



Who Gives Care to the Caregiver?

Ms. Lizette Figueroa-Rivera:

Lizette Figueroa-Rivera: Hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you. We have over 700 people participating from across the United States and Canada today. And a special thank you to Dr. Allison J. Applebaum for sharing her time and expertise with us today.

Before we begin, I'd like to introduce Sharon Saltzman, a caregiver of a small cell lymphocytic lymphoma/CLL patient who was featured in our new caregiver video clips. Sharon will share a few words. Sharon, please go ahead. Thank you.

Ms. Sharon Saltzman:

And thank you, Lizette.

As a caregiver, I would like to add my welcome to the patients, caregivers, and healthcare professionals attending the program today. The Leukemia & Lymphoma Society exists to find cures and ensure access to treatment for blood cancer patients and strives for a world without blood cancer.

As you will hear from today's presentation, being diagnosed or having a loved one diagnosed with a blood cancer can be difficult for any family. It was for my family. The Leukemia & Lymphoma Society's Information Specialists were available to provide us with personalized support, especially when we needed to find clinical trials.

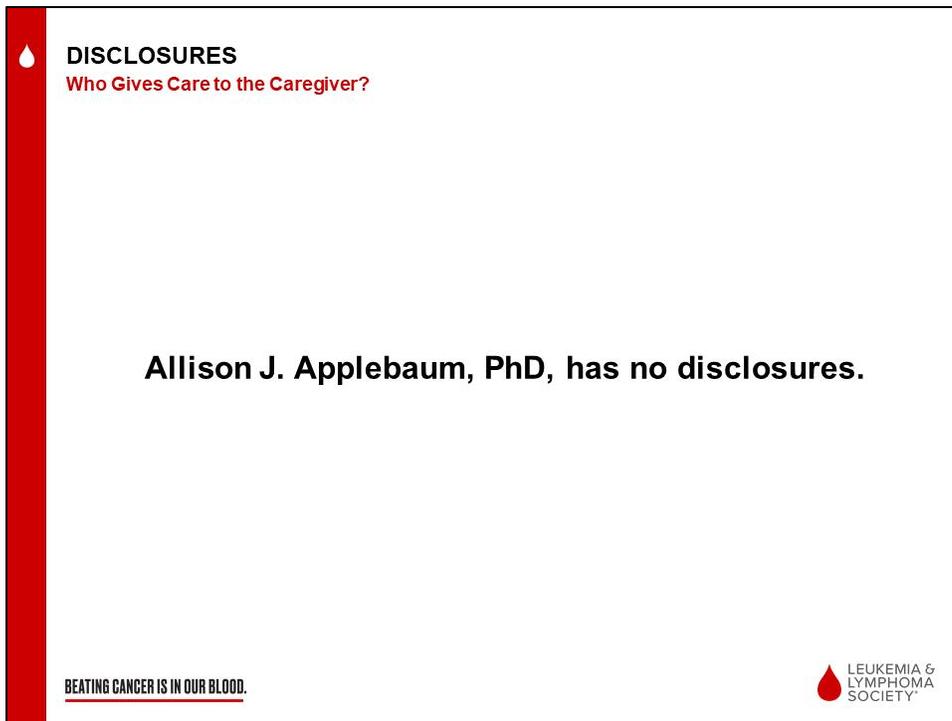
In addition, as this program demonstrated, LLS is the leading source of free blood cancer information, education, and support, and they touch patients in their communities throughout the 58 chapters across the US and Canada. I know that we drew on the support of our local chapter in Sacramento, California. LLS also acts as the voice for all blood cancer patients. They advocate for patients and survivors and their families, helping them navigate their cancer treatments and ensuring that they have access to quality, affordable, and coordinated care.

We are fortunate to have as our presenter today Dr. Allison Applebaum, who is committed to providing support for those caring for cancer patients. We appreciate her dedication to supporting the LLS mission. We would like to thank her today for providing us with information and resources for caregivers.

And now, I'll turn the program back to Lizette.

Lizette Figueroa-Rivera:

Thank you so much, Sharon. And thank you, Sharon, so much for volunteering your time today with us and for sharing your story as a caregiver on our video clips for caregivers.



DISCLOSURES
Who Gives Care to the Caregiver?

Allison J. Applebaum, PhD, has no disclosures.

BEATING CANCER IS IN OUR BLOOD.



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Disclosure

We would now like to acknowledge and thank Astellas for support of this program.



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Who Gives Care to the Caregiver

The Leukemia & Lymphoma Society

Wednesday, November 28, 2018

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Who Gives Care to the Caregiver?

Ms. Lizette Figueroa-Rivera:

I'm now pleased to introduce Allison J. Applebaum, Ph.D., Director, Caregiver's Clinic, Assistant Attending Psychologist, Department of Psychology and Behavioral Sciences at Memorial Sloan Kettering Counseling Center in New York, New York. On behalf of The Leukemia & Lymphoma Society, thank you so much, doctor, for volunteering your time and expertise with us today. I'm now privileged to turn the program over to you.

Dr. Allison J. Applebaum:

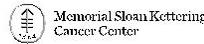
Thank you so much and good afternoon, everyone. And I'm so happy to be joining you at what is now the end of National Family Caregivers Month, in my perspective, one of the most important months for all of us.

Today, I'm going to be speaking for about 40 minutes or so about who caregivers are, what you all are doing, and, most importantly, how we can take care of one another so that you can be strengthened through this role. So, I'm going to get started.

Who are Caregivers?



- Formal caregivers
- Informal caregivers (ICs)
- World Health Organization (WHO) estimates that ~8% of the global population is dependent on others for care:
 - 1/3 US households in 2017 had an IC
 - 65.7 million Americans, 4.6 million of whom provide care to patients with cancer
 - ICs are predominantly female and providing care to a parent, and over 1/3 provide care to two or more people



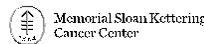
Who are Caregivers?

So, who are caregivers? I, in my role here at Sloan Kettering--I would identify as what we call a formal caregiver. I'm providing care to my patients, to families as part of my employment. But, many of us, including myself, have also been informal caregivers, meaning we're taking care of loved ones, family members, and friends, but we're certainly not financially compensated for doing so.

The World Health Organization (WHO) estimates that approximately eight percent of the global population is dependent on others for care. In 2017, just last year, one in every three households in the United States had a caregiver. This translated into 65.7 million Americans, 4.6 million of whom provide care to patients of cancer. And I imagine these numbers are rising as I speak. Caregivers are predominantly female and providing care to a parent, and over one third are providing care to two or more people at one time.

What Do Caregivers Do?

- Instrumental support
 - Activities of daily living (ADL)
- Emotional support
- On average, ICs provide care for 8.3 hours/day, for 13.7 months
- 1/3 ICs provide care for 5+ years
- Annual economic value of caregiving in the U.S. was recently estimated at \$375 billion



What Do Caregivers Do?

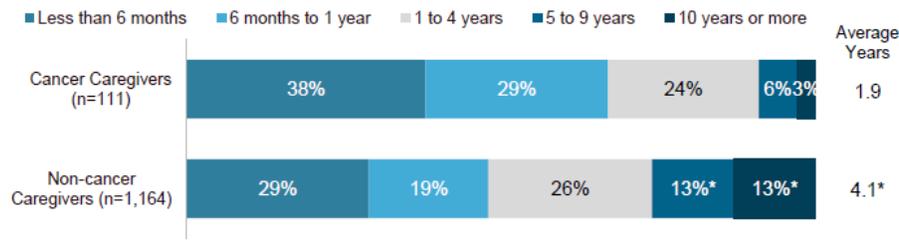
Now, what do caregivers do? I truly believe--and I always say this when I give this talk. I probably need to change the title of the slide to "What Don't Caregivers Do?" Caregivers are providing help with what we call instrumental support. That's help with activities of daily living, such as helping loved ones to get dressed, get out of bed, take their medications, go to doctors' appointments.

Caregivers are also providing emotional support, and, importantly, this is happening at the same time that their loved ones may no longer be able to provide emotional support to caregivers. And so, there may not be a mutuality in emotional support that's provided.

On average, caregivers are providing care for 8.3 hours a day for 13.7 months, on average. This is a full time job, oftentimes conducted on top of other full time paid employment. About one third of caregivers are providing care for five or more years. So, this role is not necessarily time limited. And, recently, the annual economic value of caregiving in the United States was estimated at \$375 billion dollars. I truly believe that caregivers make up the most important and fastest growing element of our healthcare system in the United States today.

