

Live Well Webinar Series:
Living Well with Chronic Pain and Illness with Toni Bernhard
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Davis Phinney Foundation

Melani Dizon (Director of Education and Research, Davis Phinney Foundation):
Oh, there's everybody. I am so sorry. Okay. Everybody's coming on now. I am really, really, really sorry. This was a glitch on my end, and I apologize. And thank you for hanging in there. I knew we had like 1500 people registered for this and there was one person on, so I had made a mistake. So, thank you for joining us. And Toni is going to be here any second. Yay. She's here. Okay. Working. And everybody is on right now. Okay. excellent. Perfect. So, for those of you, actually, no one was listening. I'm going to start over as if it never happened. Welcome to "Living Well with Chronic Pain and Illness" with Toni Bernhard. I'm really excited to be here today to talk about her story and all of the actions that she has taken to live well. I'm going to get started. I'm just gonna make sure that I do a couple of housekeeping items. I turned on the live transcript for those of you who like to see the words on the page. Great. You have it up there. If you do not like it, you can click the little arrow and then say, "hide subtitle" and it won't show up anymore.

If you look at the top right corner of your screen, you'll see something that says "view" and you can click either speaker view or gallery view. If you click speaker view, then I will be the only person on your screen right now, if you pick gallery view, you'll get to see both of us, which tends to be nice for a conversation that we're going to have today. The other thing is, if you look on the bottom of your screen and you say "chat," click the chat a little box on the right-hand side will pop up. I would love it right now if you want to say hello and tell us where you're from. And then we can know for sure that not only am I seeing numbers, but there actually are people here to say hello. Thank you from rural Oregon, Santa Rosa, Minnesota, Mary, from Detroit Anchorage, Alaska. Hello, Wayne. Oh, so good to see you here from Denver and Albany Spokane, Maryland, Austin, Texas. Awesome.

Thank you all so much for joining us and thank you for hanging in with me for those six minutes of what is going on. So, we're here. So, if you have questions throughout the day, please just put the question in the chat. If you do not want everybody to see the question, feel free to click the little arrow and then click just "panelists." And then just Toni and I and Leigh, of course, who's our magic person in the background will see it. If you want everybody to see it, you can just pick "all panelists and attendees" and everyone will be able to see your question. Again, totally up to you.

Okay, so I'm going to introduce Toni. So, Toni was a law professor for 22 years at the University of California Davis and served six as the law school's dean of students until she was forced to retire due to chronic illness. Faced with learning to live a new life,

Toni began to write books to help others do the same. She's the author of "How to be sick: A Buddhist inspired guide for the chronically ill and their caregivers," "How to Wake Up: A Buddhist inspired guide to navigating joy and sorrow," "How to Live Well with Chronic Pain and Illness: A mindful guide," which we'll be talking about today and "How to be Sick: Your pocket companion." You can learn more about Toni from tonibernhard.com and we will be sure to put that in the chat box for you as well as all the other links that we will provide.

I also want to give a shout out to professor Garrett McAuliffe, professor of counselor education at Old Dominion University in Norfolk. He's the one who introduced me to your work and to your book and all of these things. So, I'm really excited and grateful to Garrett for letting me know about this. Okay. And also, if you are here today or you registered and you have to leave early, don't worry. We will have the recording of the audio, the video, and we'll have a transcript. So, no need to worry about that. And Leigh is in the background and she is going to be putting up any links that we talk about today. Don't worry if you don't write them down or you don't have them, we will make sure that we send them in the chat or actually in the email. Okay. Toni. So, can you tell us a little bit about your life before your diagnosis? What was life like? And then what was your diagnosis story? What happened?

Toni Bernhard (Author, Former Law Professor & Dean, University of California, Davis): Before I got sick, I was in a wonderful place, because I had a couple years before I left the Dean's office where I was the dean of students for six years, then gone back to teaching and anybody here, who's been a teacher and then gone into administration and then gone back to teaching, well, understand how much more you appreciate being a teacher. And so, I was happily back in the classroom and my husband and I, in May of 2001, so it'll be 20 years in May, took a trip to Paris, which is unusual for us. We're not, I live in California and Hawaii was our big destination. We went to Paris and on the second day there, I felt sick, and I thought, "oh it must just be jet lag" because even today, when I describe how I feel, I sometimes say to people, you know how you feel when you're just incredibly jet lagged? Well, that's one of the ways I feel all the time. But it became clear after another day that I had some kind of viral infection because I had all those symptoms.

