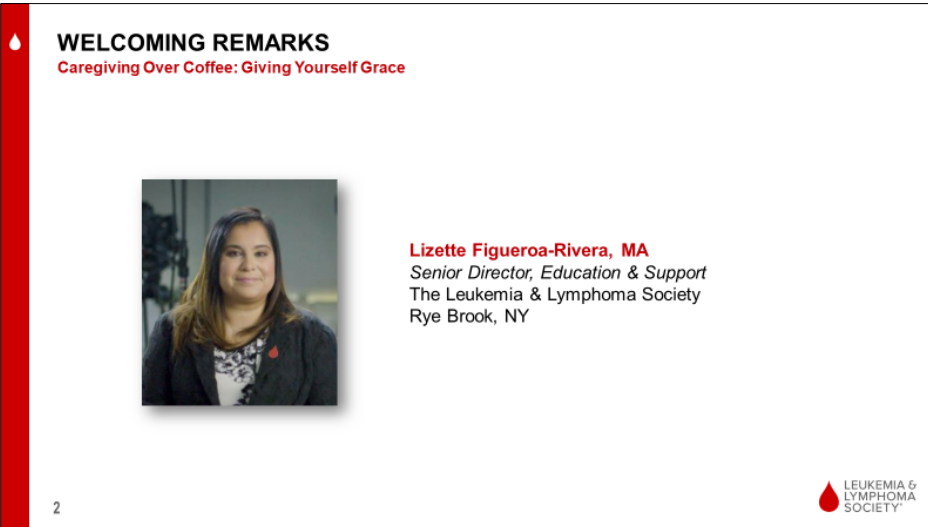


WELCOME AND INTRODUCTION




**CAREGIVING OVER COFFEE:
GIVING YOURSELF GRACE**

Mayra Gomez Padua, PhD
*Clinical Psychologist,
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San Francisco, CA*




WELCOMING REMARKS
Caregiving Over Coffee: Giving Yourself Grace



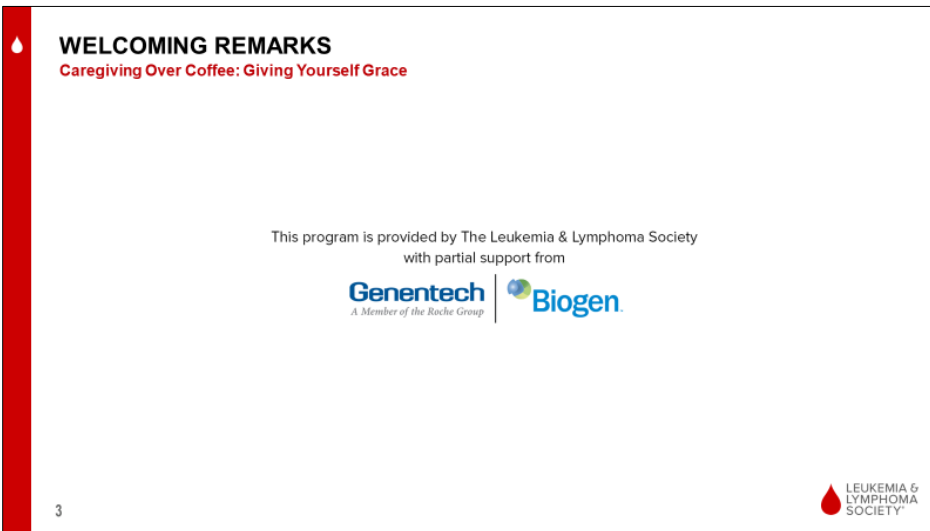
Lizette Figueroa-Rivera, MA
*Senior Director, Education & Support
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Rye Brook, NY*

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Lizette Figueroa-Rivera, MA

Hello everyone. On behalf of The Leukemia & Lymphoma Society (LLS), a warm welcome to all of you. Special thanks to Dr. Mayra Gomez Padua for volunteering her time and expertise with us today.




WELCOMING REMARKS
Caregiving Over Coffee: Giving Yourself Grace

This program is provided by The Leukemia & Lymphoma Society
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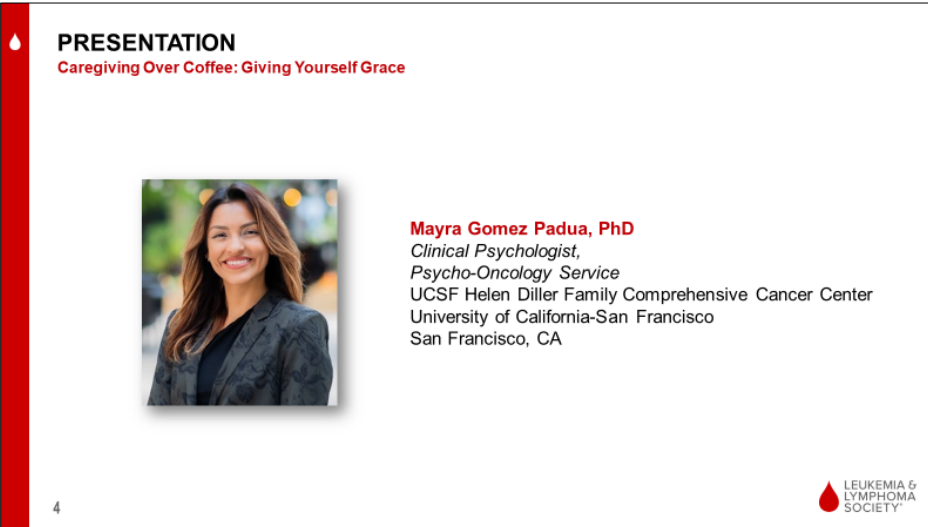
Today's webcast is provided by The Leukemia & Lymphoma Society with partial support from Genentech Inc. and Biogen.

Whether you're older or younger, you may find yourself in a new role as a caregiver. Oftentimes, caregivers are the ones that are contacting LLS first on behalf of the patient or loved one. LLS understands the important role you play as a caregiver and wants to ensure that we provide you with the support and resources that you need to be better able to take care of yourself as well as your loved one.


