Transcript: Supporting Caregivers: Real Stories and Expert Advice on Lung Cancer Caregiving

Mitch Jelniker (00:00):

Caring for someone with lung cancer isn't just a role, it is a journey filled with love, stress, strength, and a whole lot of unknowns. I'm Mitch Jelniker

Diane Mulligan (00:11):

And I'm Diane Mulligan. Caregiving just doesn't get the spotlight it deserves. And you know, today on hope with answers, we're going to be talking about what it's really like to be a caregiver. We're gonna give you some tips and some resources, and hopefully some ideas that might make caregiving just a little bit easier

Dr. Allison Applebaum (00:29):

Caregiving is certainly something that touches each and every one of us, but we can prevent severe mental health challenges. We can prevent depression and anxiety. We can give caregivers the tools and coping strategies, strategies that they need to cope more effectively with the inevitable challenges down the line.

Gail Fackler (00:47):

So what I think people need to know is that it's exhausting <laugh>. It's just, it, it physically is exhausting. It's sometimes very mentally draining, you know? So, um, but at the same time, you do gotta find time for yourself and make sure that you find some, sometimes to, for yourself to do things so that you can keep doing that, you know, and don't be afraid to ask for help.

Diane Mulligan (01:16):

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers, but first, it's a disease that affects people.

Mitch Jelniker (01:26):

Advances in lung cancer treatments over the last few years have made it possible to live with lung cancer for years after diagnosis.

Diane Mulligan (01:34):

The Hope with Answers Living with Lung Cancer Podcast brings you stories about people living truly living with lung cancer, the researchers dedicated to finding new breakthrough treatments, and others who are working to bring hope into the lung cancer experience.

Mitch Jelniker (01:56):

On today's episode, we're joined by Dr. Allison J Applebaum, a clinical psychologist specializing in psycho-oncology. She's the founding director of the Caregiver's Clinic at Memorial Sloan Kettering Cancer Center.

Diane Mulligan (02:10):

Dr. Applebaum also has a new book out called Stand By Me, A Guide to Navigating Modern Meaningful Caregiving. She's both a caregiving scientist. I didn't even know there was such a thing. And that's so cool. And a family caregiver.

Mitch Jelniker (02:28):

Well, Dr. Applebaum, thank you so much for joining us for this podcast. I, I gotta ask, what was your goal when you wrote your recent book called, stand By Me, A Guide to Navigating Modern Meaningful Caregiving?

Dr. Allison Applebaum (02:41):

There's many reasons why I wrote the book, but perhaps the most important for me to share with you is I realized, and this was particularly when we went into lockdown during the pandemic that we were at, Sloan Kettering only scratching the surface in meeting the demand for psychosocial care for family caregivers of patients with cancer. And I wanted to do something much more to assist caregivers across the country, caregivers in the trenches, caregivers who do not have access to high quality psychosocial care, whose care partners are not receiving cancer care at a major cancer center like Sloan Kettering or MD Anderson. And so, stand by me in many ways is a CliffNotes version to the type of training and education and support and validation that one would get should they come to the caregivers clinic. And I wanted to make that accessible to caregivers across the US and across the world. So that, that's probably the most important thing for me to say about why I wrote the book.

Diane Mulligan (03:38):

What's your goal, Dr. Applebaum, of, of starting a caregiver clinic like this? What is it that you hope to happen and, and have you seen any aha moments or, or amazing results from starting the clinic?