Caregiver Experience in Cancer Care

Figure 3: Duration of Care



Caregiving in the U.S., 2016; www.caregiving.org



Caregiver Experience in Cancer Care

I'm going to present a little bit of data right now that comes from a very large study that was conducted across the country by the National Alliance for Caregiving as well as AARP that canvassed caregivers across the country, some of whom were cancer caregivers, 111 of them, and some, 1,164, who were not cancer caregivers. But I want to present this data to highlight, what we find is really the unique experience of taking care of a loved one with any type of cancer.

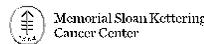
And the first piece here is, we'll see on average, cancer caregivers are providing care for 1.9 years versus 4.1 for non-cancer caregivers. This period is much shorter but is oftentimes much more intense in terms of the responsibilities and the demands of caregiving.

Caregiver Experience in Cancer Care

Figure 5: Hours of Care per Week

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Fewer than 9 hours	32%	47%*
9 to 20 hours	24%	21%
21 to 40 hours	13%	19%
41 or more hours	32%	22%
Average hours of care provided per week	32.9*	23.9

Caregiving in the U.S., 2016; www.caregiving.org

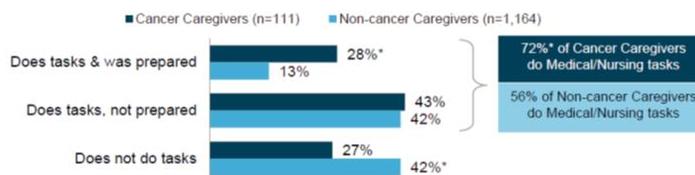


Caregiver Experience in Cancer Care

In terms of the time spent caregiving, we see that about 32 percent are providing either less than nine hours or 41 or more hours a week and, on average, providing care for 32.9 hours a week. That is a lot of time.

Caregiver Experience in Cancer Care

Figure 8: Performance of and Preparation for Doing Medical/Nursing Tasks



Caregiving in the U.S., 2016; www.caregiving.org



Caregiver Experience in Cancer Care

I think what's particularly striking to me, when I looked at this data, is the following slide, which said that 72 percent, so almost three quarters, of cancer caregivers are performing medical or nursing tasks, and oftentimes they're doing this without any prior preparation or education, certainly something that contributes to what we call caregiver burden. Very simply stated, caregiver burden occurs when the demands of the caregiving role, what you're asked to do, either directly or indirectly, exceed the resources you have to conduct that role, either internal or external to yourself.

Caregiver Burden

Caregiver Strain and Burden

Caregiver strain and burden encompasses the difficulties assuming and functioning in the caregiver role, as well as associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources. Caregivers experience differing challenges during different phases of the cancer trajectory that can significantly impact their functioning and quality of life.

Demands exceed resources

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Caregiver Burden

More specifically, caregiver burden is a multidimensional construct that refers to all the ways in which the caregiving role can have a potentially negative impact on you.

Caregiver Burden

- Multi-dimensional
 - Psychological
 - Anxiety
 - Depression
 - Physical/Medical
 - Cardiovascular disease
 - Poor immune functioning
 - Fatigue/sleep difficulties
 - Higher rates mortality
 - Financial
 - Temporal
 - Existential



Caregiver Burden

The first component of this is psychological. And it's one of the main reasons why I do the work that I do. We have found that, for example, diagnostic rates of anxiety and depression are higher among caregivers than among the patients for whom they're providing care, that the psychological experience is often times more difficult for caregivers than for patients.

There's also a physical component to burden. We know that caregivers are at risk for cardiovascular disease, poor immune functioning, fatigue and sleep difficulties, and generally higher rates of mortality. And, in effect, cancer caregivers may represent the next generation of patients with cancer, for a variety of reasons, including having a very prolonged period of increased distressed and maybe not taking great care of oneself during this period. So, it's one of the reasons I'm thrilled to be doing the webinar today is to focus on helping you all to take care of your minds as well as your bodies.

Burden also includes a financial component, either because you are no longer able to work full time because of your caregiving responsibilities or because all of the money you earn goes to taking care of your loved one. Cancer is expensive.

Existential Distress

- Multi-dimensional
 - Hopelessness
 - Powerlessness
 - Questions about identity
 - Feeling like a burden to others
 - Decreased sense of meaning and purpose
 - Guilt
 - Death anxiety



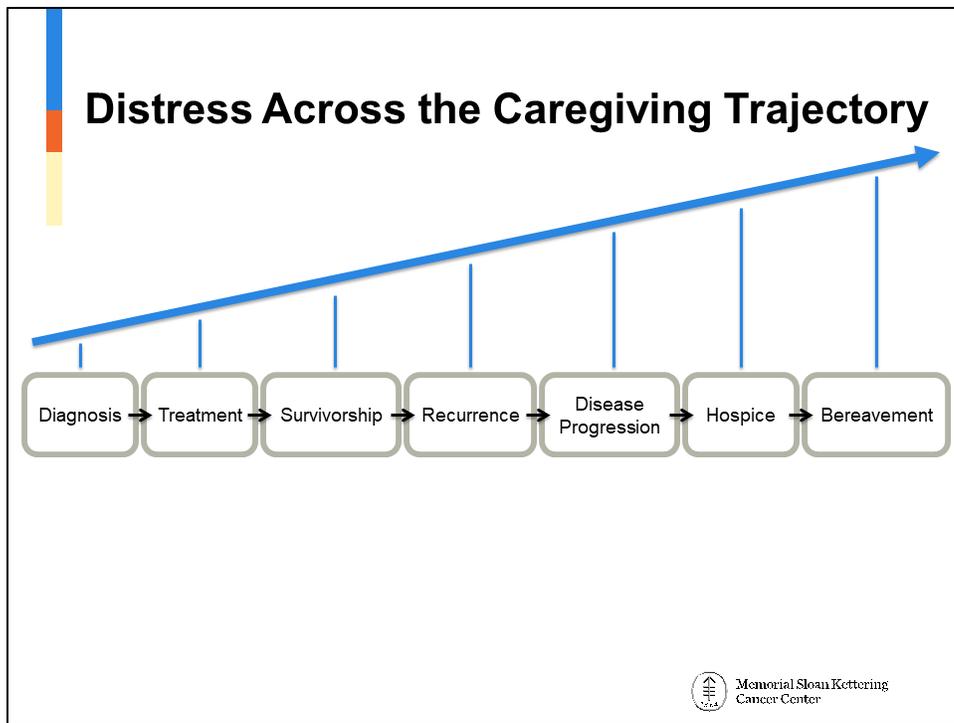
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Existential Distress

There is a temporal or time element, which we just talked about, as well as a component which I call existential. And I'm putting this on here because, when I think about the experience of caregivers who come to speak to me at Memorial Sloan Kettering, so much of what they talk about does not fit neatly into categories of anxiety or depression, per se. Existential distress is also a multidimensional construct, and it refers to the following: feelings of hopelessness, feelings of powerlessness, for example, "I cannot control my husband's cancer. I cannot control the future."

Questions about one's identity- many caregivers who are no longer able to work full time, as a lawyer, for example, may feel a shift in their identify as they become more engrossed in the caregiving responsibility. Many report feeling like they are a burden to others. Many will report a decreased sense of meaning and purpose in their life, like they've become disconnected from those things that bring them a sense of pleasure, of purpose, of meaning. Perhaps the most common word that caregivers will say is "guilt". I bet many of you on this phone call have said many things this week or thought many things this week that have to do with feelings of guilt.

And certainly, I like to bring the elephants in the room. The fact is that no caregiver comes through the walls of Sloan Kettering and does not fear their loved one's death, regardless of the site or stage of their loved one's cancer. And these all contribute to what we call existential distress and are elements that you all, if you experience them, deserve assistance with.



Distress Across the Caregiving Trajectory

Ok, so, we know that distress across the caregiving trajectory increases exponentially if it's left untreated. And we're going to talk about how to treat it in a few moments. We also know that there are particular points in the caregiving trajectory, at the point of patient transitioning to survivorship, for example, or as patients transition to hospice or bereavement care, when caregivers may experience an increase in distress.

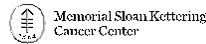
And certainly, it would make sense, if your loved one has transitioned to end of life care, that you would experience an increase in distress. But what is less, perhaps logical is the fact that we actually see a spike in distress for caregivers in survivorship. So, I want to just take a few moments to talk a little bit about this.



Cancer Caregivers are Cancer Survivors

- NCI (2013) definition of Cancer Survivor:

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”



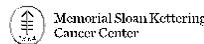
Cancer Caregivers are Cancer Survivors

So, I think the first thing I want to say is that cancer caregivers are cancer survivors. And, in fact, in 2013, the National Cancer Institute actually included caregivers in their definition of survivor. They've said: "An individual considered a survival from the time of diagnosis to the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are included in this definition."