Dr. Padua will review who is a caregiver as well as the important role you play when caring from near or afar for someone with a cancer diagnosis. LLS continues to strive to be here for you, our patients and caregivers, throughout your entire journey. Please continue to inform us how we may serve you better.

Following the presentation, we will take questions from the audience. We are also taping and transcribing this program for future posting on our website.

PRESENTATION




PRESENTATION
Caregiving Over Coffee: Giving Yourself Grace



Mayra Gomez Padua, PhD
Clinical Psychologist,
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UCSF Helen Diller Family Comprehensive Cancer Center
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Lizette Figueroa-Rivera, MA

I am now pleased to introduce Dr. Mayra Gomez Padua, a Clinical Psychologist and part of the Psycho-Oncology Service at the University of California-San Francisco Helen Diller Family Comprehensive Cancer Center in San Francisco, California.

Dr. Gomez Padua, I am now privileged to turn the program over to you.

Mayra Gomez Padua, PhD

Hi, everybody. I just want to give a really warm welcome for everybody that is joining us today from all corners of this country, so thank you so much.

And, yes, so before we get started, I just want to start off by recognizing the difficulties that come with (A) having a cancer diagnoses, all that accompanies going through this cancer journey, including treatment and the impact that it has on loved ones and family members and friends; and, also, just want to honor our wonderful caregivers who are there to support our loved ones and the people who need the love and care and support at this time. So, this is for all the caregivers and the patients too that work with the caregivers in conjunction as both of these facets are a relationship.

WHAT IS A CAREGIVER?

- **Caregivers** provide emotional, physical, and practical support care
- **Informal Caregiver** – Usually a family member, friends, neighbor(s) who cares for a patient without formal training or compensation
 - Can receive compensation through Medicaid, Veteran, or Family Caregiver support programs
- **Formal Caregiver** – Professionally hired to provide care. Often trained in medical or nursing care. May have legal and ethical obligations as a part of their professional role. Compensated for their services

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And so, as we get started, I just want to first want to start off by describing, “What is a caregiver?” A caregiver is usually someone that provides emotional, physical, and practical support. There are two different types of caregivers. We have the more typical, informal type of caregiver; this is usually a family member or a loved one of some sort. This could be a friend, a neighbor, someone who is wanting to take care of the patient without any formal background or training and technically no formal compensation.

I do want to share that there are some instances where informal caregivers can receive some compensations, and this could happen through Medicaid, for example, where you have to go through an application process. Patients who are veterans and caregivers of those patients that are veterans can also apply for a type of program; I believe it's called the “Program of Comprehensive Assistance for Family Caregivers ([PCAFC] https://www.caregiver.va.gov/support/support_benefits.asp).” There are also other types of family or caregiver support programs, so I want to invite you all, for those of you who are interested in this, to kind of look into a little bit of what might be available within your county, state, or local laws.

Transitioning to the other type of caregiver, which is a formal caregiver; this would be more of a professional individual who is hired to care for the loved one. This person is typically medically trained, and they might have some expertise in some type of nursing background, and they also have to abide by some legal and ethical obligations as it pertains to protecting the patient and the patient's rights. And typically, these types of formal caregivers are compensated for their role.

CAREGIVER ROLES

- **Helping with personal needs** – Bathroom, bathing, mobility assistance
- **Assistance with day-to-day activities** – Transportation needs, food prep, housekeeping, managing bills
- **Support in the management of care** – Medications, care planning and coordination, managing side effects, reporting complications in care
- **Emotional and/or spiritual support** – Spend time with patient and listen to them, pray together, respect their decisions

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And so, caregivers can have all types of roles. It could be one of these that are listed above, or it could be all of these and more roles that are not even listed here as this is not a comprehensive list. But some of the roles that a caregiver can have could be helping the personal needs of a loved one. This could be anything between helping them take care of their own personal needs – bathroom, bathing, assistance with moving about from the bed onto a chair, or moving from the living room into their bedroom space; assistance with the day-to-day living tasks, so this could be transportation needs, any assistance with food preparation, maintaining the home, managing bills, anything of that sort.

Support can also be provided when it comes to the management of care, so this could be talking with the medical care team around the treatment plan of the patient, monitoring medications, any care planning and coordination, any decision-making when it comes to the next steps of the care, and also even managing some of the difficult side effects that may accompany the cancer treatment as well.

And this one is often one type of support that we don't really think about, but this is also a very important type of support system that involves really being present and emotional and both spiritually and emotionally communicative and caring for the patient as well. So this could mean spending time with the patient, with the loved one and listening to them, attending to their needs, discussing enjoyable topics including any hobbies, anything that might keep the relationship going but may also serve as a little bit of a distraction, because certainly everything revolving around the cancer and always talking about the cancer can feel very heavy, not just for the patient but also for the caregivers. So, this kind of encompasses everything.

BENEFITS AND IMPACT OF BEING A CAREGIVER

- **Emotional Rewards** – Deepening relationships, personal growth and fulfillment
- **Positive Impact on Patients** – Improve treatment adherence, increase emotional support, and better healthcare outcomes
- **Social and Community Impact** – Build awareness and advocacy, community development



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When we're thinking about some of the benefits that can accompany being a caregiver in a caregiver role, it can be particularly emotionally rewarding for those individuals to care for a parent or a loved one [or] a spouse in many ways because it can deepen the relationship because both of you or all of you are experiencing really trialed times, right, so that may call for deepening of the relationships.

It can invoke a sense of personal growth and learning a little bit about oneself and learning a little bit more about the patient and the person that you're caring for. And it might even bring up some fulfillment as well.

Other positive impacts can be to the patient as well. So, there's some research that demonstrates that when there's a good positive relationship between the cancer patient and the caregivers, that this can have an improvement in both treatment and adherence and can have improvements in both the emotional aspects. So, this could reduce symptoms of anxiety, symptoms of depression, and can help minimize a little bit of the stressors that accompany all the complexities of the journey that we've been talking about.

And, also, we want to think about the social and the community aspects. This could be a nice opportunity for caregivers to really learn about this process of not just caregiving but caregiving for patients with a particular type of cancer that they might be dealing with and learning a little bit more and becoming a little bit more informative on what would be beneficial both for the caregivers and for the patients.

