



TRANSCRIPT

Self-Care—Overcoming Barriers

Felicia: I think there are two primary categories of barriers to self-care, and one of them is internal barriers to self-care. There are things within us that make it difficult for us to engage, and then there are external barriers. External barriers sometimes look like a lack of time. Oftentimes people are working full time in the workforce and have a family that they're caring for such as a spouse and children, and then they're caring for a parent with dementia. That's a lot of responsibility, so at the end of the day there's very little time to dedicate towards oneself. Another external barrier could be financial. Sometimes self-care requires you to get some respite to get a break so that your loved one is not left alone, but to hire someone to come into the home can cost a significant amount of money which is not covered by insurance. Sometimes that's a real barrier to giving someone a break, as well as lack of a social network. There just aren't friends or family readily available to help. So those are just some concrete examples of external barriers to self-care, and then internally, sometimes, people feel really guilty about prioritizing their self-care when they know that they have somebody who needs them. It feels a little bit selfish to carve out that time. Sometimes folks might avoid going to the doctor out of fear that something really might be wrong, so it's better not to know so that we can just proceed forward. Sometimes another barrier could be the belief of, "What's the use? It won't really help. Nothing will really get better if I take care of myself." Maybe it's the belief that no one will help. Maybe you've asked somebody a couple of times for help and were turned down, so you feel discouraged. And then finally I would say that maybe you're a person who never really took care of yourself, so now asking you to take care of yourself in the context of caregiving just feels impossible. So that's just a few ideas about what I have heard from folks who might be struggling with prioritizing their self-care.

Katie: I'd like to take the opportunity to ask the audience, how does this resonate with you? Which of the following are barriers to self-care for you? Multiple choice: Is it time? Is it no one can help? Money? I hadn't thought about self-care?

So we see here that over half of our participants are reporting resources of time and actually having folks to help them.

Barry: It actually pains me to see that so few people have people there to help them. That's quite sad. One of the self-care skills I think we'll need to have is how do we elicit help from other people, and maybe even people who are reluctant to help? How do we cajole them into helping us? I mean, the issue with time is a very difficult one. I'll just say that one of the most important self-care skills that there is is what's called compartmentalization. That is setting aside an hour or half hour that is your time that you protect, no matter what, and you don't let caregiving responsibilities intrude on that time. It's very easy to allow caregiving demands to infiltrate every moment of your life unless you're careful, and it takes a lot of intention to really protect time and compartmentalize it and protect it.

Felicia: Jumping off of what Barry said, cajoling family and friends for help, I want to share a couple of tips on how to do that specifically. So what you want to do first is identify who is in your network. Who could help? Think about a specific request that you have. How could this specific person help you with your specific request? There are different communication styles, and communication styles on a continuum go from passive communication to aggressive communication. Passive communication is when you kind of shut down and don't really advocate for yourself or ask for help, and aggressive communication, people with that kind of style, they tend to be more demanding. Neither one of those, neither demanding nor denying your needs, is going to help you get the help you need. Meeting

in the middle and using assertive communication is one way to be successful in getting the help you need, so to do that you want to be able to have your specific ask in mind and explain to the person why you need it and why it's important for you to get the break to take care of yourself in this very specific way. And then, negotiate the terms with the person you're asking. For example, if you want to go to see a performance at some point, first get the buy-in of that where somebody will be available to sit in for you so that you can get out and go to a performance. Then, negotiate. What day of the week could it be? What's good for you? Buy your ticket around that time if you have some flexibility. It's harder for them to say no when you are letting them kind of dictate the when or even the how. If the person is reluctant to help the first time, just restate your case. Find another way to express why it's important for you to get this break, and then once the person does help you out, really express your gratitude. Tell them how important it was for you and how grateful you are, and then maybe even offer to do something for them or bake them cookies or something just as a gesture to say thank you.

Barry: I was hoping you would say cookies. That's the key, I think.

Felicia: Is that what would get you to help out, Barry?

Barry: Anybody will do anything for cookies for sure.

Felicia: I think another way to seek help, if not for respite, is through a professional, so finding a counselor or a therapist. That is an act of self-care in and of itself by just getting someone to meet with you for an hour once a week or every other week where you can just vent and process your experience with that person and get their insight or perspectives. Have them hold you accountable for your self-care. The way to find a therapist is that you may want to consider finding a therapist who has experience in aging, caregiving, or Alzheimer's disease, and you can do this by checking in with your physician to see if they have any referrals or even call your insurance or mental health provider on your medical insurance

to ask who is in your network and who specializes in these things. They'll help to match you with someone. Another resource is a website called Psychology Today. It's a database of therapists where you can plug in who you're looking for, and then you can review their profiles and start by reaching out to different folks who are available to you online. Another kind of sidebar to that is through a support group, so connecting with a group of people going through a shared experience. That can really be a lifeline for people, and there are resources on *Bob's Last Marathon's* resource site or the Alzheimer's Association if you are looking for support groups that will work well for you. I do want to say that for support groups the fit has to be right, so I wouldn't discard it if the first time you go to a group doesn't feel right. Try another group, and eventually you will find your people.