Dr. Allison Applebaum (03:53):

I don't just have one goal, not surprisingly. Um, my mission for my career is to assure that no caregiver has to seek mental health care and psychosocial support outside of the hospital system where their care partner is receiving care. And the reason that is my mission is that we know that caregivers suffer. We know that caregivers are at risk for their own mental health challenges. A large and growing body of literature, both within cancer care and non-cancer, indicates that diagnostic rates of anxiety and depression, and even post-traumatic stress disorder are actually higher in caregivers than the patients for whom they provide care. We know that the distress could be profound, and when it's left untreated, it can increase exponentially and not only have very negative effects on caregivers themselves, but certainly have downstream negative effects on the patients for whom caregivers are providing care. And so, my goal in developing the clinical service I did at Sloan Kettering, the clinical service I've just opened here at Mount Sinai, and my mission is to have these clinics across the country is to basically to prevent those poor outcomes. We can't prevent all distress, of course. Um, caregiving is certainly something that touches each and every one of us, but we can prevent severe mental health challenges, we can prevent depression and anxiety. We can give caregivers the tools and coping strategies, strategies that they need to cope more effectively with the inevitable challenges down the line.

Mitch Jelniker (05:25):

You mentioned there are certainly some joys to caregiving, but there are also many, many challenges. For someone who's new to caregiving, what would be the most common challenges a caregiver might face?

Dr. Allison Applebaum (05:36):

Oh my gosh. There's so many challenges for the new caregiver. You know, one of them is just the information overload. There's so much information coming to caregivers, um, in the beginning, especially as patients and caregivers go for first and second and maybe fifth opinions, um, that could be very, very overwhelming as can be. The enormity of all the new responsibilities can fall on one shoulders. And for some caregivers, those are limited to, for example, just maybe transportation to the hospital. But there's many caregivers for whom all of a sudden a diagnosis and a treatment plan leads them to have to make a very difficult decision about working or not, uh, making changes to their daily life so they can be present to provide support with activities of daily living with nursing and medical tasks that we are seeing. I know this audience here is well aware that we are seeing a significant increase in medical and nursing responsibilities placed on the shoulders of caregivers. And that can be really overwhelming for someone stepping into it and me, you know, in the early phases of caregiving.

Diane Mulligan (06:37):

And I think along with that, um, while you're doing all that, there are some negative emotions that can come out, such as guilt or resentment, and definitely burnout. Yeah. What do you say to caregivers to help them manage those

Dr. Allison Applebaum (06:51):

Feelings? Yeah, so, um, guilt is one of my favorite, favorite emotions to talk about with caregivers. I think all of us naturally, um, tend to learn to feel guilt. Um, caregivers are wonderful with guilt. Uh, it's, in fact, I don't think there's a week that goes by in a clinical setting where I don't hear about guilt. When a caregiver says to me that they're feeling guilty, I'm usually hearing they feel guilty. You know, Dr. Applebaum, I shouldn't be here. I'm not the patient with cancer, or Dr. Applebaum, I shouldn't be here. I should be at his bedside. And in those should statements, the guilt, the woulda, should'a, coulda is, that's the statement I hear that I should be doing something else. And on the surface level, a caregiver saying that I am letting down my care partner by being here or not at the bedside or taking care of myself.

(07:38):

But in reality, guilt is actually a very, very powerful red flag. And it tells us that the person that we are letting down or who we're about to let down, it's not our care partner, but ourself. And so what I, I encourage caregivers to consider is when they feel that guilt, when that comes up for them to ask themself the question of how, in what way am I letting myself down? Am I neglecting my own needs? And how can I actually pivot and go in the other direction? Um, really in many ways, care, uh, guilt is a red flag that we need to improve our self-care. Um, you know, with resentment, so many caregivers especially, um, you know, those early in the caregiving journey who feel isolated, may feel very resentful of their responsibilities. Perhaps there are adult children available to take care of a parent, but it all falls on one person.

(08:31):

Um, you know, perhaps there's other potentially available caregivers, but they're not stepping up. And that resentment makes sense. So the first thing I always do is validate that it's, it, it makes complete sense to be angry and frustrated, especially when one's life is being so deeply impacted. And yet we as caregivers do not have a limitless supply of energy. And it takes a lot of energy to hold a grudge. It takes a lot of energy to feel resentment. And so anything that can be done to release some of that anger and put that aside and realize that that is not serving us as caregivers is really, really important to do. I think the other category you mentioned, Diane, is just burden or stress, which of course, every caregiver experiences, every caregiver is gonna experience burden for sure. Um, but certainly if one feels like the distress they experience every day is interfering with their capacity to take care of their care partner, their capacity to work, and their ability even just to get out of bed during the, you know, in the morning, then that's really a sign that that more higher level of care professional help will be needed.