Also, I want to invite you all to really tap into your communities because, really, community effort and really building a good quality type of support is going to be really beneficial in offsetting some of the stress that accompanies the role of being a caregiver.

CHALLENGES FACED BY CAREGIVERS

- **Emotional and Physical Stress** – Anxiety and depression emotional stress, grief and loss, exhaustion, neglect of personal health, chronic health conditions
- **Balancing Caregiving with Personal Life and Work** – Isolation, relationship strain, career impact
- **Potential Financial Strain** – Costs of caregiving, loss of income



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And when it comes to some of the challenges, these might be some challenges that some of you might be facing as well. This could accompany some emotional and even some physical stress.

Being a caregiver can be quite stressful. Not only you're seeing a loved one who might be struggling with symptoms or with the side effects or pain, and it's really difficult to observe a loved one deal with it. So, that may bring up a lot of anxiety or even depression and emotional burden of some sorts, there's stress that can accompany that.

And, of course, feeling the stress and anxiety can increase levels of exhaustion, and it can lead to maybe starting to neglect one's own needs and one's own desires to want to take care of the self. And so, as you're all listening today, I want to emphasize the importance of self-care because self-care is not only beneficial for you as a caregiver but also for your loved one. It's hard to be present for someone else if you're not taking care of yourself; so, I am a huge proponent of self-care.

And research does show that those caregivers who tend to have high levels of anxiety and stress and even levels of burnout can have higher risk for developing chronic health conditions, and this could even include problems of the cardiovascular system among others and even chronic pain.

Other areas that can be quite challenging for folks can be balancing all these different roles that accompany this journey. So maybe, for some of you, you might not just be only taking on the role of caregiver but there's other roles that you're also partaking in. Maybe you're a parent, you're a husband, you're working full-time, and so all of the stress that accompanies these different roles can make it hard to balance all of those activities and the busyness of the day-to-day life. And that can have a strain in both relationships with yourself and your relationships with your loved ones. It can have an impact with career, and it can even increase levels of isolation.

I want to also recognize that the caregiver role can be quite stressful financially both for the caregivers and patients alike. Unfortunately, cancer is an expensive disease and that accompanies a lot of stress. And so, recognizing that and understanding the challenges can make it a little bit easier in ways to help support you all in how to offset some of these symptoms and the stressors that accompany this role.

RECOGNIZING CAREGIVER BURNOUT

- **Caregiver Burnout** – A state of physical, emotional, and mental exhaustion that can occur when caregivers don't get the help they need or try to do more than they're able to
- **Signs of Caregiver Burnout** – Physical signs, emotional signs, behavioral signs
- **Causes of Burnout** – Unrealistic expectations, lack of control, role confusion
- **The Impact of Burnout** – On caregivers and on patients

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And so, again, I want to just emphasize this idea of burnout. Burning out is this idea of continuously working hard without any moment for self-care, any moment that can help you in reaching a little bit of rest. That rest state is so important for us to get back to a state of being activated and working again. And so, it can really bring strain on both the physical, emotional, and mental exhaustion.

Some of the signs of burnout to look out for are things like physical symptoms. If you're noticing yourself experiencing things like headaches, maybe increased levels of pain, even stomach upsets. Tension in the body is a very common one, around the shoulders, around different body parts. Even shallow breathing. If you're noticing that you're just not breathing enough or deeply, that could be a sign of burnout as well.

Emotional signs are also really important to recognize. Maybe you're finding yourself becoming easily irritable or annoyed or maybe you're just becoming a little bit more reactive when something triggers you in a way that's bothersome; you become really annoyed. All those symptoms can be an indication of burnout.

Also, it's really important to notice those behavioral signals. These occur when our behaviors or actions start to change. So, for example, if we're not reaching out to our loved ones anymore in the same way, maybe we're not as invested in our caregiver role as we were at the beginning; that could be a sign of burnout.

Also, the impact of burnout can be quite great both physically, mentally, and emotionally and it can also impact the relationship between the self, other family members, and the patient as well. So that can be pretty strenuous for people.

STRATEGIES FOR MANAGING CAREGIVER STRESS

- **Self-care Practices** – Sufficient rest, balanced nutrition, regular exercise and/or physical activity, hobbies, time for fun and enjoyment
- **Seeking Support** – Support groups, or supportive network of loved ones, counseling, psychotherapy, spiritual support
- **Time Management** – Setting priorities, delegating tasks, organizing daily schedules
- **Education** – Learn more to better understand and manage medical aspects of cancer care

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So, some strategies to manage stress-I want to emphasize these four pieces. The first part, again, self-care. What practices can you do to bring that love back to the self? Are you resting enough? Making sure that you're balancing the right amount of foods that you're ingesting in the body? So your body, I like to think of it as a temple and if you're treating your body by not eating healthy foods, then your body is likely to feel a little bit more sluggish, a little bit more tired, and may not be more equipped to make the decisions that your body can make when you're adding the healthy fruits and vegetables in.

Also, I want to emphasize exercise, moving your body, getting your body to move can both be physically and emotionally helpful. It helps combat any type of stress. Moving our bodies helps reduce levels of cortisol, and it helps bring up levels of other chemicals that help enhance our mood. So, this is really helpful to understand.

Also, doing things that feel good and enjoyable. If you enjoy having a bubble bath, go enjoy a bubble bath. If you enjoy some aromatherapy and lighting your house with candles, that might be something really pleasurable and something that can offset burnout.

Other things like seeking support. So, one thing that many caregivers tend to do is they're holding on to all the emotional stuff, all the tension, all the mental work that you're doing in your role as a caregiver. [However,] if you find yourself, that you're not talking about it, you're not sharing any worries or concerns, or even talking about your hobbies or things that have nothing to do with being a caregiver, that's also okay, too, and also very encouraging.

I want to also emphasize the importance of seeking psychotherapy, and I will talk a little bit more about when to seek additional support or professional support if need be.

Also, time management, how are you managing your time? Are you spending all your time on just work, work, work and no play? Is there something that you can do to balance those out, delegating tasks between other family members or loved ones that can help and spread the wealth when it comes to your caregiver roles. It's really burdensome for one person to be the sole caregiver. So, if

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there's an opportunity to take a little bit of a break, I want to invite you all that it's okay to do it, first of all, and, second, that it's a necessary part of the self-care process.

