



Can Do MS Podcast Embracing Carers Caring and Curating: A Support Partner's Journey Episode 41

Krista Sipf: Hello and welcome back to the Can Do MS Podcast. My name is Krista Sipf and I'm a Programs Manager here at Can Do MS. As a reminder, this November, we're celebrating National Caregivers Month. A huge thank you to all the support partners and caregivers out there.

At Can Do MS, we talk a lot about the journey of the caregiver or support partner. Living well with MS takes a team effort, and we often say, "MS is a we disease, not a me disease." It affects not just the person with MS, but also their family, friends, and others who support and care for them.

Today's podcast is Episode 41 entitled, *Caring and Curating: A Support Partners Journey*. As part of the embracing carer series, we'll hear from support partner, Cindy Fink, who will let us in on her perspective as she supports her family and jungles life with MS.

Roz Kalb: Hi, I'm Ross Kalb and I'm a clinical psychologist with Can Do Multiple Sclerosis. I'm excited to be here today to have a conversation with Cindy Fink about what it's like to be a care partner for her husband, Kemp[?], who lives with MS.

Welcome, Cindy. Can you introduce yourself and tell us a bit about your story?

Cindy Fink: Sure. Thanks, Roz. I'm really excited to be with you. I was looking forward to this all week, knowing we're going to have this conversation.

I am Cindy Fink and I think I would start by saying I knew very little to nothing about a MS until the man I was dating at the time, Kemp, went to a doctor's appointment and had a kind of funny symptom feeling in his arm, and he pretty quickly got diagnosed as having relapse remitting.

We were about a year after we had started dating at that point, and a year before we got married. We learned together about MS. He had relapse remitting, as I said, and people said it was a pretty good prognosis. He got on the drugs right away, and so we weren't too

concerned about it. We got married, and then we adopted our daughter, Kate, from China, something I had always wanted to do, and Kemp was game for that, so that's how we became parents. We were both working in our careers and moving up and around, and we ended up moving, actually, to Cleveland, Ohio, which is about 4 hours from our parents, because it felt like the right thing to do. There was nothing going on. really, at that point, majorly with his health. That was, I'd say, the first 10 years of our marriage.

Today, he is almost 49 and he's now confined to a wheelchair, so we've gone through all of the phases, if you will, from about 6 years ago, starting to stumble, needing a cane, using a walker, then a scooter, and now, wheelchair.

He, about 3 years ago, went on disability because we realized that his job was not helping him. Certainly, it was probably injuring his care and his health, and so I became the primary earner in the family. We became a single, I guess, income, with, then a disability income, that obviously is fixed. We also started taking on the care of him through some of my time, but also through caregivers coming into the home, which was, obviously a very different dynamic. I'd say the last 6 years has been a steady progression of changing, and constantly changing as a family into these new realities that we never expected and we had never really talked about, either, as a couple, even in the beginning with the diagnosis, because we just, at the time, I don't think had anyone counseling us to look ahead or talk ahead.

Here we are, we have a 15 year old now, almost. We have Kemp who's here, of course, every day. Most of his mornings are with caregivers, but in the afternoons, he's trying to do volunteer work and community service that he can do, generally from the house, and I work now remotely because of the pandemic, but at a pretty consuming job in my communications career.

Roz: You mentioned leaving your parents. Do you have 4 elderly parents who are on your mind, as well as Kemp and your fabulous, almost 15 year old daughter?

Cindy: Yeah. You know, that's a really good question because that, too, has changed this year. Unfortunately, my dad passed away this Spring and we needed to [crosstalk] make a decision about what to do with my mom. She has now moved to Cleveland and is in an assisted-living apartment, not too far from us. Because she has Alzheimer's, now I've got a second neurological disease surrounding me. She needs a lot of attention and care, which I wasn't having to do because my dad was doing that until just this year, really, the last 6 months.

I was telling a friend, that saying about a sandwich generation. My friends who are all my age are in a sandwich generation themselves. They've got their teenagers or their kids, and they've got their aging parents. I am that, but I also have my spouse who's right in the middle. I was telling my friend, "I'm like a double-decker sandwich."

Roz: You are a double-decker club sandwich. Cindy, how have you managed this? You had to pivot really quickly. Kemp's progression, once it started, was really quite rapid. The same time,

your child is growing up, and your parents are facing health issues. What strategies have you used during this pivot to try and manage?

Cindy: Well, I think my caveat, of course, has to be, I don't have it all figured out. You know that when we've talked in the past, I don't know if anyone has the right answers, and so I want to be clear. I'm not doing this well, even, most days. I think if I do 50% well, I feel like it's a good day. I think a lot of my strategy is plan ahead as much as possible, but that's like a day, a week, or a month, maybe at a time, because things change so much and so quickly with this disease that if you plan too far out, you're just going to be disappointed, but to try to look a day, a week, a month ahead of the things that as a family we want to do, we're trying to do, we need to do, so that we have the time to do the advance work with MS and on a mobility disorder, you need to do.

