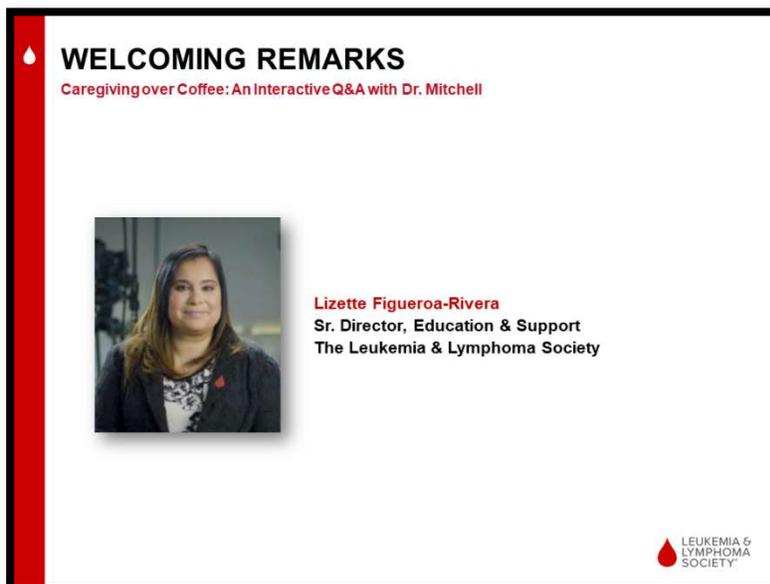




**Lizette Figueroa-Rivera:** Greetings and welcome to caregiving over coffee a live telephone and web education program. Thank you and hello everyone. On behalf of The Leukemia & Lymphoma Society, I'd like to welcome you all to our telephone and web education program Caregiving Over Coffee an Interactive Q&A.

Dr. Applebaum had an emergency and Dr. Mitchell, who has been working closely with Dr. Applebaum at Memorial Sloan Kettering Cancer Center has graciously volunteered her time today to speak with us about caregiving.



I'm Lizette Figueroa, Senior Director of Education & Support here at LLS and I'm excited to be with everyone today. We're grateful to have over 300 people participating today.

## Caregiving Over Coffee: An Interactive Q&A with Dr. Mitchell

**Speaker:** Hannah-Rose Mitchell, PhD, MPH



Now LLS is funding the critical research necessary to advance cancer cures. As the leading source of free blood cancer information, education and support for patients, survivors, families and healthcare professionals. LLS helps navigate you or your loved one's cancer treatment and works to ensure that you'll have access to quality, affordable and coordinated care. We know that caregivers and patients need help, before, during and after a cancer diagnosis and during treatment. Caregiving is challenging and LLS is here for you. As a caregiver we really do want to be there for you, and we ask you to please continue to inform us of what you need during this time.

I'd like to thank Pharmacyclics, an AbbVie Company and Janssen Biotech for support of this program.

A slide titled "DISCLOSURES" with a red vertical bar on the left side. The title is in bold black text. Below the title is the subtitle "Caregiving over Coffee: An Interactive Q&amp;A with Dr. Mitchell" in red text. To the left of the text is a portrait of Hannah-Rose Mitchell, a woman with long brown hair wearing a green top. To the right of the portrait is her name and title in red text: "Hannah-Rose Mitchell, PhD, MPH", followed by her position and affiliation in black text: "Chief Postdoctoral Research Fellow", "Department of Psychiatry and Behavioral Sciences", "Memorial Sloan Kettering Cancer Center", and "New York, NY". In the bottom right corner of the slide is the Leukemia &amp; Lymphoma Society logo.

I'm now privileged to turn the program over to Hannah-Rose Mitchell, PhD, MPH the Chief Postdoctoral Research Fellow Department of Psychiatry and Behavioral Sciences at Memorial Sloan Kettering Cancer Center in New York, New York. Dr. Mitchell, I'm proud to turn the program over to you.



Memorial Sloan Kettering  
Cancer Center.

## Care for the Cancer Caregiver

The Leukemia & Lymphoma Society  
Thursday, June 16, 2022

Hannah-Rose Mitchell, PhD, MPH  
*Chief Postdoctoral Research Fellow*  
Department of Psychiatry & Behavioral Sciences  
Memorial Sloan Kettering Cancer Center  
New York, NY

Slides adapted from Allison J. Applebaum, Ph.D., *Director, Caregivers Clinic*



**Dr. Hannah-Rose Mitchell:** Thank you so much for the introduction and I am so pleased to be here as well. I'm so glad that you know we're recognizing the magnitude of importance of cancer caregiving an issue that, you know, it gives at Memorial Sloan Kettering where I have been working very closely with Dr. Applebaum we have really prioritized in recent years, but there's so much work to be done in terms of prioritizing and recognizing the experiences of caregivers and I'm so happy to have this support to present today.

## Cancer Caregivers are Cancer Survivors

**survivorship**  
[ser-VY-ver-ship]

In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.)

**More Information**  
[Cancer Survivorship](#)

Search NCI's Dictionary of Cancer Terms

From National Cancer Institute Dictionary of Cancer Terms:  
<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship>



I like to start my talks with a quote that Dr. Applebaum also uses, and it is by the former First Lady, Rosalynn Carter.

And that there are 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. And it really emphasizes the way in which the caregiver role weaves throughout the lifespan and that we all tend to be caregivers in so many ways.

And in all of my work and I think what we what we've done a good job recognizing here at Memorial is that cancer impacts not just the patient, but the entire family, cancer is a family problem and it's absolutely essential to treat, not just patients but family and friends as the unit of care.

We're really trying to increase this recognition of the tool of cancer on the family and empower caregivers to cope with what is often the most difficult periods of their lives. I'm so glad that we have so many in attendance today who are prioritizing their own self-care and recognizing that how serious it is to be a caregiver.

In this definition here from the National Cancer Institute, you'll see that included in cancer survivors, the definition of cancer survivors by the National Cancer Institute our family members, friends and caregivers and they are considered part of survivorship experience themselves. I think that it really emphasizes that cancer caregivers are all of you, they are so many among us, and that they are cancer survivors as well.