It's a little bit daunting given what's happening now with the pandemic, because my history is not unlike people who are being called long haulers, although we hope that that long haul is not gonna last very long. I had all the symptoms of a viral infection, you know, the sore throat, the temperature, just like the flu. And I appeared to get better. I went to a doctor in Paris, and she said, "I don't think it's bacterial, but I'm going to give you antibiotics anyway." And I appeared to get better. We came home and then I had a relapse, and that relapse has lasted almost 20 years. So, the acute symptoms have gone away. I don't have a sore throat or a fever. I often call it the flu without the fever. If you think about when you have the flu, how you, your head feels stuffed, you might have headache and it's hard to be away from your bed for very long because your body just says, that's it, lie down.

I was a teacher at the law school on campus here at UC Davis, I'm in Davis. And as the semester approached, I talked to the Dean and we decided that I should take a semester's leave. I was too sick. And so, that fall of 2001 began my search for a diagnosis. And my, I have a wonderful primary care doctor. He sent me to specialist after specialist, and it really was a question of finding out what I didn't have. So, I had MRIs and CT scans and a lot of every test you can imagine and saw maybe a dozen specialists and the diagnosis was that somehow this virus had compromised my immune system and that my immune system was reading me as sick and doing all the things you want your immune system to do when you're sick, put up a fight and it's that fight that makes you feel ill. It's not the actual virus.

So, to put a name on this illness 20 years ago, they called it chronic fatigue syndrome because they didn't know what else to call it. Today, the preferred name is myalgic encephalomyelitis, in short, MCFS. But from 20 years of meeting other people with this diagnosis, I don't believe it's one illness, because we're sick in many different ways. And there are people who are less sick than I am, who can travel. I can't travel. And there are people who are worse off than I am. They cannot get out of bed. So, at the time I got sick, I will kind of try to transition to my books, I guess. At the time I got sick, I had been a practicing Buddhist for 10 years. I don't practice Buddhism as a religion, but as a practical path. The Buddha was not a God. He was just a person who had a lot of good ideas. And I think the Dalai Lama called him a great psychologist.

But when I became sick, I had this very disciplined Buddhist practice. I would go on retreats. I would meditate twice a day and I just put it all aside because all my focus was on what's wrong with me that I can't get better. And I was pretty mean to myself as if this were some defect in my character. I would go to bed and just order myself to wake up well, and part of that was because everyone around me expected me to get better. My family was wonderful. Colleagues would say things like, and with the best of intentions, you know, are you better yet? Because who doesn't recover from a virus. And so, those first years after I, what I like to say, traded the classroom for the bedroom, were pretty dark and full of self-blame, full of an identity crisis. If I wasn't a law professor who was I? I was nobody. I was no good.

And slowly but surely, I let the Buddhist teachings back into my life. And I started writing. And that's kind of the short version of how I became a writer of books on chronic illness. Although that book you mentioned, "How to Wake Up," it's an introduction to Buddhism. I couldn't resist writing up my own understanding of this path. There's a lot about chronic illness in the book because I always tell anecdotes, so that's how I came to be where I am right now, sitting on the bed, author of a few books.

Melani Dizon:

Well, I can't help but notice the parallels in there for people with Parkinson's. So many people will say like, "What is the one thing? What's the one thing I can do?" And really the people that are, you know, the absolute experts in this field, are like, Parkinson's, isn't one disease. It is many. And it's as many as there are people who have it, cause some people, you don't even know they have it and they're walking around, and they

can travel, and they can do all of these things and some people can't. And so, I think that that part's really interesting along with the part that you talked about in terms of when are you going to get better? A lot of our people with Parkinson's will hear from people, "Well, you look great. You must be doing great," and it's hard for them because they understand that people want them to have that positive attitude, right? Like what do you do with that? You're like, well, I am, but you know I'm never going to be better. This is a progressive disease. I'm not getting rid of it. Yeah. So that's tough.