And so, lastly, in learning a little bit more about what it means to be a caregiver, understanding more of yourself and medically what might be going on with your loved one can be helpful in educating yourself so you can react and respond in a way that is effective and it's not driven by stress or fear or high reactivity. Because when we don't know something, we tend to really build it up in our mind and sometimes we can do something that we call "catastrophizing," which is we can make things blow up out of proportion without even being educated. And so, what would a little bit of information do for our mental and physical wellness? So, I want to invite you all to learn more about being a caregiver and about the conditions that your family member might be dealing with or loved one.

WILLINGNESS TO PRACTICE ACCEPTANCE

- When we feel a loss of personal control, we tend to hold on tighter
- Acceptance ≠ giving up, giving in or passive resignation
- Acceptance = recognizing the reality of the situation and finding ways to live a rich, fulfilling life despite challenges.
- TIPS
 - Acknowledge and make room for difficult feelings, thoughts, symptoms or circumstances without judgment
 - Practice staying present and grounding exercises
 - Shift your perspective
 - Expressive activities – journaling, talking it through etc...

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And so next I want to recognize that sometimes it really is difficult to cope with the emotional stress of not just being a caregiver but also seeing a loved one hurting. And so, a skill that can be important in starting to practice can be something like learning to build a little bit of acceptance. So, when we think of acceptance, it doesn't mean that we're giving up or giving in or we're resigning to the fact that maybe our lives are going to be this way or that our loved one might not get healthy or go back to "normal," which is something that many people think about. And so, this is the idea of how you can understand and hold space for something difficult. Is it okay to feel sad? Is it okay to have moments of anxiety and moments of stress? We don't necessarily need to push it aside or hide it or avoid it, but what acceptance really invites you to do is can you both sit with the anxiety and just recognize it for what it is? Because sometimes when we try to push these emotions aside that feel really scary, that's us trying to control our emotions and sometimes what tends to happen when we push things aside, what happens? They tend to come back. So sometimes just recognizing that these emotions are even existing can be a very powerful tool in allowing the experience to just happen.

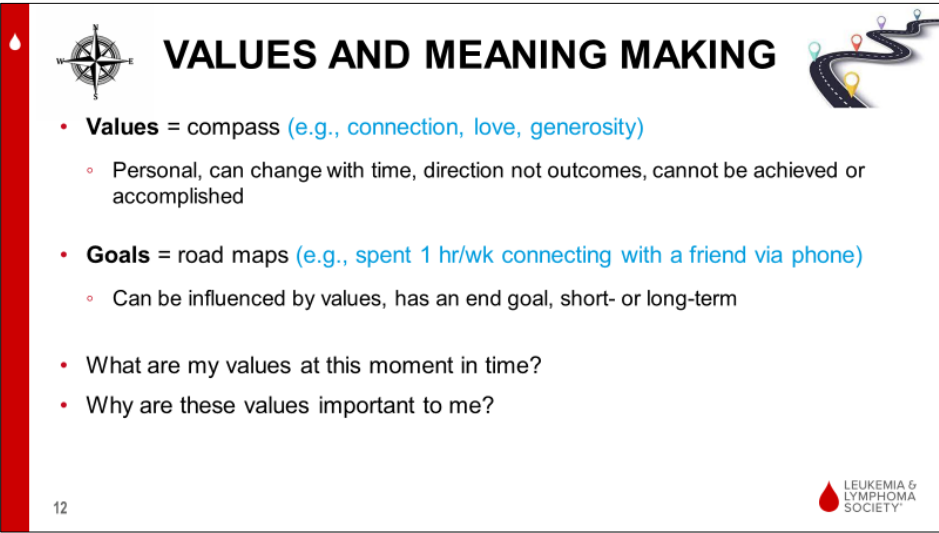
And so, again, acceptance is recognizing the reality of the situation and then finding ways that you can continue to live a rich and fulfilling life in spite of whatever challenges might exist. So this is both holding something that I recognize that this is a very challenging time and at the same time I can do something that is maybe within my reach to try to find meaning of what it means to be a caregiver or what it means to be with this person that I'm supporting in this time in my life.

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And so, some tips to really learn or start to incorporate a little bit of acceptance would be to acknowledge these difficult feelings, practicing staying present and practicing any grounding exercises. When we tend to feel overwhelmed, we emotionally can check out. And so, when we're emotionally checked out, that is an indication to us that we're feeling overwhelmed. And so, when we're feeling overwhelmed, the idea is can we tune back in, not tune out, but tune in to what your experience is? Noticing, "Huh, I'm noticing that I'm feeling some sadness." Not "I am sad," because the sense of I am sad can make it feel permanent. But if you change your thinking to, "Ah, I'm noticing that I'm feeling sadness", now that feels a little bit more separate. And from that way, you can practice a little bit of that grounding.

Shifting your perspective. Is there another way that you can think about the situation? Practicing gratitude, shifting your thought process: "I know this is difficult, and at the same time I also feel really grateful that I have the opportunity to be there for my loved one."

Expressive activities. Can you do something to allow that energy to flow which sometimes, as I mentioned, we tend to want to push it aside or not want to think about it or want to avoid it. But what happens, it always comes back. The emotions come back, sometimes even stronger. So, what that's telling us is that "Oh, we need to process a little bit of what's going on." And exercises like journaling, talking through it with yourself or with a loved one can be really powerful tools.




The graphic features a red vertical bar on the left. At the top left is a compass icon, and at the top right is a road map icon with a yellow lightbulb. The title "VALUES AND MEANING MAKING" is centered at the top. Below the title is a bulleted list. At the bottom left is the number "12", and at the bottom right is the Leukemia & Lymphoma Society logo.

VALUES AND MEANING MAKING

- **Values** = compass (e.g., connection, love, generosity)
 - Personal, can change with time, direction not outcomes, cannot be achieved or accomplished
- **Goals** = road maps (e.g., spent 1 hr/wk connecting with a friend via phone)
 - Can be influenced by values, has an end goal, short- or long-term
- What are my values at this moment in time?
- Why are these values important to me?