### Who are the Caregivers?



- Any individual providing (typically unpaid) emotional, instrumental, informational, or financial support.
- Health care increasingly relies on home care → More burden on caregivers.
- WHO estimates that ~8% of the global population is dependent on others for care
- Worldwide, more than 19 million cancers diagnosed in 2020, assume  $\geq 1$  caregiver for each
- Caregivers are predominantly female, providing care to a parent, over 1/3 provide care to two or more people, 8.3 hrs/day, 13.7 mnths on average, 5+ years

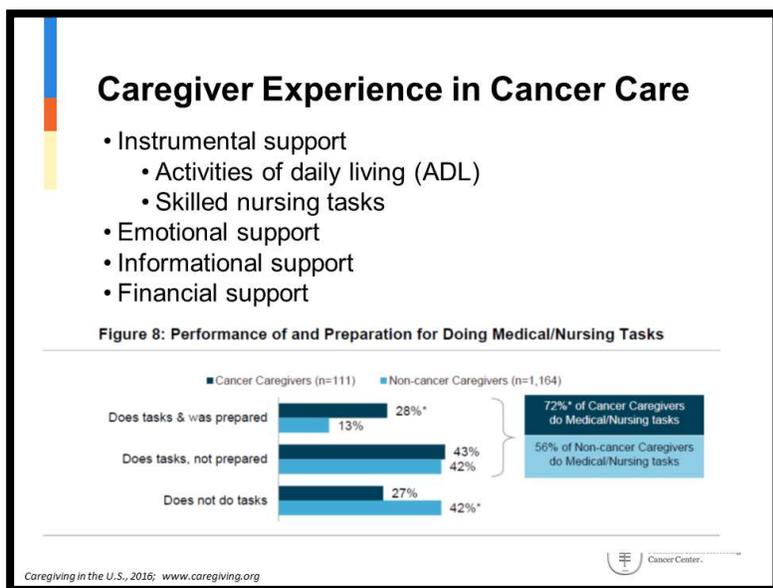
 Memorial Sloan Kettering  
Cancer Center

So similarly, what does it actually mean, what does caregiving involve, and I think a lot of people sometimes might not even call themselves a caregiver based on the things that they're doing that might seem sort of second nature or seem like just what would be expected to do. It's really anyone who's providing what is often unpaid emotional, instrumental information or financial support and I will reflect briefly on what those might mean.

But we have seen this major shift in the healthcare system that has required so much care to be provided in the outpatient settings and into the home settings so what certain acts like literal care tasks that I'm sure many people are engaged in here that needed in the past have been designated for skilled nursing personnel are now tasks that the family is required to take on.

And that much of the world is dependent on care from others and if we can I like to say that we have 19 million cancers diagnosed in 2020 and let's assume that each one of those people have at least one caregiver because kind of what's often expected know we have more than 20 million people caregiving in any given point in time.

Caregivers tend to be female; they tend to be providing paired up to adult parents and many caregivers provide care for more than one person and we'll talk a little bit about that today too as I believe.



And caregivers, on average, a study by one of my former mentors found that caregivers provided on average eight hours of care per day, but I think we'll talk about what that definition looks like too.

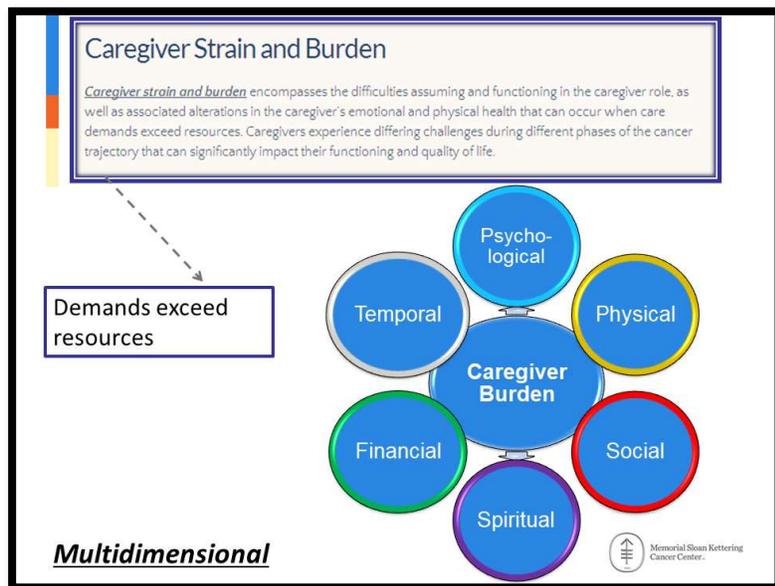
Providing care for around 13 months on average and with many caregivers providing care for more than five years and as was mentioned earlier the caregiver role is something that goes on and on and it's not limited to one specific point in time.

We mentioned the activity or the different types of support that are provided so when I say instrumental support. This is provision of assistance with day-to-day problems, the things that you need to do to sort of get through the day with the practical assistance.

We often will be referred to as activities of daily living, this also might involve actual skilled nursing tasks that I referred to before. And there's the emotional support there's the being an empathic that's being sympathetic being this person to talk to. Being the person to listen, without judgment, it's so integral to the patient's overall care and it places a burden on the caregiver which we'll talk a little bit as well.

Informational support this can be on you know researching information about the latest treatments, finding services for the patient, connecting the patient with what it is that they may need.

Financial support, I think this one is pretty straightforward that there are many, out of pocket costs for cancer caregivers. What this shows here is the notion that while some cancer caregivers report having received some sort of preparation for their the medical and nursing tasks that I mentioned that they're involved in. Many are doing so without preparation, more than four in ten are preparing these very complex tasks without any prior preparation, which I think, as many of you know is extremely scary and stressful.



And we'll talk about this concept of caregiver strain or burden and the burden or strain results when that what you're being asked to do and your caregiver role those demands and exceed what it is that you have to give. I would imagine that many caregivers on this call are feeling restricted and so they only have so many hours in the day, as well, they only have so many tools, they only have so much knowledge, they have other people to care for, they have jobs, feeling restricted in many other ways. When you're being asked to do more than what you really have the resources to give that's when you experience strain or burden.