Mitch Jelniker (09:38):

One of the things we, we often see is, is, is sometimes the caregiver themselves, we see their, maybe their health both physically or mentally declining because they're giving so much. Because how many times we, we seen a caregiver and they say, oh, I got this, I got, it's a lot, but I have it. But what are the signs that caregiving is truly affecting your mental health more than you may realize?

Dr. Allison Applebaum (10:01):

I strongly encourage caregivers with whom I work to take their own physical health very seriously. Um, you know, that, that any medical problems that might be emerging do need attention. And, and yes, you mentioned that, you know, I think we've all seen and experienced cases where caregivers do go on to have their own medical diagnoses diagnosed and during caregiving. Um, so I, I strongly encourage caregivers to view their own health as part of their repertoire of tools that they have in their tool belt. That there's no way they can continue to care for their parent or partner or child or friend if they're feeling their heart racing, you know, in, in a difficult, you know, in a more re repeated way that that needs attention

Mitch Jelniker (10:41):

And therapy, then benefit caregivers should, is that something they should consider?

Dr. Allison Applebaum (10:46):

A hundred percent. I mean, this is absolutely, um, 100%. And I think what's really wonderful is that there are so many, what we call empirically supported interventions. That means psychosocial interventions that have data behind them that have been developed specifically for cancer caregivers. You know, we know that no caregiver has the time to come to Therapy Weekly, you know, every week at 2:00 PM on a Wednesday. Like no caregiver has a regular schedule to begin with, and no caregiver has the time to give it. Quite frankly, most aren't gonna come, you know, that in, in that fashion. But what we do know is that there's many interventions that have been developed that can be delivered very flexibly over telehealth. You know, maybe a total of six or eight sessions over the course of several months that can have just as a great effect or even greater than those much longer term therapies.

(11:36):

And so engaging in support is really important. And going back to the question about what, you know, the experience of new caregivers, I think it's really important, anyone who's stepping into the role to evaluate their support network, and by that I I do mean your social support, your family, and your friends, but also whether or not you have a therapist, you have a mental health professional in your network, someone that you can be with, even if it's just once or twice, you might not need ongoing care, but there can be great benefit to having that person on your team.

Diane Mulligan (12:09):

How do you tell caregivers or what tips do you give them is probably a better way to put that, um, about balancing their needs versus the needs of the person that they're taking care of?

Dr. Allison Applebaum (12:21):

Yeah, I think I titled one of the chapters in my book that the House of Cards, the Caregiving House of Cards, because it is such a tenuous balancing act, and we as caregivers are asked to shoulder so many tremendous responsibilities, and there's only 24 hours in a day, um, the reality is that we cannot do everything at a hundred percent. And so part of what's really important for caregivers is some acceptance to understand that if caregiving is added on to their life, then something else is going to have to give just a little bit. It may be that you can't work full-time, or if you still work full-time, you might not be able to give 180% of yourself. Maybe you give one 20. Um, you may not be able to do all of the social activities you once did. Um, you may have to cut down on, on planning for, you know, time away or travel, which of course is really, really hard. But I think it is important that we are realistic with the energy and time that we have. And when I say that too, it's remembering that, um, self-care is protecting time. Self-care can be simply, I need at least a half an hour every evening just to myself, regardless of what's going on. But what, what you just brought up is one of the greatest challenges that the caregivers face, which is how do I balance everything? I'm being asked to do

Mitch Jelniker (13:34):

My own experience. When my mom was helping my dad, she was the caregiver I would go on my days off, which really worked well because I could relieve her. It was as much for her as it was for him. But as we all know, some caregivers may live remotely or in a different state, or maybe they're not supported by their family and friends. What advice would you have for them if they feel isolated?