During survivorship, caregivers are at **greater** risk for **distress** than patients

- Caregivers of long term cancer survivors report significant health problems, including heart disease, hypertension and arthritis.
- Caregivers report lower QOL and receiving less social support than do patients.
- Fear of recurrence is *equal* if not *greater* among caregivers than patients.
- Navigating return to full-time employment and shifting family roles requires negotiation.

Kim et al., 2010, 2012; Lambert et al., 2012; Papastavrou et al., 2009.



During survivorship, caregivers are at greater risk for distress than patients

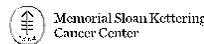
During survivorship, however, what we find is that caregivers are actually at greater risk for distress than patients. This is a time often when patients sort of return to baseline. They experience a new normal. They take an exhale. This is actually a time when caregivers experience an increase in their concern. So, we find caregivers of long-term cancer survivors--they report significant health problems, including heart disease, hypertension, and arthritis. They report lower quality of life and actually receiving less social support from friends and family than do patients.

We find that caregivers actually fear recurrence as much of their patients do--the fear of recurrence, which is so common. Caregivers are not immune to this. And certainly, navigating a return to full time employment and shifting family roles can also be complicated and require some negotiation.

During survivorship, caregivers are at **greater** risk for **psychopathology** than patients

- Baseline levels of anxiety and depression higher among caregivers than patients.
- Symptoms remained stable over 2 year survivorship period (4 groups modeled).
- Levels of anxiety and depression remained constant across time points from 6 months to 5 years post diagnosis.

Lambert et al., 2012



During survivorship, caregivers are at greater risk for psychopathology than patients

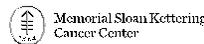
Not surprisingly then, we find that, during survivorship, caregivers are at greater risk for psychopathology, for anxiety and depression, for example, than patients. We know, again, that baseline levels of anxiety and depression are higher in caregivers than patients, and, when left untreated, these symptoms are going to remain stable over two years.

And this comes from a study of Lambert, et al. in 2012, where they examined caregivers over many, many years after their loved ones' cancer diagnosis. And they found that, if they didn't treat mild levels of anxiety and depression, that those levels would maintain constancy and, in fact, increase from six months to five years post diagnosis. So, really, the main message here is that it is so important for us to recognize, within ourselves, within other caregivers, signs and symptoms of distress and to help each other to get some help.



Institute of Medicine (IOM, 2008) “Retooling for an Aging America: Building the Health Care Workforce”

Highlighted the responsibility of health care professionals to prepare caregivers for their role and the need to establish programs to assist them with managing their own stress that results from providing care.



Institute of Medicine (IOM, 2008)

In 2008, the Institute of Medicine had a report which highlighted the responsibility of healthcare professionals to prepare caregivers for their role and the need for us to establish programs to assist them with managing their own stress that results from providing care.



How to Get Help

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



How to Get Help

So, I want to talk a little bit now about how to get help if you feel like you might need help. And the first is to just simply recognize the signs and symptoms of burden. And I'm going to talk a little bit more about them. But I do want you to think about if anything I've said thus far resonates with you and your experience.

The second is to activate support networks. And activating support networks really does mean you taking a step and challenging yourself to ask for help. Many patients of mine are surprised by how many people eventually support them after they've asked for help. But, our friends and family members, our acquaintances, our colleagues--they are not mind readers. And so, oftentimes, unfortunately, we do really need to ask for help.

I also want to encourage you to think about the fact that your support may come from unlikely sources. It has certainly been a common experience among patients of mine to say, "You know what, Dr. Applebaum? The friends and family I thought who would be there for me--they're completely MIA." And that's, unfortunately, common, and so, I encourage those patients to consider who else can they ask for help from and to be as specific as possible.

Second, when you think about getting help, I want you to really think about what we mean by self-care. And I'm going to talk later on about some specific self-care tactics. But, what does it mean to take care of yourself?

And right now, what I want to acknowledge here is that, if and when you feel guilty--maybe you feel--you're having the thought that, "I would have, should have, could have--I should be at his hospital bed. I could have got a third opinion," all of those thoughts where you feel like you might be letting someone else down, you might be letting your loved one, who is the patient, down--I want everyone on this webinar to consider that, in that moment, you may also be letting yourself down in some way. And, in fact, we have found clinically, when we feel guilty, we're actually not attending to our own needs. And so, it's a really great opportunity to actually recognize when you need to increase your self-care.

Also important for me to mention, since I am a clinical psychologist, that self-care includes expressing emotions. If we keep our emotions bottled up, if we do not express them, either with oral words, with written words, with friends, with family members, with people in support groups, we bottle them up, we're going to experience increased distressed and certainly some physical symptoms as well. So, I encourage you to express the emotions that are coming up.



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Professional Support



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Professional Support

Which leads me to the important topic of professional support, which certainly there is a lot of. You just have to find it in the right places.



Professional Support

- Many cancer centers have licensed clinical psychologists, social workers, and mental health professionals who specialize in supporting families facing cancer. Just ask!
- Phenomenal resources through organizations such as:
 - American Cancer Society
 - Cancer Support Community
 - CancerCare
 - The Leukemia & Lymphoma Society



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Professional Support

So, many cancer centers, not just Memorial Sloan Kettering, have licensed clinical psychologists, social workers, chaplains, mental health professionals, who specialize in supporting families facing cancer. They are there. They may not be that visible. But I encourage you all, wherever you are, to just ask, “Who can support me in this journey?”

There are also, of course, phenomenal resources through many organizations across the United States, including, of course, the American Cancer Society (ACS), the Cancer Support Community (CSC), Cancer Care (CC), and, of course, The Leukemia & Lymphoma Society (LLS).

Caregivers Clinic

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Most frequent presenting complaints:

- 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 and self-care
- Guilt
- Existential distress, Death anxiety



MR. WORRY
By Elgin Hongmawee



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Caregivers Clinic Memorial Sloan Kettering Cancer Center

Now, here at Memorial Sloan Kettering, we have a clinic in our counseling center where we provide specialized care just for caregivers. And what I want to do is--I just want to highlight for you what we've found are the most common reasons why caregivers come to us. And I'm doing this for two reasons. First, I want to possible normalize your own experience, and, secondly, I want to bring to light, if you are having concerns in any of these areas, this may be a good time for you to seek professional support wherever you are.

So, the most frequent presenting complaints: Number one is difficulty communicating with patients or healthcare professionals. It is absolutely overwhelming to ask difficult questions of oncologists, to have difficult conversations with your loved ones. Absolutely. And we're not necessarily taught to do this. And this is one of the primary reasons people come to me.

And this is really important to address because, in order to effectively engage in advanced care planning, for example, planning for the future, all the possible outcomes in the future, treatment decision making, you need to actually communicate with words with your loved ones' oncologist and with your loved one. And so, this is one big area of concerns for caregivers in our clinic.

We also find what I have been referring to as the networks of silence. Many caregivers will come into me and say, “Dr. Applebaum, I don't want to tell my daughter what I'm thinking because it's going to upset her. I don't want to upset her. If I upset her, she's not going to be calm. And if she's not calm,

her cancer's going to get worse." Meanwhile, that young woman might be seeing a colleague of mine down the hall, saying, "Dr. Breitbart, I don't want to tell my mom what I'm thinking. I really don't want to upset her."

We find that patients and caregivers, whatever the relationships, whatever the scenarios, oftentimes are not talking to one another. In fact, they are walking around, keeping their mouths closed, holding onto big thoughts and big ideas and lots of intense emotions. And what they're doing is, I think, quite frankly, with the intention of trying to take care of one another by protecting them and not exposing them to difficult negative emotions, in effect, they're isolating one another from each other, and they're actually making the whole circumstance more overwhelming. So, I encourage communication, communication, communication. It's not easy. And you can get assistance in this area.

Second big area is, I would say, diagnostically--is generalized anxiety disorder. And this is, I think, best--I like to illustrate with Mr. Worry. Maybe some of you on this webinar are having a little chuckle right now. These were books that I used to love reading when I was a child.

Well, Mr. Worry spends all of his time thinking about the future or ruminating about the past. And this is a problem because, if you're spending the present moment at 12:23 on November 28th thinking about what you're going to make for dinner tonight or what happened yesterday with your loved one, you're not able to fully present in this moment.

And that, not only makes it so hard to cope with all of the demands placed on all of you as caregivers, but it also prevents you from engaging fully in the present moment and deriving the good stuff that can happen, the pleasant moments, the beautiful moments, the moments of connectedness. And so, certainly, helping our caregivers to navigate and quiet their minds is one significant reason why they come into our clinic.

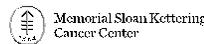
A third is insomnia and related distress. And I have a few slides on this later on because insomnia is the most distressing symptoms and complaint that caregivers report. And it's very debilitating, and I want to spend a little bit of time on it later on.

