

Insight Into Caregiving

Operator

Greetings and welcome to “*Insight Into Caregiving*”, a live telephone and web education program. It is now my pleasure to introduce your moderator, Lizette Figueroa Rivera. Thank you. You may begin.

Ms. Lizette Figueroa-Rivera

Hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you. Special thanks to Richard Dickens, MS, LCSW-R for sharing his time and expertise with us today. Before we begin, I'd like to introduce Sharon Salzman, a caregiver of a small cell lymphocytic lymphoma CLL patient. Sharon will share a few words. Sharon, please go ahead.

A WORD FROM A CAREGIVER
Insight into Caregiving

“When I couldn’t sleep, I composed haiku—my way of counting sheep.”



Sharon Saltzman

BEATING CANCER IS IN OUR BLOOD.

LEUKEMIA &
LYMPHOMA
SOCIETY®

A Word From A Caregiver

Sharon Salzman

Two years ago, I was invited to give opening remarks for a caregiver webinar, and thank you, Lizzette, for extending this opportunity to me again. At that time, life was good and I was enjoying a respite from the demands of caregiving. Then, in January of 2019, my husband Larry’s CLL broke through for the fourth time in 11 years. By the end of the summer, caregiving consumed every moment of my life.

In September, we enrolled in a CAR T clinical trial at the Fred Hutch and Seattle Care Alliance, and we left the comforts of our home and community to relocate there for treatment. In the 4 months that we lived in Seattle, sometimes I was anxious. I reached out to a friend of mine who cares for her husband who had a bone marrow transplant. On an especially difficult day, I asked her in a shaken voice how she got through their event. She assured me that she had and I would as well.

I kept a journal and I compulsively made notes. At one visit, our physician was stymied when she saw that Larry’s liver function was out of range. She asked us about his diet and fluid intake and nothing pointed to the abrupt change. On a walk, I remembered he recently started a new medicine.

Upon returning, I checked my notes, called the provider, and she confirmed that I recognized a drug reaction. Every night after I arranged his pills for the next day, I sunk into bed exhausted. When I couldn’t sleep, I composed haiku—my way of counting sheep. When my husband was reunited with his re-engineered T cells, my most critical role in the first month was to watch for signs of cytokine release syndrome and/or neurotoxicity and immediately transport him to the hospital. I was concerned that I would miss the clues. A few days before a scheduled return home, Larry became confused. I knew this was a sign and swiftly arranged for transport to the ER.

At times, the feeling of isolation was overwhelming, even though I was blessed with family and friends who were good listeners and provided comforts to me. I appreciated valuable resources available to caregivers, such as this webinar, videos, books, blogs, and chat rooms, many of which can be found through the LLS website and information specialists. Most of all, I needed to remain strong and I did, especially during dark times when Larry was frightened, angry, and frustrated.

As his health improved, so did his disposition. Caregiving can be an emotional rollercoaster when I am in the throes of giving, I suppress feelings which emerge later. We returned home in January 2020. My

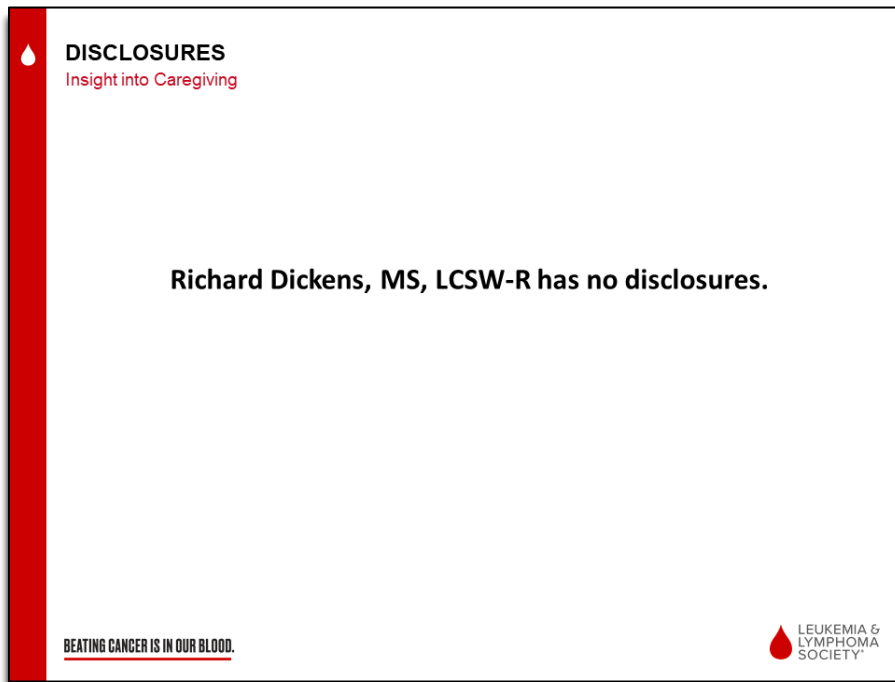
daily routine has returned, albeit a new normal. And like all of us, we are now learning how to care for one another during a pandemic.

Ms. Lizette Figueroa-Rivera

Thank you, Sharon, for sharing your story with us and illustrating how caregiving can change throughout the years. And most importantly, letting us know that caregiving, we're not alone. As I know I can relate to the emotional rollercoaster as a caregiver myself.

Thanks to all of you participating today, especially during this holiday season. It's important that we take this time to realize how important our caregiving is and how we can further take care of ourselves during this season and through this pandemic, which we are all facing together.


Following the presentation, we will take questions from the audience. Support for this program is provided by Genentech and Biogen; Pharmacyclics, an AbbVie Company; and Janssen Biotech and Taiho Oncology.



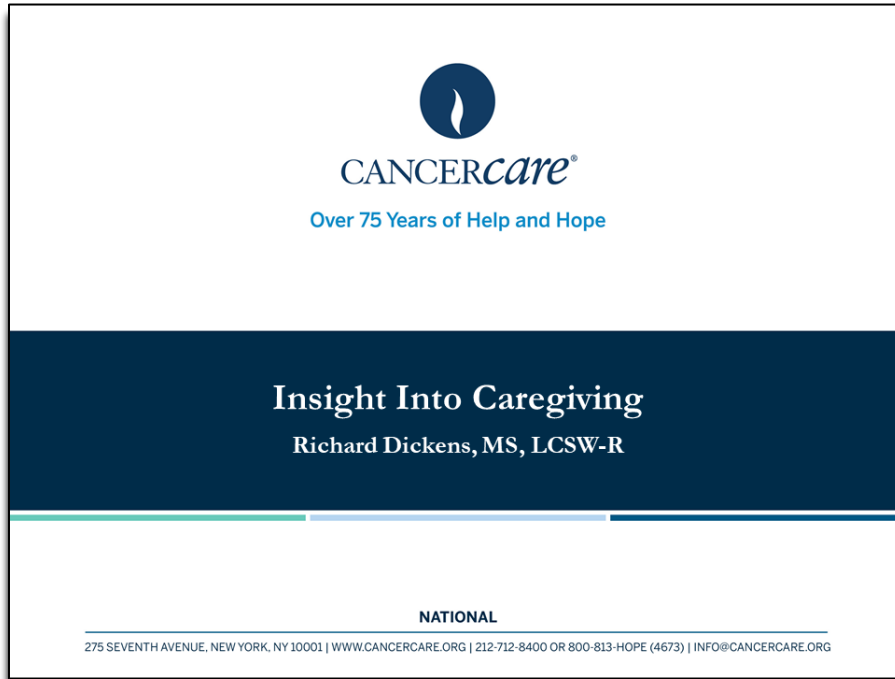
DISCLOSURES
Insight into Caregiving

Richard Dickens, MS, LCSW-R has no disclosures.

BEATING CANCER IS IN OUR BLOOD.