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Another aspect of acceptance can accompany finding meaning. Let's connect with values. What is really important for you at this time in your life? Why are you choosing to be a caregiver? And maybe even if you did not choose to be a caregiver, is there a way that you can connect with what it means to be a caregiver? How is this supporting you and teaching you something about yourself, about your relationship with your loved one, and about life? And so, I want you all to think about values in terms of a compass. Let's say, for example, my value is to connect with my loved ones, and so, how can I embody connection? And so, connection is my true north. And I want you to think of goals in terms of a roadmap. You know connection is important for you. I can say for me, as an example, connection is important for me, and I know that. I want to connect with my friends, loved ones, and even my colleagues. So, how can I begin to incorporate this into action? So, this is where the goals come in. Goals could mean, "Oh, maybe I spend some time a week calling my friends or calling my loved ones

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and spending time connecting with them and checking in to see how they're doing." So, as you see here with this example, my value of connection is what is my purpose of what I find important in my life, and my action is to demonstrate this by connecting with my loved ones by talking to them on the phone. And that's a way that I'm actively taking steps to move towards and move closer to this value.

Just because we have values, it doesn't mean we're going to reach them. I don't think we could ever reach a perfect level of connection or a perfect level of love or generosity. Those are lifelong goals and things that we strive for. And so, when we think of goals, those are a little bit more on the concrete end of things. Goals get us to those little, little steps. But, the overarching theme is, for me, connection and love and generosity; those are very important values, and I'm taking the little steps, the little goals, to ensure that I can make this happen.

So, I want to invite you all to just really take a moment and ask yourself, "What are my values at this moment in time?" And, in addition, "Why are these values important to me? How are they in service of helping you feel more connected with your life and with the people around you?"

VALUES COMMITTED ACTION

- Taking steps that are in line with one's values
- Setting small achievable goals that slowly move you towards what is important right now
- Example:
 - Values = Wellness
 - Why = "To stay mentally and physically connected with myself during these trial times"
 - Goal = To go on a walk 3x/wk for 30 minutes
- Identify barriers and find ways to modify goal to make it realistic and achievable

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And so now we're starting to get into steps, "What can we do to move in accordance to our values, move towards our values?" So, this means setting small, achievable goals. If your value is health and wellness, maybe your goal might be to go on a walk, a 20-minute walk, two times a week. And so, can you start with the little baby steps and eventually you can build up? And noticing what's within your reach, what's attainable, and what's actually realistic. Because one thing I want to say about this is that we tend to say, "Oh, yes, I'm going to go workout five times a week for one hour." Although that's a lovely goal, you want to ask yourself, "Is this achievable? Is this attainable? Is this within my reach?" And if it's not, it's okay to scale back. And so, I want to, hopefully, remind you to practice self-compassion. And just because you didn't go for the big goal, it's okay. Let's be kind to ourselves. And sometimes many caregivers are just so good at holding onto stress for everybody else in their lives. So just reminding you all to practice that self-compassion.

So, again, this is just kind of an example of how to practice this. Wellness is a value. Why is this value important? And, at the same time, what can I do to move towards this value of wellness? And so, you

see this example on the screen that talks about wanting to go on a walk three times a week for 30 minutes.

Another aspect of this is if you find yourself struggling, maybe you don't know what your values are. Asking yourself, journaling, checking in with yourself can be important. Maybe you want to ask yourself what is getting in the way of these barriers and find ways to modify these goals to make it a little bit more realistic.

WHEN TO ASK FOR EXTERNAL SUPPORT

- Significant changes in the frequency and intensity of mood
 - Sadness, anxiety, irritability, anger, hopelessness
- Significant changes in health behaviors
 - Poor quality of sleep, changes in appetite, decrease pleasure or interest in activities once enjoyed, inactivity, substance use, isolation
- Mental and emotional changes causes a disruptions in important areas of life
 - Relationships, work, day-to-day tasks etc...

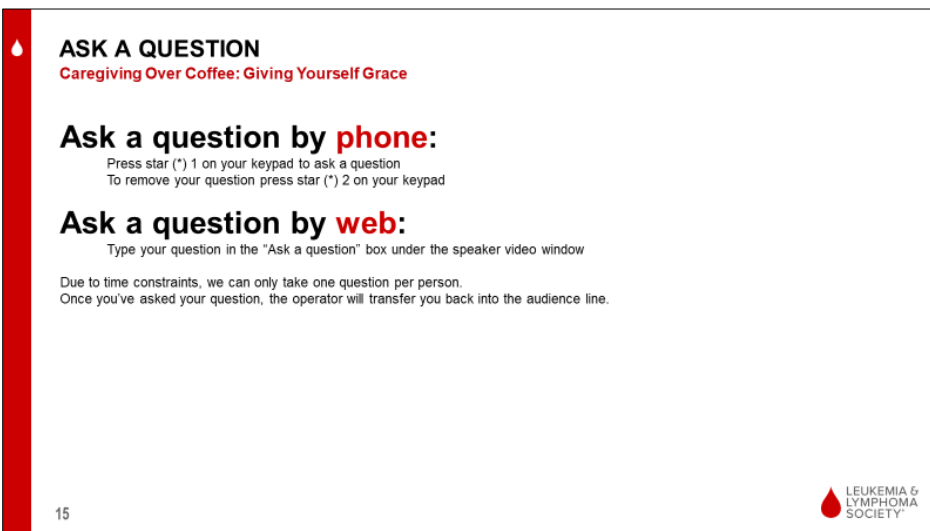
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And so, I just want to check in with you all before we get into the Q&A to ask yourselves, “When is it that I can reach out for additional support or for professional support?” This would be during moments when you're noticing that the emotional exhaustion is really intense, both in the intensity and the frequency of it. That might be a moment to reach out. When you're noticing significant changes in your behaviors – you're just not sleeping well, eating the same way, you're just not enjoying life in the same way. And, lastly, how are these mental and emotional changes causing a disruption in other important areas of your life – relationships, your work, your day-to-day tasks, etc.?

And so, I hope that this lecture was helpful for everybody, and I hope that we can get into some of the Q&A now.

