



Slide 1: CAREGIVING OVER COFFEE: CARING & COPING



WELCOMING REMARKS
CAREGIVING OVER COFFEE: CARING & COPING



Lizette Figueroa-Rivera, MA
Sr. Director, Education & Support
The Leukemia & Lymphoma Society



Slide 2: WELCOMING REMARKS

Lizette Figueroa-Rivera:

Hello, everyone. On behalf of The Leukemia & Lymphoma Society, I'd like to welcome all of you. We have over 800 people participating from across the United States, as well as other countries, including Canada, Jamaica, Peru, and Romania. Thank you all for joining us today.

Dr. Allison Applebaum from Memorial Sloan Kettering Cancer Center in New York will discuss the physical, social, and emotional challenges for caregivers, self-care, long-distance caregiving, and quality of life for both you as the caregiver, as well as the patient.

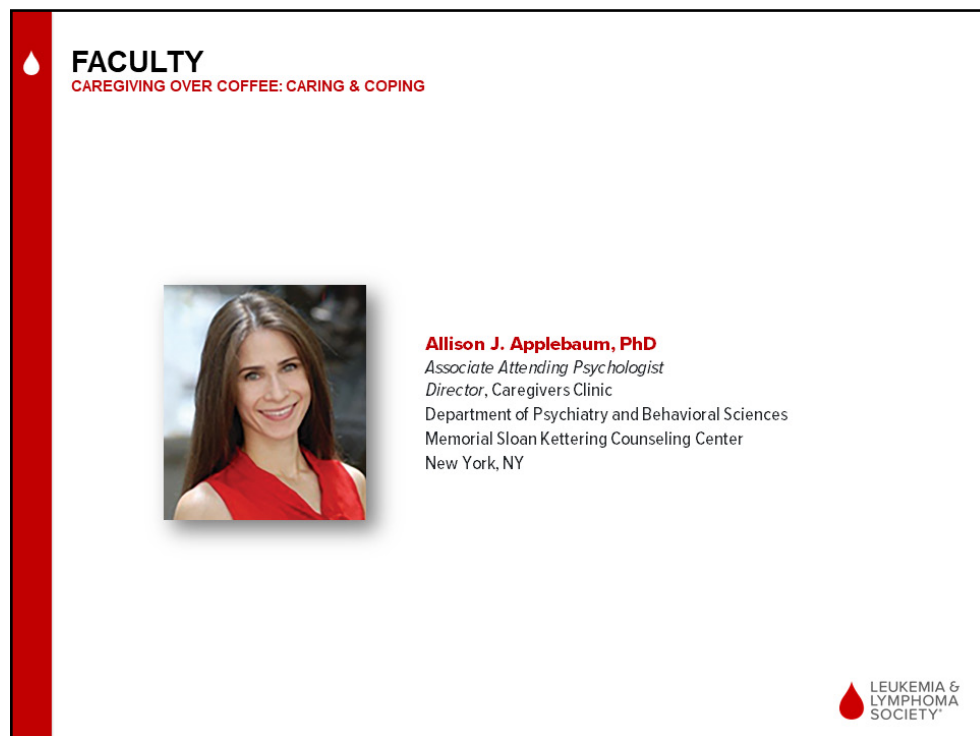
LLS helps you navigate cancer treatment and ensure that you and your loved one has access to quality, affordable, and coordinated care. Research will help us achieve the end to cancer.

In the meantime, you need help before, during, and after a diagnosis. The relationships between caregivers and people receiving care vary. Being a caregiver can be very challenging. We know that often you need to balance your work and family life along with the emotional, physical, financial, and spiritual distress as you help your loved one cope with a cancer diagnosis.


During this time, LLS wants to be here for you and your loved one. We continue to prioritize caregivers at LLS and have developed various offerings specifically for you, the caregiver. Our Caregiver Workbooks provide you with a wealth of information, tips, and activities to help you through the challenges of being a caregiver. You may view our workbook on our website at LLS.org/Booklets.

For this program we would like to acknowledge and thank Bristol Myers Squibb, Genentech, GSK, and Pharmacyclics, an AbbVie Company, and Janssen Biotech for their support of this program.


I am now pleased to introduce Dr. Applebaum, Associate Attending Psychologist and Director of the Caregivers Clinic at the Department of Psychiatry and Behavioral Sciences at the Memorial Sloan Kettering Counseling Center in New York. Dr. Applebaum, I'm now privileged to turn the program over to you.



FACULTY
CAREGIVING OVER COFFEE: CARING & COPING



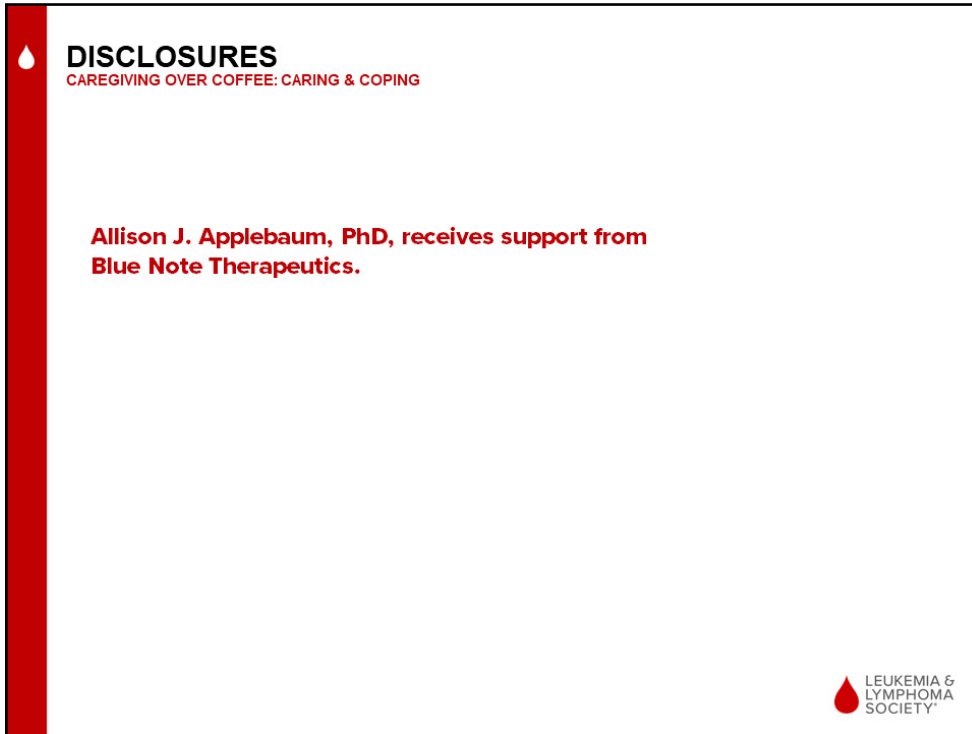
Allison J. Applebaum, PhD
Associate Attending Psychologist
Director, Caregivers Clinic
Department of Psychiatry and Behavioral Sciences
Memorial Sloan Kettering Counseling Center
New York, NY



Slide 3: FACULTY


Dr. Allison Applebaum:

Thank you so much for that and welcome, everyone. I have to start by saying Happy November National Family Caregivers Month. It's a perfect time for us to be doing this talk. I hope that you have your cup of coffee, your cup of tea, something that you can sip on while you listen.



DISCLOSURES
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Allison J. Applebaum, PhD, receives support from Blue Note Therapeutics.



Slide 4: DISCLOSURES

I want to acknowledge that I do receive support from Blue Note Therapeutics, but that relationship has nothing to do with anything I'm talking about today.



Overview of Talk

- Responsibilities and challenges faced by caregivers
- Common mental health concerns
- The benefits of professional help
- The benefits of caregiving



Slide 5: Overview of Talk (Skipped)

Former First Lady Rosalynn Carter:



*“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.”*



Slide 6: Former First Lady Rosalynn Carter

So, whenever I talk about caregivers, I always like to start with the words of Former First Lady Rosalynn Carter. She's very famous for saying that there are only 4 kinds of people in this world: those who've been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

And what this means is that we all as humans, we fall into this category and oftentimes repeatedly throughout our life, and so this is a role that touches us all. I know it touches everyone who's joining in today and perhaps this is not the first time that you have been a caregiver.

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Slide 7: NEW YORK TIMES ARTICLES

Before the pandemic, and I'm going to talk a bit about the ways in which the pandemic has impacted the experience of the caregivers, there was already a lot of attention put on the role of caregiving. And I looked at the New York Times to see the types of articles that had been published in the previous few years, and I want to share with you, this is about 25% of the titles of the articles that I found.

