

Head space



Cognitive behavioral therapy can help you manage your pain and fatigue as well as your emotions.

by Vicky Uhland

Imagine if someone constantly told you that your multiple sclerosis made you an unproductive member of society. That your balance issues meant you would be using a wheelchair soon, or your occasional memory lapses would morph into a future with severe cognition issues. Or even that because of your MS, you wouldn't be able to take care of your family.

You'd probably cut that horribly negative person out of your life, right? But imagine if that person was you. Imagine having those kinds of thoughts and not being able to stop.

"I think of those voices in my head as like a neurotic roommate," says Elysa Lanz, a Covington, Washington, resident who was diagnosed with MS in 1989 at age 28. "I think about what I would do if I had a roommate who said those things to me. I would make them leave the house, I'd change the locks and block their number on my phone."

Types of therapy

- CBT: Cognitive behavioral therapy
- ACT: Acceptance and commitment therapy
- MBCT: Mindfulness-based cognitive therapy

Lanz used to be one of the many people with MS who felt victimized by anxious and depressive thoughts about her disease. And after she had a severe exacerbation in 2007 that left her in constant pain and unable to walk without canes, those thoughts escalated.

“I knew that I had to get control over my emotions and pain to be able to continue to live a happy and productive life,” Lanz says. So she signed up for a University of Washington study on cognitive behavioral therapy (CBT) for MS pain management.

Within a few months, Lanz could see changes in her depression, anxiety and pain levels. “I learned to stop catastrophizing and obsessing about my decline and how I was going to take care of my family,” she says. “I learned that beating myself up with thoughts like, ‘Will I not be able to walk tomorrow?’ wasn’t doing any good — and was actually making me feel worse.”

How CBT works for MS

CBT is a widely accepted type of talk therapy that’s been around since the 1950s. It’s based on the idea that how you think, what you feel and how you act are all linked.

“It’s not a Freudian thing where you tell your deepest, darkest secrets,” says Meghan Beier, PhD, a rehabilitation neuropsychologist in Johns Hopkins University’s MS Rehabilitation Research Program. “It’s more of a problem-solving strategy.”

Over the years, CBT has evolved into a menu of different types of intervention strategies and techniques that can be tailored to fit the individual. But the basic tenet remains the same: If you learn how to manage your negative thoughts or behaviors, that helps you feel better.

One of the key concepts behind CBT is to put your thoughts “on trial.” For instance, Beier says, you may be having pain and thinking “I can’t stand this pain.” But is that really true? What’s the evidence for and against that thought?

Once you realize you are indeed withstanding that pain, then you can change your thought to something like: “Yes, it stinks to have pain, but here are the things I can do to help alleviate that,” such as physical therapy and relaxation techniques. The goal is to learn how to identify unproductive thoughts and then change them to help rather than harm you.

A related form of psychotherapy that focuses on thoughts and feelings is acceptance and commitment therapy (ACT). In general, people either tend to ruminate on their thoughts or avoid them, says Ivan Molton, PhD, associate professor in the University of Washington’s Department of Rehabilitation Medicine. But by learning how to accept your negative thoughts and allowing them to pass by without judgment, you can prevent them from causing you harm.

“Notice the thought, write it down, notice how much it occurs,” Molton says. “But don’t engage it. Think of it like a tape — if you wait, the tape will end. The more you engage negative thoughts, the more power they have over you.”

Mindfulness-based cognitive therapy (MBCT) operates along the same lines as ACT. One goal is to recognize that although a thought may be realistic and valid, it's not useful to you, says Dawn Ehde, PhD, a clinical psychologist in the University of Washington Medicine Division of Clinical and Neuropsychology.

"For instance, when people are depressed, they can have thoughts like: 'My MS doesn't allow me to do what I once could,'" she says. "That may be a realistic thought, but it's often unhelpful. It doesn't make you feel better." But if you use CBT techniques, you can turn that thought into a helpful one, like, "Yes, my MS is making me do less, but I can still be a parent; I can still work," Ehde says.