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Disclosures



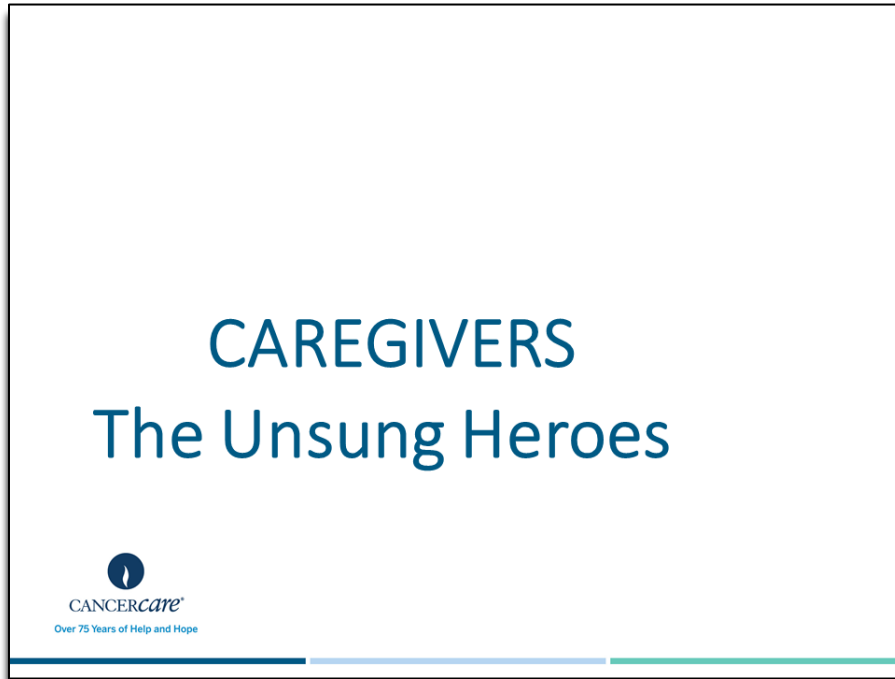
Insight Into Caregiving

I am now pleased to introduce Richard Dickens, MS, LCSW-R, MS, LCSW-R, Director of Client Advocacy at CancerCare in New York, New York. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time and expertise with us. Mr. Dickens, I'm now privileged to turn the program over to you.

Richard Dickens, MS, LCSW-R

Thank you. It is a privilege for me as well to be part of this, and it's a population that means a lot to me as well.

So, to everyone else on this line from around the world, I'm quite impressed that you call in to listen and I'm aware that even across cultures, caregiving is a very important aspect of taking care of cancer patients. And much of what I'm going to say might not be totally relevant to everybody, but it will provide some validation and hopefully some tools that will be helpful as well.



Caregivers The Unsung Heroes

The first slide is unsung heroes. I'd like to recognize the diversity of listeners. You come from diverse socioeconomic and educational backgrounds. You live in rural and urban areas, and your loved ones are treated in academic and local cancer centers. There are racial and cultural differences as well as gender and age, and you represent a wide variety of hematological cancers.

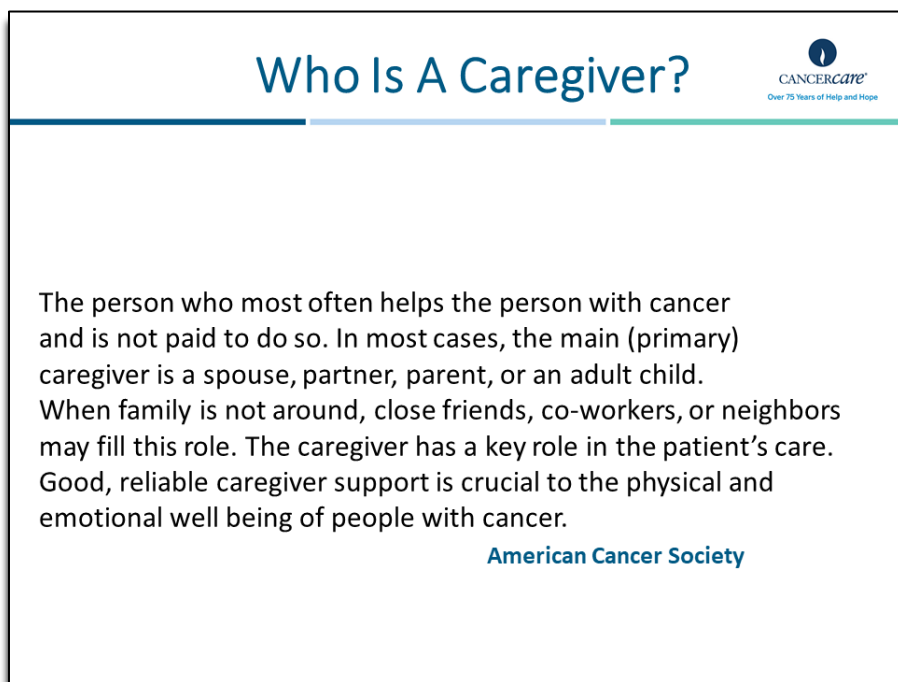
The following factors may increase the caregiver burden and this is from the National Cancer Institute of publication and formal caregivers and cancers identified. And they break down some of the areas that might experience additional burden, as in gender. Women are more likely to experience caregiver burden. And age. Older caregivers are at increased risk for caregiver burden when they have the following conditions: health problems of their own; fixed incomes; small social support networks; less time and energy to exercise, often due to lack of sleep; trouble remembering to take their own medications—all of which may lead to depression, poor health, and even early death.

For middle-aged caregivers, they may often have to miss all or part of their workday or even need to take a leave of absence. For younger caregivers, often juggling work and their own family duties, and they may have to give a part of their social lives at a stage in their life that the social activities are so important to career and family.


Race and ethnicity can also be an increased burden. Asian American caregivers often provide more caregiving hours than white, African American, and Hispanic caregivers. They also use less support services. They also receive less support services, tend to have fewer financial resources, lower levels of education, and higher levels of depression than other groups of caregivers. Asian Americans may not talk about death and dying because they believe it is bad luck. This can make it hard for healthcare providers to discuss prognosis and hospice services. Keeping a cancer diagnosis secret from the patient and not talking about it can add to a caregiver's sense of burden and duty.

For Hispanic and African Americans, strong family ties are endemic in their family systems, which may prevent them from seeking help outside of the family. As a result, they might not use local healthcare resources, including counseling and support groups, home care, long-term care, and hospice services. They usually have higher levels of caregiver strain, lower household income, and are more likely to reduce their work hours than white caregivers.

Socioeconomic status, this is social standing or class of someone that is measured by a person's education, income, and job. People with a lower socioeconomic status oftentimes struggle more in terms of access to the best care and treatment and things like that.



Who Is A Caregiver?

 **CANCERCARE**
Over 75 Years of Help and Hope

The person who most often helps the person with cancer and is not paid to do so. In most cases, the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, co-workers, or neighbors may fill this role. The caregiver has a key role in the patient's care. Good, reliable caregiver support is crucial to the physical and emotional well being of people with cancer.

American Cancer Society

Who Is A Caregiver?

We've got to move along a little bit. Who is a caregiver? Well, the person who most often helps the person with cancer is not paid to do so. In most cases, the main primary caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, coworkers, or neighbors may fill this void. The caregiver has a key role in the patient's care. Good, reliable caregiver support is crucial to the physical and emotional well-being of people with cancer. Simpler, breaking it down into two words — “care” and “give” — they mean look after and provide for the needs of and give means to make a present of.

And one site provided a beautiful synonym: “informed angel.” I offer this as the first of numerous affirmations that will appear in my talk: simple tools to challenge negative thoughts that can often arise during the crisis. And affirmations are so important. Just reminding yourself of how good you are, about what you're doing, and the term to make a present of in your service and informed angel. I hope many of you will choose to adopt that as you move forward.

By The Numbers



The number of individuals currently providing care for patients is startling: recent US national estimates of cancer caregivers range from 2.8-6.1 million adult individuals. ^(1,2)

Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, with 32% providing 41 or more hours of care weekly, the equivalent of a full-time job. ⁽³⁾

Since supporting a person with cancer can be particularly demanding, they devote nearly 50% more hours per week for providing care than those caring for people dealing with non-cancer diagnosis. ^(4,5)

By The Numbers

I didn't want to focus too much on statistics, but a brief telling of the research can affirm the degree of sacrifice offered as affirmation of your commitment and love. The following is taken from a 2020 cancer care white paper called, "Cancer caregivers and treatment decision making." This is a new study within the Patient Values Initiative™ founded in 2017 at CancerCare, which had an overall goal of enhancing treatment planning so that patients' preferences and priorities become key considerations in the decision-making process.

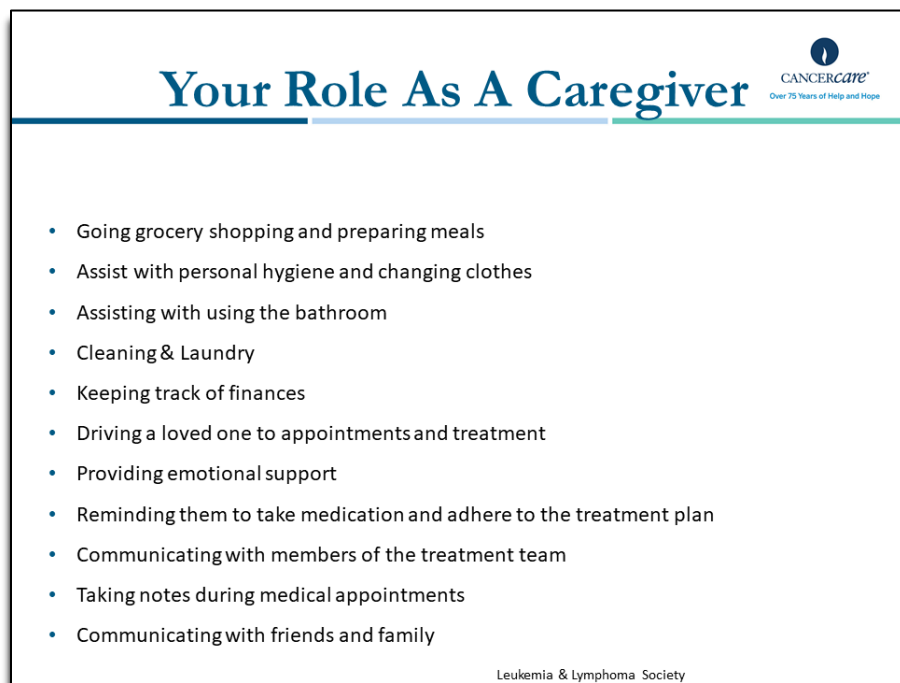
Importantly, cancer is a disease that affects whole families and those closest to the patient. Family members play an essential role in providing care for cancer patients and often are present when decisions about cancer care are being made. The number of individuals currently providing care for patients is startling. US national estimates of cancer caregivers range from 2.8 to 6.1 million adult individuals. Cancer caregivers spend an average of 32.9 hours a week caring for their loved one with 32% providing more—41 or more hours of care—weekly. The equivalent of a full-time job.