Toni Bernhard:

Well, that is really tough. You know, when people would say to me and they still say it to me 20 years later, they say, "Well, you look great." And when I first got sick, I was so angry about what had happened to me that I wanted to shoot back, and I think I did a few times, "Well, I don't feel great," you know, that kind of rather rude reply. And I came to see that people are just trying to be nice when they say you look great. The people in my life who I'm closest to, they never say that to me because they may be thinking, "Well, you look good today." And maybe I wouldn't even mind if they said it, but they understand that I never feel well. I don't have the ups and downs that some people with this diagnosis have.

But I learned that people are trying to be nice. And so, when someone says, I look great, if it's in a setting where we're just moving on, like on a zoom meeting, I'll just say thank you and let it go. If someone wants to know more, I let them ask. And so, I'll say, well, thank you. And then sometimes someone will say, well, "Do you feel great?" And that is an opening. So, I kind of take my cue from other people about how much to share. When I was first sick, I think I wrote about this in my first book, "How to be Sick," I overshared, you know, this was before texting and I would see a specialist and I would come home and I would write an email that was like, if it were printed out, three pages long and send it to my two kids who have families of their own and my best friends. And I learned that it's better to ask them about their life and see how they're doing. And if they want to know about me, however much they want to know about me, I'm willing to share. So, it's a tough one being told, "But you look great," or "Are you better yet?" It's especially hard for young people because people in their twenties can get Parkinson's and people will say, "Well, you're too young to have Parkinson's."

So there's just one thing I've come to realize is that our culture does a terrible job of preparing us for the fact that illness and pain, they come with the human condition and it can happen to people, it can come and go, or it can happen and be chronic at any age, and what we get instead are, you know, television ads that say, if you eat this food, you know, you'll be super person and never get sick and that kind of thing. And so, a lot of people aren't prepared for life. And when I think back on how I was before I became chronically ill, I didn't realize, after I was sick, I met a staff, well, I already knew this staff person at the law school, and she shared with me that I really think it was Parkinson's actually, and she was in her thirties, and she said, I come to work in pain every day. And she was in the IT division and had come to my office several times and worked on my computer. Never said anything. I had no idea. And so, it's just something that I wish people understood that the way you look is not necessarily the way you feel.

Melani Dizon:

Yeah. I think that that visibility piece is really hard for people. If they can't see the problem, they have a hard time understanding it. And I think that pain is one of those things for people that they all say that once they start to feel chronic pain, they're like, oh, this is what people were talking about because you can't imagine that someone can walk around, go about their day and be in pain. And you realize when, when it's you, you kind of have to walk around your life and not wear it on your sleeve all the time. So, it's really difficult. Those invisible illnesses are tough. So, talking about the communication piece, how, and when did you communicate with your family? Like your kids, I mean, obviously your husband was with you and then the broader community.

Toni Bernhard:

Well, it came on slowly. It's almost as if the experience for them was the same as the experience for me. First of all, waiting for me to get better. We just all assumed, well, okay. So, it's been a month. We'll wait two months. Oh, it's been two months. We'll wait three. It wasn't until I hit the six-month period that we began to think, maybe this is chronic, and I was really fortunate because my children and my husband, they just, it makes me want to cry, they just believed me from the start. They never questioned. And I've had people write to me, one woman who actually has the same diagnosis I have, whose mother, calls her and says, well, "Just get up and do, do some things. Get off the couch." And she has to spend most of her day on the couch.

Part of my illness is this orthostatic intolerance where when I stand up and move around, it manifests in different ways, for me, my heartbeat goes way up. And so, if I just go on a regular walk, my heartbeat is at 120, and it's not that it's dangerous, but it's extremely fatiguing. And so, some people just can't get up. And then I've had people say that others have said to them, if you were this sick, you'd be in the hospital. And I'm sure there's some people listening who've had those kinds of things said to them, or why don't you and your husband move to another city? It must be you know... And then of course there are people who think you're a malingerer, that you really, that it's all in your head.