Participate in a CBT study

Dawn Ehde, PhD, a clinical psychologist in the University of Washington Medicine Division of Clinical and Neuropsychology, is enrolling people for a National Multiple Sclerosis Society-funded [study on mindfulness-based CBT training for pain](#).

CBT has been used for people with MS for more than two decades, and research shows it can be effective for the depression and anxiety associated with the disease. There are also studies on CBT's impact on pain management and fatigue. And there's research underway on how CBT can help people cope with the uncertainty of MS.

CBT can be done with a therapist or on your own with books or apps (see the sidebar for suggestions) — although therapists say the DIY version requires self-motivation and may not be effective if you have a high level of distress. Because it's considered a gold standard of psychotherapy, CBT is covered under most types of health insurance with mental health benefits, Molton says.

Studies show that the most effective course of CBT therapy is eight to 16 sessions. Generally, sessions last an hour and are done weekly in person or by phone, with "homework" in between. Molton says a good CBT practitioner will give you a plan for your therapy, including thoughts or behaviors you want to address. Because there are so many forms of CBT, it can be highly individualized. So if you don't see progress after a few sessions, Molton says your therapist should make adjustments that work for you.

Here's how CBT can help you manage common MS symptoms.

Overcoming anxiety and depression

After Alejandro Guadarrama was diagnosed with MS in 2017 at age 42, he barely talked about his disease and only with his wife, mother and brother. "I didn't want to give anyone else the weight of knowing and worrying about my MS," he says. "I started withdrawing from social events and rarely left the house over the weekends." In his mind, he felt like he had a

good handle on things and preferred to fly under the radar.

But about a year later, he underwent a series of stressors. Shortly after having a second daughter, Amalia, he and his family moved from the city to the suburbs of Washington, D.C. The move happened over the December holidays, draining his energy and bringing crippling fatigue with it. The political climate created extra pressure in his job, especially as a pro bono lawyer representing low-income immigrants. And then his 5-year-old daughter, Carlota, was hospitalized for a few weeks in January because of congenital heart complications.

“I realized I had lost my joy in things. It felt like I was just a bystander in my own life,” Guadarrama says. “I could not sleep and my neurologist said I was severely depressed.”

He started taking medication for depression, but it wasn’t effective. So he called four of his friends and told them about his MS and what he was going through. “They rushed to my house and told me they loved me and my family.” That’s when his mind also started telling him that not talking to them about his MS was one of the biggest reasons why he ended up the way he did.

One friend told him about an intensive program for depression at Johns Hopkins. Guadarrama enrolled, and in the spring of 2019, began a two-month course of CBT.

“In my mind, I was convinced that my MS was doing all of this to me,” he says. His breakthrough moment came when he understood that his inability to hold ideas and impaired concentration were signs characteristic of clinical depression. Armed with knowledge, he was able to also self-identify signs of severe anxiety.

CBT showed Guadarrama that his persistent, depressive thoughts were not necessarily true. “I would tell myself that if I forgot something it was due to my MS, and it would just get worse. But there are all kinds of reasons for forgetting something.”



CBT helped Alejandro Guadarrama develop ways to manage his negative thoughts and learn to enjoy life again. Photo courtesy of Alejandro Guadarrama

Still, some thoughts wouldn't go away despite Guadarrama's best attempts at reasoning. That's when he relied on coping skills such as the 5-4-3-2-1 CBT technique. Focus on five things you see, four things you hear, three you feel, two you smell and one you taste. The idea is to change your focus and turn off unwanted thoughts for a few minutes. "With practice, this gives you better control over your thoughts," Beier says.

CBT also helped Guadarrama to put things in perspective and recognize his strengths. "Even when you're at the lowest of lows, you don't lose those strengths," he says. "Believing in that gives me hope that I could get through things."

The program taught Guadarrama to step back and evaluate how his thoughts or feelings influence his decisions. He also learned CBT-related coping strategies for dealing with memory issues.

"With CBT, I learned it doesn't matter what the cause is when I forget something — it's what I do about it," he says. "So now I write down someone's name or my supermarket shopping list rather than trying to remember it. I set an alarm, so I don't miss catching the bus home. That way, I don't forget and then get demoralized or depressed."