QUESTION-AND-ANSWER SESSION




ASK A QUESTION
Caregiving Over Coffee: Giving Yourself Grace

Ask a question by phone:
Press star (*) 1 on your keypad to ask a question
To remove your question press star (*) 2 on your keypad

Ask a question by web:
Type your question in the "Ask a question" box under the speaker video window

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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Lizette Figueroa-Rivera, MA

Well thank you so much, Dr. Gomez Padua, for volunteering your time with us today to discuss the key role that caregivers play in a patient's journey. And, as you said, it is time for the Question-and-Answer portion of our program. And for everyone's benefit, if you can please keep your questions general without many personal details so Dr. Gomez Padua can provide answers that are general in nature.

Now, Dr. Gomez Padua is able to answer questions related to caregiving, so please understand that diagnosis and treatment questions should be directed to the patient's healthcare team as you and the patient would benefit more from a personalized answer.

And we'll start from a question from the web audience. We've had a lot of participants asking about this doctor, "How do you balance being a patient and a caregiver to another?"

Mayra Gomez Padua, PhD

Yes, that's a really great question and a really hard one. I think life accompanies a lot of different roles and so both being a patient and a caregiver can be really difficult. And so, I think one of the things I want to emphasize is communication. Checking in with yourself about what is it that you need at that time and communicating with others around the needs that you might need at this time. And so, I want to invite you to connect with the community, communicating with your loved ones, and also managing that self-care could be really important.

Lizette Figueroa-Rivera, MA

Thank you. And we'll take the next question from our telephone audience, please. [Operator introduction]

Elise from Florida

Yes, hi, and thank you for your presentation. I'd like to know what the doctor thinks of how you can handle when you feel caregiving is overwhelming – it's been 14 years since diagnosis and bone marrow transplant – and you feel at this stage of the game when you're in the elderly area and you feel like you're getting abused by the doctors for being old. Elderly abuse, for lack of a better term, and you don't get your questions answered, you don't get the proper care, how do you overcome that, doctor?

Mayra Gomez Padua, PhD

Thank you and thank you for being with us today. That's a really important question. So, I think it's really valuable to advocate for yourself and for your loved one. And if you find that maybe you're not feeling supported by your medical team and you might not be getting the answers to the questions you might have, I might recommend it's okay to reach out for a second opinion. Because at the same time, you are a consumer of your medical care, and you have the right to check in and you have the right to assess what other providers are thinking about your particular situation. Thank you, Elise.

Lizette Figueroa-Rivera, MA

Yes, thank you for the question. And our next question, "Can you discuss avoidance versus acceptance? How to move from one to the other?"

Mayra Gomez Padua, PhD

A beautiful question. Yes, some signs of avoidance can mean there could be mental avoidance or physical or behavior avoidance or emotional avoidance. So, if you're noticing that you're having a particularly hard thought or negative thought, for example – this is just random – "I don't know how long I can do this," for example. That thought can feel quite scary and quite stressful. It might bring up emotions of sadness and stress and anxiety and hopelessness. And so, a sign of avoidance is when you have these types of thoughts, you might want to push them aside. You're like, "I don't want to think about this. Let me distract myself with other things." You're actively doing things to not think about it.

But what tends to happen is that thought might eventually come back. So, this is when acceptance or holding a space of willingness to accept where you currently are and mentally or emotionally can be very powerful. This could mean by just noticing, "Oh, I'm noticing that I'm having this thought, and I'm noticing that it's bothering me and I'm going to sit with it for five minutes. I'm just going to allow my mind and my emotions to be in that space." And then after your five minutes, you can even set your alarm, and then you can tell yourself, "Thank you emotions, thank you thoughts for telling me that something feels dangerous, and something feels really scary and now I'm ready to move on." So, it's this balance of learning to sit with what is showing up for you at the time instead of constantly wanting to push away those things that feel really scary. And I hope that answered your question.

Lizette Figueroa-Rivera, MA

Thank you. And the next question, "My husband is in remission and needs much less help. I'm trying to step back from taking care of him, but it's difficult. I did it for two months when he was first diagnosed. I'm really not sure how to step back. Any recommendations?"

Mayra Gomez Padua, PhD

Yes, absolutely. I want to say that it's wonderful to know that – your husband – there's no evidence of disease just yet and that's wonderful to hear. And part of the caregiver role is recognizing what might be getting in the way of giving a little bit of independence to your partner back. And so, this might be a little bit of your own anxieties coming through or your own worries of, "What is it that my partner can and cannot do?" So, I want to invite you to check in with him and ask him and use this as a collaborative experience for both of you where you can give him a little bit of that confidence and that agency to make decisions on what areas of life he might need additional support and what areas it might be okay to step back. And honoring that could be important too. And also, recognizing that there might be a discrepancy between what the patient maybe wants to do and maybe what they're capable of doing, so I also want to invite you to maybe loop in the medical team and have a collaborative discussion of what you can do. That could be helpful.

Lizette Figueroa-Rivera, MA

Yes, thank you. And the next question, "How do you communicate to the patient you are caregiving for that you need occasional separation for self-care? How could you communicate that in a tactful way without them taking it the wrong way?"

Mayra Gomez Padua, PhD

Yes, that's a hard question, especially when there might be a really strong bond between the caregiver and the patient, and that relationship might even become a little bit more dependent. I think that in this moment, I think doing it by checking in with the [patient] and asking what time of day they might want your support a little bit more and what time of day it might be okay for you to step away. Also, I think that it's important to promote self-care and agency, so inviting conversations in the way that maybe the patient him or herself might be practicing their own self-care saying, "Oh, this might be a good time for me to practice my own self-care. And what can we do to honor that for each other?"

Lizette Figueroa-Rivera, MA

Yes. I think a lot of people on this call are experiencing that. I have another question, "Any advice on guilt as a caretaker? I work for a cancer organization. I write things for caregivers about self-care a lot, but now as an actual caregiver, it feels like a joke. Self-care is nearly impossible when you do take time for yourself, and you feel guilty about it. So, any advice on that?"

