the worry, validate the concerns while also being mindful of how this can lead to distress

Notice if you are jumping to conclusions

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Long-distance caregiving

There are many ways to be a caregiver from a distance:

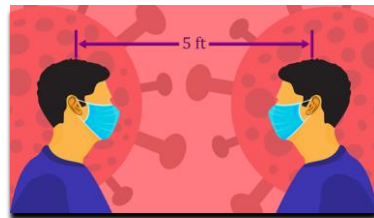
- Communicate. Talk to your loved one about their needs and how they wish to be supported during this time
- Be their right hand man/ woman. Assist in researching and managing care (e.g. investigate treatment options, what to expect, logistics, manage spreadsheets and information, speak with providers, etc.)
- Be a source of comfort.
- Be there virtually.
- Be part of the routine.



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Caregiving during Covid

- In addition to receiving vaccines, people with CLL and their caregivers should continue taking additional precautions, such as hand washing and mask wearing.
- Added burden of care during the pandemic of managing challenges related to immunosuppressed status
 - Challenges may arise in differences in lifestyle, behavior, and concerns around Covid
- Communicating about concerns and making choices that support your level of comfort
- Navigating feeling disconnected



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Strategies for managing your needs as a caregiver

1. Acknowledge your needs, worries, concerns
2. Communicate your needs, check in about your care recipient's needs
3. Attend to your own health needs (e.g. get regular exercise)
4. Allow time for daily calm
5. Prioritize time for sleep
6. Plan ahead
7. Reach out for support/ find your people



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General tips for incorporating self-care

Take an honest look at your current coping-

what is useful?

what could use some intervention?

What are activities that are realistic, accessible and restorative for you?

Tips:

Integrate self-care into your routine, even “schedule”

Small actions are important too!



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It's OK to ask for help

Utilize your support network

Challenge yourself to ask for help, whether from personal resources or professional support

Know help can come from unlikely sources



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The Gifts of Caregiving

Caregiving often provides:

- Adjustment in perspective, priorities, and attitudes

- Can strengthen relationship bonds

- Opportunity to “show up” and to be there for your loved one

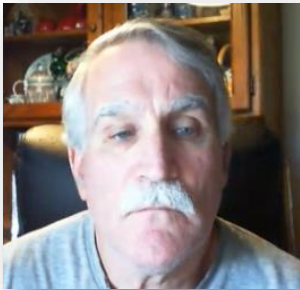
- Opportunity to choose your attitude and actions and feel positive about what you are doing



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CLL CAREGIVER

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CLL Caregiver

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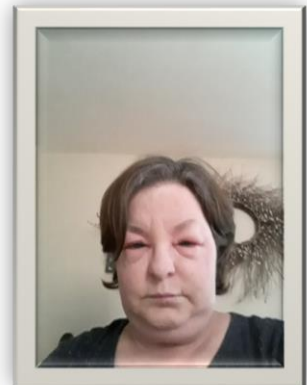
Eric's Caregiving Story



CLL CAREGIVER

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Effects of Medication



ASK A QUESTION

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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

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

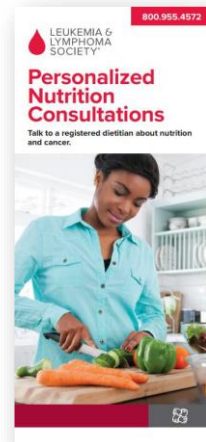
Email: www.LLS.org/ContactUs

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



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.



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LLS EDUCATION & SUPPORT RESOURCES



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



Education Videos

View our free education videos on disease, treatment, and survivorship. To view all patient videos, please visit 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



LLS EDUCATION & SUPPORT RESOURCES

LEUKEMIA & LYMPHOMA SOCIETY™ 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
- 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
- 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
- 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

*Funding for LLS 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 cancers: www.LLS.org/Finances



To order free materials: www.LLS.org/Booklets





THANK YOU

We have one goal: A world without blood cancers



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