A shortage of caregivers. More caregivers are no spring chickens themselves. Daughters still are the caregivers. Caring for the Alzheimer's caregiver. Who will care for the caregivers? When the caregivers need healing. A living wage for caregivers. For some caregivers, the trauma lingers. The Millennial caregiver. My family cares for my sick aunt, who's caring for us? At 75 taking care of Mom 99, we did not think she'd live this long. Pressed into caregiving sooner than expected. Caregiving's hard enough, isolation can make it unbearable. Strategies for long distance caregiving. Medicaid patients' shift squeezes home caregivers. Training needed for home care is lacking. Daughters will suffer from Medicaid cuts. Caregiver plus MD or RN. Caregivers sometimes must sacrifice their careers. And my all-time favorite, bear with me, how getting high made me a better caregiver.

Now these titles speak to the range of challenges faced by caregivers and those that we as healthcare providers really need to address, from the financial toxicity of caregiving to the fact that many of you are providing care at a distance. The reality that the emotional toll of caregiving does not end with the end of one's caregiving journey.

What Do the 53 Million U.S. Caregivers Do?

- Assist with activities of daily living (ADLs) and instrumental activities of daily living (IADLs)
- Emotional support
- Nursing support
 - 72% of cancer caregivers and 56% of non-cancer caregivers perform medical/nursing tasks
- On average, caregivers provide care for 8.3 hours/day for 13.7 months; 22% provide care for 41+ hours/week
- Annual economic value of caregiving in the U.S. was recently estimated at \$375 billion
- *Caregivers are critical to our healthcare system.*



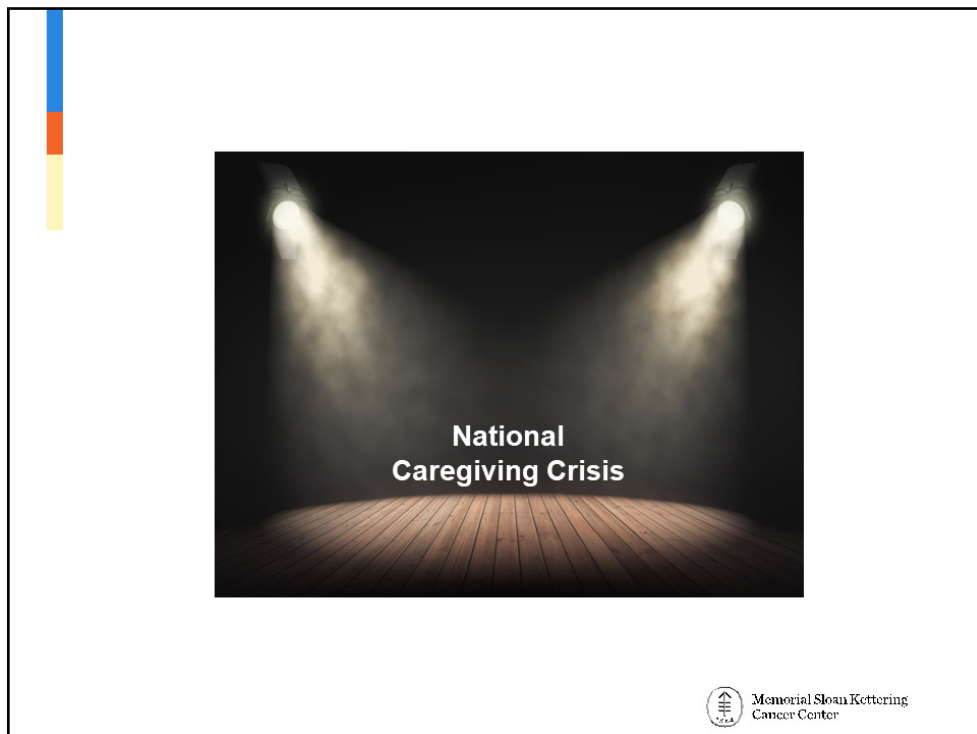
Slide 8: What Do the 53 Million U.S. Caregivers Do?

So what do the 53 million caregivers in the United States do? I just want to say this is an under-estimate. The 53 million was taken pre-pandemic and certainly we know there are more caregivers today. The last estimate was 2.8 million of these caregivers are providing care to patients with cancer.

So, caregivers provide assistance with what we call activities of daily living and instrumental activities of daily living, helping patients to live at home independently for as long as possible, helping patients to transport themselves to doctors' appointments, to cook, to eat, to take care of finances, and very importantly, caregivers provide emotional support. And this is oftentimes at the same moment when patients are no longer providing caregivers with the support that they once did. And so, we see a mismatch in support that's received.

Very importantly, and this might be the case for some of you, increasingly caregivers are providing nursing support. And in fact, the study by the National Alliance for Caregiving found that cancer caregivers, nearly 75%, were actually taking care of nursing tasks. These are tasks that historically were really delegated to trained medical professionals, and many caregivers were saying that they were doing these tasks without adequate training to do so, and that was certainly contributing to their distress.

In terms of time, on average caregivers are providing care for 8.3 hours a day for 13.7 months. So this is a full-time job, oftentimes conducted in addition to full-time paid employment. And almost one-quarter of caregivers are taking care of their loved one and providing care over 40 hours a week, which is just outstanding. And also incredible. And not surprisingly, based on these hours, the annual economic value of caregiving was estimated to be \$375 billion dollars. So certainly caregivers are incredibly important, they're critical to our healthcare system in the United States today.




Slide 9: National Caregiving Crisis

Not surprisingly, the pandemic has shown a bright spotlight on a significant role that you all play. We didn't need the pandemic to know that caregivers are important, but certainly the pandemic has really underscored the many responsibilities that you all take in taking care of loved ones, and particularly as patients have been receiving more and more care at home, there's more and more responsibility on your shoulders. And so it's not surprisingly that the majority of caregivers do experience what we call caregiver burden. This is an umbrella term for all the ways in which the caregiving role can potentially negatively impact the caregiver.

Caregiver Burden

- Multi-dimensional
 - Psychological
 - Anxiety
 - Depression
 - Post-traumatic stress disorder
 - Physical/Medical (19% report health is fair/poor)
 - Cardiovascular disease
 - Poor immune functioning
 - Fatigue/sleep difficulties
 - Higher rates mortality
 - Financial
 - Temporal
 - Existential



Memorial Sloan Kettering
Cancer Center

Slide 10: Caregiver Burden

The first component of burden is psychological and it's actually for this reason that I began the Caregivers Clinic here at Memorial Sloan Kettering Cancer Center back in 2011. So we know that diagnostic rates of anxiety and depression are actually higher in caregivers than the patients for whom they're providing care. We know that caregivers are certainly struggling with these concerns, so if you are someone who's struggling with anxiety or depression or even post-traumatic stress symptoms, I want you to know that you're not alone and these symptoms are actually quite normal. We have been seeing an increase in post-traumatic stress symptoms in caregivers as of the beginning of the pandemic.

The burden also includes a physical and medical component. Caregivers are at risk for their own medical challenges, including cardiovascular disease, poor immune functioning, fatigue and sleep difficulties, and in general having higher rates of mortality. A study by the National Alliance for Caregiving, this was pre-pandemic, 19% of caregivers said they rated their health as fair or poor in the lowest categories. And this is really a red flag for me, a red flag that we need to be paying attention to the health and well-being of caregivers.

Another component of burden is financial. So the phrase "financial toxicity" has been used again and again in discussing the financial impact of cancer care and the impact on patients, but I would like to acknowledge the fact that this very much extends to caregivers, and the financial impact of caregiving is quite significant and actually can last years and even decades after a caregiving journey has ended, and I know contributes to much of the stress that you all might be experiencing right now.

There of course is a temporal or time component to burden. Again, so many of you are basically giving all of your quote-unquote non-work or free time to caregiving. You're working much longer than 24 hour days, I know it. There's a significant responsibility here.