Since supporting a person with cancer can be particularly demanding, they devote nearly 50% more hours per week for providing care than those caring for people dealing with noncancer diagnosis. During my 30 years in cancer, first as a patient and then as an oncology social worker, I've seen profound advances in cancer, like yin and yang. They present a growing array of challenges providing good news and bad news encapsulated in the following, which sometimes when patients call us and say where did all this cancer come from or they're worried about their loved ones or they're worried about themselves if they're caregivers.

And I can tell them the good news is cancer has become a chronic disease for many. And unfortunately, the bad news is that cancer has become a chronic disease. And I think that's what led many of you to participate in this program today. Recognizing the significant emotional toll that caregiver caregiving exacts. Many psychosocial support programs and materials have been developed to support them.

Notably, however, caregivers also request resources that enable them to participate appropriately in shared decision making, since they are often essential team members intimately engaged in all aspects of care delivered and, like patients, frequently left with the long-term consequences of those decisions. Since cancer has become a chronic disease for many, these challenges can last for years,

evolving and shifting, causing significant hardship that affects finances, housing, career, family, dynamics, and much more.



Your Role As A Caregiver

CANCERcare
Over 75 Years of Help and Hope

- Going grocery shopping and preparing meals
- Assist with personal hygiene and changing clothes
- Assisting with using the bathroom
- Cleaning & Laundry
- Keeping track of finances
- Driving a loved one to appointments and treatment
- Providing emotional support
- Reminding them to take medication and adhere to the treatment plan
- Communicating with members of the treatment team
- Taking notes during medical appointments
- Communicating with friends and family

Leukemia & Lymphoma Society

Your Role As A Caregiver

So, your role as a caregiver can be monumental and likely includes many if not all of the following. If you print this list out, you might go through and check off which of these you are doing now and which were previously the domain of the patient. Because a patient's status will change throughout treatment, the demands on your time doing this will also help you identify other categories to which I will discuss more later.

Grocery shopping and the next two—assist with personal hygiene and provide help using the bathroom—those are two things that really impact very deeply the emotional state for patients and caregivers, especially if they are young adults who are taking care of parents. And caregivers, these two can have a strong impact on their roles, especially, as I said, as an adult child providing this service.

Additional tasks are cleaning and laundry; finances; transportation; emotional support; monetary compliance with medications; communication with medical team; being the scribe and taking notes; keeping family, friends, workplace updated and in the loop. Any one of these activities can take hours of your time and challenge your strength and understanding. My question is to you: How do you do that? And I'm going to ask for a pause after I say it again. I offer that as a serious question. How do you, caregivers, do all of that?

Many cancer patients when asked, "Why do you do it?" respond, "My doctor is making me take a chemo?" If they present with a sense of humor, I sometimes respond, "I've never heard of the chemo police," which helps me empower them and explore the deeper meaning of why. Choice. There is always a choice, and we'll talk about that later in this presentation. Healthcare is a consumer business. You and your loved ones are customers paying for a service, so you have a right to get your questions answered and the proper care.

Caregivers, on the other hand, don't get asked that question. It's just expected and the long-term ramifications can be equally deadly to one's spirit, strength, cognition, mental and physical health—

even without chemo. After, additionally and in many ways, most impactful over time our relationship changes. Following the guidelines LLS communicating as a caregiver worksheet, which I found was very comprehensive as regard to relationships. Managing a relationship with a patient may be one of the more unexpected challenges of caregiving. Your relationship with your loved one may change as your transition into your new roles as caregiver and patient change—change day-to-day life and the dynamics of your relationship.

Caring for your spouse or significant other. You and your spouse likely view your relationship as an equal partnership, but a cancer diagnosis might change that dynamic. Cancer can also make intimacy a challenge. Caring for a parent. When you were caring for a parent, the role reversal may feel odd at first. For most of your life, your parent may have filled the caregiver role in your relationship. Your parent may be reluctant to accept care and not want to be a burden.

Caring for an adult child. If you are a parent caring for an adult child who has a current cancer diagnosis, remember that the patient is also an adult. You must respect his or her decisions regarding treatment. Providing care for your child may feel natural for you, but if your son or daughter had been living independently prior to the diagnosis, relying on you as a parent again can feel frustrating and infantilizing and at times can also, along with the cancer, contribute to a sense of failure on their part.

Caring for a child. When caring for a child of cancer, your relationship with others may be strained, especially with your coparent. You may not always agree on what is best for your child. You may feel at times as if your coparent isn't taking on a fair share of the added workload involved in taking care of a sick child. If you have more than one child, siblings may feel left out, confused by, or resentful of the attention that the child with cancer receives from you and others.

Communicating with members of the healthcare team. The following tips will help you to better communicate with members of the healthcare team during your loved one's appointments. Write down your questions. Number your concerns in order of importance, asking the most important questions first. Let the day-to-day life in the dynamics of your relationship take over.

Caring for your spouse or significant other. You and your spouse likely view your relationship as an equal — you should prepare a list so that he or she, your child, can set time aside during the appointment to respond to your questions and in preparing a list or being invited to join them for a consult or a meeting with their healthcare professional. It's always important to ask them first if you were welcome and then also to take their lead in terms of how active they would like you to be.

Take notes. Write down the doctor's answers to your questions. Write down any important information that you or your loved one needs to remember. Notes can include the names of the members of the healthcare team, dates, and times future appointments and when and how your loved ones should be taking prescribed medicines. You can also ask the doctor if you can record the conversation so you can listen to it again later.

Ask for written information about the patient's diagnosis, treatment plan, and lab results. Keep everything in one place. This way nothing gets lost and you always know where to find the information. Share this information with all the healthcare professionals your loved one sees for any health reason and encourage the healthcare professionals.

Online portals offered by the hospital or treatment center. Make sure you know who to contact in an after-hours or an emergency situation when you need immediate assistance. Ask what signs or symptoms require a trip to the emergency room. Ask where you can find credible information online or printed resources pertaining to your loved one's diagnosis or other needs.

I want to share with you a story about a patient who was in one of my groups over 20 years ago. I'm going to call him Lou. I don't remember his name and I'm pretty sure it wasn't Lou, but just to humanize it. In my first few years as a social worker, I ran many groups. I could see the diverse

reactions between my patient and caregiver groups. After one patient meeting, an older, gregarious, yet realistic member with a bad prognosis asked to speak to me after the group.

His quiet, sweet, but somber wife was down the hall and a caregiver group which hadn't let out yet. I'd met her before. Quiet and lacking in his vitality in humor. Lou said to me I never realized how hard this was on my wife until we attended a group at the hospital. After an educational presentation by a doctor, the group split into patients and caregivers and a sliding door was closed between us. In my patient group, we laughed. Shared stories about our doctors and info about treatment. But there were no sounds coming from the caregiver side. When the sliding doors were finally opened, all the caregivers were quiet and had red or teary eyes, including my wife.

There is no right or wrong side of this story, but it highlights that patients while confronting their own mortality have control in treatment decision-making, accepting death or not, frequent admiration and support from friends and family, while the burden of holding their lives together falls on the caregiver. Especially when the patient is debilitated by treatment, who is not only worrying about what happens to the patient, but also what then will happen to them. In many households, that's the thought not to be spoken.

"Be positive" is the mantra to the patient from the caregiver and to the caregiver from the patient. Sometimes there's a healthy dose of denial, especially in cancer, but when the dose becomes reality then important matters get left undone, such as wills, healthcare power of attorney, beneficiaries, etc. And the caregiver has an added burden of addressing them on their own.

