



Spotlight on Caregiving

Operator

Greetings and welcome to Spotlight on Caregiving, CLL, a live telephone and web education program. It is now my pleasure to introduce your moderator, Lizette Figueroa-Rivera. Thank you. You may begin.



Welcoming Remarks

Lizette Figueroa-Rivera

Hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you. We have over 400 people participating from across the United States, as well as other countries, including Canada, Iraq, and Israel. Special thanks to Dr. Marni Amsellem, for sharing her time and expertise with us today.

Mr. Eric Weber is here with us and is a caregiver for his wife who was diagnosed with CLL in 2018. Thank you so much, Eric, for being with us today on such short notice.

LLS recognizes how caregivers are also going through the cancer journey. In 2013, the National Cancer Institute included caregivers in their definition of survivor. They said, “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.”

At LLS, we want to make sure that caregivers also receive the information and support they need to advocate for their loved one. LLS has many support services for caregivers, including a caregiver online chat, as well as our online community.

Caregiving for CLL can be a challenge, as the chronic nature of this disease not only impacts folks physically, but also mentally, as patients may go through different phases of treatment, like watch-and-wait, to be in and out of different therapy regimens. It's hard not knowing how the disease will react and hard to anticipate when it will come back. LLS wants to acknowledge your experience and assist you in providing care for yourself and your loved one. Thank you for being with us and coming together and letting us help you to know that you're truly not alone.

For this program, we would like to acknowledge and thank Eli Lilly and Company for their support. Following the presentation, we will take questions from the audience.

DISCLOSURES
SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA



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



Disclosures

SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA (CLL)
Recognizing and Meeting your Needs as a Caregiver

Marni Amsellem, Ph.D.
Licensed Psychologist
Smart Health Psychology



Spotlight on Caregiving: Chronic Lymphocytic Leukemia (CLL)

I am now pleased to introduce Dr. Marni Amsellem, licensed psychologist in Connecticut, New York, and Maryland at Smart Health Psychology. And Mr. Eric Weber, a CLL survivor, will speak after Dr. Amsellem.

Dr. Amsellem, I'm now privileged to turn the program over to you.

Marni Amsellem, Ph.D

Thank you so much, Lizette. Thank you for inviting me to join you all. And thank you, all, for being here today, and for taking care of yourself by carving out this time to address whatever your needs currently are, whatever they might be, whatever they have been, and just taking that time to focus on that.

Lizette, thank you also for setting the greater stage of the impact of caregiving and the cancer journey.

"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

First Lady Rosalynn Carter

And I think this quote by a former First Lady, Rosalynn Carter, really summarizes our identity as a caregiver and the realities of caregiving; that "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." So, we are one or more of those at any given point in our life.

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



You as the Caregiver

So, bringing the focus to you as a caregiver and thinking about how you might identify as a caregiver. I know a lot of cancer caregivers do not, necessarily, feel great about that being that term is something that necessarily resonates with them. But essentially, in which ways? Thinking about this and how you relate to the label, the identification of a caregiver, how does that resonate with you?

Have you been a caregiver in other areas of your life? How is this the same and different, and which ways are you currently providing care? Is it kind of direct care, nursing care, attending appointments,

researching options and services, providing emotional support, bringing meals over, etc., etc.? So, there are so many ways in which, even if you are not necessarily providing, say, nursing skills, that in no way is limiting to how we can identify as caregivers.

So, just general tips to—I guess, overview-- to talk about, right now. And, by the way, these slides are going to be not so much heavy on data because we're really here to talk about what our needs are and how you can best be aware of what they are and support yourself.

So, top line points and things, again, you might already know, but it's always important to hear and to remind yourself that you are a caregiver, regardless of how close you live to your loved one with CLL, that being a caregiver does not mean that you will have a reduced quality of life. In fact, the final slide that I have talks about some of the amazing impacts of being a caregiver, positive impacts. And that, throughout your caregiving journey, a reminder to pace yourself and to take care of yourself as you, too, are someone with needs and limited resources.

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?



Recognizing Your Needs as a Caregiver

So, in recognizing your needs as a caregiver, they might fall under these general categories of informational needs. What is it that you would like to learn about management of side effects, for example, or treatment options? How can you get that information? What sources are reliable? Where can you go, who can you turn to?

Your emotional support needs, of course. How is all of this, for you, feeling? What are your stress levels like? How are you dealing with the emotional impact of everything that you have been facing or might be facing in the future?