Dr. Allison Applebaum (13:59):

Well, there is certainly an increasing number of caregivers providing care from a distance, right? I think the pandemic really highlighted that fact, and I it's remained and it's endured. Um, oftentimes I think it's really important the, at the outset of the caregiving journey for all members of the care network, those who are on the ground in person, and those who are remote to, to create a list of every aspect of caregiving that that needs to be attended to. And then what can be done is look at that list, see what can be delegated to those who are not in person. And often there are many responsibilities ranging from providing financial support to coordinating various healthcare professionals, to creating a meal train that can be done remotely. And helping those remote caregivers to feel just as important and just as part of an integral team as those on the ground is a really important step. And again, I think communicating early on, one of the themes throughout my book and my, my work is how important it's that we communicate, communicating early on between those caregivers on the ground and those remotely is gonna be very important.

Diane Mulligan (15:05):

You know, I always in a situation where all of a sudden a patient needs that type of care, especially at the beginning, everybody says, oh, just let me know what I can do. What a smart thing to have a list and say, here's the list. How do we delegate this out so that everybody does feel like they're contributing, but they're contributing at a level that makes sense for them? I, I love that idea. I don't know

Dr. Allison Applebaum (15:28):

If in my book, but one of the things I say in my book is not just about delegating to caregivers your network, but that every caregiver should have that running list of everything. Not just caregiving related, but like everything else in your life, like your laundry, the gardening, the shopping, the, like, everything else you need to do. Because then when your well-meaning friends say, Hey, Allison, what can I do to help you? You can be like, well, let me just get open up my list and tell you. And the reason I say that is that the more specific we are with our asks, the more likely we are to get our needs met.

Diane Mulligan (16:00):

Absolutely.

Dr. Allison Applebaum (16:00):

So you're saying it's when I, I'm not sure what, I'll get back to you, not helpful, but you're saying, you know what? I don't have food after tomorrow in my refrigerator. Any way you can help with that, that's gonna more likely get you a concrete, you know, assistance.

Diane Mulligan (16:13):

I remember a, a friend of ours went to a, a person that we had all kinds of things set up for, but, but nobody had thought about them shoveling the walk. And so beautiful example, he went and set up a whole set of guys to make sure that the walk was shoveled every time it snowed. And they lived in Denver at that time, and it snowed all the time. So it really helped. So I think that's great. Tell me also about boundaries. How do you set healthy boundaries with the patient and maybe with that other, the other caregivers in that network?

Dr. Allison Applebaum (16:41):

Yeah, boundaries are so critical. Again, going back to energy, you know, I, I often will encourage caregivers to consider whether the people they're surrounding themselves with are draining their energy or buing themselves up.

Jim Fackler (16:52):

Mm-hmm

Dr. Allison Applebaum (16:52):

<affirmative>. Um, boundaries are really, really important. You know, it's very, I think it can be particularly difficult to set boundaries with care partners per, particularly those who are very dependent on caregivers, as was my father with me physically and otherwise dependent. Um, but there's always room for boundaries, whether they're time boundaries or emotional boundaries. Going back to what I just shared a few minutes ago, I think the best thing to do is communicate and to be clear about the boundaries that are being set. Um, that, that way there's no assumptions being made. There's no misunderstanding. Dad, it's really important for me that I get tomorrow night off, I've been feeling really burnt out. I'm not gonna come back to the apartment till Saturday. Is that okay with you being really clear about that as opposed to my dad then feeling abandoned by me? Right?

Mitch Jelniker (17:40):

Yeah. You only have so much gas in the tank, right? So, yeah, good advice. I'm curious, what are the long-term psychological effects of caregiving, especially after caregiving ends?