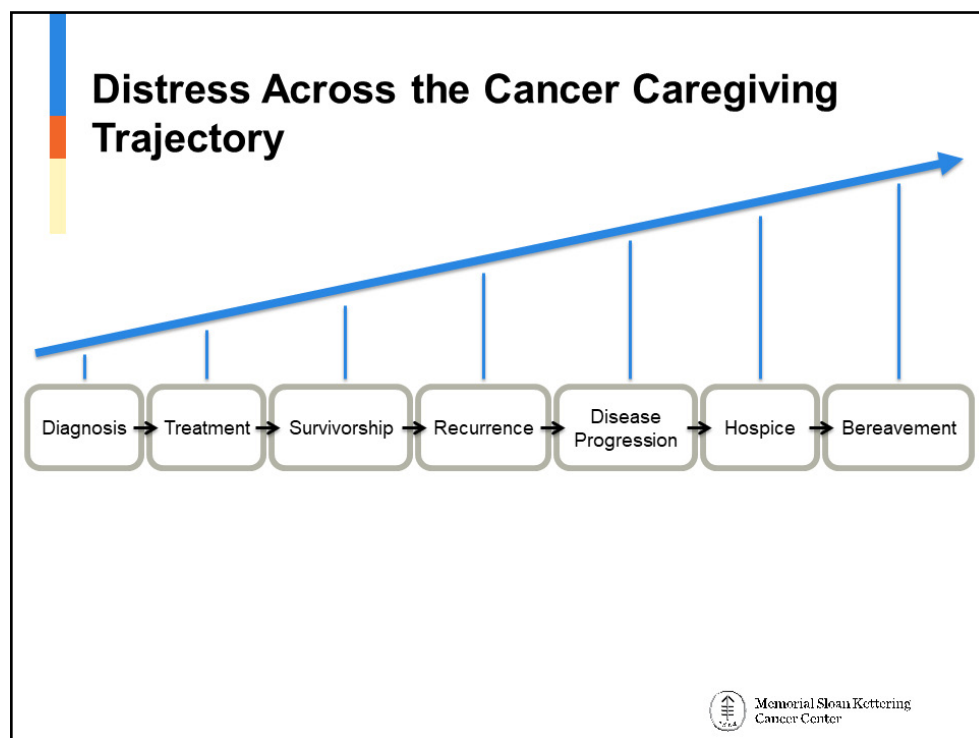
And all of this I think is complemented or balanced by what we call an existential component of burden. Existential distress is the distress that we feel when we take a moment and reflect on the fact that we are human. I think everyone listening here today or watching here today is human. We're all mortal. And we and our loved ones all will eventually die. And regardless of the type of cancer your loved one has, regardless of the type of treatment

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your loved one receives, regardless of what prognostic information you were or were not given by a healthcare professional, every caregiver has concerns about mortality, has concerns about the future, and this absolutely drives much of the burden and distress that we see among caregivers.

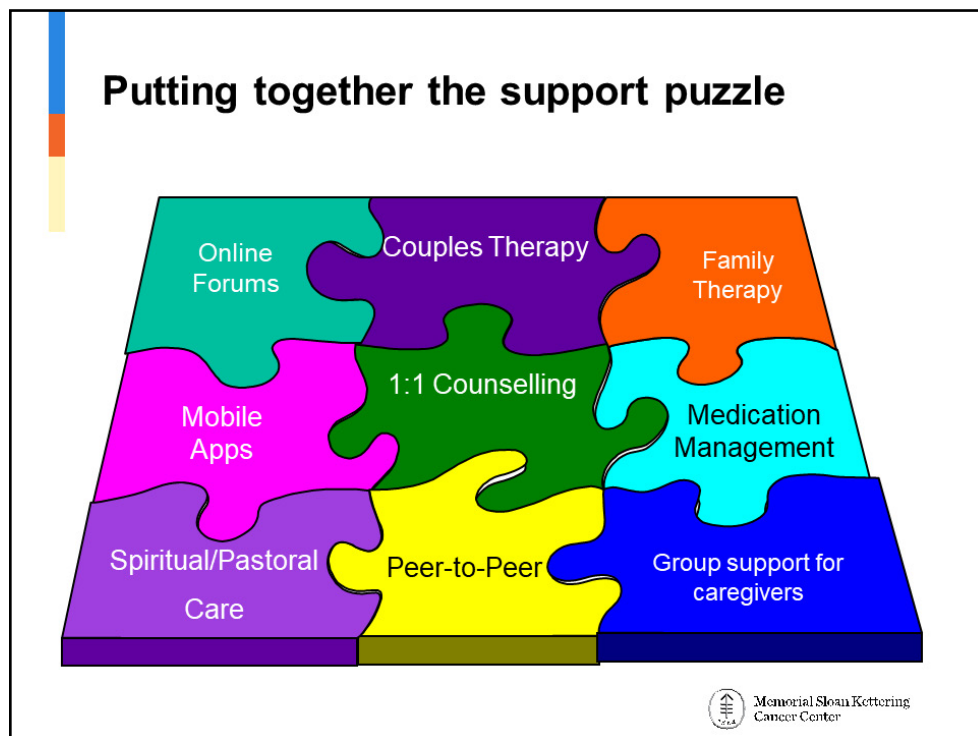


Slide 11: Distress Across the Cancer Caregiving Trajectory

Now, it's really important to acknowledge that when left untreated, distress increases exponentially across the caregiving trajectory. This is an entire trajectory in a situation from a patient's diagnosis through if treatment weren't to work in the future and a patient unfortunately were to decline and eventually die. But if we don't actually treat distress early on, we know that that distress increases.

I want to highlight some particular points for you on this trajectory. It's likely no surprise to anyone here that distress logically does increase as patients transition to hospice care and caregivers into bereavement, but I want to highlight earlier on this period called survivorship, which is a word that I think gets a lot of different definitions in the literature, but this is often a period where patients have finished their treatment and for many patients we actually see psychologically an improvement in well-being, an improvement in quality of life. Many patients will say to me I feel like I have a new lease on life, I've returned to my new normal, quote-unquote, things are great.

Paradoxically we actually see a very different experience in caregivers and I'm wondering for those who are joining us today if this might be the case for you. We actually see that in survivorship this is oftentimes the first moment when caregivers actually take an exhale, when they actually connect to all of the many negative emotions they might have been avoiding during the initial phases of their loved one's diagnosis and treatment, because actually there's no crisis in that moment, caregivers allow themselves to feel all of these emotions. And at that moment then there's a significant increase in distress. And so we actually see a very different response among patients and caregivers in survivorship and very importantly this is often a time when you and your patient, you and your loved ones who are the care recipients are not actually engaging so much with our healthcare system, with cancer centers, or with your cancer doctor, and yet this is at the same moment when you as the caregiver are really in need of support. So I just want to put this all on your radar. I think many caregivers feel like, well, he's doing fine, I should be doing great right now, and the truth of the matter is that it's usually when patients are doing fine that caregivers actually allow themselves to feel a lot of the negative emotions that are absolutely valid to feel.



Slide 12: Putting together the support puzzle

There's a lot of different types of professional and non-professional support out there and I want to highlight a few of these for you today, because there's a lot of options and now that we're in this, this world of virtual care and tele-medicine and tele-health and all of these webcasts, I think there's even more options out there. So I want to just briefly go through what these options are and who they might benefit.

So, the first of course is one-on-one counseling. You as a caregiver meeting with a mental health professional, such as myself, a clinical psychologist, or a social worker, or a psychiatrist, for one-on-one counseling. And this is certainly beneficial for individuals who are experiencing a high level of distress and really need to work out a lot of the different concerns they're having.

There's also couples therapy and in this context this is really beneficial when you are in a coupled or partnered relationship and one member of that dyad is the patient with cancer, and one member of that dyad is the caregiver.

If you are in more of an other familial relationship, let's say you are taking care of a parent or you're taking care of a child or a sibling, oftentimes family therapy can be very helpful. Family therapy is also really helpful if there are multiple caregivers involved in the care of the patient and you're having difficulty negotiating responsibilities. This is more often the case than not, and I'm sure resonates with some of you listening today.

Medications are helpful at certain times. There are certainly moments when having an antidepressant or an anti-anxiety medication can be very helpful in assisting you to cope with the challenges of caregiving. And I would just caution that medication should never be used in isolation, meaning just taking a pill is not going to take away the distress of caregiving, but taking a pill in combination with engaging and counseling or psychotherapy can actually be very helpful, and so this is something that the psychotherapist or the counselor or the provider you're working with can make a referral for you to speak with someone about getting medication, if they deem it fit.

There are many, many, many groups out there for caregivers and I say this with a little bit of a laugh because I think that there's many benefits to group support and there's also some challenges and dangers to group support. So, the benefit of group support is that when we are in groups with other caregivers we address one of the most important

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challenges caregivers face, which is that of being isolated and feeling alone and feeling like no one actually gets it. And being in a group could be incredibly helpful in addressing those concerns. The challenge, however, in some of these groups is when you have so many caregivers together, all of whom are experiencing incredible distress, it can feel (A) overwhelming, and (B) you might not feel like your voice is being heard and you're getting the support you need.