And burden, we like to view as this sort of multi-dimensional construct so if we click through this, we can see sort of what comes up so first there's a psychological burden, caregivers experience anxiety, depression, mental health problems, some even present with post-traumatic stress, some even have thoughts that life is not worth living.

And then the physical, we have here so that the pain that caregivers may experience from the actually physically demanding tasks or from having inflammation in their body, because of stress. The impact on their sleep tends to be very impacted and again I think we'll probably talk about that more today. Their immune functioning so when you know you're feeling really stressed, you may feel more likely to develop a common cold, for example, and that's an impact of the strain and stress of caregiving.

Health behaviors tend to be impacted so maybe not keeping up with the diet and exercise that has been ideal in the past or unhealthy habits like tobacco use or alcohol use.

Socially, a lot of caregivers' report isolation, having relationship conflict, whether that's with the patient or with others in their life, due to their overwhelming circumstances. And then these role changes, that suddenly you're required to maybe spend less time socializing with certain people, COVID has really impacted that too.

Spiritually, an existential threat that comes with a cancer diagnosis, the word cancer itself, has us confront our spirituality and people's belief systems might feel really challenged when they're required to go through this horrific experience.

Next we have the financial burden; this is the changes in employment status. Because of the caregiver role taking on the caregiver role the treatment costs, the many out of pocket human costs that caregivers are required.

And then finally temporal so this means, like the time that's spent actually caregiving that the demand is so large ended that's time that's often taken from other responsibilities or activities.



**Accessing Your Own Support**

- Recognize signs and symptoms of burden
- Activate support networks
  - Challenge yourself to ask for help
  - Support may come from unlikely sources
  - Identify professional sources of care
- Recognize what is meant by self-care
  - Guilt is a red flag
  - Self-care includes expressing emotions

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I think in the Q&A we'll really have the opportunity to talk a little bit more about strategies for self-care like what is it that we do I you know I want to offer support. Just in summary, briefly here, I want to talk about some key points, which is that just described the burden and now that you know you are aware of the sense that this burden is so common in cancer caregivers.

Look for the signs and symptoms of burden, are you feeling strange, do you feel like maybe you don't have the resources to keep up with the demand and if that your experience there's a very good chance that you're experiencing caregiver strain and that you are in a position where it's important to access support, whether that be self-care or looking to your social support network.

Asking for help is so difficult for anyone, especially caregivers, I find that caregivers within my work here in our caregivers clinic at Memorial tend to report prioritizing the patient so much that it can be really challenging to ask for support for yourself during this time when your world and maybe others in your family's world surrounds the patient. But challenge yourself to ask for help, look for unlikely sources of support, sometimes our typical support system can be really difficult to activate during this caregiving experience.

Certainly, professional sources of care and I'll provide a brief list of those later, but I mean the fact that you're all here today is the first step in that, I think that's incredible. There's other sources in the community, like cancer care we there's the National Association on Caregiving and resources and considering going to a licensed social worker or psychologist or someone who can provide you one on one support.

I will be very happy to talk about more specific strategies for self-care in the Q&A, because I think those types of questions will come up.

But I just want to say that when it comes to self-care, guilt is a huge red flag, so if you're feeling like I shouldn't be taking time for myself that's a thought that I encourage folks to look out for to catch yourself saying I shouldn't be doing this and that there's probably a need to take care of yourself. That can include expressing emotions like that reaching out to your support network or doing what it is that makes you feel well and makes you feel best in whole.

I'll just finally emphasize here that the caregivers are a critical member of the treatment team. If you're unable to take care of yourself, it's going to be very difficult to take care of the patient so I'm encouraging you all and again emphasizing how valuable it is that you all came here today and are looking to gain resources.

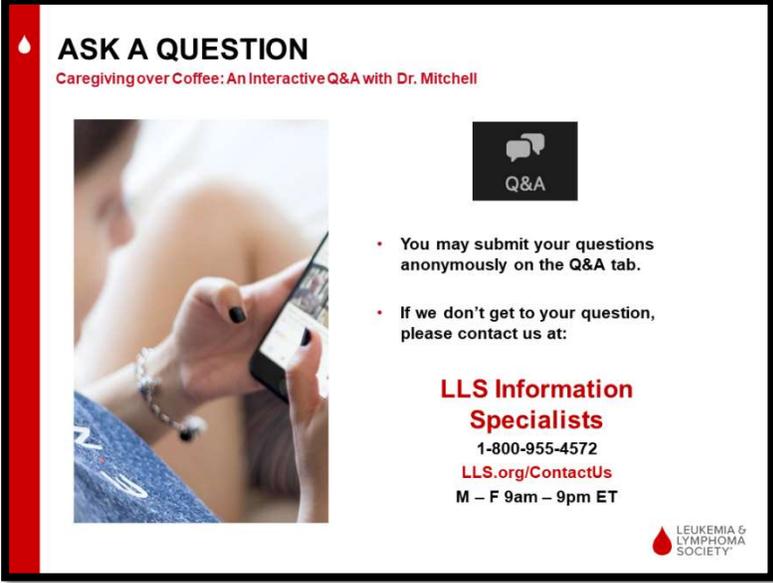
### Acknowledgements

- Thank you to ongoing participation in psycho-oncology & caregiving research by cancer patients and caregivers
- Dr. Mitchell is supported by: P30 National Cancer Institute (P30 CA008748) and T32: National Cancer Institute (T32 CA00946).
- Dr. Allison Applebaum contributed to the presentation and provided content for slides

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I really am excited that we have had many questions come in and we'll transition into this Q&A phase. I'm excited to address what's coming up for the folks who are in this room. I do want to just briefly thank the caregivers who I work with for providing me so much insight and knowledge and vulnerability and then of course my mentor Dr. Applebaum who was very upset that you couldn't be here today, but for providing content for today's talk and these slides as well.