What are some of the practical needs that you have? And what are some of the personal needs you have? If you are balancing this with other things in your life, which I'm guessing (I, of course, can't see any of you, but I imagine) that's everybody, you're balancing caregiving demands with everything else you have going on in your life. Paying attention to how the interplay is between all of these various needs.

How are your needs as a caregiver being met? How might you better address these needs? And that's something that I hope that you do take from this conversation, today, what are ways in which you can possibly make some tweaks? And how, of course, might your needs change over time?

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

Awareness of Caregiver Burden

So, I'll throw out this term here of caregiver burden, also something that, no doubt, not everyone has heard before. Caregiving can be a lot. That doesn't mean it's a lot, all the time. But it certainly can be, particularly, when you are talking about caregiving in chronic, over time, a condition that can change that is very much going to be a long-term proposition. So, burden can involve multiple dimensions. So, this is just important to call out here.

Certainly, emotional distress in cancer caregiving, there absolutely can be an increased risk of anxiety and depression. So, that is something to throw out. And we'll come back to this topic, as well. But if this is something you're suspecting in yourself or another caregiver, or certainly with your loved one with CLL, this is something to pay attention to and bring to the attention of the healthcare team, your healthcare team. And there are ways to help manage, and that's a positive thing.

Certainly, another burden is on your own physical health. Again, you're not caregiving in isolation. You also have your own health to take care of and, certainly, if, for example, you are so focused on providing care, doing your day job, you may be taking care of other family members, etc., putting off your own doctors' appointments, or routine exercise, or smart dietary decisions, that absolutely can creep in. So, something to pay attention to that your own physical health needs can absolutely feel the impact of caregiving, if you're not paying attention to this.

Financial impacts, of course. And we will be not spending a whole lot of time on this particular topic, but I believe that there is some additional programming and another point that LLS is providing on this topic. But, absolutely, this can be a concern, as well as the chronicity of caregiving. This is not something that you're facing it now and then it'll be over a week from now, necessarily. So, this is something to pace yourself for.

So, all of this highlights the importance of addressing distress and your needs and seeking support. So, this is a common theme, throughout this conversation we're having today.

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

Managing the Uncertainties of CLL

So, focus on some of what I would imagine everyone on this call has experienced in some way, managing the uncertainties of CLL. So, chronic worry and rumination, that means kind of like having thoughts over and over again that aren't necessarily bringing you to a resolution on something, kind of intrusive in nature, are very commonly experienced by caregivers.

How can you best prepare yourself and adapt to this uncertainty? And, for treatments, depending on where you are at, where your loved one is at in their CLL journey. So, of course, this can very much be manifested in the challenges of not knowing and just waiting. And so, also, once you're kind of there, making adjustments between the watch-and-wait and active treatments.

So, generally speaking, again, we could talk for—at length about this particular topic. But general tips that I would recommend is this, just kind of like what we're doing right now. When you notice that you are having these types of worries, that acknowledging them is a healthy thing. You are calling that out to yourself, you're giving it a voice. That validates the concerns that you are having while, also, it allows you to be aware that they can be impacting you.


And, by identifying them, this can help you say, okay, well, this is happening, what can I do to redirect my thinking here or what can I do with these worries right now? What would be useful? And I will come to some of those tips also on slides further on.

And, notice if you are drawing conclusions about the future. I do know that none of us have crystal balls, or at least ones that really work, that can tell us what will happen in the future. We just don't know. So, I think that's an important general lesson for all of us that we might need to remind ourselves of from time to time.

Long-distance caregiving

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

- a) Communicate. Talk to your loved one about their needs and how they wish to be supported during this time
- b) 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.)
- c) Be a source of comfort.
- d) Be there virtually.
- e) Be part of the routine.



Long-distance Caregiving

I wanted to create a slide on this very important topic. And many of you might be providing care for loved ones from a remote place from a care recipient. And so, that is kind of how life is. We might not live with the person. We might live with the person we're caring for; we might not, right?

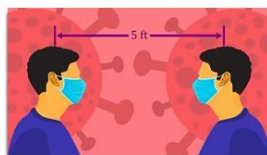
And there are many ways in which we can be a caregiver from a distance. And, just highlighting some, this is not a comprehensive list. But, just like you were maybe doing before with your loved one, communicate. Talk to your loved one about the needs that they might have, everything related to their health and well-being, and how they desire to be supported during this time. They might appreciate the fact that there is that physical distance, too, that you can be that person to them that isn't there for, necessarily, the day-to-day physical stuff. But you can be that kind of trusted source of support from a distance. But you can hear things, being a little bit physically removed.