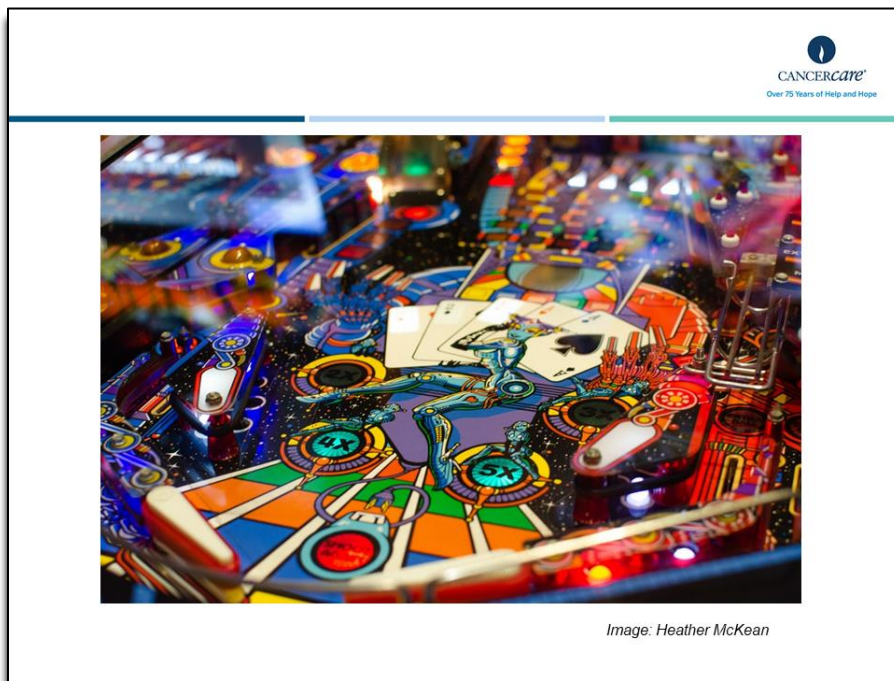


Image: Heather McKean

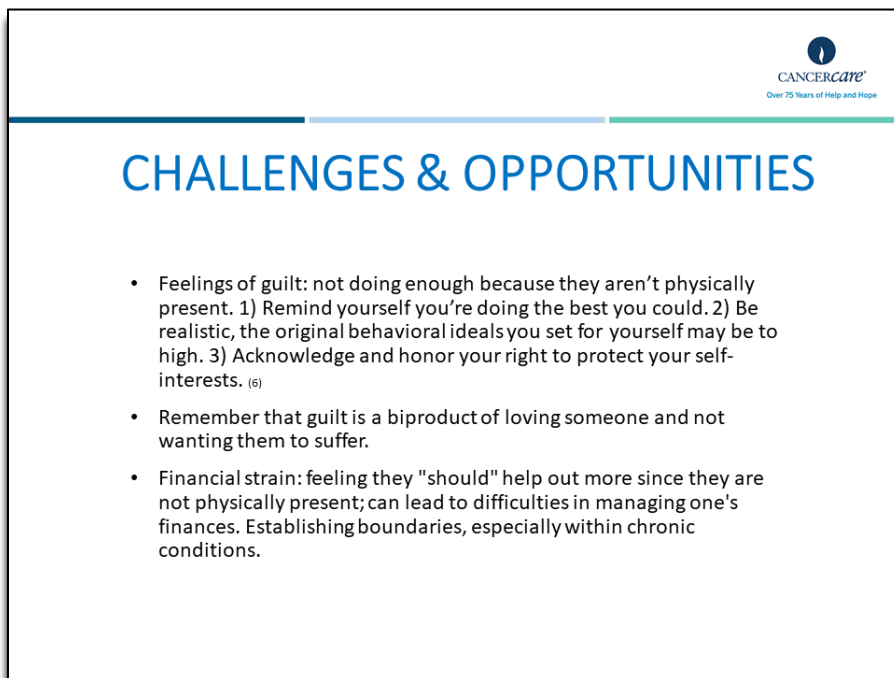
Image of Pinball Machine

The following slide is a pinball machine. In journalism, a picture is worth 1000 words. For patients, the picture is often a rollercoaster with constant ups and downs. Over time and through the many stories I hear, I've come to see caregiving as an old-fashioned pinball machine. Like a ball bouncing around, sometimes you hit the bumper and get 10,000 points trying to manipulate the machine just enough to keep the ball rolling while all the while afraid of game over.



Long Distance Caregiving

The next slide is long-distance caregiving and the challenges and opportunities. And I'm going to list them and also then just highlight what the opportunities are.



Challenges & Opportunities


So, the challenge: feelings of guilt and not doing enough because you're not present. A good way to address these self-defeating feelings is cognitive behavioral therapy, or CBT, by reframing the negative self-talk or by changing your behavior. Opportunity. Remind yourself you're doing the best you can. Make adjustments to the original behavioral ideas you said, which may now be too high and unrealistic.

Honor the right to protect your self-interests, such as a job, family, school, etc. Perhaps most important, remember that guilt is a by-product of loving someone and not wanting them to suffer. Another challenge is financial strain, which has a name in cancer, called “financial toxicity.”

Opportunity, behavioral action, establishing boundaries. Every family has historical roles and rules. Changing boundaries can open a new set of challenges, especially if the patient is a matriarch or patriarch, but they are primary for maintaining some semblance of balance. Boundaries bring order to our lives.

As we learn to strengthen our boundaries, we gain a clearer sense of ourselves and our relationship to others. Boundaries empower us to determine how will be treated by others. With good boundaries, we can have the wonderful assurance that comes from knowing we can and will protect ourselves from ignorance, meanness, or thoughtlessness of others. Boundaries involve your belief system, values, morals, emotions, and your life experiences. Healthy boundaries serve to define who you are, contain you, and protect your essence.

Boundaries are the guidelines in relation to self and others, and establishing of healthy boundaries is necessary to having successful and enjoyable relationships. Establishing healthy boundaries can be a difficult task but one that offers great rewards of closeness and connection. Boundary setting is a process. Healthy boundaries ensure self-respect, self-love, and self-accountability. Healthy boundaries teach us to be responsible and lead to self-trust, which leads to a mature life in which we can enter and sustain intimate relationships.



CONTINUED

- Resentment: “why me?” built-up feelings of frustration by you or by your family. Before these thoughts overwhelm you break the overall caregiving tasks into smaller parts and decide what you are capable of doing.
- Uncertainty: of emotional and practical challenges that a cancer diagnosis brings. Ex: Worrying how the PWC is doing since you’re not there to witness it and help.
- Frustration: navigating things from afar can come with new challenges. Identify a task you’re good at: finance, advocacy, health care, etc. and reinforce that challenges also present opportunities.

Continued

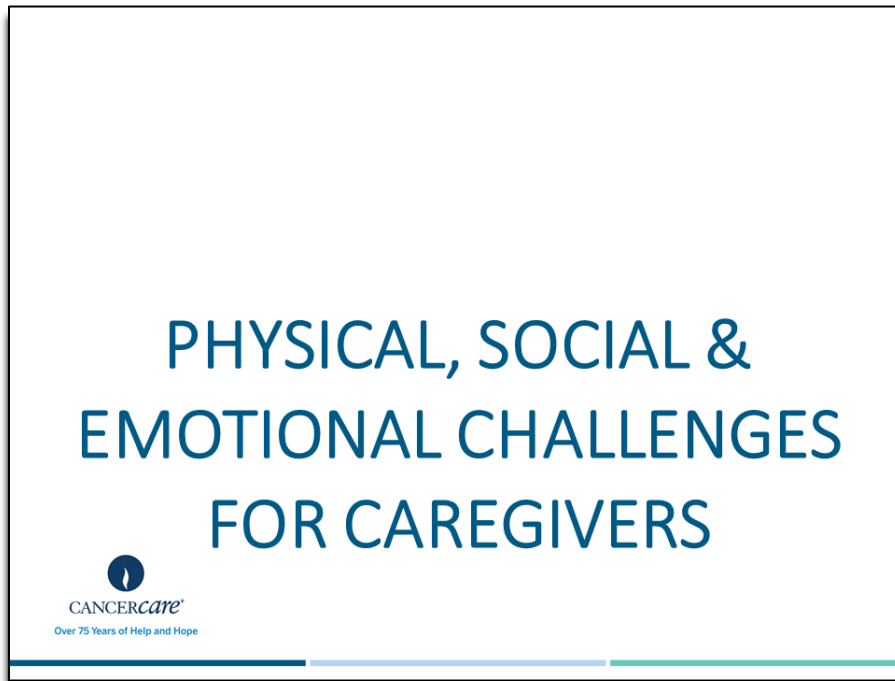
So, challenge, resentment. “Why me?” by you or family members. These are dangerous thoughts that have historical implications on your role in the family and can create ongoing tension.

Opportunity. Before these thoughts overwhelm you and the other caregivers, break the myriad of caregiving tasks into smaller parts and realistically identify what you are capable of doing. Challenge.

Uncertainty of emotional and practical challenges because of distance. Opportunity. Long-distance caregivers might not be there on a daily basis, however, when they do visit they are on duty 24/7. So, they might put in more hours but they’re not there as often.