**ASK A QUESTION**  
Caregiving over Coffee: An Interactive Q&A with Dr. Mitchell

**Q&A**

- You may submit your questions anonymously on the Q&A tab.
- If we don't get to your question, please contact us at:

**LLS Information Specialists**  
1-800-955-4572  
[LLS.org/ContactUs](https://www.lls.org/ContactUs)  
M - F 9am - 9pm ET

 LEUKEMIA &  
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**Lizette Figueroa-Rivera:** Thank you so much, Dr. Mitchell for the presentation. For the folks on the line, it's time for question-and-answer portion of this program. For everyone's benefit if you can please keep your questions general in nature, without many personal details so Dr. Mitchell can provide answers that are really general in nature. We will not be addressing specific disease or treatment questions during this program.

Now to ask a question, please click on to the Q&A button on the bottom of your screen.

So, Dr. Mitchell our initial question today the person states "I'm not just a caregiver I have multiple roles, as many of us do. Can you please address ideas for self-care, along with the challenge and meaningful moments one juggling while balancing multiple roles? I'm a psychologist, care partner, a support group leader, volunteer and more."

**Dr. Hannah-Rose Mitchell:** This is a poignant first question, there's a lot of research on what we call role strain, which refers to this idea of juggling multiple roles like caregivers are suddenly jolted into often without preparation. We tend to see role strain often in women a lot, who are traditionally expected take on multiple caregiver roles for parents who are providing both childcare, but also just anyone who has other parts of themselves that are not just limited to their caregiver identity.

One thing I'd like to pull from this question is the idea of looking for meaning or meaningful moments. I think that it's insightful to think about looking for sources of meaning in the caregiver experience and that often can be really challenging to recognize because caregiving involves so much suffering. There's all these existential concerns, there's feeling overwhelmed as was so clearly pointed out in this question and that can all be linked to disconnecting from other parts of your identity.

But that type of suffering doesn't really preclude you from experiencing or doesn't fully stop you from experiencing other positive emotions or growth or connecting with sources of meaning. So, looking for ways around you to find what it is that you value, what it is that makes you feel connected and thinking, really, really small. I work with a lot of caregivers who report that

providing care to a loved one in itself can have some value and meaning. For example, I work with a caregiver right now, who talks about the way that how being a caregiver as part of her identity in a really positive way that she's provided care for multiple people throughout her life and she's modeling that for her daughter. So, encourage having empathy and compassion for yourself and looking for these sources of meaning in everyday things.

**Lizette Figueroa-Rivera:** Sure, thank you so much, and the next question, doctor. "I'm on disability, for a very expensive condition and taking care of our chronically ill child. My husband who's supporting us was diagnosed with lymphoma last year. On our first visit to the oncologist, I was given a packet for the caregiver. How am I automatically assumed to be the caregiver for him when I'm already a caregiver for myself and our child?"

**Dr. Hannah-Rose Mitchell:** That's a great question, it really reflects how loaded the word caregiver can be and I kind of touched on that in our presentation. A lot of people might really not call themselves or consider themselves caregivers and I sort of defined the caregiver quite broadly. I know it can be any family or friend who is somehow involved, I also think that what is highlighted here in this question is that there's this big onus that's getting put on the caregiver or so-called caregiver that suddenly like you might be expected to do these sort of skilled nursing tasks.

And I want to recognize that it's a sort of a societal problem that we face and systemically it's an issue that we're working to advocate for support for caregivers and things like that but in the meantime, know it's not really fair that you're in this role and while in this role you must be taking care of yourself. It sounds like you have your own health concerns and I'm going to probably use the phrase self-care many times today, but this is taking care of yourself first so that you can adequately take care of the patient is so integral.

**Lizette Figueroa-Rivera:** Thank you and the next question. "My husband is keeping his diagnosis a secret for various reasons, including professional. This makes it harder for me to ask for help and also explain why we are so careful about COVID, any ideas?"

**Dr. Hannah-Rose Mitchell:** This is tough and it comes up a lot because it stifles the way the caregivers are able to communicate. Sometimes the language that we use might feel really restricted by what the patient even wants or the patient wants to hear. My suggestion is for this caregiver specifically or just any caregiver who feels somewhat restricted by the patient's wishes and concerns, even if you feel like it's really valid or are kind of on the same page about it is to seek out sources of support for yourself, where you know you are able to disclose some of the experiences that you are feeling or feelings that you're having.

Certainly, it does create a challenge with COVID related concerns, but I think it's perfectly valid to take very extreme precautions for COVID at any stage or for anyone right now and that it might feel really uncomfortable. Some of the challenge might be sitting with the discomfort around setting boundaries with others or choosing not to disclose and still having that communication say we can't do something, because of the pandemic and everyone else seems like they're doing it. Look at challenging yourself there, what's the thought that's coming up, do you think that they might not like you anymore or how is that going to impact your relationship? And it might be worthwhile to look at what's coming up for you what might be another helpful way to think about it, because it sounds like you're doing everything you can just sort of protect your family.

**Lizette Figueroa-Rivera:** Yeah, and continuing really on the self-care. “Can you suggest additional coping mechanisms for the emotional rollercoaster that we experience as caregivers? I exercise, eat a healthy diet, get enough sleep, have a social network, but still struggle with the emotional response to my husband’s multiple myeloma, heart failure and type two diabetes.”

**Dr. Hannah-Rose Mitchell:** Well, first I want to provide feedback that it’s so incredible that you are doing all those things because it’s so challenging while in the caregiver role and while experiencing distress and an emotional roller coaster is a really poignant way to put it. That there are so many ups and downs throughout the caregiver experience, and I think that Lizette reflected on that at the beginning, talking about all the different stages of treatment in which the caregiver distress is evident.

I think that looking for ways to take care of yourself spiritually and emotionally during this time, is going to be really important too. It might require confronting the question of what that really means for you, whether that’s accessing different sources of support in your life, finding professional support to talk about those emotions, journaling for some people and really using the resources around you that are really dedicated for emotional wellness.

What I really liked about that question was that it captures how comprehensive it is and that we can do things for physical health that should ideally help our emotional health too. Caregiving also comes with a range of really distressing experiences and then it’s quite not uncommon to have those emotions you’re describing.

**Lizette Figueroa-Rivera:** Right. “And what do you do with the person you’re caring for that is extremely depressed but not willing to see a professional?”