You can be a support in so many different ways. Going onto the next one, you can certainly use all of your researching and Internet's skills in terms of finding information; investigating options; or reading up on what to expect; having phone conversations with medical providers, if that is something that your loved one is open to; planning logistics; perhaps helping manage information gathering and spreadsheets of tracking expenses.

These are all such important resources that you can offer, really, from anywhere. Of course, you can be a source of comfort from anywhere, and you can kind of, just like I am virtually here with you right now, you can be virtually there with your loved one and be part of their routine. Maybe you start off by sending a text message every morning or reach out at regular times. There are so many ways in which you can be providing care from a distance.

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



Caregiving during Covid

I also thought it would be important to talk about something that is very relevant to people on this call, which is the times in which we still continue to live, which is during this pandemic and the challenges of what it can be like to live with immunocompromised status, as well as care for loved ones who might be.

So, that again, we could speak more at length and interactively on how all of this can be. But some general points is [are] things that I certainly heard, over the course of the past few years, are there are so many challenges. Whether it's the feeling of being disconnected and feeling like there are things that it really makes sense to not be a part of because of protecting health. Your navigation of isolation or reduced interactions, as well as any challenges that have arisen in terms of differences and what people feel comfortable with, in terms of attending things in person and different levels of COVID exposure.

So, these are very real concerns for people. And we're still there and also feeling like, in many ways, others are not still there. But we might still be, if we're needing to follow various precautions and also, of course, the worry around this and managing worry, so that it feels like something you are more comfortable with. And, again, there may be some questions on that topic we can come back to later.

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



Strategies for Managing Your Needs as a Caregiver

I have here some strategies for managing your needs as a caregiver. And, again, we kind of relate back to these that have already come up here, but I think starting with this top one of acknowledging your own needs, as a caregiver, as a person, your own worries and your own concerns.

I think bringing awareness to this, to yourself, is only going to serve you well. Then, you can say, “Okay, I have this concern. I’m pretty worried about this or I’m being asked to do this, or I’m not being asked to do this, and that’s hard for me.” What can I do to help myself address this need, now that you’ve called it out for yourself? This will only help you show up more usefully as a caregiver, and you will be feeling less distressed as a person. So, super important.

Communicating your needs. If you do recognize that you have an unmet need to anyone, whether it’s you would like to be, kind of have a greater role in care, or you’d like to have a more reduced role in something. You’d like to have other caregivers in your care recipient’s world step up a little bit. Once you’ve acknowledged what that need is, finding an appropriate and useful way to communicate that is only going to help you. Obviously, all very context dependent, so not only communicate your needs but checking in about your loved ones’ needs. And, again, this might be (they can change over time and they often do) and they might be different from what you might assume that they are.

And this is why communication is so important, not easy. It’s sort of a word that we throw out there—Is okay, here’s a solution but not always so easy to do. And it is a very useful thing but also, practically, can be so challenging for any number of reasons: our own barriers, not wanting to go there, kind of fear of what could be elicited. Certainly. If you’re talking about a loved one, there’s whole history of your own past relationship with this person and relationship dynamics.

So, attending to your own health needs. We also had alluded to that, previously. Really, the importance of noticing, recognizing that you have a lot that you need to take care of, including yourself. And whether that’s getting regular exercise, if that has fallen off, making the appointments for your own medical care that you’ve been putting off because it’s not urgent. Preventive health is so important. This is what keeps us healthy, of course, and keeps us on top of problems, very early on, before they become much bigger problems. So, so important for you to be taking care of your health.

Additionally, time for whatever it is that you’re needing that brings you calm, that brings you some sense of respite and peace, like distance from stressors. So, we can keep that pretty open. This might vary, day to day. Maybe daily calm, some days will be like being in nature, staring at a photo of a tree. Other days, it might be listening to soothing music, going on a walk, being by yourself, going to your favorite place, I don’t know, coffee shop, doing something for you that feels very peaceful. And I say daily because it’s important to do this, regularly. It doesn’t have to be a grand gesture, every day. It can be just staring out the window for a few minutes and looking at something pretty but just allowing yourself something, even if it’s a very hectic day and there’s a lot of burdens or a lot of needs coming from a lot of different directions in your life.

Prioritizing time for sleep, along those same lines. Sleep is essential. It allows us to restore for our bodies to do the things that they need to do and emotionally helps us kind of regulate how we show up for others, as well. So, prioritizing that is a necessity. And, maybe also integrating the daily calm may be right before to help encourage and promote that sleep, too.