I have found that there are some groups that are more productive than others and those are what we call the closed groups. Closed groups are groups of caregivers that come together regularly for a set number of sessions with the same individuals in the group. So you're together with the same 6 caregivers for 8 weeks. Those could be great because you can really make deep connections with one another and get to know one another. Those are preferable to what we call the drop-in groups, where anyone can come at any time and you don't really know who's going to show up. And so, if you are looking for group support, I encourage you to look for what we call those closed groups.

I also encourage you to think about peer-to-peer counseling. And so, this means you are not going to be meeting with a mental health professional per se, but meeting with an individual who was a caregiver at some point in their life and who has a lot of expertise and information about the role. And here at Sloan Kettering we do have a peer-to-peer program where we match our current caregivers with our experts, those who've been in the role before, they're no longer in it, and they provide support. And it's much more flexible, and free of charge often, than meeting with a licensed mental health professional.

There's lots of mobile apps out there. I'm sure everybody has a smart phone and these could be great. I think that mobile apps are a wonderful complement to the type of therapy and support you can get with a mental health provider and a group, individually, family, or couples. A lot of these apps out there are particularly beneficial for learning, self-care strategies, meditation tools, relaxation strategies that can help you to calm your body. I think these are the best uses of mobile apps right now. But I certainly wouldn't want you to be relying just on a mobile app if your distress is particularly high.

I also want to acknowledge that a big component of receiving mental healthcare is also receiving some spiritual or pastoral support. Inevitably one's caregiving journey can evoke challenging questions that address our spiritual beliefs, our religious beliefs, our understanding of the world, the meaning of life, and so having support with a trusted spiritual or religious pastor or counselor can be incredibly helpful.

And finally, there are online forums. And so I want to say that online forums again, we could consider this an online forum, this is an opportunity to learn, to ask a question, there's lots of wonderful online forums where you can ask questions and be in big groups. But again, these are not the places for you to find really in-depth personalized care. I think they really need to be an adjunct to other support that you receive.

Common Reasons Caregivers Seek Professional Support



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

Memorial Sloan Kettering Cancer Center

Slide 13: Common Reasons Caregivers Seek Professional Support

So why might you want to come to see a clinical psychologist like myself, why would you be seeking support? Here are some of the most common reasons folks that come to the Caregivers Clinic here at Sloan Kettering.

The diagnostic category of generalized anxiety disorder, this is a fancy term for saying this caregiver has a lot to worry about and spends a lot of time worrying. I'm going to break this down for a moment because I think it's important to define what worry is. Worry is repetitive thoughts about the future, so it's future-oriented. And that's to be contrasted with rumination. Rumination is repetitive thoughts about the past. I personally have worried about at least 100 things in the past 20 minutes, especially the fact that my slides didn't work in the beginning, and my guess is you all have also worried about something in the past 20 minutes. We oftentimes don't feel like we have control over our worries. And sometimes those worries get really loud and they make it really difficult to focus on the present moment, and they take away from our capacity to take care of our loved one. And so, this is one of the reasons why folks come to see me and my colleagues and this would be a good reason for you to seek care.

Another reason is many caregivers find it very difficult to find a balance between taking care of a loved one and taking care of themselves. And often I will hear caregivers share with me feelings of guilt, like I shouldn't be here with you, Dr. Applebaum, I really should be home with my husband, he's the one who's sick. And learning to actually give oneself permission to take care of themselves is a very, very, very good reason to come in.

It should also be acknowledged that while certainly many of us, if not most of us, don't choose to be caregivers, we can choose certain ways in which we engage in this role, and we can choose ways in which we can integrate more of our own life, our own goals and our own needs into our caregiving journey. And so this type of concern is a good reason to speak with a counselor.

Another is dealing with insomnia and related distress. I would say of all of the concerns caregivers share with me, perhaps the most distressing is not being able to sleep. For many caregivers they have never had difficulty sleeping before their loved one had their diagnosis or treatment, but now their sleep is completely disordered. And oftentimes it's because of worry that sleep gets disordered, and so we do a lot to address insomnia and sleep concerns. And it should be said that if you haven't had a good night's sleep of course your mood is going to go down, it's going to be harder for you to function and it's going to be harder for you to take care of your loved one.

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Another big category that comes up is around communication. So many caregivers come to see me because they feel like it's incredibly difficult to communicate with members of the healthcare team and with their loved one. For example, they feel a lot of anxiety around having what we call advanced care planning conversations, talking about what type of care their loved one wants right now, what kind of care they might want in the future, and so we do a lot of communication skills training to help caregivers to feel more confident in their ability to communicate. Much of this work focuses on breaking what we call networks of silence. I'm curious if this resonates with any of you. So often caregivers will say to me I really don't want to talk to my husband about this because I know it's going to upset him if I bring up this topic. Meanwhile their husband, the patient, is seeing a colleague of mine down the hall and basically saying the same thing to my colleague, saying, well, I want to talk to my wife about this, but I really don't want to burden her. And so what happens is that family members or care partners are basically withholding certain information and preventing themselves from actually having very open and vulnerable dialogue. And so, a lot of the work we do is around helping to facilitate this type of conversation. And this is another reason why it's good to seek support.

And finally, support is of course needed to address that existential distress I mentioned, anxiety about death, anxiety about the future. This is a really, really good reason to seek care.



Slide 14: Self-Care

So, it's great to have professional support and of course it's very important to engage in self-care. So when should we be engaging in self-care? I can't hear you live answering me, but I hope that the answer that you all have is that we should always be engaging in self-care, okay?

What is Self-Care?

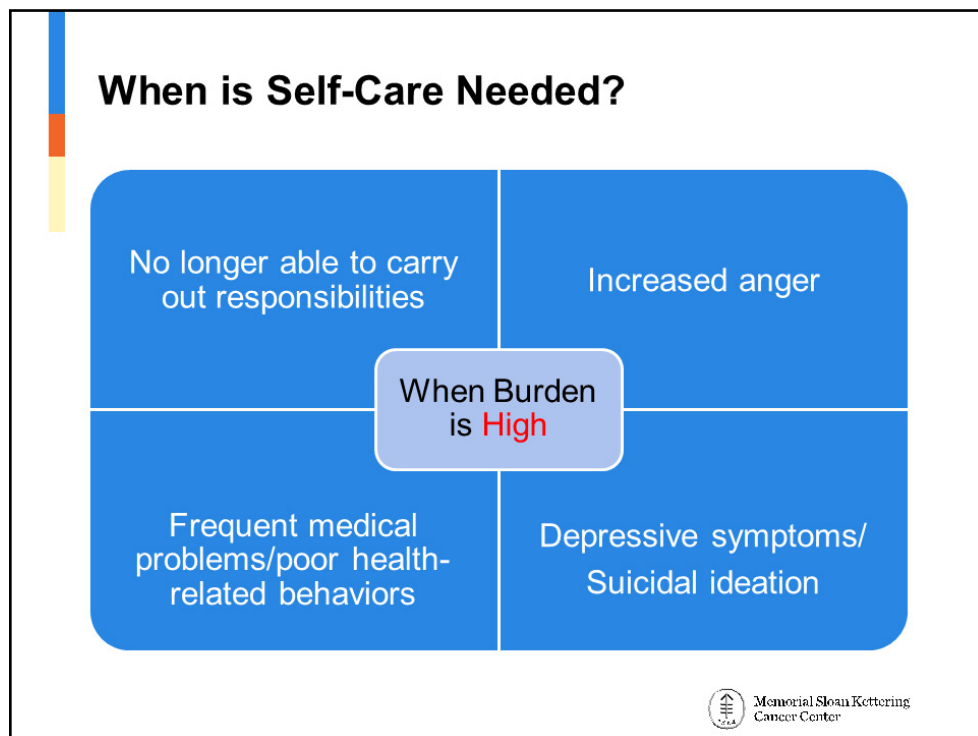
- Self-care is about being deliberate in taking time for yourself for the betterment of your mind, body and soul.
- Self-care is NOT about being selfish. It is about replenishing and refreshing your spirit in different ways.



Slide 15: What is Self-Care?

What is self-care? This is about being deliberate and taking time for yourself for the betterment of your mind, your body, and your soul.