**Dr. Hannah-Rose Mitchell:** This is tough too and ultimately has to come from the person themselves, so the loved one who is feeling that way may, that’s ultimately their call in having a perspective around that is key.

What I think is most useful and the most important thing you can do is express how you feel, so using I statements like, I feel, in whatever situation know that this particular emotion in order to express to the patient or your loved ones, the impact on you too. And perhaps that may encourage them, of course, everybody’s very different I don’t know about this particular loved one, but I would say broadly my feedback is to enhance communication, speaking from oneself like using that is expressing your own feelings.

**Lizette Figueroa-Rivera:** Right. And the next question. “How do I give my young adults support but also space? I want to be there for every visit, but not make her feel like I don’t think that she can do certain things on her own.”

**Dr. Hannah-Rose Mitchell:** Yeah, I think that’s really similar and what’s key here and when we talk about anyone who in this room who is caring for young adults, adolescence, developmentally experiencing cancer during that time is so particularly challenging.

It comes in a way that’s highly unexpected, and they often will feel very isolated and disconnected from seeing aged peers and other challenging conversations for them to have.

And I think as a parent or caregiver of a young adult, it can be really important to have an open line of communication, while acknowledging their independence. The fact that you’re asking

that question, I think is indicative of a really healthy attitude and awareness of your loved one's autonomy and that you know they're in a stage where they're transitioning into independence.

You want to help them foster that you want to kind of mentor them and help them, you know, provide them. Show them that you're there for them to provide them the resources and tools that you can and recognize or provide; let them know like hey I think you're doing a really good job with this. I see that you're doing that on your own and empower them a little bit in their independence.

**Lizette Figueroa-Rivera:** Sure, and someone is asking. "Is there an elevator statement that can be used for those who do not understand how caretaking is completely consuming and always the person is thinking of those who want some of your time when there's no reserve left to give anymore?"

**Dr. Hannah-Rose Mitchell:** I'll respond in two ways, so one is that I think it's important for that to come from you, so how is caregiving impacting you and what meaningful ways that has, but I love the idea of writing out an elevator pitch. So, what it is that you're going to tell me? A question I often get will also be from people who ask me how I can help or the right feedback to get or feedback that they feel comfortable with.

Let's take some of the things that I shared earlier and integrate that into your elevator pitch. Saying something along the lines of, I'm required to give around the clock care or we are coping with cancer together as a family. Sharing that you're part of the unit of care and that's recognized by science and the health care system so that the patient and the family are the unit of care. We're coping with cancer together and that's taken a big toll on us as a family and taking a lot of our resources.

**Lizette Figueroa-Rivera:** Right and the next question. "I often do not speak at meetings; my wife has with her cancer doctor. I occasionally asked questions; however, we've not been assertive enough about side effects and the pain they cause. How assertive can I be, can we be while we're in that doctor's office?"

**Dr. Hannah-Rose Mitchell:** This is a wonderful question. I work in multiple health systems and one thing I've seen consistently is that patient and family caregivers are your own best advocates. So yes, being assertive is incredibly important, as you recognized in that question, you need to be as an assertive as you can, and you feel comfortable and as much as possible.

And practice being assertive maybe that might involve you and a friend, or you and your loved one literally role-playing what conversations are going to look like with providers, because it can be so tough to get your questions answered.

We encourage our patients to have plans before meetings. You might want to be on the same page as your loved one to say something like would it be okay with you, if I asked the doctor what we may expect from this treatment and or what the side effects or pain might be? Come in with lots of questions, take notes, because it's so key to have these conversations. If they don't come up where you feel like you're not being assertive enough results in this continued cycle and network of silence between everyone that it's important to break and get in there and really advocate for yourself.

**Lizette Figueroa-Rivera:** Sure, and how about those folks that the patient does not want them to be in those meetings, or even a caregiver that's a long-distance caregiver that may not physically be in those meetings?

**Dr. Hannah-Rose Mitchell:** This is key too and sometimes in family systems can be really complicated so there's one person who wants to be in the meeting or one person who doesn't or one person who is taking on the advocate role. This is where we really encourage communication and I know all families are different, so this advice doesn't fit all. And I think that open lines of communication are so important during this critical period. It's fundamental to the patient's care and that it's important to be on the same page in terms of prognostic, understanding of the illness, what you expect around treatments and side effects.

Having conversations about what people's roles are and recognizing that there's all different types of roles that caregivers provide. Some people might define their role a little bit differently or step up and do something a little bit different for the patient and that might be a way to build on different folks' strengths.

Another element of that question, is if the patient doesn't really think that's what you're asking, like if the patient doesn't really you know want the caregiver and, again, I think that's important, and you have to value that and recognize the role of the caregiver as part of this unit of care and having conversations with the patient in advance to see as you can be on the same page as much as possible.

If anything, express your concerns in a way that can get integrated into the questions that the patient then asks. So, you empower the patient to ask questions on behalf of us as a team and sharing with those I statements what it is that you were feeling and how the caregiving is impacting you.

**Lizette Figueroa-Rivera:** I think that's a really good tip for caregivers that you know if you're allowed to one the patient does not want you to be a part of it to still have that communication, so the patient can get some of those questions answered, for both of you, I think that's really important.

**Dr. Hannah-Rose Mitchell:** Whole family, yeah.

**Lizette Figueroa-Rivera:** The next question. "How do I stop worrying all the time that the one I love the most won't make it and that our futures is very much in doubt? How do I deal with feelings of resentment about our life being tied to my husband's health needs and what you were speaking about earlier Dr. Mitchell the guilt and resentment that it breeds?"

**Dr. Hannah-Rose Mitchell:** Yeah and you're reflecting of that existential crisis that comes up with caregiving, the uncertainty about the future. Uncertainty on handling and facing uncertainty can lead to anxiety, so we know that this can result in a clinical psychological symptom and the worries sound like anxiety here.

I think this is also a place where communication can be really helpful. And, while I do recognize, every patient and caregiver relationship are distinct, some caregivers and patients are the closest person in your life while others this absolutely might not be the case.

But we do know it's effective to share your experiences and feelings with your loved one and that can bring you closer and they also may be experiencing similar worries. They may be

hesitant to express for multiple reasons and parts even shields that caregiver, so the open lines of communication about that can be really key. I'll make a pitch also here for mental health services and to cope with some of those worries that you're having.