Planning ahead, in terms of managing worry, that can really help, too. So, you kind of leave that vague and open to however it is that you’re needing. But if there’s things that are unknown and unexpected or that there’s a lot going on, just giving yourself what you are needing there.

And, finally, reaching out for support, as you are needing and finding the people that support you, as you are needing. And, it might vary, depending on what you’re needing, too. So, if you’re needing some time away from everything and you just want to spend time with people that have no relation to what’s going on in your world as a caregiver, that might be what you’re needing then. However, if you are wanting to connect with other caregivers, certainly, there are ways to do that and, certainly, with all of you on the call today, you know that there’s a whole community out there.

And, just generally as a caregiver, I started by saying that giving yourself some appreciation for I am appreciating you for making this time for yourself today. I've been working with caregivers for a long time. And one of the hardest things to do is to carve out that time to give yourself. So, you showing up today is really so important and so essential.


Even if you're listening to this, you're doing something else, too, that's fine. You are still here. You are noting your needs and recognizing that they are there and that you can, you are worth it, to take the time however you realistically can.

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!



General Tips for Incorporating Self-care

So, back to the topic of self-care. I would recommend taking an honest look at what you are doing in terms of coping, and asking yourself questions. What is useful for you in what you're doing? And what could use some additional tweaking? If you notice, for example, that you kind of have given up fitness that used to be a go-to, stress-relief for you but things have just been so busy and you haven't, how can you re-integrate that back into your routine, into your regular repertoire?

And asking yourself, again, realistic is the key here and also important to you, restorative for you. What activities--do a little brainstorming here--are realistic, accessible, and restorative for you right now? That same question, if you asked yourself that six months ago, might be different kinds of activities.

And my recommendations would be to integrate self-care into your day and, when necessary, schedule it into your day. There are days where it will not happen, unless it is scheduled. And if you add it to your calendar and you see it on there, not to x that out and skip over it but to do something. And, again, even if it's five minutes, it does not have to be everything that you're needing. It's just something. Small actions are important, too.

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



It's OK to Ask for Help

Back to this point about support for yourself: It is okay to ask for help. I would encourage you to look at your support network and utilize your support network however it is usable for you to do so. And, a lot of people, whether you are someone going through treatment or you are a caregiver, do not feel comfortable asking for help. I imagine if we were in the room, and I'd asked for hands to go up, that would be a lot of people.

But it can be so useful to do so. And such a relief. We're all experiencing challenges. So, the challenge can be here to ask for help, whether from the people in your own network or professionally. And on the point of professional support. This can be something where you are attending your own therapy, you are joining a support group for caregivers. There are a whole lot of options out there. And, I encourage you, if you are feeling like you could benefit, that you do that. That's why the services are there.

And that help, of course, can also come from unlikely sources. And always be open to whatever is, or whoever could be useful, in terms of you feeling like you're getting what you're needing.

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



The Gifts of Caregiving

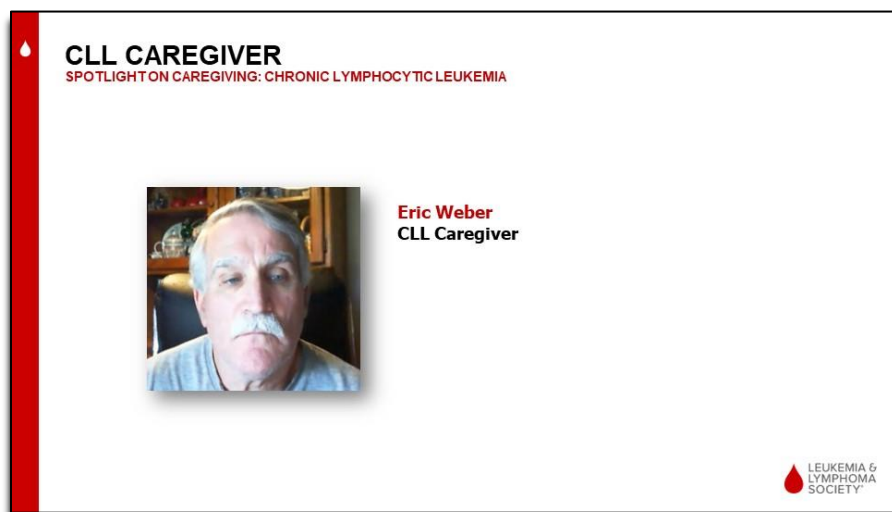
I'm going to end with this slide. And I know I'll be back for Q&A at the end. But I wanted to talk, kind of leave on this idea of the gifts of caregiving.