Self-care is not about being selfish. It's about replenishing and refreshing your spirit in different ways. So many caregivers will say to me, I am so selfish for taking the time to come see you, or it would be so selfish of me to go to the gym for 2 hours when I know that he's going to be alone. The reality is that if we aren't actually taking care of ourselves, then we are going to just be even more depleted and it's going to be more and more difficult to take care of our loved one. So, it's important that we practice self-care every day, but it's particularly important that we are practicing self-care when burden is really, really, really high.



Slide 16: When is Self-Care Needed?

So, when burden is high. How do we know burden is high? You might feel like you're no longer able to carry out your responsibilities. You might be saying phrases to your friends or family like, I can't even keep my neck above water, I can't do this anymore. These are statements that indicate that you're really, really distressed and burnt out.

You might feel like you have a lot of anger, a lot of anger that's coming out for you in the context of taking care of your loved one, and that's totally valid and totally normal, but it's also a sign that you might need some space for expression of emotions.

I'm sure that everybody who's calling in today has had the experience that when you are feeling stressed and burdened, you get a cold or flu or in more recent times, harder to recover from COVID, for example, because your immune system is depleted. And if you are finding yourself having a harder and harder time recovering, you're more susceptible, this is also a moment when it's good to examine self-care.

And of course, very important for me to say, if ever you're feeling very depressed, if ever you have feelings that this is just too hard, life is too hard, that's a time when it's very important to take care of yourself and that will include, of course, in that case, speaking with a trained mental health professional.

Self-Care Tips

- Schedule self-care as you would a medical appointment or work meeting
- Integrate one self-care activity into every day, more on stressful days
- Take an honest look at your current coping strategies
- Think SMALL
- Make sure self-care activities are in line with good sleep hygiene



Slide 17: Self-Care Tips

So, I want to give you some self-care tips because very frequently I will have caregivers say to me it is just impossible for me to do anything else, I'm already working a 52-hour day. And I want to acknowledge that and I also want to make a point to say this, when I described self-care just now, I did not use the oxygen mask metaphor. My guess is you all are familiar with the oxygen mask metaphor, airplane, got to put on your own oxygen mask before taking care of anyone else, right? But the reality, and I'm sure many of you know this, when you are in crisis, when things are very difficult, it's impossible to take time to put on that oxygen mask. And I don't want to invalidate that fact. I want to acknowledge there are certain moments you can't put on that oxygen mask. So I want to qualify and say that this is for when you are not in crisis, this is for when you do actually have a moment to pause, have a little bit of space, this is when I want you to engage in self-care. And I want to give you some tips to make it a little bit easier.

And the first is I want you to schedule self-care as you would a medical appointment or a work meeting. Full disclosure, on my Outlook, on Thursdays at 12 noon I have blocked out for 15 minutes and I put in an appointment that has been recurring since 2015 when I was in the thick of my caregiving journey, and it says breathe. Have it on there as a reminder. I have those 15 minutes every week to myself, nobody can schedule something for me. And I want you to think about doing something similar. I want you to schedule it so that it's carved out and protected, so that you can have that time for yourself.

Also important to integrate one self-care activity into every day and more on stressful days. And by self-care activity I don't mean spending an entire day at the spa because you can't do that every day, if you can do it once a year that's amazing. I want you to really think small about it, but I do want you to do at least one thing for yourself every day. We are of course having unseasonably warm weather right now. I'm in New York City, I took an extra-long walk to work this morning to breathe in some of, I was about to say the fresh air in New York, but to breathe in the air of New York City before getting into my office, to feel the sunshine on my skin, that would be considered self-care.

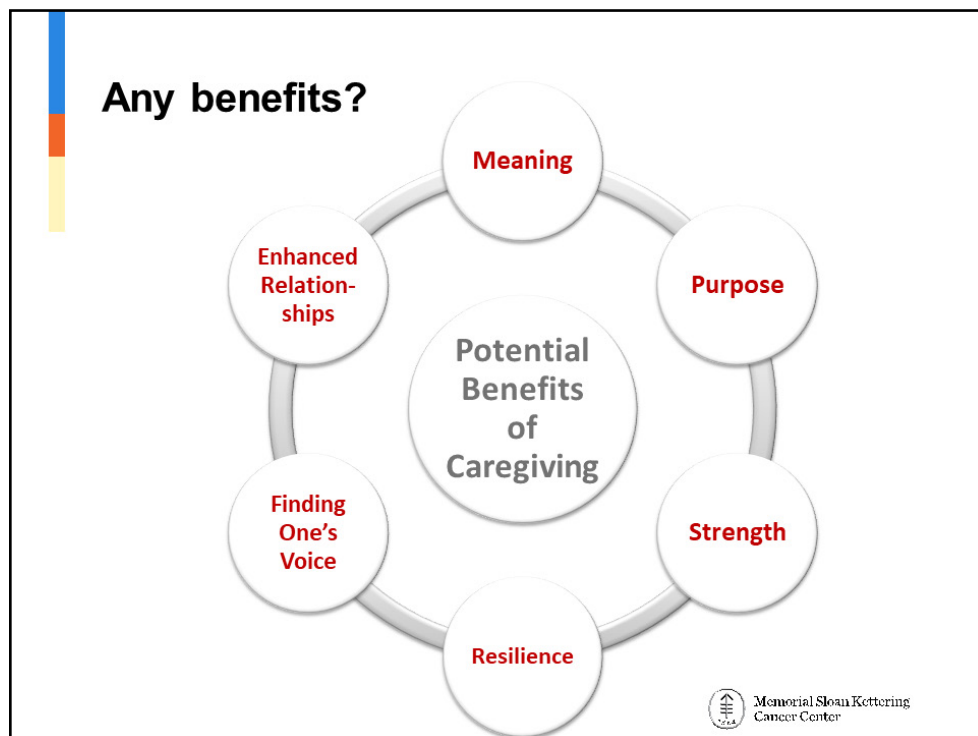
I want you to take an honest look at how you're coping. Many caregivers drink an extra glass of wine, many caregivers avoid thinking certain things, I want you to think about what you're doing to take care of yourself and what's healthy and what's not.

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I also want you to, as I said, think small. It could be as simple as having a cup of your favorite type of tea and drinking it while you listen to your favorite music. It could be reading a book at night for 15 minutes that is just an escape, or watching your favorite television program, something that you do just for yourself.

I also want to acknowledge, it's very important your self-care activities are not going to impair sleep hygiene. So sleep hygiene, it's an umbrella term, for all the things that we can do to help us to get better sleep at night. And one of the pieces where caregivers struggle is wanting exercise, wanting to take time to take care of their bodies at night, but then finding it difficult to both exercise and get to sleep at a good time. And we want to stop exercise at least 2 hours before bedtime, so I want you to consider if you are working out or exercising or going for some sort of activity at night, to at least create a buffer of 2 hours before the end of that exercise and bedtime.



Slide 18: Any benefits?

So, I just talked about the fact that there are many potential negative impacts of caregiving on your psychological well-being, on your physical well-being, on your financial well-being, on the time you have available, and I want to just end by acknowledging some benefits. And I wanted to start by saying that I am not talking about the power of positive thinking, I'm not talking about turning lemons to lemonade, I will be the last person on earth to ever deny the challenges of caregiving. Taking care of my father was the hardest thing I've ever done. But it was also the most meaningful. And my guess is for all of you, there is an opportunity to connect to meaning and purpose and some benefits. And I want to just acknowledge what these might be.

So for many caregivers they can, through taking care of a loved one, connect to a sense of meaning of life, or meaning in caregiving, or a sense of purpose. Many caregivers have said to me I was feeling lost before taking on the caregiving role and now I have a purpose, now I have a reason to be, something that keeps me going.

Caregivers have said to me that they never knew how strong they were until they became a caregiver. That it taught them how strong they were. And that now they can take those strengths as they move forward.

Caregivers, and many in bereavement, will say to me that they are feeling resilient. That, and in fact I'll even say that in the context of the pandemic, I've had so many caregivers say to me, and in fact many patients who have received stem cell transplantation for blood cancers, have said to me this pandemic, coping with COVID, this is nothing compared to taking care of my husband during his transplant. That the challenges of caregiving, the challenges that caregivers have faced have set them up for incredible strength and resilience. Doesn't negate the challenge, the hardship, the potential loss, but it is a possible benefit.

Many caregivers have said to me that they found their voice through caregiving. For example, one individual said that she was always shy, she was someone who was shy her entire life, but because she had to advocate for her cousin, she had to speak up in doctors' appointments, she found her voice, and that she was able to take that forward with her after her caregiving journey ended.