And the people who are around me all the time and these days with the pandemic, that's pretty much my husband, but before the pandemic, the people who were around me got it, because they could see, like, after we would visit maybe for an hour, one of my kids would say, "Mom, you're wilting," because they could see it, but other people don't see it. And one of the consequences that I'm sure will resonate with some people is that a lot of my friends went missing. They just stopped being in contact, and I think there's lots of reasons for that. One is that you become unreliable. So, you make a lunch date and that morning you can barely move you're in so much pain, and you have to cancel. And so, I have one friend who's stuck with me all these 20 years because that doesn't bother her, but there are others who it bothers.

And then I think the larger number are people who are averse to illness. It scares them. It reminds perhaps of their own mortality, but it also reminds them that this could

happen to them. And they just don't want to be around someone who isn't well, what I think is important for people to understand is that what I went through this, there was so much bitterness and even hatred at times, for people who stopped being in contact, and then one day I realized that this was about them, not me. And if you said to them, "Do you wish Toni well? Do you want her to get well?" they would have said yes. And so that was a beautiful day in my life. It was the day I stopped feeling bitter about friends who dropped away. And again, this goes to the fact that people are not adequately prepared for the realities of the human condition.

Melani Dizon:

Yeah. Right. Thank you for that. In your book you talk about the "not to do list" and the "want monster." Can you talk a little bit about those two?

Toni Bernhard:

Well, the "not to do list" was something that just came to me one day because before I got sick, I lived by the to-do list. I was a list-maker and I actually still am, you know, I have a sticky here, "Tuesday. Parkinson's night." But I realized that I really wasn't taking good care of myself physically or mentally, because I wasn't focusing on things that I really shouldn't be doing now that my life had what I call it is, and I talk about it in "the green book, How to Live Well," I talk about my life being turned upside down because that's how I felt. And if you're going to turn it a to do list upside down, it becomes a not to do list, and I really enjoyed writing that chapter because I thought of things, some are really obvious, but we tend to ignore even the obvious things. I can't remember exactly how I worded it, but you know, when your body says to stop doing something, find a way to stop doing it.

I have a tendency to, still 20 years later, ignore what my body's saying, but if I actually stop and stop whatever I'm doing, and just take three breaths and pay attention to the physical sensations in my body, Whoa. Then I can hear what my body is saying. So that's one not to do. Don't keep on trucking. Now I recognize that sometimes people don't have a choice, but maybe anticipate that and find some work arounds. So that's one. And then another is something that I talked on briefly, which is, do not blame yourself in any way, shape or form for what's happened. You know I think that people read my books and write to me and the number one thing is people saying, "Until I read your books, I had never shown compassion to myself. I didn't have trouble being kind to others." How do I define compassion? The easiest way? It's simply being nice, being kind. And people would say, "Well, I always am that way with others, but not with myself." Now I'm remembering what I wrote, that's good, cause it was five years ago. I was joking with Mel about how you can forget what you wrote about. And the example I gave was you go out and you stay out way too long with your friends, longer than your illness will comfortably allow. And so, what happens the next day? You say, you stupid idiot. The way we talk to ourselves, it's just amazing. You know, use stupid idiot. Why didn't you come home sooner? You deserve the way you feel today.

So, what I suggest people do is think about what they'd say to a friend who called them up and said, I'm such a stupid idiot. I yada, yada, yada... They would try to comfort them

and support them and say, no, it's fun to be with your friends. It's hard to come home. And what I tell people to do is then say that to themselves. It's really hard though, because I feel the effects of yesterday. I stayed out too long, but it was just irresistible. That's being nice and kind to yourself. So, one of the, not to do things is to not blame yourself in any way, shape or form. And I want to say that it doesn't mean you can't learn from your mistakes. I'm not saying just be blind about things you could do better.

In that example, say, you know, next time, maybe when I arrive, I'm going to say, "You know, I probably am going to have to leave before you're done," or something like that. So, learn, and then let it go. Yeah, because I can't think of a day that goes by that I don't make a mistake of some kind. So, learn from and let it go and always be kind yourself. So that's how this not to do list came about.