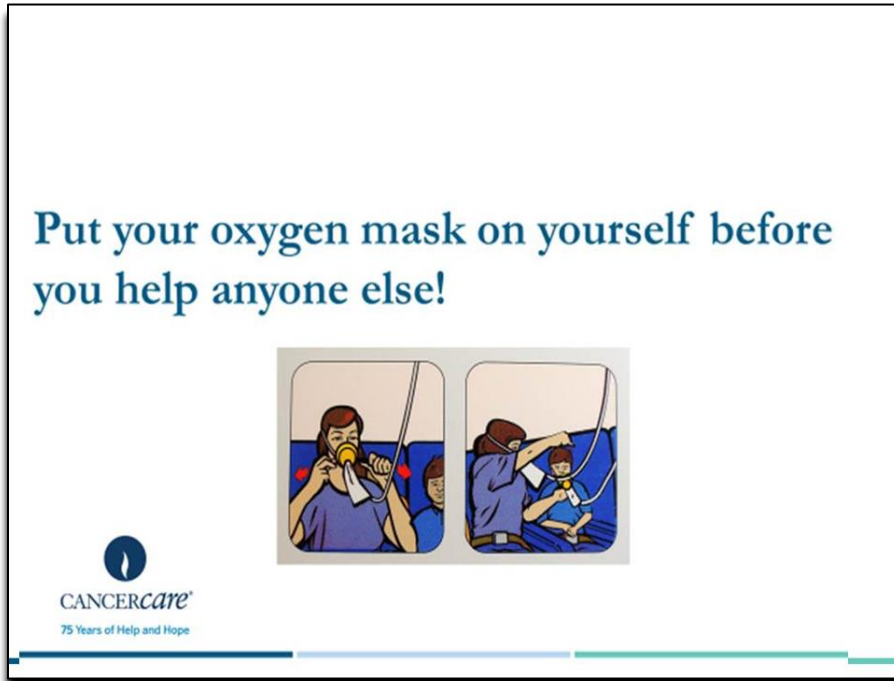
Challenge. Frustration navigating from afar. Opportunity. What you're good at. Finance advocacy, healthcare, et cetera. Give thanks for technology. And in terms of also what you can do through a Listserv, I queried other social workers who work in hospital settings and to find out whether or not they can do three-way telemedicine. And doctors don't often offer that, but indeed, they can do that and you could ask that. And even if you're long-distance, you could be the person who really takes responsibility for many of the healthcare issues from a long distance. You could build their relationship with the healthcare team. That could be your role.

Challenge. Uncertainty of emotional and practical challenges because of the distance. Challenge. Frustration. Navigating from afar. Opportunity. Identify what you're good at. Finance, advocacy, healthcare, etc. Give thanks for technology.



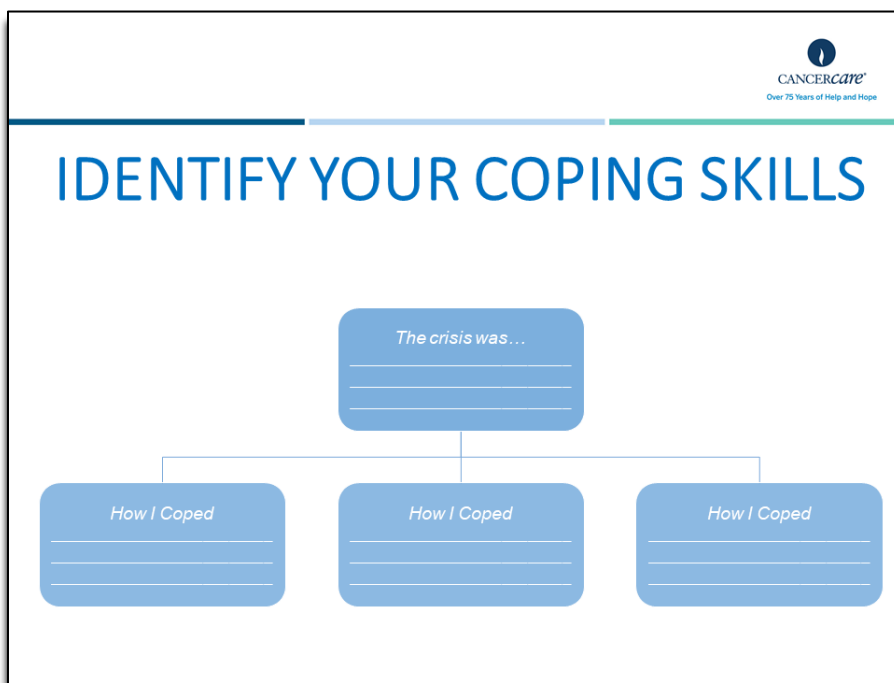
Physical, Social & Emotional Challenges for Caregivers

Physical. I'm going to go now into physical, social, and emotional challenges for caregivers.



Image

I love this slide and I think it speaks for itself. Most of us have flown at one time or another. Put your oxygen mask on yourself before you help anyone else. That is so integral in terms of taking care of yourself, and it's so integral in the stress and the lack of oxygen that can be the result of caregiving.



Identify Your Coping Skills

FDR

“F” are Feelers; those who you have a strong sense of fellowship with. Photo by [Artyom Kabajev](#) on [Unsplash](#)



“D” are Doers; those good at doing concrete tasks.



Image created by [Lélie Lesage](#).

“R” are Researchers; those with good understanding of technology and finding resources. Photo by [Alvaro Reyes](#) on [Unsplash](#)



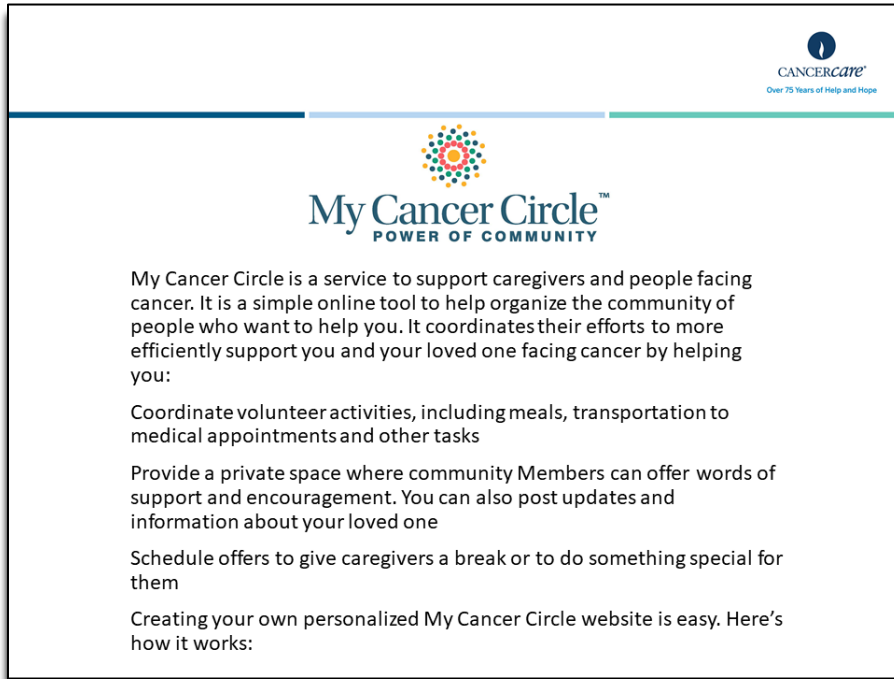

CANCERCARE®
Over 75 Years of Help and Hope

FDR

Now, I'm going to move ahead to FDR. An ex-colleague of mine created this acronym for a presentation she gave years ago. To those who have a network of supports that can help to identify the skills of each so they will feel their help is most useful. Most of us have a diversity of friends, even if it's just a couple. So, F in FDR are for feelers. You know those people. Those are the ones you have a strong sense of fellowship, who are good listeners and laugh and want to hear your stories and offer emotional support.

D is for doers. Those are people who are good at concrete tasks. They might not be good talkers or listeners. They might not be good in a lot of interpersonal areas, but they might be terrific at cleaning the apartment or the home, at taking you to an appointment and taking the caregiver out for a change, at dropping off a meal.


R is for researchers. Those were technology skills and are good at finding resources. I would say that by this presentation, I myself am often challenged in resource technology and resources. So that would not be one of my roles. But definitely, find out. Think of your friends and those three ways. Feelers, doers, and researchers. And decide, which we'll talk in a bit, too, about how to assign them or ask them to do specific tasks.



The screenshot shows the My Cancer Circle website. At the top right is the CancerCare logo with the tagline "Over 75 Years of Help and Hope". The main heading is "My Cancer Circle™" with the tagline "POWER OF COMMUNITY" below it. The text describes the service as a tool to help organize the community of people who want to help you. It lists several features: coordinating volunteer activities, providing a private space for support, and scheduling offers for caregivers. It concludes by stating that creating a personalized website is easy.