And finally, for many caregivers there's a possibility of enhanced relationships. And I want to say that this is not even

Caregiving Over Coffee: Caring & Coping

November 7, 2022 **Speaker:** Allison J. Applebaum, PhD

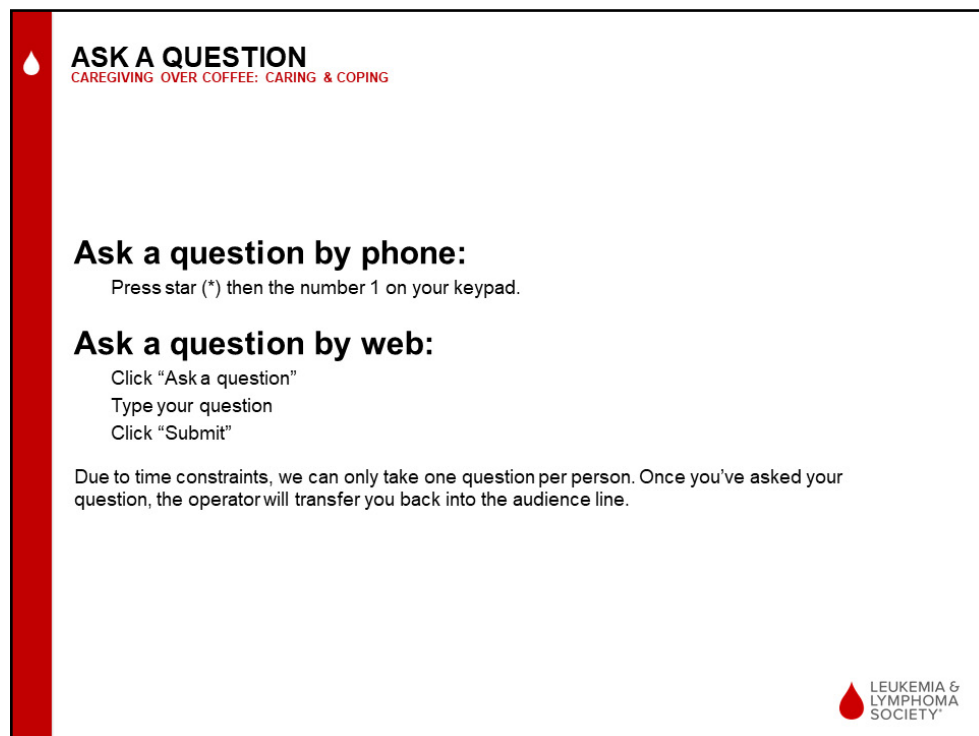


necessarily an enhanced relationship with the patient with cancer who you're taking care of, but for many caregiving highlights other people in one's life who are important, and yes, certainly you find out who your real friends are, you find out who's going to help, you find out who doesn't care. It's a great way to really figure out who's in your circle and not. But for many caregivers they do find a greater enhancement of their relationships with a select few, and these are individuals who turn out to be really, really close for the rest of one's life.



Slide 19: Thank You!

So I want to end on that point. I want to thank you all for joining today. I know it's hard, especially if you're currently a caregiver, to take time out of your caregiving responsibilities, and I know that we have a lot of time for questions and I'm looking forward to hopefully answering as many of them as possible.




ASK A QUESTION
CAREGIVING OVER COFFEE: CARING & COPING

Ask a question by phone:
Press star (*) then the number 1 on your keypad.

Ask a question by web:
Click "Ask a question"
Type your question
Click "Submit"

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



Slide 20: ASK A QUESTION

Ms. Figueroa-Rivera:

Well, thank you so much, Doctor, for the great information that you provided to all of our caregivers joining. And like you said, it is time for the question-and-answer portion of our program.

We'll take the first question from our web audience. Doctor, a caregiver is asking how can I be a good caregiver for a patient who is in denial? How to deal with my own feelings of frustration when my family member is in total denial?

Dr. Applebaum:

This is such a good question because this is such a common experience. I want to remind you that the only person that we have control over is ourselves. We cannot change how someone else thinks, we just can't. The only person we can really, really help is ourselves in this way, and so what I would want you to focus on, as opposed to trying to encourage or nudge the patient to get out of denial and face certain information, is to think about the different emotions that are coming up for you. My guess is that there's probably fear, probably sadness. I would encourage you actually to focus on giving yourself an outlet for these emotions.

Second, while it isn't your responsibility to help a loved one out of denial, it is the healthcare professional's responsibility to be honest and direct about what the future holds. And if you are concerned about what your loved one knows, doesn't know, thinks they know, confused about what they know, I encourage you to talk to the healthcare provider and have them share again any information you think is not clear. Hook that doctor into the conversation. I want you to take the responsibility off of your shoulders, you have enough.

Ms. Figueroa-Rivera:

Thank you so much. And we'll take the next question from our telephone audience, please.

Operator:

Certainly. The next question comes from Elise, go ahead.

Elise:

Thank you Doctor for your time. My husband is 13 years out from a bone marrow transplant and what's making caregiving exceptionally difficult, he's 76 years old right now, he was 65 or 64 when he started this process, and I feel that we are encountering a lot of age discrimination from the doctors, based upon comments, very derogatory comments, that have been made. And I'd like to know how to handle such a thing. It seems to be happening with all the doctors and the side effects right now have been harder with the graft-versus-host disease than actual diagnosis and transplant which was 13 years ago on November 2nd. Thank you.

Dr. Applebaum:

Elise, this is such a good question, so sorry to hear this is your experience, that's devastating.

Elise:

Yes, it has been.

Dr. Applebaum:

Just hearing your voice, you sound like someone who's outspoken, I want you to take your outspoken self and speak with patient representatives or some representative in the healthcare system where he's receiving care. Your husband should receive the same care anyone at any age should receive. Certainly as our bodies age, the ways in which we cope with certain symptoms, certain treatments, certain side effects can differ, but in terms of the value of life, the value of treatment, the importance of certain care, shouldn't matter if you're 50, 100, or anywhere in between. And so I want you to actually bring this up directly with someone who is in a position to actually potentially intervene. And I also would just encourage you, if you haven't brought this up with the people who you feel are discriminating against your husband, I encourage you to speak directly to them about what you're perceiving here. It's not okay.

Ms. Figueroa-Rivera:

I'm sorry you're going through this, Elise. And if you do need any support and advocacy, please contact us.

Doctor, the next question, I'm having trouble dealing with my loss of my sex life during this awful myeloma journey. I'm the caregiver. Any recommendations?

Dr. Applebaum:

Well, I'm really proud of whoever asked this question, I think we don't talk about sex enough in terms of the impact of caregiving on one's sex life, it's a part of what it means to be human, to have that part of ourselves. I think that many caregivers have said to me, you know, who am I to care about sex when, thank God, he's alive? And the truth is that, we as humans have these different parts of ourselves that are important, despite whatever is happening medically.

You know, I would encourage you to open a dialogue with your loved one about the difficulty you're having and a lack of an intimate life. And I would really encourage you to speak with him or her or whoever your partner is about what can be integrated into your life so that your needs can start to be met. There might be many physical or emotional reasons why your care partner is unable to engage in sexual activity, but those reasons may not prohibit that person from engaging in intimate activity that could be a little bit different. And so there's certainly room for negotiation. I should say

this is a really good reason to work with a mental health professional because talking about sex is difficult and it's great to have a mental health professional in the room. But I do want to just validate and say this is an important area and it's one that deserves attention. So thank you whoever brought that up.

Ms. Figueroa-Rivera:

Thank you. And the next question, can you please cover compassion fatigue and heartbreak syndrome?

Dr. Applebaum:

So, I am not familiar with heartbreak syndrome, I can sort of extrapolate, but I can certainly talk about compassion fatigue because it's certainly something both professional caregivers, healthcare professionals feel, but also we as caregivers for our family members and friends feel. It is really hard to, for a very long period of time, continue to give of ourselves to another. Earlier today I was meeting with some students and one of my students described himself as a caretaker. And I had to correct him and say no, no, no, we're talking about caregiving, because you are giving of yourself to another, you're not taking, that's the opposite. We get compassion fatigue when we give all of our resources to others. And when we bear witness to suffering on the sidelines, I want to acknowledge it can be very painful to watch a loved one suffer. It could be very painful to feel powerless. And this, over time, can very much wear on us. It's because of compassion fatigue in those moments that having opportunity to take care of yourself, taking small breaks from caregiving if possible, having others step in if that's possible, giving yourself a moment of respite, of change, integrating activities into the day or week that have absolutely nothing to do with caregiving, is really, really important.