The want monster was something that comes actually out of my Buddhist background where the Buddha talks a lot about how we get trapped in desires that result in a lot of emotional and mental suffering. And it's easy to get that because think about all the things you want right now, just think about all the things you want. Now which of those things are you likely to get? So, you know, sometimes we get what we want, but a lot of the time we don't. And I have a friend, Sandy, who is a Buddhist. These are people I haven't been able to see in a long time now. And when her kids were little, she would take them to someplace like Toys R Us and they would just go, "I want this mom, I want this mom." And she taught them that that was just their want monster. And that the want monster was always going to appear. And you didn't have to always feed it because, and now I'm getting off of what Sandy said, but we get ourselves in this place where we think if only, so for me, it's, if only I could wake up, not sick tomorrow, I'd be happy for the rest of my life.

I don't think so! I mean, no matter how healthy you are, you've got problems of one kind or another. You may have children who are struggling. My son, who's 13 and a half now, and this distance learning, it's not ideal for her. At 13 and a half you want to be with your friends. You don't want to be sitting on a computer like this. You want to be in person and, you know, young people these days, they're wonderfully physical too. There's a lot of hugging. And so, the want monster, the best way to handle the want monster, it's really a mindfulness practice, it's just to recognize it's present. Oh, there I am wanting not to be sick tomorrow. Oh, maybe it'll happen. I still hope it'll happen. Maybe it'll happen. Maybe it won't, but I'm not gonna live obsessed with it coming true. Because most of our wants don't materialize. So that's where the want monster comes in.

Melani Dizon:

Okay. So, I know mindfulness is a big part of your life. Can you talk a little bit about how you define it? You were very specific about it in your book, and then also, what does it look like to be mindful while living with pain? A lot of people with Parkinson's, they just, they're in pain. So, what does it doesn't look like?

Toni Bernhard:

Yeah, well, I have pretty bad osteoarthritis, you know, just because I'm chronically ill doesn't mean other things don't come down the road. And I'm in a lot of pain today and my shoulders, anyone who has arthritis in their shoulders, osteoarthritis, knows that it actually manifests in your arms. Like if you try to reach for something or reach behind you. So, let me go back to mindfulness. There are lots of ways to define it. I call it caring attention to the present moment. And you could say remembering to pay caring attention to the present moment, because there are so many benefits of mindfulness, but you have to remember to bring your attention to what's happening right now. And the reason I use the word caring is that the example I give is, you know, if you're sitting on a park bench and you're mindfully paying attention, I love the expression from this Buddhist monk is a way to think about the present moment is to say to yourself, what is being known now? What is being known now? And of course, then, you have to remember to do that, and everyone can come up with a phrase that is helpful to them. But if you're on a park bench and you're doing that and you see some kid who's about to run out into the street, I hope you'll get up, stop the kid and not say, "Ah, I'm practicing mindfulness." So that is why I add the word caring because it's not a selfish practice. And so, bringing your attention to the present moment, I have a lot of different techniques for doing that. One that I really love is actually not in this book, because after I wrote the book, it's one that my husband developed while he was teaching mindfulness in Folsom prison.

We live about 45 minutes from Folsom prison. And he's a Buddhist chaplain, which basically gains him entry to the prison. And there were a certain number of inmates he was allowed to work with along with the therapist in the room. And he started to teach them how to meditate, mindful men, that meditation following your breath. And one of the guys said "I can't do that. My cell is tiny, and I have a bunk mate and he's always got the TV on." And so, my husband came up with this idea of, he calls it the three-breath trip, I call it three breath practice, and it's actually in that little pocket guide, which is my latest and last book. Three breath practice where you just stop what you're doing and take three conscious breaths. And all that means is you're paying attention to the physical sensation of the breath coming in and going out of the body.

And one of the prisoners said to him, "I do it during TV ads. It's wonderful because it brings me to the present." And when you're in the present, there are a lot of benefits. One is that you're not ruminating about stuff in the past, that I was talking about, the stuff you wish you'd done better. And for me, the big one is that I'm not worrying about the future. I am a worrier, where I couldn't worry about my kids, give me anything, I'll worry about it. But you know, mindfulness practice has allowed me to say, "Oh, there I am worrying again." And then bring my attention to what is being known right now to the present moment. One of the things I like to say is, to me, the greatest benefit of mindfulness practice is not being mindful, although this can be nice too, is the other senses, sounds and sights, that are present right now, but being aware of what's going on in your mind. And as one of my first teachers, Jack Kornfield used to say, "The mind has no shame."