My Cancer Circle

So, this leads us right into My Cancer Circle. My Cancer Circle is an app. It is a service to support caregivers and people facing cancer. It is a simple online tool to help organize the lives of those — to organized community of people who want to help you. It coordinates their efforts to move efficiently, support you and your loved one facing cancer by helping you. It's a place that they can go and you can give updates, and they could read about the person every day or every week. They don't need to call you all the time. You could also say what you do need: somebody to drive somebody to an appointment or to, as I mentioned earlier, drop something off. Those are things that could be posted on one side.



THE GIFT OF GIVING

To be a caregiver is to know the gift of giving includes:
sacrifice, responsibility, compassion, love, devotion.

To reach out to others for help allows them to share in
the burden and experience the gift of giving.


The Gift of Giving



SELF CARE FOR CAREGIVERS

Self Care For Caregivers

A Caregiver's Bill of Rights I have the right..



To take care of myself. This is not an act of selfishness. It will give me the capacity to take better care of my relative.

To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.

To get angry, be depressed, and express other difficult feelings occasionally.

To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

To _____
(Add you own statement of rights to this list. Read the list to yourself every day.)

Jo Horne, author of Caregiving: Helping an Aging Loved One


A Caregiver's Bill of Rights I have the right...

Finally, I'm going to leave it here without going through them is the Caregiver Bill of Rights. And there is a Patient Bill of Rights established with every hospital, but many caregivers don't realize there's a Caregiver Bill of Rights. I'm going to encourage you to go through them and to examine them deeply yourself.

HealthinAging.org
Trusted Information. Better Care.


Caregiver Self Assessment Questionnaire

The Caregiver Health Self Assessment Questionnaire was originally developed and tested by the American Medical Association, <https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire>. The questionnaire can help caregivers look at their own behavior and health risks. With their healthcare provider's help, this questionnaire can also help caregivers make decisions that may benefit both the caregiver and the older person. In turn, the questionnaire can help healthcare providers to identify and provide preventive services to an at-risk population which may be hidden. It may also improve communication and enhance the healthcare provider-caregiver health partnership. This questionnaire is meant to serve as a guide only. Be sure to speak to your healthcare provider about any concerns you may have about the questionnaire or your results.



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Health Aging.org



It begins with the breath


“The single most effective relaxation technique I know conscious regulation of breath.”
Dr. Andrew Weil

Image: Allie

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It begins with the breath

Finally, that takes us to breathing. I've mentioned that before: the importance of breathing. But a simple breath exercise is done by simply taking in three deep breaths using the diaphragm. Taking in a deep breath; holding it for a manageable count of three, four, or five; and then exhaling. Doing that three times anywhere or anyplace. People don't have to see you doing that or know you're doing that and that won't really, if you do that, will find it slows the biological rhythm, de-stress, and it gives you some moments of calm.



Finding Meaning

I feel useful and needed

Caring for my relative gives my life a purpose and a sense of meaning.

I would not have chosen the situation I'm in, but I get satisfaction out of providing care

The Lord won't give you more than you can handle.

In general, I feel competent as a caregiver

Since becoming a caregiver I have become more aware of my inner strengths

Since becoming a caregiver I have become more self-confident

Since becoming a caregiver I have grown as a person

Since becoming a caregiver I have learned to do things I didn't do before


I trust myself to make the best decisions for my close friend/family member

I believe the doctors/clinical team value my input about treatment

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Finding Meaning

Now I believe we've gone over and I want to make time for questions and answers. Finding meaning comes out of Viktor Frankl's "Man's Search for Meaning," a 1984 book that is quoted all the time. Human beings' ability to find meaning working or doing a deed, experiencing or encountering someone and take toward unrepresented suffering when it happens.



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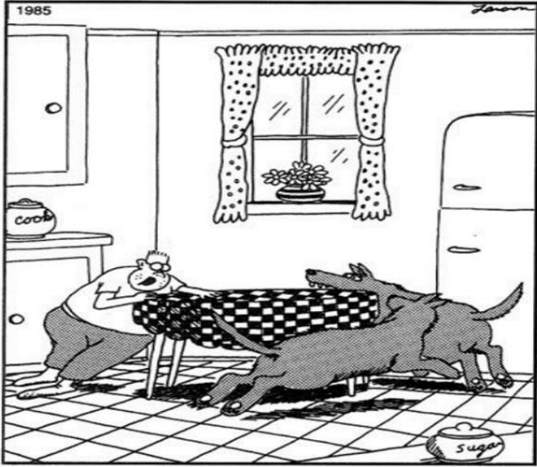
Existence and Choice

"Grief is a process, but recovery is a choice."
Choice always exists, even in the bleakest situation.

"Don't forget to laugh!"
Finding your inner strength when it feels lost.

Existence and Choice



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Luposlipaphobia: The fear of being pursued by timber wolves around a kitchen table while wearing socks on a newly waxed floor.

Image: Gary Larson, Far Side Comics, 1985

Image


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Can You Imagine?

Can You Imagine?
For example, what the trees do
not only in lightening storms
or the watery dark of a summer's night
or under the white nets of winter
but now, and now, and now – whenever
we're not looking. Surely you can't imagine
they don't dance, from the root up, wishing
to travel a little, not cramped so much as wanting
a better view, or more sun, or just as avidly
more shade – surely you can't imagine they just
stand there loving every
minute of it, the birds or the emptiness, the dark rings
of the years slowly and without a sound
thickening, and nothing different unless the wind,
and then only in its own mood, comes
to visit, surely you can't imagine
patience, and happiness, like that. By Mary Oliver

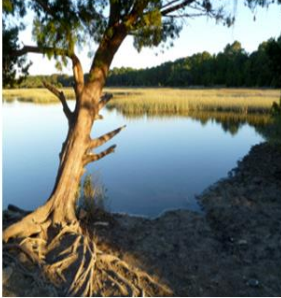


Photo by: charlotte hutson wrenn 2010

Can You Imagine?

Finally, another metaphor: “Can You Imagine?”

“For example, what the trees do not only in lightning storms, or the watery dark of a summer’s night or under the white nets of winter, but now and now and now whenever we’re not looking? Surely you can’t imagine they don’t dance, from the root up, wishing to travel a little, not cramped so much as wanting a better view, or more sun, or just as avidly more shade—surely you can’t imagine they just stand there loving every minute of it, the birds or the emptiness, the dark rings of the years slowly and without a sound thickening, and nothing different unless the wind, and then only in its own mood comes patience, and happiness, like that.” Poem by Mary Oliver.

With that, I will open the line to questions and answers.

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- 2 National Cancer Institute: Health Information National Trends Survey 5, Cycle 1. 2017. <https://hints.cancer.gov/data/survey-instrument.aspx>
- 3 The Caregiver Factor: Understanding the Medical Journey _Caregiver_Report.pdf of the Caregiver and their Information and Support Needs, Rx4Good; (2018) http://rx4good.com/admin/wp-content/uploads/2018/06/RX4G_Caregiver_Report.pdf
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- 5 J. Clin Oncol 34, 2016 (suppl 26S; abstr 4) <https://meetinglibrary.asco.org/record/136381/abstract>
- 6 Seltzer, Leon, F., 9 Ways to Talk Yourself Out of Unnecessary Guilt. Psychology Today, (June 11, 2016). <https://www.psychologytoday.com/us/blog/evolution-the-self/201506/9-ways-talk-yourself-out-unnecessary-guilt>



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References

Resources

- [Cancer and Careers](http://CancerandCareers.org), 646-929-8032 Cancerandcareers.org provides essential tools and information for employees with cancer through a comprehensive website, free publications, career coaching, [insurance information](#), and a series of support groups and educational seminars for employees with cancer and their healthcare providers and coworkers.
- [Cancer Legal Resource Center](#), 866-843-2572, a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles, employers, and others coping with cancer. Offers a toll-free Telephone Assistance Line (866-THE-CLRC) where callers can re. The CLRC provides free information and resources on cancer-related legal issues to cancer survivors, caregivers, health care professionals receive free and confidential information about relevant laws and resources for their particular situation.
- [Caregiver Action Network](#), 800-896-3650; educates, supports, empowers and speaks up for the more than 90 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.
- [Centers for Medicare & Medicaid Services](#), 877-267-2323 Centers for Medicare & Medicaid Services, CMS, is part of the Department of Health and Human Services (HHS). Offers online tools to [compare hospitals](#), [nursing homes](#), [home health services](#), [doctors and other health professionals](#), [Medicare health and drug plans](#), [where to get covered medical items](#) and [hospice services](#).
- Check with [Community agencies, religious institutions, or your hospital social worker](#) for information on respite care programs.
- [Department of Aging and Disability](#) in your state. Services vary according to each state guidelines but can include: utilities, rent, mortgage assistance, legal help, transportation, etc.
- [Eldercare Locator](#), 800-677-1116 The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older Americans and their caregivers with information on senior services. Search the website database for local resources, or call the toll-free number to speak with an information specialist.
- [Family Caregiver Alliance](#), 800-445-8106; [education, services](#), research and advocacy. [Online groups, including an LGBT group](#). Has a free download publication, [Handbook for Long-Distance Caregivers](#)
- The [Family and Medical Leave Act \(FMLA\)](#) Most employers are required to provide up to 12 weeks of unpaid, job-protected leave for family members who need time off to care for a loved one.