Compassion fatigue, here's the flip side, I think there's a silver lining, which is that for many of us, the person we're taking care of is living longer and longer and longer because treatments are getting better and better and better, and that's wonderful. So that means that for many of us our caregiving journey isn't just 3 months long. For many of us it's a decade long or even longer. And inevitably that compassion fatigue is significant. So that's another great reason to speak with a mental health professional.

Ms. Figueroa-Rivera:

Thank you. And the next question, how do I cope with anticipatory grief? It just comes and goes.

Dr. Applebaum:

Whoever asked this question, the way you just described it, it comes and goes, this is spot on. So I describe anticipatory grief and waves of grief after an actual loss, as waves of an ocean. They come up, they hit you in the face sometimes, and then they come back out.

The best way to cope with anticipatory grief is the same best way that we cope with actual grief after a loss, and that is allowing that wave to come up, allowing it to be expressed, and then allowing it to go away. If the wave hits you, for example, for me when waves just hit me, I would feel a lump in my throat, I'd feel myself getting tearful, and then I'd want to hide it sometimes from my dad. And doing that repeatedly was not helpful. What is helpful is stepping out of the environment, giving space for expression, allowing yourself to cry, allowing yourself to talk about what's coming up for you. So the best way to cope with anticipatory grief is to express it. Find a trusted friend, maybe don't talk about it with the person you're taking care of, but talk about it with a close friend, talk about it with a therapist, write it out in a journal, record voice memos, put it out to the universe, I don't care how you do it, but get it out of your system. It's really, really the only way that we can helpfully cope. Otherwise what's going to happen, we hold those emotions in, down the line it's going to be harder to cope with them and the emotions are going to be even more intense and even more impairing.

Ms. Figueroa-Rivera:

Thank you. The next question, how do I deal with social ghosting? Some of our closest family and friends have not offered to help with anything and have not even checked in.

Dr. Applebaum:

This is so common, the social ghosting, this avoidance. Look, the reality is that everyone has their own priorities and for some individuals it is too emotionally draining to continue to support us as caregivers. It's too emotionally difficult to be connecting to the idea of caregiving, illness, and potential loss. And ultimately, I can appreciate that if this has happened to you, you might feel really angry and really sad and those are very valid emotions that you should feel and should express. And I want you to think about, so those people have totally disappointed me, who has pleasantly surprised me? Most caregivers can think of at least one person who has stepped up, even if it's in a small way and a way they never thought that they would, to help. And so maybe there's just a reordering of social network that happens. I think that's natural. So yes, it's devastating, it's really sad, but at the same time try to fight against it and sort of resist it, it's not a good use of your energy, you guys have enough on your plate. I want you to actually focus on who are the people who are supporting you, cultivate those relationships, connect with those individuals.

Ms. Figueroa-Rivera:

Thank you. And the next question, can you address the cancer patient who is also a caregiver? Can a job of being a caregiver increase the chances of the cancer to recur?

Dr. Applebaum:

This is such an important question, because increasingly caregivers are patients and patients are caregivers. But let me say this, there is no data to show that if you're a patient with cancer and you're also a caregiver, that your caregiving role and responsibility will directly make your cancer progress. There is no impact of caregiving on cancer. We don't have that data, that data does not exist.

Yes, caregiving is stressful, that's why I'm here talking to you all today, right? And so, if you are someone who is in a dual role of patient and caregiver, everything I've said has a brighter spotlight on it. You need to focus even more on self-care. You need to talk to a mental health professional. You need to keep up with your medical appointments. And by the way, you probably need, more than anyone else, to ask for help with caregiving. It might just be too much for you to do it all on your own. I encourage, if that's you, to delegate as much as possible.

Ms. Figueroa-Rivera:

We have a lot of people on the line who are saying that they feel alone in caregiving and sometimes it's really hard to ask for help. Do you have any tips on how to ask for help?

Dr. Applebaum:

I think it's interesting, right, where we're not taught to ask for help, it's not something we were taught in school. Simply putting it out there and saying, you know, labeling exactly what it is you need help with. So I think it can be overwhelming to ask for help in a general sense, like I need help with caregiving or I need help with taking care of my dad. That's an overwhelming statement. But I could find it easier to say something like, I could really use some help with cooking him dinner this week, could you assist? So I think for those of you who are struggling with asking for help, I want you to come up with specific asks. Make it as tangible and direct as possible, so that you can get the help you actually need. I think that's the other piece, is that there's a lot of people who probably want to help, but if you're very general about needing help you might not get it. But if you say, you know, I could really use somebody to help him to

get to his doctor appointment on Tuesday morning when I have a work meeting, can you do it? That's going to be more likely to get you the support that you need. So I actually encourage you just to be specific with your asks, take a deep breath, and ask. It's incredibly courageous to ask for help. It's not an admission of failure, it doesn't mean you're a bad caregiver, it doesn't mean you're an incompetent caregiver, in fact it means you're an incredible caregiver who wants to do the best that they can.

Ms. Figueroa-Rivera:

That's great advice. We'll take the next question from the telephone audience, please.

Operator:

Thank you. Our next question comes from Loretta, go ahead.

Loretta:

Yes, how can I get my husband to go to get tested at his doctor's appointment, the dementia? I feel that he's in early stages of dementia. He's also half deaf and it's very borderline, sometimes he's clear and sometimes he's totally unclear. And he doesn't remember what day it is and there's signs of dementia definitely. The direct question is how can I get him to go to get tested at a doctor's appointment, if I specifically say it's the dementia?

Dr. Applebaum:

I think it's often very difficult for the people we're taking care of to take suggestions from us as caregivers, but easier to take suggestions from healthcare providers. And so I don't know if there's a primary care physician who's involved in his care, but I would encourage you to speak with that individual or someone who's really in charge of his care and bring it up the fact that you're noticing these neuroconcerned and you think it could be helpful to have what we call a baseline neuropsychological assessment. And it might be more productive to have that doctor say to your husband, we'd love to integrate this type of testing into your routine care. I'm guessing you probably already tried, but if not, I think the best thing to do is actually hook the healthcare provider in, because that person is actually going to have to sign the referral for you.

Loretta:

I see. Okay, thank you so much for your time and effort, I certainly appreciate all your help, thank you.

Dr. Applebaum:

My pleasure.

Ms. Figueroa-Rivera:

Thank you, Loretta. The next question, my spouse is progressing in her blood cancer treatment and her doctor will soon be testing for her remission status. However, my spouse can't seem to move out of thinking of themselves as fragile, and likely to become very sick. They're very accustomed to me and everyone around them thinking of them as sick and fragile. What's a helpful response to this situation?

Dr. Applebaum:

This is really interesting. So there's something about the patient identity being fragile and weak that your spouse has taken on. I think that it can be very scary for patients who've been through a lot, who have had experience with being

fragile and sick, to then move into a survivorship phase or to move into a different phase of treatment, and to let go of a certain part of their identity.

The best thing you can do is, there's 2 steps. One is what we call validation. Acknowledge what she's saying to you. I know that you feel fragile, I know that you feel weak, I know that this is hard for you. You want to validate what's being felt and said. But secondly, you want to encourage a shift. So I know that you feel weak, I know you feel run down, I know you feel all these things, but I see you getting stronger. Or, that it sounds like the medical team sees things changing. And start to see if you can help her with her thinking.

I will also say that this type of thinking, this process I just shared with you is what we call part of an approach of therapy, a therapy approach called cognitive behavioral therapy. And so, she may really benefit from working with a trained CBT practitioner, cognitive behavioral therapist, who might be able to help her in her thinking about what it means to have a transition in her identity in terms of care.

But, it's always important to validate, validate, validate, acknowledge what's being said, and then also gently suggest a shift in perspective.

Ms. Figueroa-Rivera:

Thank you. And the next question is about spirituality. How do I address the patient's belief that spiritual faith over seeking out medical or drug options is what's going to allow them to beat their diagnosis?

Dr. Applebaum:

This is really a hard one, it's a common concern brought up. Many patients who hold tightly to certain spiritual or religious beliefs feel that those ideas and beliefs are going to help them medically versus engaging in traditional Western medicine. And what I would encourage you to do is acknowledge the benefits of both of them together. So I would encourage you to acknowledge the benefits of prayer, the benefits of spiritual practice, whatever those are specifically for your loved one or your care partner, and the importance of integrating what we know works in terms of Western medicine. They don't need to be mutually exclusive. So I encourage a discussion around can both happen, does this have to be either-or, can you go for the transfusion and engage in this sort of spiritual practice, can they both happen at the same time or can they both happen concurrently. So I really encourage a sort of "both-and" approach.