So, I know we've spoken about burden. We've spoken about some of the emotional impact of caregiving. But this is something where I feel like there are many on this call that could speak to this slide and share some experiences that are going to be so much more insightful than just reading this to you right now. But, in my experience, what I have seen, what I have experienced on my own is that caregiving often provides a whole lot of positives. It can. It can certainly very much affect how you see things, how you prioritize, how--like the attitude that you choose, to very globally to down to something specific.

Caregiving also can help strengthen relationship bonds. It has the potential to do so. Maybe that's something you have experienced. Caregiving provides the opportunity to show up and be there for your loved one. Again, it kind of provides us the opportunity to choose your attitude and your actions and really feel positive about the impact of what you are doing, the things that you're choosing to do--and knowing that you are doing a lot.

And for those here, doing the best you can. And I think that's an important thing to know, too. We all have limitations. Acknowledging those and recognizing that you showing up and you doing what you can is absolutely good enough. And asking questions about how you can improve is very much part of doing the best you can, too.

So, with that, I am going to introduce Eric. I'm going to turn this over to you, Eric.



CLL Caregiver

Eric Weber

Okay, thank you and hello, everyone. My name is Eric Weber, and my wife, Belinda, was diagnosed with CLL leukemia. I don't remember the exact date, but it was actually some time in, I think, early 2017.

She just wasn't feeling [well], she had extreme fatigue, and she kept going back to the doctor. And, finally, they did a white blood count test and discovered her white blood count was very high. So, at that point, they sent us to an oncologist, and he did the more severe testing, whatever it is. And it was determined that she had CLL leukemia.

So, that was somewhere around the middle of 2017 and, at that point, she had no other symptoms other than the fatigue. So, we kept going. At first, it was every three months; but then, as her white blood count numbers started to increase more rapidly, it was every month. And it was probably around April 2018 when the doctors decided (and we went for a second opinion and they agreed) her white blood count was up. It wasn't crazy, crazy high, as some people's numbers get. But because of the count and because of her extreme fatigue, they decided that they would be a little more proactive and start with the rounds of chemo.

So, she went through her first round of chemo towards the end of April 2018. It was kind of funny because she had no reaction at all to the medication during the procedure. And we kept joking about, “Is there really medicine in that IV or is it just water?”



CLL Caregiving

But somewhere between the third and fourth week after that first round of chemo, she started to get some hives and some rashes. And it started to get a little more severe. So, they put her on some prednisone (Prednisone Intensol™, Deltasone®, Rayos®), which is a standard when you have a bad reaction.

Well, I guess the combination of the chemo in her system and the prednisone, the prednisone actually had the opposite effect. And my wife blew up like a--well, you can see in the pictures there. She ended up gaining almost 18 pounds of water weight. And it was really, really severe. Her eyes almost were shut. You can see how puffy her face is, and it was all over her arms and her legs. And it was disgusting. She was oozing all over the place.

So, of course, we went off the prednisone. And it took a good six weeks, maybe even longer, before she was totally normal again. But, interestingly enough, after the first round of chemo, her white blood count numbers went down to somewhere in the 4,000 range, which is incredibly low. And, of course, we asked the doctors and doctors just shrugged. They went like, I don't know. We don't know what to tell you. It happens. So, because this whole world with cancer is very much unknown.

They just said, well, maybe we got lucky. We'll just have to watch it. And, for quite some time, actually, for another year and a half, almost two years, her numbers stayed in the 6,000 to 7,000 range, which is below the 10,000 or 11,000 that's considered normal. And she was doing fine, but she still had the extreme fatigue. So, we're at a point now where her numbers are starting to go up again, not tremendously and not that fast, but here we go again. And, of course, it is leukemia and, unfortunately, you're stuck with it forever, until they come up with the wonder drug or whatever. So, it's been kind of a roller-coaster.

CLL CAREGIVER
SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA

Eric's Caregiving Story

LEUKEMIA & LYMPHOMA SOCIETY*

CLL Caregiver

For me, as a caregiver for my wife, I try to be as supportive as I possibly can. I'm kind of semi-retired now, so I'm able to help a lot more around the house and just be there for her more. But it's difficult because, from her side of it, it's leukemia. We just keep putting Band-Aids on it, until it hits again. Yeah, you can go into remission and, yeah, it can last years, maybe. But, it's just the unknown. And that's the biggest thing, the fear of the unknown. You just don't know.