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References

Resources continued

[Medicare Rights Center](#), 800-333-4114. Provides free counseling services to people with Medicare questions or problems. MRC helps people with limited incomes access benefits that can help pay their Medicare premiums, deductibles and co-pays

[National Alliance for Caregiving](#), a non-profit coalition of national organizations focusing on issues of family caregiving. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, a government agency, and corporations.

[National Coalition for Cancer Survivorship](#), 888-650-9127 Is the oldest survivor-led cancer advocacy organization in the country, advocating for quality cancer care for all Americans and empowering cancer survivors. NCCS believes in evidence-based advocacy for systemic changes at the federal level in how the nation researches, regulates, finances, and delivers quality cancer care. [Offers the award-winning Cancer Survival Toolbox](#).

[Triage Cancer](#) Provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers.

[Ulman Foundation](#), 888-393-3863; provides a community of support for young adults ages 15-39, and their loved ones, impacted by cancer. Direct services include one-on-one support, exercise & wellness programming, [college scholarships](#) and [free lodging at Ulman House in Baltimore, MD](#).

[Stupid Cancer](#), 877-735-4673 Builds online and offline support communities nationwide through local events, social media, educational workshops, an international annual conference and a live weekly talk radio program, [The Stupid Cancer Show](#), which airs Mondays at 8pm ET. Also offers [message board for young adult spouses](#).

[Well Spouse Association](#) advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner.



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References

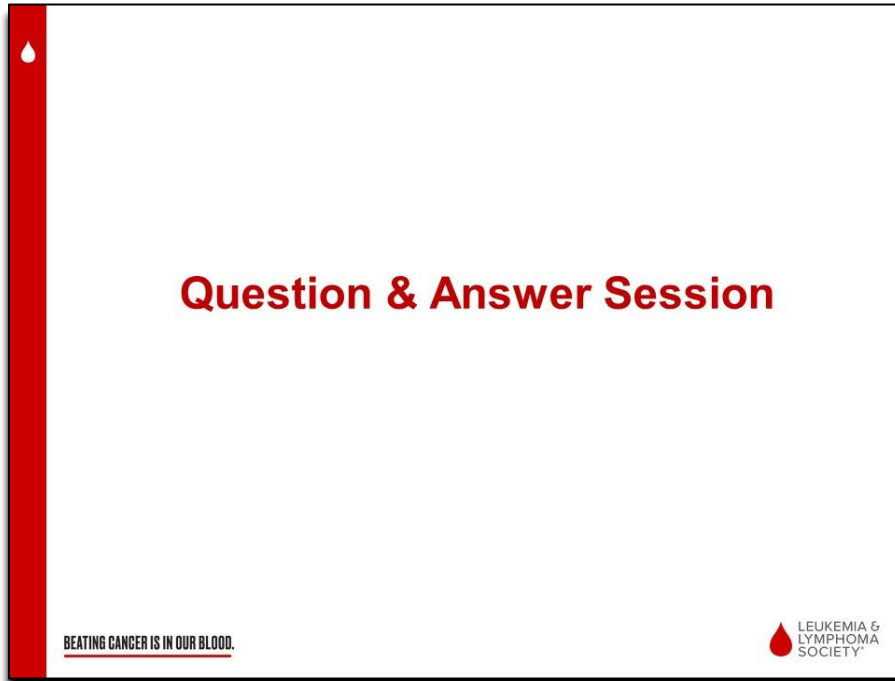


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Q&A Session

Ms. Lizette Figueroa-Rivera

Thank you. And we'll take questions that are general in nature. We won't be taking questions that are specific about diagnosis or treatment today. That will be addressed with a hematologist-oncologist. But if you do have questions in regard to caregiving, we would be happy to take them. I'm going to start with a web question

So, Rick, the first question from the web is how do you know when you're doing too much to help a loved one? At what point is *enough* enough?

Richard Dickens, MS, LCSW-R

That's a great question. And it's always going to be different for each individual. If you're asking that question, that means that there's something inside of you, a stress, a concern that a demand that is beginning to question how much more can I do this, and what do I do if I can't continue to do this? How do we help the patient?

So, there is no time, no one moment usually, that enough is enough. But again, raising that question, asking it, feeling it, that is an indicator. And that isn't good opportunity for you to reach out to others supports, other caregivers, also to reach out to the healthcare team perhaps if a lot of your concern is related to medical or side-effect issues. But it's a great question that each individual has to know when enough is enough. But first, they have to listen to their internal clock, their internal self, to recognize that they are getting close to that. Wonderful question.

Ms. Lizette Figueroa-Rivera

Thank you. And the next question is how do you deal with the fact that your loved one needed 24/7 days-a-week care, which you are unable to provide? Sometimes you feel totally inadequate and useless.

Richard Dickens, MS, LCSW-R

Well, that's a common question and another good one. Again, I don't have an easy answer for that. 24/7 care is very seldom covered by any insurance. Even Medicare or Medicaid often covers a few hours for an aide to come. But 24/7 also usually means that the person needs more acute care, a nurse or somebody who can visit. It's very expensive.

Oftentimes, if there's a larger support network, people will try to find somebody to provide that care. Again, if it's a professional only, they will go through the healthcare team where they will go through legitimate healthcare provider organization for that service. If you know of somebody though in private practice, a nurse or a doctor retired or somebody, a social worker who can provide the skills needed, then you might approach them and you might ask and see if you could do it out of pocket.

There are no organizations that have those kinds of funds because they run into the thousands of dollars weekly and it is very, very hard. I wish I had an easier answer. That's one that my colleagues and I struggle with, but it takes a lot of soul searching and it really demands that you open up that question to the full group of people who are involved in your loved one's care, including if your loved one is aware of all of this, your loved one, to make the best decision for everyone involved.

Ms. Lizette Figueroa-Rivera

Thank you. The next question: Why is end of life a reluctant topic for doctors? Aren't there physical signs that indicate it is near? Caregivers would likely focus on quality time of their loved ones versus medical appointments and superfluous tasks.

Richard Dickens, MS, LCSW-R

Another great question. You're all listening really well and raising all the questions that we deal with on a daily basis. My colleague and supervisor often says if you know one cancer patient, you know one cancer patient. And I would extend that to say if you know one caregiver, you know one caregiver.

The truth is doctors are all different themselves. They were trained still, but life is what they — at all costs, for the most part, is what they are trained to do to provide life. So, that sort of question when it gets to a point that the patient and definitely the patient if they're capable of it has to be the one to be involved in that discussion. And really watch the terminology. Many times I hear people saying "but we want quality of life" or "how much longer do I have to do this" or "I'm sick all the time" but they don't really state exactly what they need. Length isn't as important to me as quality of life.

What can I do to have the best quality of life for whatever life I have left because this treatment right now is making my life miserable? Those are honest questions. And for the most part, in my years in social work and more so in the last 10 years or so, doctors often know when end of life is near because of newer treatments is that is something you have to do with the patient. And most doctors when I hear back from people, when they hear that and they recognize it, they will be honest in terms of addressing it holistically and compassionately. But you do have to make sure you're asking the right questions and you do have to make sure that the patient is fully onboard with that.

Ms. Lizette Figueroa-Rivera

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

Operator

Our question comes from Elise calling from Florida. Please state your question.

Elise

Yes. Hi. How are you today? Hope everybody is safe. My question is my husband was diagnosed with AML 11 years ago this month, and he had a bone marrow transplant and he is in remission from leukemia, but he has graft-versus-host disease, which in my opinion has been harder than diagnosis and transplant itself. Why after 11 years is caregiving harder than it was at the very beginning with the diagnosis and then the bone marrow transplant?

Richard Dickens, MS, LCSW-R

Elise, my heart goes out to you and I don't have an easy answer. I myself have had an allogeneic bone marrow transplant almost 30 years ago. I got very little graft-versus-host disease and I do know that was unusual. And I do a lot of my work in blood cancers and in graft-versus-host with patients who are struggling with that. They've come a long way since I went through my transplant, but there's

still so much further to go and it is so demanding. It really alters the relationship. It alters the life tremendously.

Again, there's no easy answers. If you sought other opinions, sometimes there could be some newer, breaking tools that could help alleviate some of those issues or going to another doctor or another center just to find out how somebody else would address those graft-versus-host issues. But it's most important at that time that you're honest, the two of you, that you're communicating honestly, and that you're talking about the future.