I think that for many of us, having a strong spiritual identity, religious faith, can be very beneficial and I never want to negate that. I would never want you to prevent your loved one or your care partner from engaging in these things. But it's not a replacement for the types of therapies that we have, that we know work in terms of medicine.

Ms. Figueroa-Rivera:

Thank you. And the next question is about challenges to being a caregiver to your young adult child. So how to be present, yet not overbearing, because you're the only caregiver and you're afraid to distance yourself from your adult child.

Dr. Applebaum:

It's tricky because I think that the relationships between parents and adult children, they change over time. It's one thing to be a parent, it's another to be a healthcare proxy. I'm making an assumption that that might be one of the roles you have.

I think the best approach here is open communication with your adult child. Maybe you start by saying something like I love you so much, I want to do everything I can to take care of you, and I don't want to push you away, what are the

best ways in which I can take care of you? Or, negotiating with your adult child around what are the certain elements of caregiving that are most important that you take care of. I don't know, for example, that your adult child has a close friend or romantic partner who might also be involved, but there might need to be a negotiation around different roles. But I think the best thing that you could do is actually just talk openly about it, sandwich in I love you so much, I want to take care of you, I don't want to push you away, can we talk about how I can do that? You're really inviting a conversation in.

Ms. Figueroa-Rivera:


Thank you. And our last question today, when you cannot handle all of the duties, who do you call?

Dr. Applebaum:

Everyone at some point is going to feel some version of this, that I just can't handle it all. And so you want to think about who can, in the immediate, take over any of the literal logistic day-to-day responsibilities you have, like who can take over for me today and tomorrow. And then, who can support me in the long run. I think that if you have the capacity either through out-of-pocket pay or through Medicaid, to hire a home health aide, home health aides are godsend, and can be incredibly helpful to prevent this burnout situation. I think the best thing you can do, and it's always complicated to figure out how to do this, is take a step away from caregiving. If you get to that place, think about who you can call, who is in your network, are they friends, are they family members, are there coworkers, if not, are there paid professionals or healthcare professionals, home health aides, visiting nurses, other folks who can come in and provide respite and support.

Really this is not a job that one individual can do on their own for the long run and we all need help at some point. And so I do really encourage you to, even if you're not at that point now, actually the best thing is if you're not at that point to problem solve and think about now, who would be those people who you'd call. The answer is different for each one of us. I can't give you a blanket answer. But it's going to be thinking through who exists in my social support network, who are the people I can call on, do I know any home health aides or home health agencies that I can refer to at that time, because I think it's really important that you get some folks to come in and support you.

LLS EDUCATION & SUPPORT RESOURCES



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All email messages are answered within one business day.

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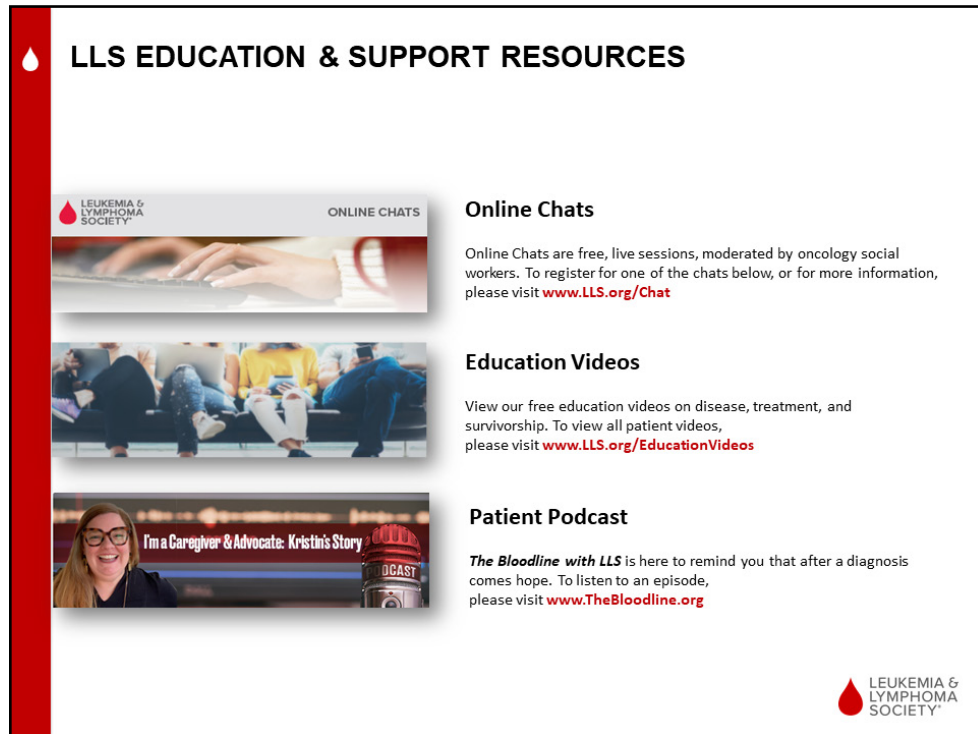
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Slide 21: LLS EDUCATION & SUPPORT RESOURCES

If we were not able to get to your question today or you want more information, you may speak to an LLS Information Specialist at 1-800-955-4572 from 9 AM to 9 PM Eastern Time, or you could reach us by e-mail at LLS.org/ContactUs.




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




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 I'm a Caregiver & Advocate: Kristin's Story

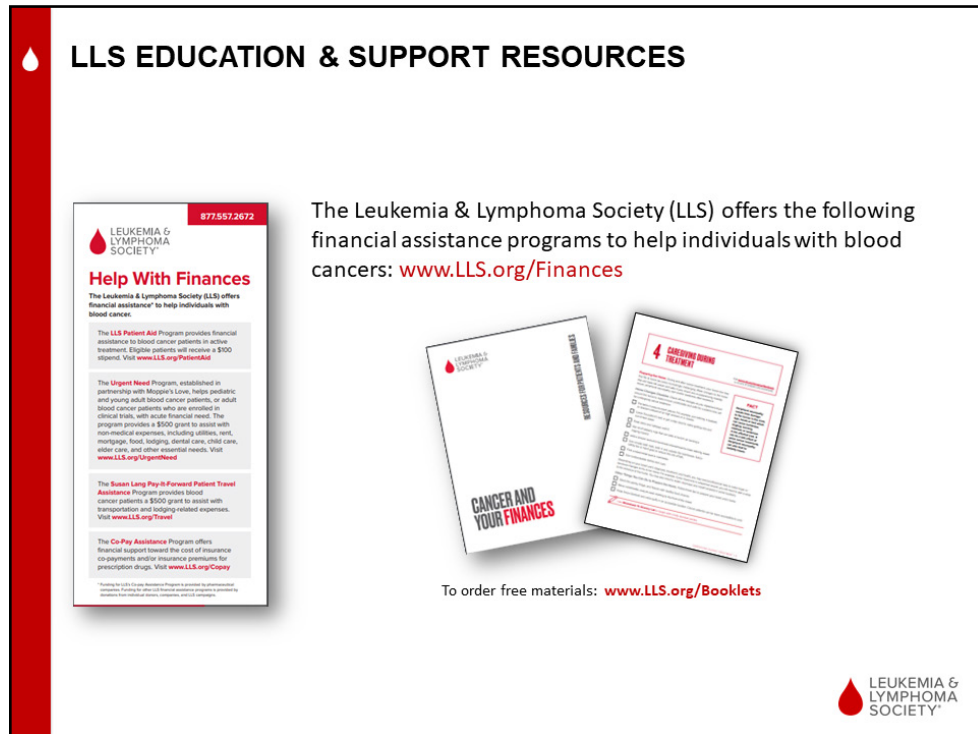
Patient Podcast

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



Slide 22: LLS EDUCATION & SUPPORT RESOURCES

Information Specialists are available to answer your questions about treatment, including clinical trials, and answer other questions you may have about support, including financial assistance for treatment.



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

Slide 23: LLS EDUCATION & SUPPORT RESOURCES

As a reminder, you can download and print the slides, as well as listen to the audio and view the video, on our website at LLS.org/Programs.

Again we would like to acknowledge and thank Bristol Myers Squibb, Genentech, GSK, and Pharmacyclics, an AbbVie Company, and Janssen Biotech for support of this program.



Slide 24: THANK YOU

Dr. Applebaum, thank you again for volunteering your time with us today. And, on behalf of The Leukemia & Lymphoma Society, thank you all for joining us.

Goodbye and we wish you well.

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