Next, which I imagine is probably common for many of you, is the difficulty maintaining the balance between your caregiving responsibilities and taking care of yourself. "How do I take care of everything I need to do for my husband and work fulltime and take care of my kids? And how in the world am I going to take of myself as well?" And finding that balance takes a lot of work. But, it's critically important, just as important as taking a vitamin or a medicine.

Yes, we do talk about guilt, and we do talk about guilt in the context of self-care as well. And, of course, we do address the existential distress and the death anxiety that comes up for many caregivers across this care trajectory.

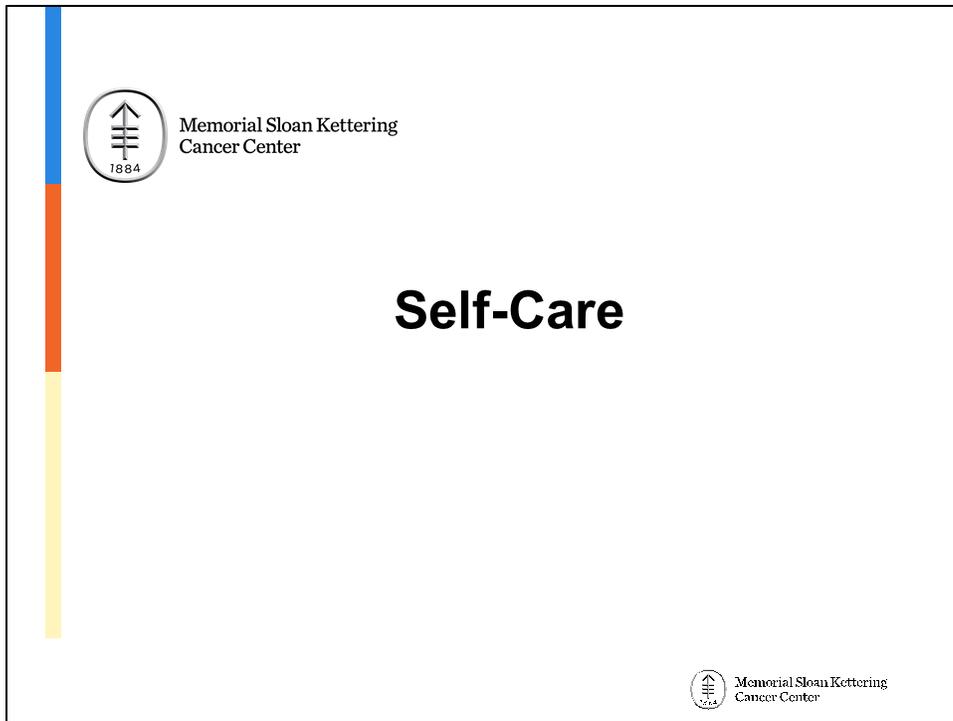
Caregiver-Specific Interventions (2018)

- Cognitive Behavioral Therapy for Insomnia (CBT-I)
- Problem-Solving Therapy
- Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C)
- Emotion Regulation Therapy for Cancer Caregivers (ERT-C)
- Communication skills training programs



Caregiver-Specific Interventions (2018)

I'm happy to say that about seven or eight years later, here in 2018, we have a large and growing body of what we call empirically supported treatments, supportive services that we know work to address caregivers' specific needs. And these include cognitive behavioral therapy for insomnia, specifically for caregivers, problem solving therapy, specifically for caregivers, meaning-centered psychotherapy for caregivers, which helps to address the existential concerns that I was speaking about earlier, emotion regulation therapy for cancer caregivers, which focuses specifically on helping caregivers to manage their worry and rumination, and a growing number of communication skills training programs to help caregivers to navigate those difficult conversations. So, there is a lot out there, and certainly, mental health professionals across the country are receiving training in these and other support approaches.



Self-Care

Ok, so, it's all well and good to come to the caregivers' clinic and to receive professional support. But, it's also important, in addition to that, or independent of that, that everyone in this webinar is engaging in what we call self-care.

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.

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The slide features a vertical bar on the left with segments of blue, orange, and yellow. The Memorial Sloan Kettering Cancer Center logo is positioned in the bottom right corner.

What is Self-Care?

What is self-care? I think this phrase gets thrown around a lot these days. Self-care is about being deliberate in taking time for yourself for the betterment of your mind, your body, and your soul. Very important: self-care is not about being selfish. It's about replenishing and refreshing your spirit in different ways. And, quite frankly, I think that the negative connotation of the word selfish might need to be adjusted. This is really about acknowledging that, in our world, we are the most important people, in our own existence as a human on this earth.

When is Self-Care Needed?

- ALWAYS.
- When burden is high:
 - No longer able to carry out responsibilities
 - Increased anger
 - More frequent medical problems
 - Poor health-related behaviors
 - Direct communication of depressive symptoms/suicidal ideation



When is Self-Care Needed?

When is self-care needed? I want you all--before I progress, I want you to take one deep breath and think, "When do I need to take care of myself?" When is self-care needed? Self-care is always needed, always.

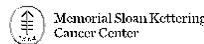
However, it is particularly needed when burden is high. We know burden is high, for example, when you're no longer able to carry out your responsibilities, when you find you're experiencing an increase in anger or irritability, you're sort of taking it out on other people in situations that are not related to caregiving. When you, on your own, are experiencing more frequent medical problems, it is, unfortunately, cold and flu season now. If you find that you're coming down with more colds, more flus, more sinus infections than usual, that might be a sign that your burden is high.

As is, if you are noticing that you are engaging in more poor health related behaviors--so, what are those? Those would be not going to the gym or exercising enough, if at all. That would mean drinking a little more alcohol than you would like. That would mean beginning to smoke again. That would mean eating poor food choices, not attending to your nutrition. Anything that maybe you're doing because, in the moment, it feels good, but actually is not helping your body and your soul--those are the poor health related behavior and also something that caregivers tend to engage in when they're feeling particularly burdened.

And, of course, we need to take care of ourselves if you or anyone is expressing feelings of depression or even the most severe thoughts that life may not be worth living. Of course, this is a time where, not just self-care is needed, but professional support is, of course, needed as well.

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



Self-Care Tips

So, I imagine that many of you listening in right now are thinking to yourselves, “Well, how in the world can I actually take care of myself when I’m running around from appointment to appointment, to chemotherapy to radiation, to this treatment, to that treatment, and I’m trying to take care of my children, and I’m trying to work part time, and I’m trying to sleep?” And I agree with you. And it’s for this reason that I want to talk about some self-care tips that patients in my clinic, all of whom are caregivers, over the past ten years, have found to be particularly helpful. And I will say that I have tried these too. I practice what I preach.

The first is--I want you all to schedule self-care as you would a medical appointment or a work meeting. And what I mean by that is, if you’re somebody who uses an electronic calendar like Outlook or you use an old school pen and paper calendar, I want you to actually put on your schedule, block off time, whether it’s five minutes or a half an hour or, if you’re lucky enough, a few hours just for you. And I actually want you to put this on your schedule so that it’s on there and it’s protected and it is honored as would a phone call with your boss, taking your loved one to a doctor’s appointment, or going to the grocery store. It’s very, very important to actually schedule self-care so that you can make sure you have the time.

Second, I want you to try to integrate at least one self-care activity into every day and more on stressful days. I know that might sound like a lot. But, we’re going to talk about what these might be. But, at least one thing--it can be very small.