Guilt is a common experience I mentioned it earlier, it's a big thing that comes up, but I think if you're experiencing that guilt. It might be a sign that there's a need to take care of yourself, it's okay to feel as though you're feeling frustrated that your own self-care has been placed to the side, this is where I introduced the putting your oxygen mask on yourself before you can put it on someone else. You need to be able to breathe in order to take care of someone else, so setting aside time for yourself can be actually really instrumental in the patient's care.

Sometimes that requires a shift in your mindset what I can do for myself to best care for my loved one, to be fully present in those moments that we have together in a way that maybe I don't resent them as much.

Taking that little going and getting a manicure or going for a walk or making yourself a snack that you really enjoy or something even small, but that you feel like is meaningful and important to you can ultimately bolster your capacity to take care of the patient and to make meaning out of the moments that you do have with them.

**Lizette Figueroa-Rivera:** Yeah, definitely and the next question. "How is caregiver fatigue treated? It is a real issue and can be a detriment to the cancer patients and survivors' health and wellbeing and both caregivers and patients suffer when there's that caregiver fatigue."

**Dr. Hannah-Rose Mitchell:** Wow, that last point of the question really gets at that idea of how interrelated the patient and the caregiver are and how the patients can suffer to have the caregivers not at max capacity.

There are a couple of elements to this, so first I would introduce the oxygen mask metaphor again on self-care, with this you have to set aside time for yourself in order to stay up to par for being able to take care of another one.

There are multiple reasons why you might be experiencing fatigue too. It could be from the actual physical demands of caregiving I mentioned that people are literally doing manual labor, physical tasks of caregiving also maybe being up really early for appointments going all day, taking on other tasks late. I worked with the caregiver who had to take on all the landscaping and yard work that she had never done previously so all those things can be quite exhausting. Your sleep can be really impacted and I'll come back to that but just want to say that, like the stress response that we have in our body can result in fatigue.

Earlier someone asked about the negative emotions and not even though they were doing all these other things to take care of themselves, they still felt those negative emotions. That can really wear and tear your physical health to resulting in symptoms of fatigue.

If you have stress in your body, there's a physiological response, cortisol levels are higher, there can be inflammation and things that make you feel physically fatigued, so this is a common problem, as you reflected.

Self-care is number one, looking at sleep really check tech doing an assessment and a lot of caregivers I know a lot of caregivers' experience insomnia, and we've seen up to 75% of caregivers report symptoms of insomnia, which the general population is more like a third. So

do a little self-assessment of insomnia, are you taking greater than 30 minutes to fall asleep every night, are you waking up multiple times throughout the night having difficulty falling back to sleep, has that been going on for several months and you might have full blown insomnia.

There are some resources, the gold standard treatment for insomnia, they suggest anyone who can access it in their communities is cognitive behavioral therapy for insomnia. It can be really good to engage in this during your caregiving experience, because insomnia is a habit that lasts for a really long time and to address it early on or change your sleep patterns early on can be key.

To make it more accessible to everybody there's an app, it's called CVT-i Coach and the VA actually created it. It's free to download on anyone's phone or iPad or things like that, so if you feel that you can do an assessment of your insomnia on there, it also just gives tools for what we call sleep hygiene, so how to improve your sleep.

Fatigue and sleep are separate issues, technically, but I do think that you could be reflecting the experience of many caregivers who have insomnia, so I wanted to spend a little time talking about options for sleep. So, I recommend the CBT-i coach app or finding anyone in your community who does cognitive behavioral therapy for insomnia, or just spending a little time researching it and again prioritizing your own sleep needs.

**Lizette Figueroa-Rivera:** All right, thank you and I just wanted to point out that one of the caregivers on, she mentioned that in caring for her aunt because she's in another state. The aunt would call her during the appointments and put her on speaker phone. That's a way that she was able as a long-distance caregiver to be a part of that conversation and feel a part of that conversation.

**Dr. Hannah-Rose Mitchell:** And yes, I'm so grateful that caregivers to share that innovative solution and I meant to say that earlier in the question about multiple family members throughout the country, yes, we have Telehealth now too so many appointments might occur online and I encourage everyone to ask if there's ways to bring in multiple people or what that might look like and certainly I love the speakerphone idea I think that's innovative.

**Lizette Figueroa-Rivera:** Yeah, it's definitely a great way. A lot of us don't live close to the people that we're providing care to but, as you said, technology is making us closer. That's definitely a good way for our caregivers to be able to be a part of it.

We do have a question and this question was asked by multiple folks. "They're asking how do you deal with a patient who's very mean or non-communicative with you?"

**Dr. Hannah-Rose Mitchell:** Yeah.

**Lizette Figueroa-Rivera:** Like they share their frustration with you.

**Dr. Hannah-Rose Mitchell:** That comes up a lot so first know that you're not alone. I'm really glad that you mentioned that multiple people experience that, because it can feel really tough.

It's so challenging to be giving all of yourself for someone who may not express gratitude. And I reflected on that earlier, our relationships with our patients tend to really vary and that they can be different qualities. Caregiver stress, actually the levels of caregiver stress that people experience has not been really linked to what the quality of the relationship looks like generally

in the literature, so it doesn't mean that if you are closer with them or less close or have more conflict. But conflict in itself can certainly be a cause of stress there, so you think that's worth taking a really good look at.

In our clinic here, we have services for families and couples actually going through the caregiver experience to work on their relationship conflict and communication during that time and if you have access to those sorts of resources it might be a really worthwhile time to engage in that.

I think one thing is having a lot of self-compassion, if you're not really getting it from the patient, how can it come from within. You know what is it that you'd like to hear and what can you tell yourself, what are the positive self-statements that you can really tell yourself about how good of a job you're doing.

I will say that every single one of you who are on this call is doing an incredible job as a caregiver, because you're here and you're prioritizing your self-care, clearly invested in how you can improve the patient's care as well. Being really compassionate with yourself, because sometimes that's where we can access it most readily.