It's very helpful. And if I can move from that into chronic pain, the first thing I want to say is, can mindfulness help with chronic pain? My answer is it helps a lot of people. It might not help everybody. It's not a magic pill. I'm not opposed to pain medication, as long as it's taken, you know, with an understanding doctor and in a smart way, but mindfulness can be helpful in several ways. When you're in pain, there's actually three things going on. And I write about this in one of my chapters. The first is just the pain itself. And the second and third are both in the mind. The second is your reaction to the pain. It could be aversion. It could be frustration; it could be anger. It could be compassion. So, there's the pain.

And then there's this mental reaction. And then the third are the stressful stories that we then spin off of our reactions. So, this morning I'm having a lot of trouble with pain in my shoulder, which means it's hard to reach things with my arms. Then there's the reaction, which is, it's been different things. Sadness, a little frustration, but the stories are where the real mental suffering is. The stories are things like I'm going to be in pain like this every day for the rest of my life. No one is going to want to hang out with me because I'm in pain and I can't stay. We just spin these stories that we then believe without even questioning their validity. So, the way mindfulness can help with chronic pain is to help you be aware of how you're making things worse.

There's the basic pain, and there's even ways to work with that, which I could get into if you wanted to, but there's the basic pain, but then there's the way we make it worse by spinning tales, by fantasizing about how bad our life is going to be. I'll never be happy again. I'll always be in pain. And when you become aware that you're doing that, you can stop. I have several practices. One is this three-breath practice, another one, I just call drop it. You know, just drop it. Then bring your attention to what's going on in the moment for you right now. And, you know, maybe you have to do that again and again, but that's fine. So, mindfulness can be very helpful with pain. It can help you see the ways in which you're making the physical sensation worse with your scary stories.

Melani Dizon:

Yeah, absolutely. So, I want to get to some questions from the audience, but I just want to ask one more. One of the chapters that I found especially interesting was the one around labeling and mislabeling medical conditions. So, can you talk a little bit about the power of language when it comes to talking about a chronic illness?

Toni Bernhard:

Yeah. I happen to suffer from not just this illness that is wrongfully called chronic fatigue syndrome. Everyone gets fatigued and a good night's sleep, well maybe you need two, but a good night's sleep will cure that, this is an illness. And the other that I write about is restless legs syndrome. And I happened to hear a late-night comedian, make some nasty comment about, "Oh your legs are restless, poor you," that kind of thing. So, I have suffered from this for 25 years and anyone who's listening, who has it, knows this is not restlessness in your legs. This is a kind of painful, creepy, crawly, you have to keep moving in order to try to get it to go away. And it's not just in your legs. I get it in my hands. And interestingly enough, I have gotten it mostly under control only in the

past 10 years with a low dose Parkinson's medication. There are now two approved by the FDA, Mirapex® and Requip®, for use in a very low dose with people with restless leg syndrome, it's a neurological disorder.

And so, what happens is people who have conditions that are mislabeled like that, or that are poorly labeled are, they're just not taken seriously. And so, it's a real problem. I don't know if this happens with Parkinson's, I would think not, but it certainly happens with it happens with rheumatoid arthritis, which is actually an autoimmune disorder. It shouldn't be called arthritis and a woman in her twenties wrote to me and said, "People say to me, you're too young to have arthritis. You're too young to be in pain." Well, this is an auto-immune illness that they sometimes give chemotherapy to people, that's how, like other auto-immune illnesses. So, I'm not sure what the future will be with chronic fatigue syndrome. There is this very strong movement to change the name, but yes, labeling can affect how people treat you and how doctors treat you.

Melani Dizon:

Okay. So, Wayne asks, how does war language and metaphors affect you? You know, fight, battle, warrior, all of those things, are those helpful for you or are they not helpful?