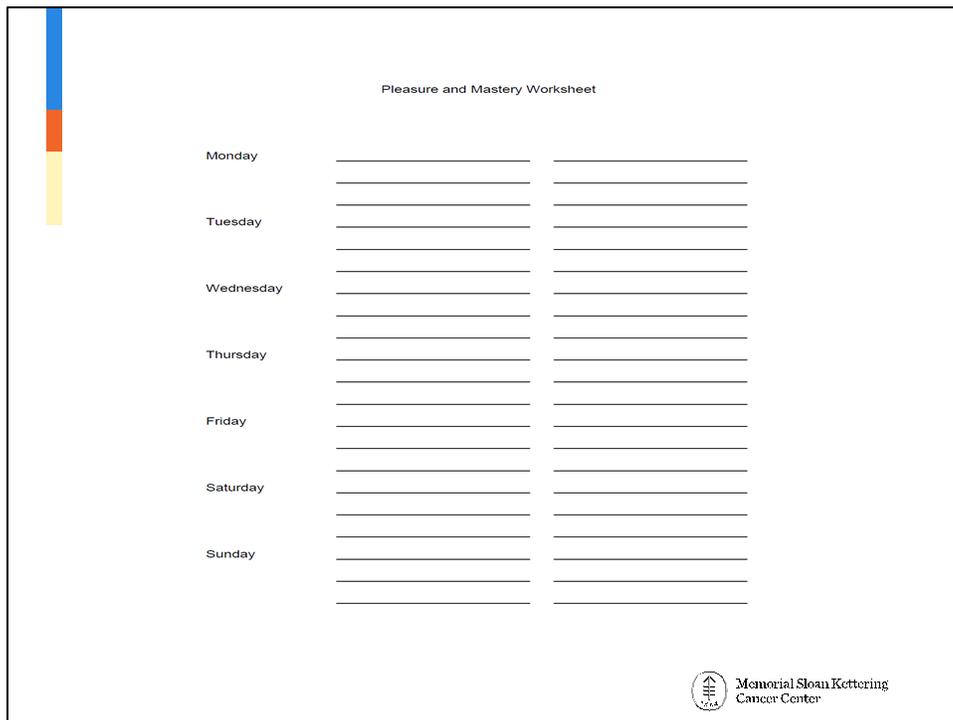
But, if you know, for example, that, for a variety of reasons, the upcoming week is going to be a stressful one, then that’s the time when I would want you to plan, in advance, to have at least two or three things during that week, even if they’re just ten minutes long, that you can do for yourself. Maybe it’s making sure that you can take a few walks around the block. Maybe it’s buying your favorite kind of ice cream. Maybe it’s talking with a close friend across the country. Maybe it’s going to a movie. Whatever it might be--making sure that you’re doing it.

I also want all of you to take an honest look at your current coping strategies. What is working? And if there are a lot of things that are working, that's wonderful, and I want you to continue to do them. Or what's not working right now? Maybe there are certain friends your originally thought you wanted to support you. But you're actually finding that they're actually burdening you some more. Maybe talking to them is not helpful.

I really want you to look at what you're doing. I want you to take an honest look at how much you're exercising, an honest look at what you're eating, at honest look at how much alcohol you're drinking, if you drink, an honest look at tobacco use, if you are engaging at this time. I think, most importantly, I want you all to think small. So, certainly, self-care can be something as luxurious as going to a yoga class or going for a massage. But it can also be spending five more minutes in your shower while you play some music that you really like or drinking a hot cup a tea in the morning in a moment of quiet or doing a little gardening.

I am in New York City. I admit to you that, down the street are lots of buildings and sirens. But--you can't see my office. But it is filled with plants because I love to garden and merely just pruning the plants in my office to make me feel a little bit more calm. And that's something small that I can do. I want you to think of the small things that you all can do.

And I also want you to make sure that your self-care activities are in line with good sleep hygiene. I'm going to be talking about this in a moment. But this idea is that, for many caregivers, the only time during the day that you have free is at the end of the day, at night. But, if you want to be asleep at midnight, you cannot go to the gym at eleven PM. That is just not going to help you sleep. So, it's very important that you schedule your exercise routine in a way that's not going to interfere with your sleep.



The image shows a worksheet titled "Pleasure and Mastery Worksheet". On the left side, there is a vertical bar with four colored segments: blue at the top, orange, yellow, and white at the bottom. The worksheet itself is a grid with seven rows, one for each day of the week (Monday through Sunday). Each row has two columns of horizontal lines for writing. At the bottom right of the worksheet, there is a logo for Memorial Sloan Kettering Cancer Center.

Pleasure and Mastery Worksheet

This is one of the handouts that I use with some of the caregivers who come to our clinic. It's called the pleasure and mastery worksheet. And basically, when a caregiver says, "You know what, Dr. Applebaum? I just don't think I can do anything over the course of the next week," I take this out, and we sit together. And we write in at least one activity each day that could bring one sense of pleasure

or mastery, mastery meaning a sense of accomplishment. Now, while cleaning my apartment may not be pleasurable, when it's done, I feel a sense of mastery, and that feels good. And so, I would put that on there. The idea is that you want to actually be purposeful and schedule these things that you make sure you're making time for you to have some good feelings.

Autogenic Relaxation Instructions

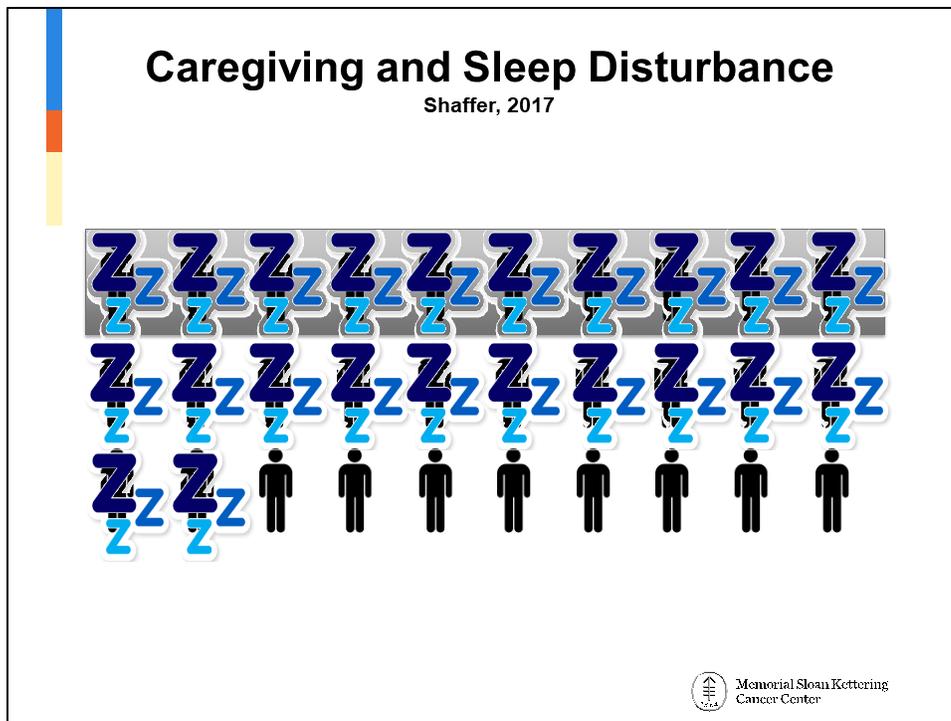
This exercise lowers physiological stress, increases blood flow, and decreases muscle tension through the repetition of simple words and phrases. The script below is one example of many variations. The script may be memorized or recorded on tape:

My right arm is warm and heavy. My right arm is warm and heavy.
My left arm is warm and heavy. My left arm is warm and heavy.
My right arm and my left arm are warm and heavy. My right arm and my left arm are warm and heavy.
My forehead is calm and relaxed. My forehead is calm and relaxed.
My face is calm and relaxed. My face is calm and relaxed.
My entire head is calm and relaxed. My entire head is calm and relaxed.
My chest is warm and heavy. My chest is warm and heavy.
My stomach is calm and relaxed. My stomach is calm and relaxed.
My entire upper body is warm and heavy, calm and relaxed. My entire upper body is warm and heavy, calm and relaxed.
My right thigh is warm and heavy. My right thigh is warm and heavy.
My right lower leg is calm and relaxed. My right lower leg is calm and relaxed.
My left thigh is warm and heavy. My left thigh is warm and heavy.
My left lower leg is calm and relaxed. My left lower leg is calm and relaxed.
My entire right leg and my entire left leg are warm and heavy, calm and relaxed. My entire right leg and my entire left leg are warm and heavy, calm and relaxed.
My entire body is warm and heavy, calm and relaxed. My entire body is warm and heavy, calm and relaxed.



Autogenic Relaxation Instructions

There's also many, many relaxation and meditation scripts which you can find online. There's wonderful apps like *Head Space* that you can put on your phone that you can use to help you to relax in any environment, with the exception of driving a car. And these can be done while you're in a waiting room, while you're trying to go to bed, any time when you're feeling particularly stressed. But I bring them up because some of the best self-care activities may only take five minutes, like some deep breathing, diaphragmatic breathing, autogenic relaxation. If you just Google autogenic relaxation, you'll probably come up with thousands of hits of different scripts that you can use that help to calm your body and mind, if followed.



Caregiving and Sleep Disturbance (Shaffer, 2017)

So, I mentioned that I wanted to take a moment to talk about insomnia. And I want to talk about this because, in the years since I've been working in the caregivers' clinic, I have found that--and this has certainly been borne out in the scientific literature as well--that insomnia and related fatigue is perhaps the most distressing and impairing of concerns for caregivers.

And, in fact, if a caregiver comes to my clinic for the first time and they say, "Dr. Applebaum, I had terrible insomnia last night. I did not go to sleep at all," I will say to that caregiver, "I cannot evaluate your mood. I cannot evaluate your level of depression today," because we all know that, if we've not slept, we certainly don't feel happy. And so, it's very, very important that we pay attention to our sleep habits.