Much like that last question or two questions ago about when is *enough* enough, is not necessarily to talk about when do we want to end this, stop treatment altogether, stop taking care of yourself in that state you are in now, but more so what do we want to do together? What do we want? What do you want, Elise, and what does your husband want for the rest of your life? However long that will be.

And definitely making an appointment either at an oncology center with a psychiatrist or clinical social worker or nurse who are well trained in these questions or with somebody else because it really goes beyond just the health issue to quality of life. And it is really, really important in that discussion that the two of you come to an agreement that there will be times that you will need to take care of yourself if this is going to continue, and you're going to have to find ways to do that. It's not an easy discussion for either of you but it is a discussion one of the many that unfortunately doesn't necessarily have an answer at this point other than the individual inability at some point, much like all of us, to continue what they're doing now.

Ms. Lizette Figueroa-Rivera

Thank you for the question. The next question is what is a healthy way to deal with resentment and feeling not appreciated by your loved one?

Richard Dickens, MS, LCSW-R

That is another great question, definitely. I touched on it just briefly in terms of boundaries and resentment and "why me?" I'm going to probably address that in a shorter version. What I've learned over the years is that in relationships, there are good things and bad things that developed long before the cancer. There are roles, there are boundaries, there are behaviors that developed.

What I've found, and I don't have an easy answer or a magic wand as to why, sometimes the stress of cancer actually helps change that tension and the negative behaviors or the negative feelings because of the enormity of the cancer. Other times, it exacerbates them and it makes the relationship and those behaviors that existed before even worse, which could include resentment and often does.

But again going back to Elise's question into the one about boundaries: You don't have to take that necessarily. You have to find some healthy way, mental health way, to address that if it continues and you have a strong responsibility to the patient. But sometimes, too, the drugs, the medications, the stress of chronic cancer can change a patient's behavior. And if that's the case, you might want to arrange to reach out to the healthcare team and find out what's happening. Is there a change because of medication, because of the cancer? And maybe that could be addressed. Or else boundaries are going to be necessary, maybe. But most important, you're not going to be helpful for the long run if you keep allowing that to happen to you. There are healthy outlets for being angry and resentment and disappointed, but they can be dismissive, and they can be terrible on one's self esteem and relationship.

Ms. Lizette Figueroa-Rivera

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

Operator

Thank you. Our next question comes from Erica calling from Texas. Please state your question.

Erica

I wondered if you had any tips and tricks for dealing with chemo brain—specifically the worsening effects. Doctors and PAs don't seem to have a lot of insight into the fact that it's a real thing for me, so just wanted your opinion on that.

Richard Dickens, MS, LCSW-R

Erica, it is a real thing. I've been in oncology for 25 years and definitely it was somewhere way back then in the 90s when it was given a name. It tends to affect women more than men, and it tends to affect breast cancer patients more than other diagnosis in some of the literature that I've read. It is usually not long term, but there are instances and studies that showed that it is.

A lot of that probably would be helpful again, as I've mentioned before to actually approach a mental health professional and also then working with the medical team or a doctor to try to increase your memory and work out certain ways of making lists and doing tasks that you can do properly. It's not easy and I don't have right in front of me cancer care. CancerCare.org. We have a whole list much the same as LLS of many fact sheets and booklets, and we have several on chemo brain.

At this point, I don't think there's any magic bullet to clear it up when people have it. I do know over time usually it's not too long, meaning months and maybe a year. And I do know sometimes it can diminish and you can find ways to deal with it. But at this point, I don't know any magic bullet, but I do know that you are suffering and that is always disheartening, and I encourage you to continue to try to find some way to get answers.

Ms. Lizette Figueroa-Rivera

Thank you. And our next question is how to deal with the stress of the unknown, such as a chance of relapse. How to handle the anxiety of knowing your child could lose his or her life.

Richard Dickens, MS, LCSW-R

That's another one that will never go away, but if it doesn't diminish over time then really that's going to be another one to try to get some mental health supports. It's a reality. I had several recurrences and many people on this line probably will. We have no control over that. Early in my work as an oncology social worker, I came to recognize that the hardest thing for people to accept is the uncertainty about cancer, especially when we are on top of the news, when we follow all the latest discoveries and things like that, but we're not dealing with cancer all the time.

It's easier to think, "Oh, I'm sure that they can find this early" or "I'm sure that they can treat this right away" or "I'm sure that they can make sure that there's no cancer at all." It used to be permission, and that's still used, but this is a cognitive issue that's sometimes helpful. Began to recognize that NED, or "no evidence of disease," is kind of implying a realistic optimist.

I learned that term from a young adult gentleman who was in one of my earliest groups. He had a lymphoma and he did everything he could to beat that, but he was going to be a realistic optimist and realized that he didn't have total control over everything. Faith, prayer, talking to friends. Those are ways that you can address it if scans come up or as, again, the fear for some reason arises. But find ways that you can manage it, and it will diminish over time. Again, if it doesn't for some reason, then that's a time to really look for some professional help. Great question.

Ms. Lizette Figueroa-Rivera

Thank you. And our last question, after the dust settles, how does a caregiver get back to his or her own life?

Richard Dickens, MS, LCSW-R

After the dust settles is going to be different for everybody here, especially in hematologic cancers, because for so many hematologic cancers there are long watch-and-wait periods. So, for many, the dust is settling. But much the same as the last question is there's always this underlying fear of when will it come back, will it come back, and, for caregivers, the same thing.

I attended a conference and one of the speakers had said survivors are the same as caregivers and that the term survivor is associated with caregivers too, but the feelings are equal. Not the feelings necessarily physiologically, the somatic feelings that could be long-term effects from the cancer, with the stress that a long-term caregiver is under can establish a lot of long-term lingering effects, especially such as fatigue and chemo brain or cognitive dissonance. So, there's no easy answers to that.

But gradually, maybe don't jump back into life fully, which can be a little overwhelming, especially if you've been a caregiver for a long time. Maybe inch your way back into it. It will come back. Over time, believe it or not, you will get back involved, reestablishing relationships if they fell by the wayside. But it will come back and it will feel natural again, and you will find ways to cope with the "what if" and worry from time to time about some additional dust falling. Great question.

LLS EDUCATION & SUPPORT RESOURCES

HOW TO CONTACT US:

To contact an **Information Specialist** about disease, treatment and support information, resources and clinical trials:

- Call:** (800) 955-4572
Monday to Friday, 9 a.m. to 9 p.m. ET
- Chat live online:** www.LLS.org/InformationSpecialists
Monday to Friday, 10 a.m. to 7 p.m. ET
- Email:** infocenter@LLS.org
All email messages are answered within one business day.



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Ms. Lizette Figueroa-Rivera

Thank you. Yes. Well thank you so much, Mr. Dickens, for sharing your expertise with us today and your continued dedication to blood cancer patients. I know we did get a lot of questions. If we weren't able to get to your question today, you can call an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from 9:00 AM to 9:00 PM Eastern Time or reach us by email at infocenter@lls.org.

The slides are available on www.lls.org/program and LLS does have an online chat for caregivers. You can go to lls.org/chat to learn more about our caregiver chat.

LLS EDUCATION & SUPPORT RESOURCES

LEUKEMIA & LYMPHOMA SOCIETY ONLINE CHATS



Online Chats are free, live sessions, moderated by oncology social workers. To register for one of the chats below, or for more information, please visit www.LLS.org/chat.

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

LEUKEMIA & LYMPHOMA SOCIETY PATIENT PODCAST



The Bloodline with LLS is here to remind you that after a diagnosis comes hope. To listen to an episode, please visit www.thebloodline.org.

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LLS Education & Support Resources

Again, I would like to acknowledge and thank Genentech and Biogen; Pharmacyclics an AbbVie Company; and Janssen Biotech and Taiho Oncology.

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Help With Finances

The Leukemia & Lymphoma Society (LLS) offers financial assistance* to help individuals with blood cancer.

The **LLS Patient Aid** Program provides financial assistance to blood cancer patients in active treatment. Eligible patients will receive a \$100 stipend. Visit www.LLS.org/PatientAid


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

The **Susan Lang Pay-It-Forward Patient Travel Assistance** Program provides blood cancer patients a \$500 grant to assist with transportation and lodging-related expenses. Visit www.LLS.org/Travel

The **Co-Pay Assistance** Program offers financial support toward the cost of insurance co-payments and/or insurance premiums for prescription drugs. Visit www.LLS.org/CoPay

*Funding for LLS's Co-pay Assistance Program is provided by pharmaceutical companies. Funding for other LLS financial assistance programs is provided by donations from individual donors, companies, and LLS campaigns.

The Leukemia & Lymphoma Society (LLS) offers the following financial assistance programs to help individuals with blood cancer: www.LLS.org/Finances



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

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Thank You

Mr. Dickens, thank you again for volunteering your time with us today. On behalf of The Leukemia & Lymphoma Society, thank you all for joining us for this program. Please let us know what you need from us during this time and you take good care during these holidays. Thank you.