Dr. Allison Applebaum (17:51):

This is an important question. Um, it's another, um, topic that I'm focusing on in some of my research with bereaved caregivers That's happening right now. Um, we know some of the long-term effects do include, um, trauma, post-traumatic stress disorder in its most significant form. Um, depression and anxiety for sure. Um, for those who go through the death of a care partner, one could experience what we call complicated grief, um, or prolonged grief disorder. There's some, um, discussion about the, the language in the nomenclature, but the idea is that, of course, grief is very painful and grief is very normal. But when, um, grief is unable to be processed healthfully, it can actually lead to mental health challenges. And this is again, why support is so important. Just as I said, it was important for caregivers early on to assess their support network, both professional and personal. So too is it's so critical for caregivers, particularly those whose caregiving journeys have ended through the death of a care partner to evaluate what, what their support is.

Diane Mulligan (18:57):

Well, thank you so much. We can't tell you how much we've enjoyed this and, and learned a lot. So it was great. And we're looking forward to the research that you have coming out. When is it coming out?

Dr. Allison Applebaum (19:06):

Summer. This summer. We're looking at the data right now. So I hope to publish, um, this fall. The, the trial I mentioned with those four, those 200 caregivers, um, with some of those, uh, psycho numerological outcomes. And I hope to show something positive. We'll see. And, uh, and I do have a trial right now where we are following caregivers into bereavement. And what I'd like to show is that those who've received a certain type of psychotherapy that addresses some of the distress we know is particularly critical around end of life will help those caregivers in bereavement.

Mitch Jelniker (19:36):

Dr. Abba, thank you so much. Great information. My pleasure. Good guidance. We appreciate you. We're honored to be joined by a remarkable couple, Gail Fackler and her husband Jim. Now Gail has stepped into the role of caregiver with strength, with Grace, supporting Jim through his journey with small cell lung cancer.

Diane Mulligan (19:55):

And together they share the daily realities of giving and receiving care, but also the love and the lessons that they found along the way. This story is about partnership, patience, and the power of showing up for one another.

Mitch Jelniker (20:13):

Gail and Jim, thank you for joining us for this discussion about caregiving. Gail, let's start with you. Take us back to the day Jim was diagnosed with lung cancer. What was the first thought that went through your mind?

Gail Fackler (20:26):

Uh, the first thought when he said he was told he had cancer, and he said, I've got cancer. Uh, it was shock, disbelief, uh, or it, in that one moment, our whole world turned completely upside down, <laugh>. So just, uh, I, I didn't even know how to respond. It's like sort of felt frozen.

Diane Mulligan (20:48):

And, and Jim, you know, for you, all of a sudden you're hearing that word, one of the things that has to go through your mind is, geez, I'm Gail's gonna have to really take care of me through this. What, what is that? Like?

Jim Fackler (21:01):

It felt like it, like it, uh, certain shock, pretty much like Gail, when the doctor came in and told me I had cancer, it just really, truly for Loop and,

Diane Mulligan (21:19):

And Jim to be thinking about being cared for by someone else, that, that Gail was gonna have to kind of take over here. What was that like?

Jim Fackler (21:28):

Same thing as it's now, it's very, very difficult for me to accept how traditionally I've always been helping others. So to have her take on 100% of what goes on our property house and everything, it just, it's difficult. It's un it's unnatural.

Mitch Jelniker (22:06):

Yeah. 'cause you all had split so many duties around the house, cooking and everything else that Yes. That's completely foreign to you.

Jim Fackler (22:12):

It is. And uh, one of my favorite things was cooking, and now I can't really even do that.

Diane Mulligan (22:24):

Well, Jim, we're gonna get back to you in a minute, and Gail, we're gonna talk more about your side, the caregiver side. Okay. Um, and I, I'm wondering what is the hardest part about watching Jim battle this lung cancer?

Gail Fackler (22:39):

The fact that he can't do anything. And I, I tend to oftentimes get resentful because I'm doing it all. And then I then I try to stop and say, okay, how is he feeling about this? And it's like, I know he hates that because he was so used to pitching in and helping and doing so much. And for him to be able to not do anything, it's, it's, uh, extremely difficult for him. So I try to remind myself of that, that he, he doesn't want what he's got. <laugh>. He would like to have his old life back.