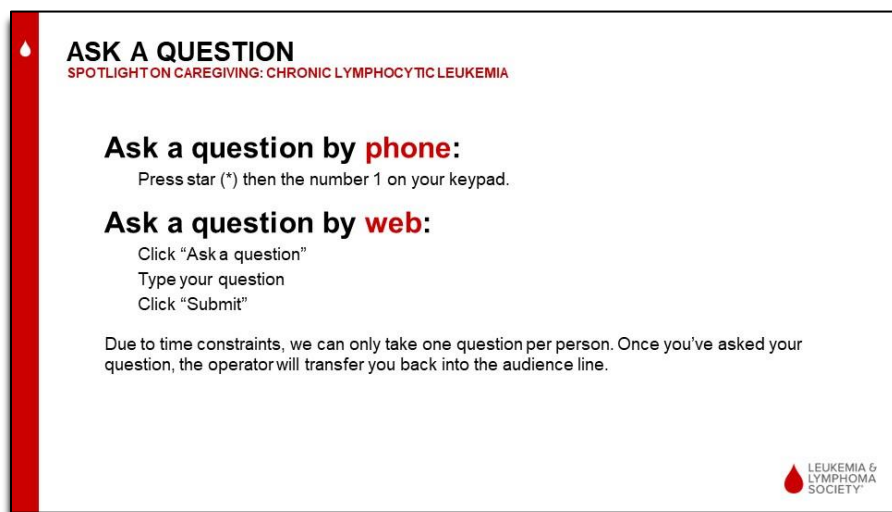
And it's tough. As her husband, it's like, what do you say? There's not much you can say or do, other than just to be there and support her. We all need hugs every once in a while, and that's what I do and try to do. And it's a double-edged sword for me because me and my whole family is heart disease. And I've already gone through two heart attacks. And with heart disease, it's a little more fixable. But it's still, never know when it's going to hit again. It could be five years, 10 years. You just don't know.

So, I've got to keep an eye on myself, so I can be there for her and, I guess, for both of us. Again, the biggest thing is just the fear of the unknown and what's going to happen when. And, at this point, it's made us closer because I have been very supportive. And I understand what she's going through because, from my own side of it, I have it as well. Because with heart disease, you never know. I even said to my cardiologist at one point, sometimes, I feel like a walking time bomb and because you just don't know.

And with CLL, it's a very similar thing. So, in that respect, we have that in common. But still, I can't worry about that because I do what I can to take care of myself, but I try to do as much as I can to take care of her and to be there for her. And, I guess, as a caregiver, it can be difficult. But, sometimes, you just have to chin up, and bear it, and be there because that's what it is all about. These are the things that you learn that's important in life.

So, we try to go out and enjoy things together. And, at this point, of course, the other issue that we have to deal with is the financial aspect of it. Right now, she's working, but she doesn't want to work anymore. But she can't retire until next year. And the problem is, if she stops working now and something were to happen--I mean, I don't know if you've seen any of the numbers for some of these treatments, but they can get pretty hairy. So, that's something that weighs on us, as well.

But, as they say in any of those programs, we take it one step at a time and just try to be there for both of us, for each other. And I guess the only one positive thing about this kind of leukemia or cancer is that it can be slowed down a bit. And as the years go by, we're seeing more and more new medications come out. And who knows, maybe we'll get lucky one day. Maybe there will be that magic pill that will either permanent remission or cure it, whatever you want to call it. And that's really all we can do.




ASK A QUESTION
SPOTLIGHT ON CAREGIVING: CHRONIC LYMPHOCYTIC LEUKEMIA

Ask a question by phone:
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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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Ask a Question

Lizette Figueroa-Rivera

Thank you so much, Eric, for sharing your story. I know that it is difficult, and I'm sure that Belinda is very thankful to you for all of your years of caregiving. I know that it isn't the easiest thing to share your story.

So, for everybody on the line that is asking a question or sharing their story verbally through our telephone, thank you so much. And, thank you so much for being here. As Dr. Amsellem says just taking time for you to be here today is taking time for you, which is very important, which I think was also part of Eric's message.

I do want to thank both speakers. It is time for our question-and-answer session. So, for everyone's benefit, if everyone can please keep their questions general in nature, without many personal details, meaning that we're not really taking disease questions today or treatment questions. These questions and concerns are from you as a caregiver, and we want to spend the time addressing any tips or any kind of support that we can for you, as a caregiver.

Now, Eric, you did mention fatigue, that your wife does have fatigue. Marcia is asking Dr. Amsellem: How do you deal with other family members who don't understand the fatigue your spouse feels when the CLL member continues to work? They think it's no big deal, and they can still do everything, when they can't. And fatigue is a very big concern. They expect her spouse to continue to do things that he's no longer able to do at this time.