And a lot of this research was done by Dr. Kelly Shaffer, who I had the honor of mentoring here at Memorial Sloan Kettering for the past two years. She's now down at the University of Virginia. But, she's done some great work exploring caregiving and sleep.

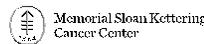
So, if you've been experiencing worse sleep now than ever before since your loved one's cancer diagnosis, you are not alone. We know that between two fifths and three quarters of cancer caregivers report clinically significant sleep disturbance, and that's compared to only one third of the population. So, this is really, really striking. This is really important for us to note.

What is Insomnia?

- Rule of 3s:
 - ≥ 30 minutes: fall asleep, waking in night, before alarm
 - ≥ 3 nights per week
 - ≥ 3 months

... despite adequate opportunity

... & distress / impairment



What is Insomnia?

But just because you've had a sleep disturbance doesn't necessarily mean that you are actually someone who has insomnia. So, when we think about insomnia, we think about the rule of threes. It means that it's taken you more than 30 minutes to fall asleep, that you're waking in the night and you're getting up before your alarm. This is happening on three or more nights per week, and it's happening for at least three months, if not more. Importantly, these three are happening in the context of having adequate opportunity to sleep. So, you actually had an opportunity to go to sleep at night. And it's causing distress and impairment.

And I think one of the reasons why I wanted to bring up insomnia and sleep disturbance here today is that, for many caregivers, before their loved one's cancer experience, they didn't have trouble sleeping. Some did, and that makes this harder. But some never did. But, the experience of always being on call, on watch for symptoms, for side effects, for adverse events, all of the reasons why you can't turn your phone off, which, obviously, would be great for sleep, if you could, contribute to an experience that creates insomnia for many caregivers.

Insomnia Treatment

Today's date	Example: 4/5/11							
1. What time did you get into bed?	10:15 pm.							
2. What time did you try to go to sleep?	11:30 pm.							
3. How long did it take you to fall asleep?	55 mins.							
4. How many times did you wake up, not counting your final awakening?	3 times							
5. In total, how long did these awakenings last?	1 hour 10 mins.							
6. What time was your final awakening?	6:35 a.m.							
7. What time did you get out of bed for the day?	7:20 a.m.							
8. How would you rate the quality of your sleep?	<input type="checkbox"/> Very poor <input checked="" type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good	<input type="checkbox"/> Very poor <input type="checkbox"/> Poor <input type="checkbox"/> Fair <input type="checkbox"/> Good <input type="checkbox"/> Very good

Insomnia Treatment

The good news is we have wonderful treatments for insomnia, including cognitive behavioral therapy for insomnia. And I'm going to give you the one or two lines on this. And basically, this is a tracker for your sleep. And basically, we ask our caregivers to think about when they're getting in bed, how long it takes them to go to sleep, and when they're getting up in the morning.

And the one tip that I want to give everyone on this webinar right now is that, if you lie in bed awake at night for more than, let's just say, five minutes, I want you to get out of bed. The more that you lie in bed awake, you pair your bed with being awake. And it actually makes your bed a place where you're more likely to stay awake. And, in fact, my preference is not to get in bed at nine in order to fall asleep at ten, but to get in bed when you think you're about to fall asleep, so possibly reading on the sofa for 45 minutes while your eyes get sleepy and then getting into bed, if possible.

Certainly, happy to talk more about this, but do want to acknowledge we do have many wonderful non-pharmacological treatments for caregivers. And I think this is important because many caregivers will say, "I don't want to take a medicine that's going to knock me out. What if there's an emergency? I have to wake up." And that's why it's important that we address insomnia without medications.



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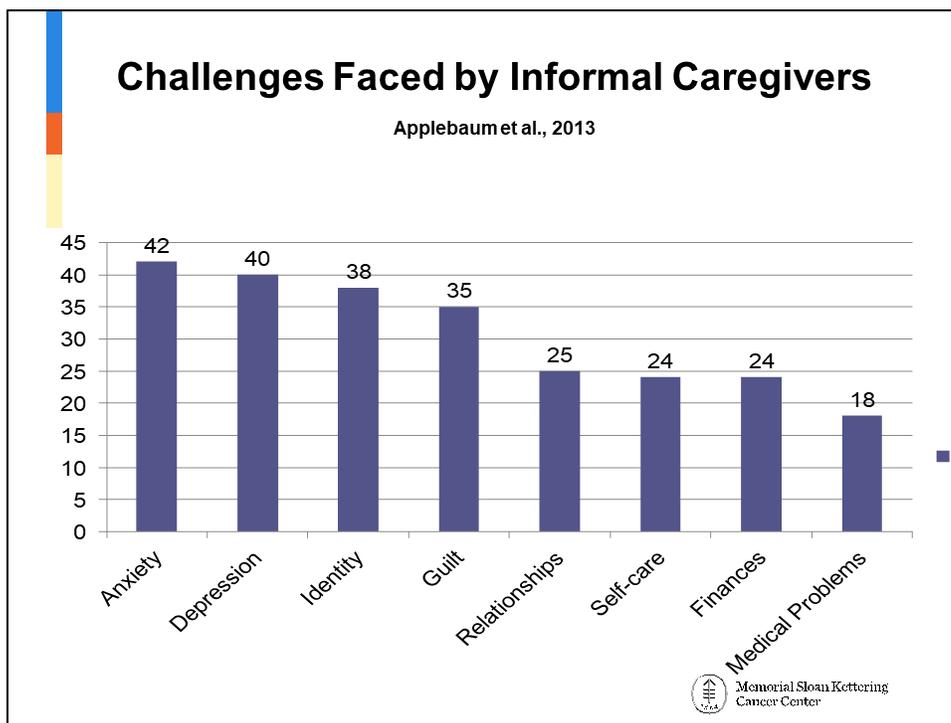
The Benefits of Being a Caregiver



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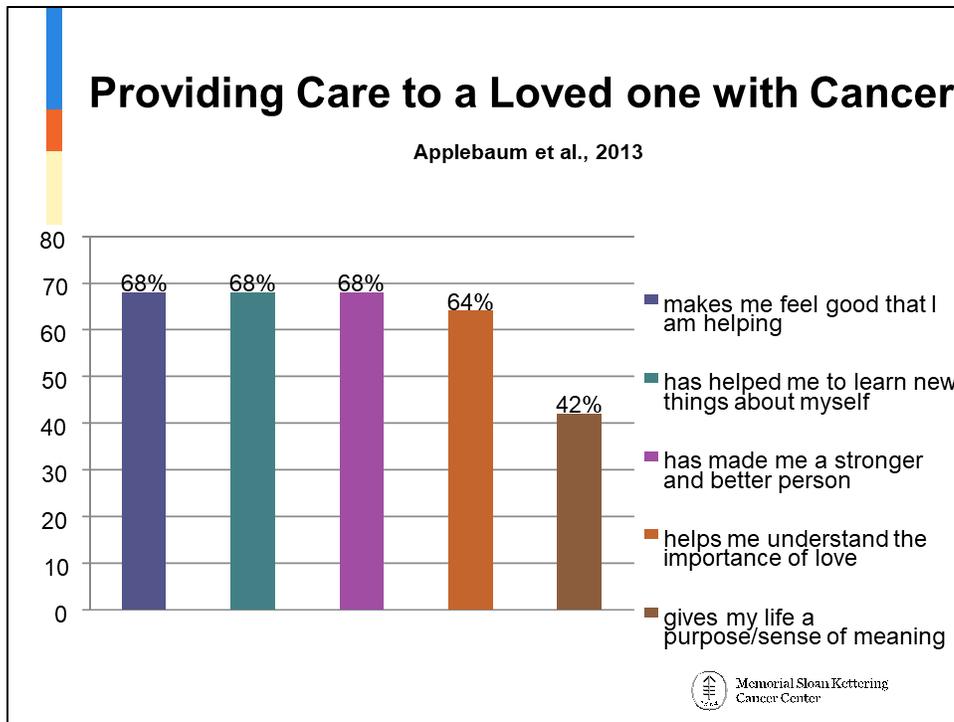
The Benefits of Being a Caregiver

Ok, I know my time is going to run out shortly. But, I don't want to end on a negative note, and I do think it's important that we talk briefly about the benefits of being a caregiver. And, quite frankly, this is one of the reasons--one of the other reasons why I do the work that I do.



Challenges Faced by Informal Caregivers

Certainly, there are many challenges that I've reviewed thus far, and this was a simple study I conducted here at Sloan Kettering where I was looking at the different areas of concerns our caregivers are reporting, not surprisingly, based on all that I shared with you, concerns around anxiety and depressions and relationships and self-care and finances.