If we want to go on a picnic, let's say, in the middle of summer, we can't just pack up and quickly go on a picnic. That used to be us, that's not us anymore. We need time to plan it and a lot of that planning falls on me, which I'm happy to do, it's just that having the time and the attention to do it. One of my strategies, I'd say, is planning ahead.

I think the other strategy, and I don't know if this is a strategy, but it's a mindset that I've really tried. I'm trying and I'm not always good about it, but I'm really trying to remind myself is that we all have 9 lives. By that, I mean, I look around at my friends and they are becoming empty nesters and they're going on trips with their spouses, and they're doing things that sure, Kemp and I would love to do, and probably do easily, more easily than we can do it now, but I remind myself, Kemp and I traveled a lot when we were first married and when we were dating, and even when Kate was little. We were bouncing around a lot to the places on our list, and I'm so thankful we did that, because that was like one of our 9 lives, and we did that. It's not to say we don't have other places we want to go now, but I try to remind myself that I've been in that situation. I've had those memories, those experiences with Kemp.

The same thing, sometimes with Kate, oftentimes, she'll look at friends who are out throwing the softball around with their dad in the backyard, and she laments about how she doesn't get to do that. That breaks your heart, but I try to remind her that her dad, for her first probably 7 to 8 years, was that Dad. She doesn't have all those memories, but I can show her pictures, [crosstalk] tell her stories. She had that part of her 9 lives also, and it's like trying to appreciate that we each get a bunch of different lives in our life, and this is the life right now.

Roz: Given the fact that you have this double-decker life, where do you find a carve out time for you and your own wellness, your emotional wellness, your physical wellness, how are you getting those little tidbits that you need to sustain yourself?

Cindy: I will be honest. I don't think that I do it well. I think this is one of the things that it's the first thing to go, especially now that my mom's in the picture and I've got that extra layer of the sandwich added on, the last thing that I take care of is myself. I'll be honest. I had to make a pledge to myself earlier this year, and it was actually my dad, because he was up here in

Cleveland with us at the end of his life, telling me I had to "watch my health better", those were his words, that I needed to get back on track. I've made an effort this year to do all of those primary care visits and those checkups, and those things that we all know we're supposed to do, like our annual evaluations. I made a list and I decided, "You know what? I'm just going to have to find the time, and I'm going to go down and schedule each one," because Kemp keeps reminding me that if I don't do those things and I fall down, we're all sunk. That's what he always says, and he's right. We're all sunk if I go down. Having to be really deliberate about those kinds of things, I think, is important.

The other thing this year that I've done is what I call "micro habits". I've been reading a number of articles about micro habits and how it's hard to take on a whole, new, big habit. So many people tell me I need to take up yoga. If one more person tells me to take up yoga, I'm going to scream, because I don't have a minute in the day to go out of this house to a yoga studio and take a string of classes, but I can get down on a yoga mat and stretch every morning. I decided that's a micro habit. I'm trying to do those small things that aren't big efforts in taking on a new initiative and a new project, but small, little things that I feel like, "Okay, I can carve out 5 minutes for these 5 things during my day. The stretching is one, and it sounds silly, but flossing my teeth is one, just some of those things that I feel like I'm doing something for myself, adding extra vegetables at lunch, the healthy things that we all should do, but we kind of forget to do. I remember to do them, but I have to find time to do them.

Roz: When we talked another time, you used a phrase that really intrigued me. You said that in order to do all this, you, and in partnership with Kemp, had to curate your life to make it work. Could you say a little more about what that means?

Cindy: Yeah. I guess that's one of the other strategies when you asked me that question. Kemp and I have had in the last 6, 7 years, really had to divide and conquer, because there's just no way that I can do everything that we would have both ended up doing. It can't all fall on me, so we've had to divide and conquer, and we had to do it based on our abilities and our interests, sometimes, but more based on our abilities.

Like homework, Kemp's really good and he's here at the house, and there's nothing preventing him from managing the homework at night with Kate. He takes that on. Grocery shopping, thank God for the pandemic and all of the delivery services. He can grocery shop. I haven't grocery shopped in a couple of years because he can be in charge of managing that whole process in ordering and everything. Kate and I, of course, have to put it away. That's one way we're curating, planning, and managing our lives, to think, "How are we going to divide and conquer based on abilities?" The worst thing for Kemp, I think, is if he feels that he doesn't have a place and value in this family anymore. He does, it's just that sometimes they're different than when he was working full-time or before, when he was able to walk without assistance of a mobility device. The curating is finding out what we're each able to do and good at, and then saying, "Okay, we're going to divide up that way."