**Lizette Figueroa-Rivera:** Right, giving yourself that greatest, I think that's very important, as well as knowing that you know a lot of times it's frustration and people are scared, and they are open enough to be scared with you. As their caregiver but sometimes people don't know how to really communicate that.

**Dr. Hannah-Rose Mitchell:** Yeah, like I mentioned earlier. Expressing your own, being vulnerable with your own emotions sometimes can model to your loved one what it is that might be useful and open up channels for more communication about the feelings that are occurring for everyone, as a whole.

We know that these interpersonal processes, the way that you talk about things and process them together really matter to both the patient and caregiver and it's a very, very interpersonal process.

**Lizette Figueroa-Rivera:** Right and I love how our caregivers are typing in another caregiver also says that she memo records appointments on the phone so she can send it to all her adult children. That's another great idea for the other folks out there.

**Dr. Hannah-Rose Mitchell:** A wonderful strategy.

**Lizette Figueroa-Rivera:** Yeah, so another caregiver for a child. "How do you handle or is there a need for concern when your child who's also a patient seems not to care about treatment as much?"

Being a teenager there's some understanding that there's also a desire to want to get better, but the child is not expressing interest in regard to treatment. So, the parent really wants to know is there anything they can do to get the child to be more proactive or is this something that's just transitional?"

**Dr. Hannah-Rose Mitchell:** Yeah, I think this reminds me a little bit of the other question about a young adult and I really want to emphasize that it's just really tough developmentally. That it's just such a difficult age to be experiencing this and it doesn't feel normative what any of your same age peers are going through.

There can be a big discrepancy between the sense of urgency that the parent or caregiver is feeling and what the teenager, in this case, is feeling. I think you might want to look at that frustration that you might likely be having and take a good look at what that's telling you, which might be related to how hard it is and how much concern you have about the patient or in this case, your child.

Look for strategies and even acceptance of their own attitude around, of course, you know it does really matter, and you want to have your health care team on board with the level of engagement they had and things like adherence are really important.

Those are really critical factors like information and knowledge that they have going to the survivorship stage and have to think about things in the long run. I think in the present moment it sounds like it's quite normative, it really does, and I can recognize and appreciate the kind of frustration that a parent might have there and are just concerned worries and wanting to see that reflected in someone else but you know it could be okay that they're not experiencing the same kind of worries or concerns.

**Lizette Figueroa-Rivera:** Thank you, the next question. "We have so many doctors' visits, lab appointments, PT, OT, social workers other treatments, we're always on the run. It's not easy to find the time to enjoy each other, so how can we get more out of life and make this time better?"

**Dr. Hannah-Rose Mitchell:** Yeah, so I mentioned the temporal demands of caregiving and that goes for the patient as well. We're living just life, everyone's busy and then to take on this incredible time-consuming experience of cancer can be quite challenging.

It's tough, I like to say think about really starting small, think about looking at all the really little things, it might look incredibly different. We tend to see that we're in this completely new normal and things look so drastically different than the types of things that may have been more like a date night or whatever it was that in the past you did that with that allowed you to enjoy each other, this might have really changed.

In our meeting centered approaches here at MSK, we think about any access to sources of meaning in your life that might be something you are able to do together. Reflecting on memories or finding humor in moments when you're stuck in the car together for a long time in traffic or enjoying a sunset that you may see. It may sound silly, but there are even in these times of suffering there are these little moments around us that can bring pleasure and joy and you can engage in that process together.

I also want to say that I think it's important to recognize the incredible love that you're showing through the act of caregiving and I hope that may, in some ways, bring you closer together. And a lot of caregivers do report feeling really empowered by that love or that their relationship is strengthened by the caregiver experience.

**Lizette Figueroa-Rivera:** Yes, we've also heard that too. The next question. "How do I prepare for the end stages of caregiving?"

**Dr. Hannah-Rose Mitchell:** Yeah, so I think it reflects what it is that was mentioned earlier regarding the timeline of caregiving and your caregiving role, frankly, never really ends in a lot of ways. So, depending on what comes next, so if you're transitioning out of cancer care and going back to your previous roles or freeing up time, it may feel really odd and that may feel

really jarring. Of course, we also can be talking here about bereavement which is very relevant, and there's very unique concerns like anticipating what your grief might look like.

I wanted to answer this question as broadly as possible because the end stages can mean lots of different things, but I give the feedback that it just simply doesn't end. I like to view different stages of caregiving as transitions and think about what it is that you're going to gain with skills and that you look forward to bringing with you into your next transition and your next stage can be helpful to planning in that way.

**Lizette Figueroa-Rivera:** Sure, thank you so much, and the next question the beginning of the question that I think that we have addressed it. "How do I cope emotionally with the burdens of caregiving when the going gets tough?" But the second part of this question. "How do I cope with feeling isolated and alone?"

**Dr. Hannah-Rose Mitchell:** Yeah, and caregivers experience and report isolation so much, and I think that this has come up a lot during the pandemic, everyone's feeling isolated and we are experiencing that so much. There are multiple reasons why this could come up in the caregiving sense, one, you may not feel like you can really share with the patient, or you want to protect the patient from certain feelings or experiences like we reflected on earlier, I think that communication can be useful there.

Accessing support, even just being here today being this sense of connection that we probably all just knowing that there are others in this room, that there are other caregivers who are offering specific strategies can be helpful.

We can talk about resources, I suggested looking up Cancer Care is an organization that has caregiver support groups and things like that. One thing I find tends to be a challenge is people actually having time for accessing social support and sometimes you don't really have time to go to lunch with friends or do whatever it was previously that may have made you feel connected. Suddenly your new normal of caregiving just disconnects you inherently because of the experience. But that's why maybe accessing other people were going through a similar experience might be helpful in that sense.

I just wanted to say that's a really common experience and social support is so important, so looking for whatever, however it may show up for you, even animals can offer support for loved ones.

**Lizette Figueroa-Rivera:** That's true and I do want to echo what you're saying, Dr. Mitchell, that you're not alone and just being on this program with so many other caregivers and so many caregivers actually submitting questions that are very similar in nature. Just to know that you're really not alone, and there are other people that you could reach out to, and we will have resources for you as caregivers.