Mitch Jelniker (23:15):

So, for sure. And so you, you've, you've touched on this, but I'm curious how this has all impacted your marriage, uh, since the diagno diagnosis. What things have become more challenging, for example, just in your relationship?

Gail Fackler (23:31):

Pretty much everything. Uh, communication oftentimes, because there are many days he doesn't feel like talk. I think he doesn't feel like talking. He doesn't talk. He sleeps a lot of the day away. So conversations that we just used to have about anything, everything, things going on in the world outside of our home versus friends versus anything. There's so many times we don't have that, um, intimacy there that's changed dramatically. It's kind of not there because he's so weak and he just can't do things. So, so yeah, it's had a huge, huge impact.

Diane Mulligan (24:08):

Well, and I know that for a lot of caregivers, they feel guilty over some of the negative feelings and, um, sometimes they even feel resentful. I just wondered, have you experienced this? And, and how do you deal with those feelings? <laugh>,

Gail Fackler (24:21):

Absolutely. I've experienced it. Lots of resentment. Um, and, uh, guilty sometimes when I go out and do things, and I know he's sitting at home by himself and I feel guilty about that <laugh>, you know? Uh, but then again, it's like, okay, so am I supposed to not live anymore too? I mean, I don't know, you know, that's always a challenge. Wondering about that. Uh, how do I handle it? Not, well, a lot of times, a lot of times it's, it's, um, feeling sorry for myself or just again, res feeling resentful. Uh, other times I get together with friends. I mean, I'm on a ladies golf league, so I do golf once a week, so I try to get out and do things, but sometimes I don't. I just wanna be alone and not talk to anybody. So it, it just depends on the day and how I'm feeling.

Mitch Jelniker (25:14):

Well, it's good to hear that you're getting out on occasion because what so often happens in the caregiving role is that you don't take care of yourself, uh, both mentally and physically. So is is that a challenge for you to focus on yourself and care for yourself?

Gail Fackler (25:31):

Sometimes. I mean, I'm trying to take care of myself physically because somebody's gotta run things in the house. So it's like, I really have to take care of care of myself. So I try to do my, you know, my annual physicals and different things, uh, with that and try to, uh, you know, one of the things that's therapeutic for me as far as the mental part of it and is, uh, when I go for walks in the morning, sometimes I have friends I walk with if I've got one particular one. But if she's out of town, I walk by myself. And that's really therapeutic because I just, you know, listen to the birds, say the blue sky, look at nature, and, and it's just calming for me. And I come back and I feel somewhat energized after I, you know, I go walking in the morning. 'cause it's just quiet and peaceful

Diane Mulligan (26:14):

And, and it, sometimes I think it's hard for people who haven't been in the caregiving role to really understand what it is you're going through. What do you wish that people would understand about caregiving?

Gail Fackler (26:26):

I swore I told Jim, my mother was always a caregiver, and I said, I'm not my mother. I am not like her at all. She just always had that role, you know, and she was that kind of person. I'm not, I always thought I'd be the one taking care, being taken care of, you know? And so it didn't work out that way. So what I think people need to is that it's exhausting <laugh>, it's just, it, it physically is exhausting. It's sometimes very mentally exhaust draining, you know? So, um, but at the same time, you go do gotta find time for yourself and make sure that you find some, sometimes to, for yourself to do things so that you can keep doing that <laugh>, you know, and don't be afraid to ask for help.

Mitch Jelniker (27:09):

Then in the midst of all this caregiving, of course you're still trying to, you know, you're, you're still focused on your marriage or your relationship. Right? Right. How has intimacy in your relationship changed both emotionally and physically?