Marni Amsellem, Ph.D

Absolutely, fatigue is one of the side effects, generally speaking, that is invisible, or it can be invisible, and so hard to understand. Why don't you just rest a little bit more and everything will be, everything will feel better. And it is very frustrating to deal with. But, then, to have the lack of understanding from others because it is pretty invisible.

And, perhaps, compassion from others makes it very challenging. So, you can never really ultimately shape how other people perceive experience, but what people are walking away from when people are understanding about the overall picture of how someone is doing, that is a bit outside of your control.

However, what is within your control is sharing what you feel could or might be useful, might be useful for some people to hear, even if that particular family member or whomever is not really, it's not really resonating with them, sharing with others and maybe also getting the support you need around that, as well. And, also, we are educators. We are educators of ourselves, and our own experience, and to others.

So, sharing what feels important to share--maybe having, I think having that family member be on this webinar today and just hearing about the impact of fatigue and putting it in the context of, this is a very common thing to happen, this is very frustrating, and this impacts how the energy that people then have to do other things like work, like attend family events, etc., that this is a very real thing.

And the other thing you can manage is your--try to manage--is how you're responding to that person. And you, again, if that person is not able to see it, all you can do is try to focus on the things that are a positive use of your energy, the people that are supportive, doing what you can, and trying to quiet the noise. So, I think that was a long answer to that question. I hope that was useful.

Lizette Figueroa-Rivera

Definitely. And, Eric, I know that you said that your wife does experience fatigue. Have you experienced this from other family members? Or, is there a way that you and your wife have been able to communicate that she does have fatigue due to the CLL?

Eric Weber

Well, to be perfectly honest, most of our family members have been pretty supportive. But we've encountered people, let me put it that way, who just don't get it.

And, we try to explain it, or I try to explain it because my wife doesn't want to deal with it because it's affecting her. And, it gets, in all honesty, it gets to a point where just people can be ignorant sometimes, and that's reality. And those are the people that you just stay away from. Because you have to take care of yourself. And if they're not giving you the positive feedback or help that you need, leukemia is a serious thing. And emotional well-being has a lot to do with your physical health.

So, I've learned over the years, even before this, that those negative people just don't need to be there. And, sometimes, it hurts. And, sometimes, it's tough. But you got to do what you got to do. It's not affecting them. It's affecting you and your affected person or family member, whoever's got the leukemia. And you become protective and just do what you need to do. And if it gets difficult, honestly, we've cut people off because it's just not worth it.

Lizette Figueroa-Rivera

Right. Like Dr. Amsellem said, you're quieting that noise. And I think throughout this COVID pandemic, I think a lot of us have really learned how to try to quiet that noise and get a sense of peace by doing something that we each can enjoy or can, like you said, relax us or bring us at peace.

I know that we're talking about family now. But, Barbara had a question, actually, she's saying that it is so frustrating to hear so many times that health care teams, when this does not exist for us. So, how can we make it happen?

There are a lot of folks that don't have a big healthcare team with extra supports, besides the doctor. So, Dr. Amsellem, how can Barbara get that extra support from other healthcare professionals?

Marni Amsellem, Ph.D

You showing up today, Barbara, is huge. LLS; other patient support organizations; gathering information; connecting with other patients, of course, or caregivers; building your network and perhaps sharing resources that way are absolutely tools.

And yes that is an important point that I'm hearing that, as a member of a healthcare team who is in a metro area, it's assumed that there is access. And it can be assumed. And that is not absolutely the case everywhere. So, recognizing all of these other resources outside of whatever the services are that you use, and also going back to the provider or having the patient ask if there are other resources that you can be referred to outside of what had been provided.

So, always asking, being curious and seeing, examining what is out there. And we do live in this age of information, which is obviously a mixed bag of what you're going to get. But there are a lot of great tools and resources and people to connect with out there. And I know that we're going to be ending with a slide that might also help address that question, too.

Lizette Figueroa-Rivera

Yeah, and Barbara, also, if there isn't a social worker, if you can ask for a social worker or a navigator within the healthcare system. And if they do not have, ask the doctor or nurse to find somebody in your community. Because they are very good at connecting you with different types of therapists, different types of healthcare professionals that could really assist you and your loved one.

Lizette Figueroa-Rivera

Dan is coming up with a good point, Dr. Amsellem, about faith and how faith plays a part in caregiving.