The next question. "Is there any type of compensation for being a caregiver?"

**Dr. Hannah-Rose Mitchell:** Yeah, so this is tough like the short answer isn't ideal, I guess. Unfortunately, the opportunities are fairly limited, and they tend to vary by state and regulated differently in each state. In New York, for example, if your loved one is a Medicaid recipient there's this consumer directed program that would allow you to be compensated at the Medicaid hourly rate, that may be helpful for some folks if you formerly register your career as an official caregiver.

There are opportunities through the VA if your loved one is receiving care through the VA their caregiver supports there.

I think I kind of alluded to this at the beginning of my presentation that I think we see this as sort of a public health problem and there aren't a ton of options. Our hope is that these sorts of compensation, become more broadly available, but I think way too limited now. But yes, I would look into the state specific options, just definitely if your loved ones a Medicaid recipient and see what might be available to you, and certainly the VA have a lot of resources actually.

**Lizette Figueroa-Rivera:** Great, thank you and the next question. “How to answer, how are you doing when you're just trying to get through the day and how to handle social celebrations when you don't feel like celebrating but don't really want to be alone either?”

**Dr. Hannah-Rose Mitchell:** Yeah, this comes up a lot, I think all the patients we consider the caregivers the patients in our clinic and the caregivers with whom I work often say that the how are you doing question is so difficult, like what the honest answer is not what people are really going to want to hear.

So, you're not alone with that, and I want to emphasize that I think that this goes back to having your elevator statement, of course, it may vary on depending on who's asking you. But figure out what you're comfortable telling people and that you don't have to have a perfect answer all the time and question what is it that's really driving us to feel a certain way, stick with the sort of societal expectations and standards around how to respond to those things and have some flexibility and compassion with yourself and answer in the way that feels authentic and meaningful to you and honest. So, I think that's quite okay to say that things are not 100%.

That second part of that question was about celebrations. You may be experiencing as a caregiver, I alluded to this earlier, caregivers experience anxiety and depression symptoms and you may be feeling kind of withdrawn, it's difficult to get going, it's difficult to involve yourself in those things.

There's two parts to this, take a good look at why that's coming up for you and if it's because you're just feeling low, sometimes getting going and going to these things can help once you act into doing it might improve your mood a little bit. I also think it's so important to just recognize it's okay to set that boundary for yourself and that you might be able to honor someone or celebrate in a different way. And that you're prioritizing your needs and your self-care as going through this crisis and find a way that is most effective for you to respond to those invitations and feel free to decline if that's what you really need to and might be time that you can use for self-care, for example.

**Lizette Figueroa-Rivera:** Sure, thank you and our last question today. “There's so many supports for patients, are there any support services for us caregivers?”

**Dr. Hannah-Rose Mitchell:** Yeah, so I think that is so key I mean I'm so glad you're here and, obviously, that The Leukemia & Lymphoma Society supports caregivers. I would also look at resources through The American Cancer Society, The Cancer Support Community, The National Alliance for Caregivers, Cancer Care I mentioned before.

We refer patients all the time to Cancer Care, and they have cancer or caregiver specific groups nationally, that I believe you can access online. I also would encourage everyone to just look into the resources that are available at your cancer center.

At Memorial, we have our caregiver's clinic, Dr. Applebaum runs that, and I've been working in it the past two years, and we see many caregivers presenting with a range of concerns and where we really work hard to support the caregiver and psychosocial needs here.

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**Lizette Figueroa-Rivera:** Great, well thank you so much. A special thank you to you, Dr. Mitchell for volunteering your time and expertise with us last minute, so we really do appreciate you and thank you for answering so many questions and letting people know that they're not alone.

Now, if we weren't able to get your question today or you want more information, you may speak with an LLS Information Specialist at 1-800-955-4572. And we're open from 9 AM to 9 PM Eastern or you can reach us at [LLS.org/ContactUs](http://LLS.org/ContactUs).

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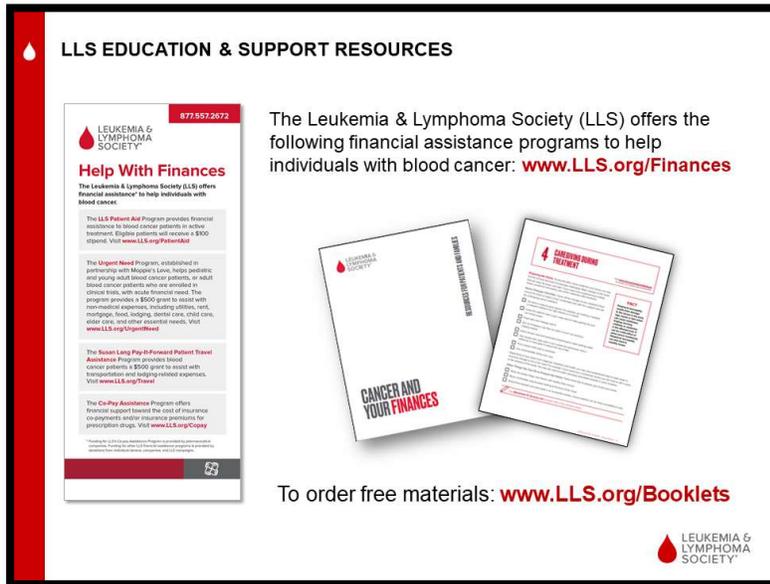
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**Caregiving Over Coffee: An Interactive Q&A with Dr. Mitchell**

**Speaker:** Hannah-Rose Mitchell, PhD, MPH

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For the professionals on this call, if there are any, please note that there are no continuing education credits for this program.

And as a reminder, you can download and print the slides, as well as view today's program at [LLS.org/Programs](https://LLS.org/Programs).

Again, I'd like to thank Pharmacyclics an AbbVie Company and Janssen Biotech for support of this program.

Again, Dr Mitchell, thank you for volunteering your time with us today, and on behalf of the Leukemia & Lymphoma Society, thank you all for joining us, take care and remember we're here for you as well as your loved ones, let us know what you need, and let us be there for you, thank you.

**Dr. Hannah-Rose Mitchell:** Thank you, thanks to all the caregivers.