Mayra Gomez Padua, PhD

Thank you. Guilt is what we call a secondary emotion. Emotions like sadness, happiness, fear, those are what we call primary emotions, meaning they're universal and every human being in the world experiences it. But things like guilt and shame—usually they stem from a place of our thoughts. So, I want to invite you to really think about, “Ooh, guilt is showing up. What's causing me to feel guilty? Ooh, is it this thought that I'm not doing enough? Okay, let's explore that a little bit.” If this thought that I'm not doing enough is resulting in guilt, where did this thought even come from in the first place? Maybe this is something that we learned from our childhood. Maybe this is part of our culture, that part of our culture is that we are givers, and we don't take care of ourselves. So, recognizing a little bit of where this is coming from can be very powerful in understanding its trajectory but also coming into a place of, “Ooh, okay, now that I know that I am having this thought that's associated with this guilt, and now that I know that this thought is coming from this belief system, is there another way that I can think about it?” “How is this thought that I'm having and this emotion that I'm having flawed or unhelpful to me?” Because this feeling of guilt is just a feeling, but the thought of “I'm not doing enough,” is that really true? So you want to take on the role of being an investigator and ask yourself, “Ooh, do the facts really even say that, that I'm not doing enough?” And if the facts are indicating that, in fact, you're doing a lot, then that should help offset this feeling of anxiety.

Lizette Figueroa-Rivera, MA

Thank you. And we'll take the next question from our telephone audience please. [Operator introduction]

Shannon from Alaska

Thank you. As one of several caregivers, the patient seems to be kind of in denial of their prognosis. Is there a way to address conversations when everybody around knows things aren't looking great, but the actual person doesn't seem to really realize it or doesn't want to face it?

Mayra Gomez Padua, PhD

Thank you so much for your question. I want to just recognize that this is very difficult. What you're sharing is a very difficult thing to navigate, especially when the patient is not ready to address the circumstances at hand. And so, I think this could be a good place, if it's available, for the patient to seek a little bit of counseling to talk about it with somebody. It might be helpful. Sometimes patients feel uncomfortable, not wanting to discuss it with their loved ones who are very closely connected with many aspects of the care. So sometimes getting a third person's perspective, if that's available, can give them a little bit of an opportunity to really express what might be going on.

If that's not available at this time, it's okay. I think it's important to recognize that this avoidance I would want to call it, or not wanting to recognize what might be going on, it is stemming from maybe a little nervousness or a little fear. And so, checking in with them and asking them what you can do to support them—“Is there any specific questions that they have, is there any information that you can help provide for them, and what could you do to be there as they're learning more a little bit about what's going on?” But I think professional help at this moment could be a very beneficial thing.

Lizette Figueroa-Rivera, MA

Thank you. And the next question, “How common is it for the cancer patient to act angry towards the caregiver? That is what's happening in my case. I'm just wondering if that is a common occurrence.”

Mayra Gomez Padua, PhD

Yes, it does happen, and I think many patients respond to their condition in many different ways. Some patients may want to isolate. Some patients might feel angry and frustrated. And it makes me wonder where that anger and frustration is coming from. Usually, it might come from the shift in the roles. My assumption is maybe this patient was very independent and did a lot for themselves and maybe doesn't have the same capacity anymore and so that can lead to a lot of frustration and anger to the change in one's identity. And so, if there're any opportunities that you can have a conversation and invite a dialogue, that could be really helpful.

Lizette Figueroa-Rivera, MA

Thank you. And this question is actually from a patient, a leukemia patient. She says, "I have chosen quality of life over treatment. I'm 90 years old but my children want me to get treatment. How do I make the most of my time with them, so we don't just fight over treatment?"

Mayra Gomez Padua, PhD

Thank you so much for this question. And I think these are really difficult decisions, you know, definitely for the family and the loved ones but also for the patient, because I imagine you're having to navigate what's important for you at this time and trying to find meaning in how you want to live your life. So, I really want to invite you both, maybe you and your family can talk about values and checking in with each other about what's important at this time and what are the ways that we can make the most of our time together. Many patients find that this would be a time where you're just enjoying it with family, looking at old photos, reflecting on old stories, maybe spending time in nature. And also recognizing that the decision that you're making is okay and also recognizing that being a child and witnessing your parent make a difficult decision is really hard as well. So, holding space for both of these processes I think would honor where the two and where both sides and both perspectives are at this time. Hopefully, this was helpful.

Lizette Figueroa-Rivera, MA

Thank you. And someone is asking, "Can the doctor talk with me or does the patient need to sign a consent for the doctor to be able to speak with me directly?"

Mayra Gomez Padua, PhD

So as like for therapy if they wanted to do individual therapy? What do you mean?

Lizette Figueroa-Rivera, MA

For a caregiver.

Mayra Gomez Padua, PhD

For a caregiver. Good one.

Lizette Figueroa-Rivera, MA

Yes. Just wanting to know if the caregiver can speak to their loved one's physician or if that's not really allowed due to confidentiality. Just wondering in their role.

Mayra Gomez Padua, PhD

Oh, I see. I understand the question. Yes, it's a great question. I think caregivers can have different roles and one of the roles are being part of the medical team. And so, the caregivers, from a medical team's perspective, the caregivers are seen as an active member of the care team. So, this is a really important time where if your presence, if being active in your loved one's care is going to help enhance the treatment, improve the patient's quality of life, address any barriers that might be getting in the way of care, I think this is a really important thing. The patient needs to make a decision whether they're okay to have you present as the caregiver. A verbal informed consent will suffice in many instances. Some people, once that verbal consent is in place, it is documented. Also, you might be able to, with the patient's permission, add yourself to your medical team's messages. If, for example, there's some messaging or interchange happening over emails, over a medical record system, then that could be a way that you might be looped in. But I think it's more than okay, and I think as long as it's a collaborative effort, it's perfectly normal and acceptable for the caregiver to be present.

Lizette Figueroa-Rivera, MA

Thank you. And the next question, "I have a 39-year-old son with lymphoma. He lives in Florida, and I live in Colorado, so a long-distance caregiver. How can I find out resources available to him in Florida where he lives?"

Mayra Gomez Padua, PhD

Yes. I want to recognize that it takes a lot of effort to be a long-distance caregiver, so I just want to first recognize that. And I actually have a few patients who are caregivers for their parents who are in California, and so I oftentimes find that the caregivers are usually being helpful in managing the care from afar so that hasn't seemed like too much of a problem.