Providing Care to a Loved one with Cancer

But I asked these caregivers some very pointed questions about some benefits. Specifically, I asked them about some of the potential gains they might have made in their caregiving role. And, in fact, in this sample of caregivers in 2013, close to 70 percent said that, “providing care to my loved one makes me feel good that I’m helping. Providing care to my loved one has helped me to learn new things about myself. Providing care to my loved one has made me a stronger and a better person.” Sixty-four percent said that, “providing care to my loved on has helped me to understand the importance of love,” and 42 percent said, “Providing care to my loved one gives my life a purpose and a sense of meaning.”

And I want you all on this webinar to take a moment and think about if you have experienced any of this. Have you been able to connect to some of the good that can come from the caregiving role? This is not about the power of positive thinking. I am certainly not preaching turning lemons to lemonade. I’m acknowledging the fact that, despite the suffering that you all are experiencing as caregivers, you can, at the same time, experience benefit and growth.



“Marriage is just as effective as
chemotherapy.”

-Rebecca Johnson, M.D.

Cancer caregivers are the next generation
of cancer patients.



“Marriage is just as effective as chemotherapy” (Rebecca Johnson, M.D)

So, I just want to finish by acknowledging--this was said by Dr. Rebecca Johnson. “Marriage is just as effective as chemotherapy.” I couldn’t agree more. You all are on the front lines. You are fighting a very difficult system on behalf of your loved ones. You are doing it with your blood, sweat, and tears. And it is so necessary and so needed. And we need to take care of you because we do not want you all to become the next generation of patients with cancer.

**WE TREAT
PEOPLE
WITHOUT
CANCER, TOO.**

It's a helpless feeling to find out someone you love has cancer. Friends and family are often hit just as hard as the person diagnosed. That's why we offer caregiver support services to help people deal with this difficult situation while knowing their loved one is being taken care of. At Memorial Sloan Kettering, we're here for everyone affected by cancer, whether they're our patient, or a caregiver.
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“We Treat People Without Cancer, Too”

So, this concludes my presentation, and I think we’re going to have time for some questions. Thank you.

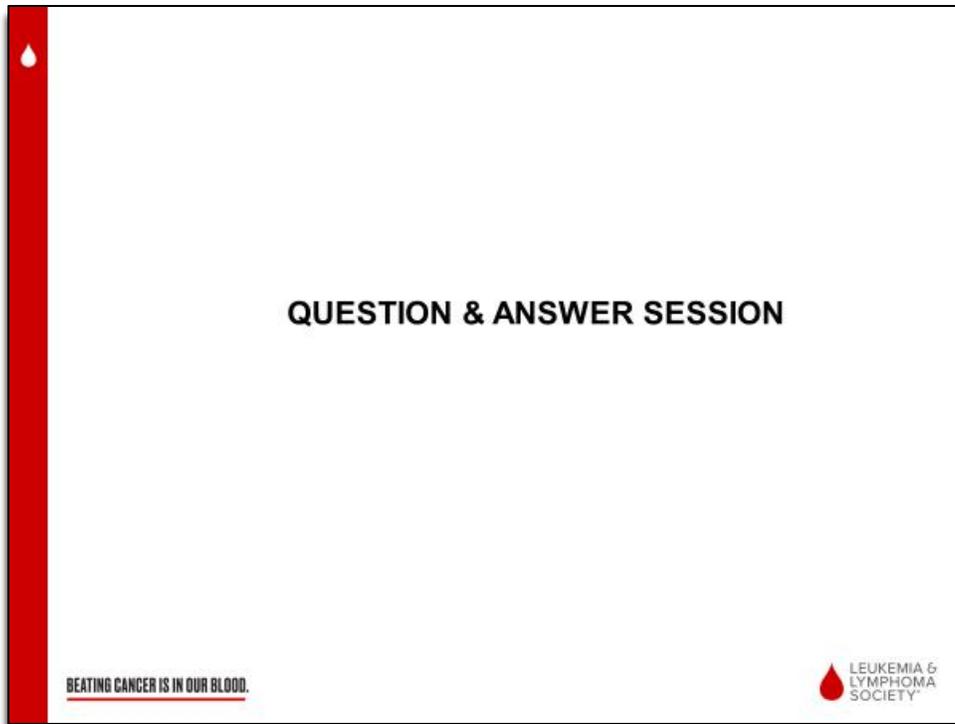
Thank You!

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Slide 38 – Thank You!

Ms. Lizette Figueroa-Rivera:

Thank you, Dr. Applebaum, for your very informative presentation.



Slide 39- Question & Answer Session

It's now time for our question and answer portion of our program.

Ms. Lizette Figueroa-Rivera:

Thank you.

Doctor, we'll start with a question submitted on the web. How do you handle a patient that doesn't follow doctors' orders?

Dr. Allison J. Applebaum:

This is such a difficult scenario when patients are not following doctors' orders, perhaps when they're not being adherent to certain medications or following nutritional guidelines. Obviously, this is difficult for you, as caregivers, because you're sort of tasked with encouraging them strongly to do that. But, I want you all to recognize that there is, inherent in the caregiving role, an element of powerlessness.

So, if you find that they're not following doctors' orders and they're not listening to your encouragement to do so, I encourage you to reach out to that doctor's office. And, oftentimes, what we find, here at Sloan Kettering, speaking to the oncologist's nurses is incredibly helpful, and, oftentimes, they will then speak with the patient and talk to them about what they are or are not doing.

It's very important that, if your loved one is not following through with the recommendations their doctor is giving, that you let that doctor know. You should not be dealing with this on your own.

Ms. Lizette Figueroa-Rivera:

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

Operator:

Thank you. Our question from the phone comes from Ralph, calling from California. Please state your question.

Ralph:

Hi, doctor. Are there quantitative metrics for stress, especially biological metrics, for instance, measuring endorphins? I can give you a backstory, if you want. But, that's the question. Thank you.

Dr. Allison J. Applebaum:

There are quantitative measures of distress. There are many quantitative measures of reported distress, so symptom reports. And there are a number of studies coming out, one of them which is mine, which has looked at the stress hormone cortisol and looking at the cortisol levels in caregivers at various times in the trajectory.

I don't know if that suffices to answer without the backstory. But, happy to answer more, if you'd like.

Ms. Lizette Figueroa-Rivera:

Thank you for the question. And our next question--actually, we received many questions about long distance caregiving. Any suggestions? A lot of caregivers now are not living close to their loved ones.

Dr. Allison J. Applebaum:

This is such a hard scenario. My heart goes out to everyone who's in this circumstance where they're providing care at a distance. Obviously, you are navigating multiple competing demands.

And so, the initial concrete piece of feedback I have is, one, to the extent that you can, create a support network for the patient on the ground in their local community, whether it's other family members or friends who can help, number two, to take advantage of the technology, for example, such that supports today's webinars, using Skype, for example, or FaceTime, and making sure that you are not using the distance as an excuse to not be communicating directly and face to face with loved one because we actually can do that today with our technologies. I certainly have found that that's helpful.

Third, I think the biggest challenge--the challenge is the more emotional challenge is the guilt that comes up for many caregivers who are not able to be physically present with the patients. And, for that, I encourage you to think about how you are prioritizing your own life and you own needs as well as the patients. And, if for example, making a point to travel more or less frequently would be beneficial--but, really, concretely, it's about doing what you can to create a network on the ground for the patient and communicating both with that patient and that network. Take advantage of Skype. Take advantage of FaceTime. Take advantage of all the wonderful technologies that we have.

Ms. Lizette Figueroa-Rivera:

Thank you. And our next question is, what are ways that hospitals are experimenting with providing greater support and resources for caregivers, and what hospitals already have exemplary programs in this regard? I think a lot of people are very happy to see that your hospital does have a caregiver's clinic.

Dr. Allison J. Applebaum:

Yeah. It's a really great question. And I think that there is a growing trend in the comprehensive cancer centers across the United States--I don't need to necessarily name them all--where they will have, either a program such as the one we have here, which has psychologists and psychiatrists supporting caregivers specifically, or other mental health professionals, such as a department of social work, who will provide individual or group support.

I think that what's happening across the country is that more and more hospitals are taking notice of facts that caregivers are key members of the medical team. There's new legislation out this past year that requires hospitals to document the name and contact information of a caregiver at the point of a patient's discharge. And, as a result of this, what we're finding is that these hospitals then are paying more attention to caregiver needs.

So, while I don't know which hospitals specifically across the country, I think that, again, this is where, if you just ask, you're likely going to find that there are services. Now, maybe it's not a fully developed caregiver's program, per se. But, likely there's at least one social worker who focuses on supporting families and is a person who can support you.