Toni Bernhard:

They're not helpful for me. And I'm going to say, I want to recognize that they are helpful for other people. I really tuned into this. People who've read this green book will know there's an afterward. Six years ago, I had a bout with breast cancer, and I was very fortunate. I had a lump removed. I had radiation, I didn't even need chemo and it's six years later and I'm doing fine. But one of the things that I tuned into, especially since I'm stuck at home with the illness, I went online. And because there are hundreds of support groups for women with breast cancer, and some of them are, well they are angry about it, and one of the favorite expressions is F blank, blank, blank cancer. And one day when I was in a support group and I read other people then saying, yeah, yeah! I thought, you know, when I say that to my body, when I say that to my breasts, if you'll excuse that, I'm saying that to my body and my body is doing the best it can. My body hasn't betrayed me, things happen. And boy, am I fortunate that I have good medical insurance. I don't have anything to complain about. And so, for me, that anger doesn't work, it makes me feel bad. It makes things worse. So that said, it may be helpful to other people. I don't know. It's not helpful to me.

Melani Dizon:

Okay. Somebody said, when your partner or friends are well and want to do stuff, travel, go camping, dinners with friends in the evening and that kind of thing, how do you deal with that? I mean, you know, out of COVID, what did 20 years look like for you when you were managing that?

Toni Bernhard:

Well, I've had my heart broken many times over my inability to do things. So, I'll give two examples and then I'll tell you what I do about it. It's actually a Buddhist practice. One example is that my husband, maybe five years ago, went to LA where one of our

children lives with a grandchild. And he took her to Fiddler on the Roof. Fiddler on the Roof is my family's story, except they didn't live in the country. They lived in Odessa in the Ukraine. And that story of coming over to this country because of the pogroms against Jews, that's my family story. That was for me to take our granddaughter to not my husband. He's not even Jewish. The other example was even harder. One day, again maybe three, this was shorter, so maybe four years ago, our whole family, that's my son, daughter, their spouses, and our two grandchildren. And my husband met up at Disneyland in Southern California and spent the day at Disneyland. And I couldn't go.

So, what do I do about that? Well, what that tends to give rise to is envy and anger. And what I realized was that, again, those kinds of mental reactions and the mindfulness practice helps you see that your mind is doing this. How many times have you been angry and not even realized it? So, mindfulness helps you see things sooner. And there is a Buddhist practice that really has no English translation it's called *mudita*. But what it means is, sometimes it's called empathetic joy, it's this ability to find joy in other people's joy; to feel joyful for other people when they're having a good time, even though you're stuck at home. And when I first started practicing this, I tell you, it felt fake.

But what I would say to people is keep doing it, even though it feels fake. And with both Fiddler on the Roof and the Disneyland trip, I was able to feel happy for them. And the true blessing was when I had this feeling that they were having a good time for me. Because they didn't want me to be unhappy and I wanted them to be there. So, in some sense, you could say, what's the problem? Well, of course the problem is our minds, but you know, we work with that. So, think about feeling joyful for others. And this is happening to me now because with the pandemic, things are starting to open up. And I have a friend who is in California going to fly to Portland to see her daughter because she's had the vaccination and, you know, I'm still going to be stuck at home, so my first thought was "fly to Portland!" and then "I'm really happy for her. She's going to get to see her daughter after a year." So, it's an antidote for anger and envy.

Melani Dizon:

Right. Good. Well, I really appreciate you taking the time. I loved hearing about... let's see, (reading from the chat), in the pocket guide, Toni mentioned when she was maybe talking about mindfulness, three breaths, a separate publication, or part of her books, that's part of the pocket guide, right?

Toni Bernhard:

Just real quickly, the first book I wrote, which is the orange one, I wrote in 2010, and I did a second edition in 2018 before this pocket guide. And so, this three-breath practice is both in the second edition of "How to be Sick," my first book and it's in the pocket guide.

Melani Dizon:

Okay, great. And everybody, we will definitely send you the links to those. So, you will know where to get it.

Toni Bernhard:

My daughter created that website. I gave her the content, but she wrote it.

Melani Dizon:

Oh, nice. Well, thank you so much. It's been, such a pleasure to talk to somebody who is dealing with something other than Parkinson's, but this is a universal issue, this idea of pain and struggle and the things that come up in our life, and these are universal principles that we can share and practice. And I think it's really, really great. And it's been so nice talking to you finally, after reading your books. I've absolutely enjoyed it.

Toni Bernhard:

I've really enjoyed it, Mel.

Melani Dizon:

Thank you. Thank you everybody for being here. Sorry, we got a little bit of a late start. We'll send you all the info soon. Thank you so much. Bye bye.

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