The other thing I think I might have meant that day, Roz, was I think it's like what I was saying earlier, the advance work. I want us to be able to do the things that we wanted to always do. We wanted to take Kate to Disney World, so when she was 9, we went to Disney World. Kemp was in a scooter at that point. A couple years later, we went to Epcot. He was in a wheelchair at that point. We didn't just decide to go to Disney World and show up down there. We had to really plan those trips. We had to do a lot of research. We had to ask a lot of people for help when we were down there, but we did it and we have great memories. She got the Disney World experience that we wanted her to have, but it took advanced work. It took effort to plan it, and so that's, I guess, the other way that we curated. We talk about what we want to try to do, and then we try to figure it out. It just takes time and planning.

Roz: You're describing a remarkable partnership, and I think one of the things I want to call out here is it's a partnership in which each of you contributes and gives, and each of you receives. That's what helps the partnership, I think, feel healthy or sound healthy to me because everybody's thriving with the way you two work together. What do you think, as a last and tough question I think, what do you think are the ways in which your partnership is built on strengths, ways that had to change or evolve, what would you say about your partnership over these years together with Kemp?

Cindy: I think the challenge within us is that it hits you when you're young. In many ways, you end up becoming an older couple than you are chronologically, and you get to face things, health issues, and just kind of the quality of life that you would probably face when you're 40 years older, but you're doing it when you're in your 40s in our case. I think having a friendship has been the most important thing that no matter what is going to come next, loyalty and friendship is, at the end of the day, the thing that's there and stays there. This is where I have the hardest time. I think that you cannot demonize the person, you have to demonize the disease. I have to be mad at MS.

I think about the grief cycle and how anger is right up there at the top of the grief cycle. There's no question, I am still in the grief cycle with the fact that MS is in our lives. It's easy to get angry at Kemp, and I'm really awful sometimes at it because I get too angry, too quickly at them, when I need to be angry at the disease. It's like having those conversations, I think, and calling each other on it, like, "You know what? You're being angry at me. I think you're misplacing your anger right now." I would say those are a few things that have kept us going.

The one other thing I'll say that I'm starting to realize is I can't do it all and I can't pretend to do it all. I need to realize where my weaknesses are. In my case, I am not a good caregiver. I never went into medical, nursing, physician, anything. I'm just not good at that. I don't have the patience or the kind of nurturing personality that the saints who do go into medical professions have. Kemp and I talk a lot about that. I have to outsource for that. I have to find other people, if at all possible, who can help him with those things, so that I can do the things that I probably am better at, like curating our experiences, managing our finances, going to work every day to make that primary earning. We talked quite a bit about that, as well, which

is, "What should we take off of me," because it's not my strength, if at all, possible. Sometimes families can't, I realized, and people can't, but recognizing and being honest with yourself and knowing what you're good at and what you're not, and then what are you going to do about it, I think, is important.

Roz: If you had one message that you wanted to give to other support partners out there, whether they're new to the role or further along, what would it be?

Cindy: I think it's that you're not alone. I think in the beginning, when Kemp's health was starting to first decline, it felt like I was the only person in the world who had a relationship like this, a family like this, this kind of stuff was happening to my family. I think a lot of it again is because you're young when MS happens and hits you, so you're looking around at other people and friends who are in the prime of their life and fortunately, I think in most of our cases, our friends are not sick with a chronic disease. You just don't see it in your friends group, in your view group. It felt really lonely. I think you have to find, and I have yet to consistently find this, but you have to find, even if it's virtually, someone else who's experiencing this, or in our case. We found a really great social worker at the MS Center where Kemp goes, and she knew so much about families dealing with MS that she became someone to talk to. She could share experiences and perspectives, and it felt like, "Wow, we're not dealing with this alone."

I'd say to everyone, "Find someone, find a group, whatever it takes, but don't feel like you're the only one dealing with this because you're not."

Roz: You've given so many gems of information and recommendations to people in your situation, and I can't tell you how much I appreciate it. One of the things that comes through loudly and clearly is how important communication has been to the two of you. I'm just thrilled that you came today to share all of this. Thank you, Cindy. Appreciate it a lot.

Cindy: You're very welcome.

Krista: This podcast is part of Embracing Carers, an initiative led by EMD Serono, in collaboration with leading caregiver organizations around the world, to increase awareness and action about the often overlooked needs of caregivers.

Thank you for tuning in to this episode of the Can Do MS Podcast. Please check out more of Embracing Carers' program on our website, cando-ms.org.

Thank you for joining us and have a wonderful week.

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