I think that if you look at some of those kind of nationally recognized organizations, if you can look through where your parent or your family member is getting care in whatever medical healthcare system, then that might be a good place to start asking the healthcare system what the local support is. Medical team members, nurses, they're often really good at knowing what's available locally, and so having conversations with them would be really helpful. I often find the simple Google search can be a really good way to find some community support that might exist.

Lizette Figueroa-Rivera, MA

Thank you. And the last question today, "I'm finding it harder to cope now that my husband is in remission. During treatment I didn't have time to reflect or think. Now that I do have the time, I can't stop worrying about the cancer returning. After your loved one is declared in remission, how do you process everything you've been through and what can help with the constant worry of return?"

Mayra Gomez Padua, PhD

Yes, a beautiful question. I think that this is a very common thing that during active treatment, the focus is on just getting better, healing, staying positive, go, go, go kind of mindset. And so, with no surprise, I just want to normalize that it does happen a lot where now it's time to reflect about all that stuff that you just went through; it's a lot, a lot. And so, I think that I want to also recognize the fear of recurrence is also very common, and it might be there. So, it's okay to hold and recognize that the fear and the worry is there.

TRANSCRIPT

Part of the ways to navigate the fear is looking into facts – what are the medical team stating? Is your loved one keeping up with their medical care? What preventative or healthcare activities can get you to help ensure that the healing process continues during survivorship and use that both individually but also collaboratively? How can you both work together to kind of get over the trauma of all that stuff that you just went through? But also talking about it if there's any survivorship groups, community survivorship groups, that would be a really nice place to talk and normalize all the things that accompanied the cancer journey and how the level of support changes once you're in the stage of survivorship.

Lizette Figueroa-Rivera, MA

Well, thank you and thank you for that question and all of your questions. And thank you so much, Dr. Gomez Padua, for your continued dedication to patients and for being able to present for us today.

Mayra Gomez Padua, PhD

You're welcome.

CLOSING REMARKS

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

Email: www.LLS.org/ContactUs

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



Personalized Nutrition Consultations
Talk to a registered dietitian about nutrition and more.

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

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Lizette Figueroa-Rivera, MA

And if we weren't able to get to your question today, you can call a Leukemia & Lymphoma Society Information Specialist at 1-800-955-4572. Information Specialists are available to speak with you from 9 AM to 9 PM Eastern Time and you can reach out to them at www.LLS.org/ContactUs.

You may also contact an Information Specialist to order a caregiver workbook which contains worksheets to help you stay organized and information and resources to use throughout the caregiving journey. You may also download the workbook and worksheets on our website at www.LLS.org/Booklets.

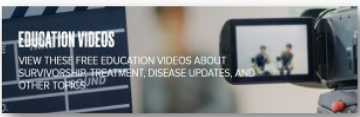
LLS EDUCATION & SUPPORT RESOURCES



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.



EDUCATION VIDEOS
VIEW THESE FREE EDUCATION VIDEOS ABOUT SURVIVORSHIP, TREATMENT, DISEASE UPDATES, AND OTHER TOPICS/ISSUES

Education Videos

View our free education videos on disease, treatment, and survivorship. To view all patient videos, please visit www.LLS.org/EducationVideos.



Engaging with Loved Ones: A Caregiving Story

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.

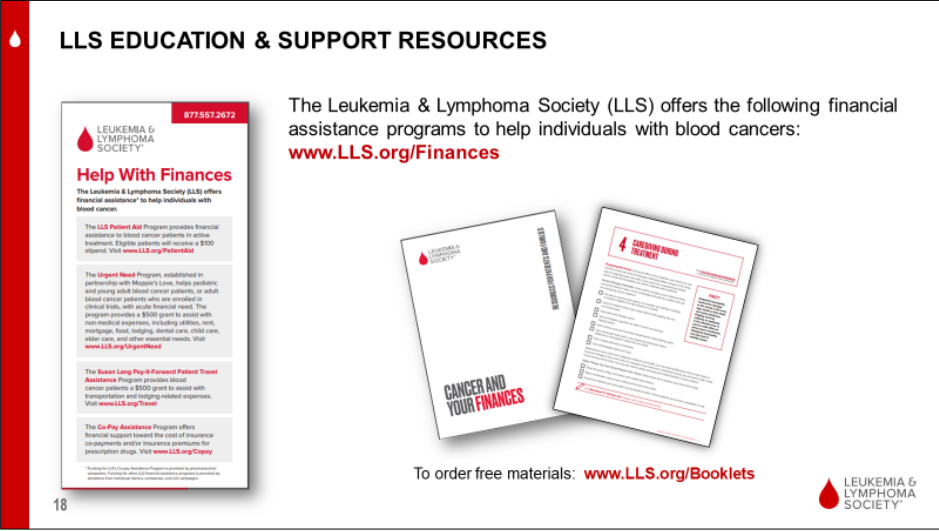
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Also, patients as well as caregivers can schedule a free personalized nutrition consultation with our dietitians at www.LLS.org/Consult.

And LLS offers a variety of education and support resources, including online chats, one specifically for caregivers, which are free live forums that are moderated by oncology social workers.

We also offer free education videos and podcasts.



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

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

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

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The Leukemia & Lymphoma Society offers financial assistance to help individuals with blood cancer. For more information, you can visit www.LLS.org/Finances.

And The Leukemia & Lymphoma Society is proud to partner with Dollar For, a national nonprofit organization that helps patients apply for hospital debt forgiveness and eliminate medical bills. Their services are completely free. Please visit www.LLS.org/DollarFor for more information. That's www.LLS.org/DollarFor.

Please note that continuing education credit is not being offered for this program.



Again, we would like to acknowledge and thank The Leukemia & Lymphoma Society as well as Genentech Inc. and Biogen for their additional support for this webcast.

And thank you, Dr. Gomez Padua, for sharing your knowledge with us today.

To all of the caregivers, patients and professionals participating in today's program, on behalf of The Leukemia & Lymphoma Society, thank you for sharing your time with us. Goodbye, and we wish you well.