Gail Fackler (27:23):

Uh, physically it's kind of been by, uh, wayside, but we, a couple weeks ago had a talk about that because sometimes I'm just, you know, I feel like I'm in robotic mode all day long. You know, I gotta do this, I gotta do this. It's, it's the things, the, it's the physical labor, things around the house, inside, outside, whichever it is. And then I, then the resentment builds up. But I said, what I'm looking for from him, I know he can't help me, but I said, you know, just sitting next to me or, you know, putting your arm around me or just some, some sort of touch, you know, <laugh> helps a lot. It makes me feel like I'm a person again and I am a wife, not just your, uh, caregiver, but I'm still a wife. 'cause a lot of times I don't feel like a wife anymore.

(28:12):

So it's just, for me, it's getting some, some physical touch. And, uh, so he's, he is been working at doing that. He's kind of making him aware because he thought I was looking for the compliments, like, thank you for doing this, thank you for, and it's like, yeah, that's nice. But, you know, that doesn't still make me feel like a wife. A wife should be some intimacy and for the age we're at, I guess. And, and the, the medical situation or his health, that's, that's a lot, you know, that helps me a lot if he just gives me some sort of touch and stuff. So

Diane Mulligan (28:46):

That communication is so important and making sure that you talk to your partner about the needs that you have as well. But I'm also hearing, boy, a lot of frustration and, and I think that that's very common. What is the best outlet that you have when you're, you're just kind of at your wit's end? What do you do?

Gail Fackler (29:06):

Uh, different things, but sometimes it is going and talking to friends. We've, we live in an awesome neighborhood where I've got quite a few friends, so maybe it's going, getting together with them and just talking so that I can, in fact, one of my <laugh>, my elementary school friends, she called me the other day just by chance. Her husband's got Parkinson's and she was venting about that. And it's like, oh my God, that's the same thing I'm going through right now. You know, it's, it is kind of the same, same things. When she was telling me things she was doing, it's like, that's what I'm doing. <laugh>. You know? So it kind of felt good to have some, uh, some camaraderie on that, I guess, or to know somebody else. But the other thing that helps, well, walking in the morning for me, and the other thing is, um, getting involved. We've been involved in some cancer organizations, which we didn't do initially, but getting involved in that has helped because when we do get together with, on our Zoom calls, or actually together physically at a summit or something, it's just so good to talk to others who understand where you're coming from and what's going on in your life.

Mitch Jelniker (30:12):

They get it. And, and you don't feel, uh, alone because you are not, uh, there are many, many people in this caregiving role. So when you're with other caregivers and perhaps they're new at this, what advice do you give them? What do you tell them?

Gail Fackler (30:25):

Be sure to carve out a little bit of time for yourself. And some days that is a challenge, you know, there maybe isn't time to do that, even if it's 10, 15 minutes of just at the end of the night, maybe reading with, uh, or something like that, or making a phone call or something that you enjoy, uh, music or something like that. But just try to find a little bit of time, even if it's very little, just for yourself that you can have some peaceful, quiet time if that's what you need. I mean, that's what I need. But anyway, just take time for yourself.

Diane Mulligan (31:01):

How do you keep the joy in your marriage and, uh, and take time to have fun? What do you guys do?

Gail Fackler (31:06):

I was thinking back on that. It's like, boy, joy used to be to our travels. You know, we loved traveling, traveling abroad. We just, we loved doing that. And it's like, or just doing things hiking or biking. We did bike trips, you know, we did a lot of different things and it's like, okay, we can't do any of that anymore. To the point of, and what's happened with Jim, just to kind of tell you is his cancer is, is uh, NED right now, which is awesome. However, the side effects from the cancer treatments is what impacted him to the point he can't walk. His walking has become where he can barely walk. He can't walk without assistance. And his talking, his speech became slurred. So those are the things that happened as a result of cancer treatment. Joy is the small things now. That's what I have to look at.