Ms. Lizette Figueroa-Rivera:

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

Operator:

Thank you. The next question comes from Marsha, calling from Florida. Please state your question.

Marsha:

Yes, hello, doctor. Have you noticed whether there's been teaching programs for doctors, for oncologists that are working with the patients in terms of also working with the caregiver?

In my experience that I've been a caregiver to my husband for over ten years--with a blood cancer--it's only been on oncologist I've gone to that, when I'm sitting in the room, also looks at me and says, "How are you doing? What's going on? What are you observing?" I mean, you're talking about social workers and things like that. But, I'm talking about dealing directly with the doctor that's working with your patient--with the patient.

Dr. Allison J. Applebaum:

So, I agree a million percent with what you said. It is so rare that, if I'm in an appointment with my father, that the doctor's going to say, "And how are you doing, Allison? Is everything okay with you?" Rare. Rare that that would happen.

However, it is something that I, personally, in a lot of the research that I do in working to develop training modules for all oncologists and all professionals who work in oncology to recognize--to not just ask "How are you?" and that's really important, but, B, to recognize any signs or symptoms of burden or distress so that you all can get the support that you need.

I fear that, currently, it's not in general practice. My hope, my wish, my dream, is that that changes in the course of the next few years. Whereas--as oncologists starting in medical school, up through residency and training and oncology, that part of their training is in communication skills, not just with patients, but with family members as well. So, I think this is an area that we really can do a lot of work in, and it's starting to get attention. But, not yet.

Ms. Lizette Figueroa-Rivera:

Thank you for the question. And our next question is, what role does culture play in caregiving? How can we take the best care of our patients if we don't know what other cultures do, and is cultural competency issues being researched?

Dr. Allison J. Applebaum:

I am so, so happy that this question has been asked. Thank you to whoever posed it.

I'm going to give a little plug and say that in January of 2019, the first textbook on cancer caregiving is being published by Oxford University Press. I've edited this textbook, and we have a chapter on this topic specifically.

Yes, cancer caregiving--this is culturally constructed. And it is really important that we understand, that we learn, that we ask about our patients' and their family members' backgrounds to help us understand what it means to be a caregiver. There are many cultures where it is the norm that your parents live with you and your children and that you are going to take care of their parents until their end of life, no questions asked. That's not the norm in many cultures here in the United States where, for many individuals, being a caregiver is perceived as, "This is not exactly what I bargained for," per se.

So, yes, we do need to be addressing and assessing our patients and families cultural background and how those play into the perception of the caregiving role, expectations, and subsequently, quite frankly, how burdensome it might be because if you're someone for whom the caregiving role is just something that you expect as just part of your natural life trajectory, it may not be as distressing as if you're someone for whom that's not necessarily part of your cultural narrative.

So, yes, there is research being done. We have summarized some of that literature, and it is very important for us, as professionals working in this space, to understand the backgrounds of our patients.

Ms. Lizette Figueroa-Rivera:

Thank you. And the next question is, I'd like to know what I can do if the person I'm taking care of becomes verbally and emotionally abusive and I cannot take it anymore?

Dr. Allison J. Applebaum:

This is such a difficult circumstance when the person that you're taking care of is lashing out, either verbally or physically. And oftentimes, it happens because of side effects of treatment, of medications, or neuro-cognitive changes that happen because of cancer or its treatment. Oftentimes, it's not the patient's intention to lash out.

The first piece here is--and this goes back to what's meant by self-care. You have to protect yourself. There's no circumstance where you're getting injured, per se, because of the patient's abuse, is okay. And so, I think that you do need to acknowledge with a medical professional that this is happening.

This is sadly quite common and also not talked about enough. And if you are in the circumstance where the patient is lashing out at you in these ways, I want you to tell the medical team because I want you to get the type of help that you particularly need in your circumstance. Sometimes, for example, patients who are taking high doses of steroids will have an experience of rage. It's time limited. But, it's very scary, and it's a time where you should not be alone with that patient. There should be other people around. And so, I think it really is about communicating about what's happening and not handling this on your own. You should not be handling these moments on your own.

Ms. Lizette Figueroa-Rivera:

Thank you, doctor. And we do have some patients on the line, and one patient is asking, how can the patient, in turn, help and support the caregiver?

Dr. Allison J. Applebaum:

I am so happy for this patient to be on the line, and I'm so happy that he or she has asked this question. How can you help the caregiver?

The first is simply asking, "How are you doing?" and acknowledging that your caregiver, your loved one is partner with you in this care and maybe even asking the caregiver what it is that--"What can I do to help you better in your taking care of me? Is there anything that I'm doing that's making it hard for you to take care of me?" or, "What can I do better to help you take better care of me?"

But, most importantly, just taking a moment to thank your loved one for all their doing. Tell them that you love them. Tell them that you are deeply grateful for their time and energy and just to thank them for what they're doing and then to ask them, "How are you doing this all this?"

The main message I have for you all today is communication is always better than not communicating. But, that's a really great question. I'm glad that it was asked.

Ms. Lizette Figueroa-Rivera:

Thank you. And the next question is, do you have any advice for young patients and caregivers who do not relate to peers and/or family?

Dr. Allison J. Applebaum:

Yes, yes, yes. So, there certainly are many young adult caregivers and patients across the country who are feeling really isolated because their peers don't know what it's like to be a caregiver. It almost might feel like, for example, you're going through your life stages in a backwards order, per se.

And so, what I encourage you to do, if you fall into that category, is to look for support groups, specifically for young adult caregivers. They do exist. There are phenomenal materials from the American Cancer Society, for example, around this issue.

We here at Sloan Kettering are lucky enough to have support groups specifically for young adult caregivers. There's more and more attention being given to them. So, my biggest piece of advice is, while you may feel isolated in your community immediately, if you look for others, they are out there. And certainly, most hospitals are recognizing that young adult patients and caregivers require their own support because of the natural sort of uniqueness of going through this a different time in life.

Ms. Lizette Figueroa-Rivera:

Thank you. And our last question today is, what do you feel is the most important task of a spouse or caregiver of a cancer patient?

Dr. Allison J. Applebaum: The most important task of a caregiver--oh boy. I think that the most important task to really--and it's going to be cliché--but to truly take a deep breath in through your nose and out through your mouth and check in with yourself about how you are doing as a caregiver and to think about what you need to do to strengthen yourself so that you can face whatever comes your way in this journey. That is the most important thing.

And it's going to be unique for everyone on this webinar, what that means. But, pausing and taking a moment to consider, "How am I doing, and what do I need?" That is the most important. If I had to say one thing, that would be the most important.

 **LLS EDUCATION & SUPPORT RESOURCES**

- **Information Specialists**
Master's level oncology professionals, available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.
– **EMAIL:** infocenter@LLS.org
– **TOLL-FREE PHONE:** 1-800-955-4572
- **Free Education Booklets:**
– www.LLS.org/booklets
- **Free Telephone/Web Programs:**
– www.LLS.org/programs
- **Live, weekly Online Chats:**
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Ms. Lizette Figueroa-Rivera:

Well, thank you so much, Dr. Applebaum, for sharing your expertise with us and for your continued dedication to providing support to those of us providing care for a loved one with cancer.

You can contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from nine AM to nine PM, Eastern Time, or you can also reach us by email at infocenter@LLS.org. And Information Specialists are available to answer your questions about treatments, including clinical trials or any other questions that you have about support or even financial assistance for caregivers or family members of patients.

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

LLS EDUCATION & SUPPORT RESOURCES

- **LLS Podcast, *The Bloodline with LLS***
Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: www.thebloodline.org
- **Education Videos**
Free education videos about survivorship, treatment, disease updates and other topics: www.LLS.org/educationvideos
- **Patti Robinson Kaufmann First Connection Program**
Peer-to-peer program that matches newly diagnosed patients and their families: www.LLS.org/firstconnection
- **Free Nutrition Consults**
Telephone and email consultations with a Registered Dietitian: www.LLS.org/nutrition
- **What to Ask**
Questions to ask your treatment team: www.LLS.org/whattoask
- **LLS Community**
Join the community of blood cancer patients, survivors and caregivers: www.LLS.org/community
- **Other Support Resources**
Blogs, support groups, financial assistance and more: www.LLS.org/support

Slide 41 – LLS Education & Support Resources



Slide 42 – Thank You

Dr. Applebaum, thank you so much for volunteering your time with us today. And, on behalf of The Leukemia & Lymphoma Society, thank you all for joining us on this program, and we hope that you will join us in the future as we strive to keep you up to date on the latest advancements for all blood cancers as well as providing more support for caregivers.

Take good care.