Barry: So we've mentioned mindful breathing and mindfulness in general. The term "mindfulness" has been kicked around now for about 10 years in the popular culture, but I still think it's very confusing for a lot of people as to what it is. I'll just say briefly that for mindfulness the definition is "non-reactive awareness" to do certain exercises and to help us kind of deal with whatever is going on in our life without having a huge reaction to it. It's to be able to abide as much as possible. When people think of a mindfulness exercise sometimes they think, "Well, this is going to be meditation. I'm going to have to get in the full lotus position on the floor. It's going to hurt my knees." It doesn't have to be anything like that. When I introduce mindfulness to folks, one of the most basic things that I work on with them is something called the five senses exercise. You can look up "five senses exercise" online, and it will come up very quickly. It's basically to help people focus on the present moment. Do not be worried about what's going to happen in the future or have regrets about what happened in the past. Simply be present. It's a very simple exercise. I say to folks, "I'd like you right now to focus on five things that you can see." I'll give a few moments for that, and then I'll ask for four things they can hear, three things they can touch, two things they can smell, and one thing

they can taste. When people focus on their senses they almost automatically draw themselves into the present, and it becomes very relaxing for them. That's the easiest and most basic example of mindfulness that I recommend, the five senses exercise. The other thing that I'll just mention very briefly is that I'm a big lover of nature and just the ability to even look out the window and watch the birds at the birdbath or just take a walk down the block and look at the trees, or if you're so inclined, to identify the trees and see where the trees are and the seasons. Are they budding? Are they leafing out? Are they turning different colors at this time of year? Again, that focus on nature is a way of bringing oneself into the present, and it is a very beneficial way of spending time. I think it's a very important way of caring for oneself.

Just the most basic format for breathing exercises is to breathe into your gut. You don't want to breathe in your shoulders. You know, your shoulders go up and down, and that's very shallow breathing, but when you breathe in your belly you get a much deeper breath, and that has a much better physiological effect. Really try to focus on one thing as you're breathing, and that can be very hard because the mind naturally jumps around from topic to topic. What I often do is try to come up with a relaxing visual image. Sometimes I have people imagine they're lying on the beach, and while they're imagining lying on the beach just breathing slowly and steadily, and that tends to put them in a more restful state of mind. So there are many, many ways of doing mindful breathing, but that's one.

Katie: Felicia, one of the questions is specifically related to feeling guilt when asking for help from friends or family.

Felicia: That's a great question. I think it couldn't hurt to seek some support around that through a therapist and to practice role playing asking for help. I think it's also calling on your assertive communication style and really believing that you need this help and why you need the help. Again, I think that sometimes

caregivers don't know how to ask for help, and their ask is broad. I think that people will be more responsive if the ask is specific, so it's really believing that you need help and being able to express why you need help. Asking in a way that is specific, I think, is a way to get the support that you need.

Barry: If I could offer a quick example of that. I worked with a caregiver years ago who had an index box with index cards, and when someone said, "Let me know what I can do to help," she would open the box of index cards and say, "Pick a card." Every card had something very specific written on it like mowing the lawn or picking up groceries or going to the drugstore. It was giving people choices, but just as you said, Felicia, the task is very specific, which will increase your chances of getting a positive response.

Katie: There's a really important question here about specifically discussing the issues facing caregivers who are not spouses, but adult children of their loved ones living with dementia. There are really two issues: 1) what if that relationship is imperfect; and then, 2) balancing being a sandwich generation and caregiving and parenting at the same time.

Felicia: I would say that the imperfect relationship is a particularly challenging one that I've seen people really struggle with, and that's where therapy really comes into play. It's working with somebody to process what happened in the past. You know, when a parent and a child have a complicated relationship, the dementia diagnosis kind of takes away the ability to repair that relationship over time, so it's a lost opportunity for the adult child—to have the opportunity to process that with a therapist so that they can come to a place of forgiving the parent in order to support them in their illness. I think that's going to be critical.

Barry: Yes. And then in regards to the sandwich generation, which is a big topic unto itself, I would just say that all of us have multiple family roles that we have to attend to, and we can't put all of our time

and energy into one of those roles be it a caregiver, a spouse, or a parent to our children. Somehow we have to figure out ways. We can't clone ourselves unfortunately, and we have to divide our time up in a way that is fair to everybody involved, including ourselves, so we can accept that we have limits as human beings and we're not going to be able to be the perfect parent, perfect caregiver, and perfect spouse all at the same time. Compromises are going to be made. So that helps reduce the self-criticism that sometimes makes sandwich caregiving so difficult. I think when people think it through and come up with a plan and fine-tune that plan over time, that's really all we can ask anybody to do, to do the best that they can.

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