(31:51):

It's like waking up in the morning and the first thing I do is listen to make sure he is breathing. It's like if I hear him breathing, it's like, oh, we have another day to, we get to spend another day together. You know? So that's joy. Joy is, like I said, there are a lot of days he doesn't talk much, but if we have a day where we have an actual in-depth conversation about whatever it happens to be, be it the news, the politics, the what's going on in the neighborhood, um, that brings joy. Just to have a, feels like a normal conversation versus other things, you know, where it's no conversation or I'm having to say, you need to do this, you need to do this. 'cause a lot of times it's a parent child type relationship. And it's nice when we can have a conversation where it's more like husband, wife, uh, so it's really the, the small things. It's, it's little things

Diane Mulligan (32:41):

Today. I think that's so important, um, that, that when you thought about it, that that's what you came back to. Because it is those little things during the day that sometimes we take for granted that you don't take for granted so much anymore that can really bring you back. Right,

Gail Fackler (32:55):

Right. And he falls a lot because of his, he's lo because of the fact he can't walk. He's lost balance and he falls a lot. And so it's like we get to the end of a day, it's like, oh, nothing, nothing bad happened today, <laugh>. It's like, whew, <laugh>. So that's joy. It's like we got through a day with, with no coincidence.

Mitch Jelniker (33:14):

Yays a big deal. That's a, yeah. It's, that brings plenty of joy. I, I imagine

Gail Fackler (33:18):

It does.

Mitch Jelniker (33:19):

Well, let's, let's bring Jim back into the conversation so we, we can ask him a few things about this whole process.

Gail Fackler (33:26):

Alright.

Mitch Jelniker (33:26):

Um, Jim, I know what, what, what moments make you feel supported or understood in this new role where you're being cared for?

Jim Fackler (33:37):

Uh, she supports me and yeah, the frustration comes through for both of us. Me, because of the cancer and her, because of what she's required to do now. But she's really good at figuring things out. Things I used to be able to do. She now does.

Diane Mulligan (34:10):

So Jim, tell me, what do you appreciate most about Gail, especially in her role as a caregiver?

Jim Fackler (34:16):

How she cares for me and takes on these roles. I mean, even basic stuff like where do we go to eat tonight? And she'll come up with something that used to be my job that I wanted to do, but because of my physical invitation, she takes on that role. So she helped me out a great deal and that makes me feel good. And at the same time, I'm very angry and frustrated that I cannot do things I used to do. The cancer has changed our life dramatically. So we're trying different things to make it better. And it is something just as simple like a touch. Uh, and like you say, she appreciate getting recognized for what she's done, but what she, she really watches the physical,

Gail Fackler (35:55):

Like in a marriage. Yeah, <laugh>. Yeah. Yeah.

Jim Fackler (35:58):

Well, we, we try to keep, I, I try to get more engaged a lot of times. Like she's, uh, I just don't feel like talking because it is very difficult.

Mitch Jelniker (36:17):

Yeah. I have a question for, for both of you really. Are there unexpected blessings or maybe connections that have come from this whole caregiving relationship?

Jim Fackler (36:27):

Well, I've tried to be more engaged with talking about different issues

Gail Fackler (36:36):

And uh, I was gonna say, and blessings probably for me are realizing in the neighborhood. 'cause we, we've only lived in South Carolina for five years. We we're really from the Midwest. So, um, but I have found in the neighborhood, we are in the blessings are the, the people we have here. Because when different things happen where I need assistance, things I can't do, I can call. And they all just come, they come, they want to help and they come. And it's like, we're so blessed to be where we are in this community because people help us, you know, in the little area that we're in, they, they're there to help us. We have a lot of different people we can call on 'cause we don't have any family here. So it's, yeah. So that's been a big blessing. <laugh>.

Diane Mulligan (37:18):

Well, it's always great to count your blessings and it's clear that the two of you have done that. And I think that's a wonderful thing. And, and I just wanna thank you both for, for this interview 'cause you've been so open and vulnerable and I can't imagine how many people will be helped by the fact that, that you really shared the way you did. So thank you so much for that. Make sure to subscribe to the Hope with Answers Living with Lung Cancer Podcast. You'll be notified every time a new episode is available. So visit us online@lcfamerica.org where you can find more information about the latest in lung cancer research, new treatments, and more. You can also join the conversation with LCFA on Facebook, Twitter, and Instagram.