Marni Amsellem, Ph.D

Yeah, and I will reiterate that, that is very true. It absolutely does. Was there a specific question? I'm just looking in the queue to check to see if there was a question.

Lizette Figueroa-Rivera

It isn't mentioned. So, can faith play a part of caregiving for the patient, as it relates to community?

Marni Amsellem, Ph.D

Absolutely. Faith is something that, truly, it comes from within. It's something that we can utilize as a coping resource, truly. So, if we tend to rely on faith for any sort of challenge, navigating any type of uncertainty, this would be a fantastic time to also call upon faith and recognize that it's very much an individual journey.

But it's very much a part of coping for so many people. And that, absolutely, is worthy of talking about right now, in this way.

Lizette Figueroa-Rivera

Thank you. And, also, Patricia is asking about sleep. How can you tell if weird sleep patterns are just from being depressed, like sleeping so much in a day and staying up late or just CLL tiredness or fatigue?

Marni Amsellem, Ph.D

Well, certainly, there can be some screening done by healthcare, whoever the healthcare provider is. Perhaps, brief screen to kind of assess for other, assess for depressive symptoms. But a great point is raised, and that there is, of course, a lot of symptom overlap.

If sleeping excessively or really not enough, it can be a part of depression. But it also--sleeping a lot and feeling fatigue and low energy--is also part of CLL. How is it disentangled, an assessment for the individual, it's what I would recommend there.

Lizette Figueroa-Rivera

Thank you. The next question is a question about financial assistance. Tashi is asking, as a caregiver, are there financial assistance programs we can apply for as a caregiver or is the patient the only one who can fill out the application?

So, I just wanted to let Tashi know that we are having another webinar in regards to financial assistance programs, as well as financial planning, and that will be on June 21st. You can go on [LLS.org/Programs](https://lls.org/Programs) to find that program and register.

But we also have Information Specialists that can assist. We do have a section on our website called "Other Helpful Organizations" that also has other programs where there are financial assistance programs for not just the patients but people around the patient.

There have been some sibling programs for financial assistance. So, an information specialist can definitely assist you in finding some programs that would benefit you, directly, as well as everyone.

I just wanted to say thank you to everyone for providing questions. And, basically, I just wanted to ask Dr. Amsellem, as well as Eric, if you have any closing remarks that you wanted to say in regards to caregiving.

Marni Amsellem, Ph.D

Eric, do you want to start?

Eric Weber

Sure. I guess for me, the only really thing that I can say is your emotional health is almost as important as your physical health. And, as a caregiver, try to take care of yourself so that you can help take care of your significant other or whoever it is you're taking care of. And just be as supportive as you can and helpful. And just remember, you're not alone out there and they're not alone. And the more you make them feel, or your mate feel, that you're not by yourself, the better off, the better chance you'll have to win the fight.


Marni Amsellem, Ph.D

Well, I could not have summarized that any more succinctly. And I think Eric just hit on a very important points there. Take care of yourself. That is incredibly important. And offer yourself some kindness in there, too. This is a lot.

Lizette Figueroa-Rivera

Yes, it's very important to offer yourself, as a caregiver, that grace and that kindness. Thank you so much, both of you, for really sharing your time with us and volunteering your time with us, today.

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
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LLS Education & Support Resources

And, if we were not able to get to your question today, you can contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from 9:00 a.m. to 9:00 p.m. Eastern time. Or, you can go to LLS.org/InformationSpecialist. Or, email us at LLS.org/ContactUs.

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

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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

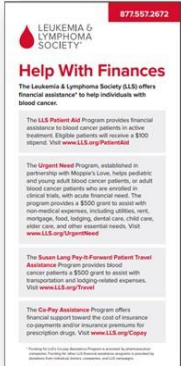


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You may find our caregiver chat at LLS.org/Chat, or our online community at LLS.org/Community. We also have free telephone nutrition consults for caregivers, as well as patients. To make an appointment, you can go to LLS.org/Nutrition.

Again, we'd like to acknowledge and thank Eli Lilly and Company for support of this program.


LLS EDUCATION & SUPPORT RESOURCES



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



LLS Education & Support Resources

I know there were many questions about financial assistance. And, in addition to visiting LLS.org/Finances, please listen to our webcast that's upcoming, as I mentioned, on June 21, 2022. And you may register at LLS.org/Programs.



Thank You

Dr. Amsellem, Eric, thank you both, again, for volunteering your time with us. On behalf of The Leukemia & Lymphoma Society, thank you all for joining us for this program. And please let us know what you need from us during this time--and take good care.