The goal of his CBT course, Guadarrama says, was to learn skills that could help him "create good habits and routines that take you out of the situations that make you feel bad, sad or mad. CBT is a part of how I see things today. I like it. It gives me a chance to order my feelings and thoughts."

Coping with anger

In 2013, Kristin Caulfield was 41 years old, had a PhD in nursing, was a Harvard-Macy fellow and was on the faculty tenure track at George Washington University. And then she was diagnosed with MS.

Her main symptoms were cognitive, including reduced processing speed. As her symptoms worsened, they began affecting her job. "I had to retire," Caulfield says. "And I was so angry and resentful, and then I was diagnosed with depression. I didn't realize how much of my identity was wrapped up in my job."

For two years, Caulfield focused on what she couldn't do. "The thing I've always been able to depend on is my cognition. I've always been the smart one. So losing it was crippling."



Kristin Caulfield, diagnosed with MS in 2013, says that CBT helped her manage her anger.

Photo courtesy of Kristin Caulfield

Finally, Caulfield realized her life vision was in the past. "I'd always say things like, 'I used to be able to ...' or, 'Before MS ' I call it going through the tunnel." So she decided to see a neuropsychologist, met Beier and began three years' worth of CBT.

One of the first things Beier taught Caulfield was how to stop focusing on what she couldn't do. "We came up with a visualization of a dark cloud over me, and how it always blows away and sunshine comes through," Caulfield says. Then they designed workarounds so the cloud didn't appear as often.

"The goal is to not suppress your anger, but limit it," Beier says. "Give yourself worry time or

anger time — for instance, say, ‘I’ll let myself think about this for five minutes.’ Or tell yourself: ‘Now’s not the time to think about this. I’ll think about it at 5 p.m.’ That allows you to have thoughts but not ruin your day.”

They also worked on practical tips to deal with cognitive challenges, like setting alarms to pick up the kids from school. Caulfield also uses hourly alarms to help prioritize things that are good for her, like rest and exercise. And they instituted a “50% rule.”

“I was always so disappointed I couldn’t get things done,” Caulfield says. “So each day, I make a list of three to five things I want to accomplish. If I get 50% of that done, it’s a good day.”

Now, Caulfield feels at peace with her new job: taking care of herself and her family in their new home in Hawaii. “It’s taken me a long time to accept that,” she says. “It’s a slow process — there’s no magic fix. It requires patient engagement through CBT.”

Handling pain, fatigue and sleep issues

After her 2007 exacerbation that left her with neurological pain, neuropathy in her hands and feet, and severe spasms, Lanz found that CBT helped with her depression and anxiety. And that in turn helped with her pain. “My perception of my pain levels dropped because I wasn’t focusing on it so much,” she says.

Ehde, who teaches eight-session CBT pain-management courses like the one Lanz took, says the key is educating people about how their thoughts, behaviors and emotions affect their pain, and vice versa.

“Pain is not a sensory phenomenon,” Ehde says. “For instance, say your arm hurts, and you think, ‘Oh no, here I go again. This pain is just going to get worse.’” That can trigger the “fight or flight” response to stress, in which your muscles tense up, your blood pressure rises and you become anxious. And that in turn can create more pain and suffering. But if you can alleviate that stressful thinking, you can change how your brain processes pain in ways that can reduce pain and suffering, Ehde says.

Ehde is currently enrolling people for a National Multiple Sclerosis Society-funded study on MBCT training for pain (for more information, visit ntlms.org/paintrial). The theory is that MBCT training can help you notice the pain, and then notice the reactions you have to that pain that are helpful or nonhelpful. Then you can disengage from the unhelpful reactions and respond with self-compassion. And that helps you relax, which lessens the pain.

Lanz learned to focus on what she could do — cook dinner, walk around the cul-de-sac — rather than what she couldn’t. She also learned to visually flush down the toilet worries like, “What if I can never walk again?”

“When I was out walking, I would look at the trees and say internally: ‘Stop and find something beautiful to think about. Be in the moment and don’t worry about the future,’”

Lanz says.

Within a few months of practicing these types of CBT techniques, Lanz says she had alleviated most of her depression and anxiety about her pain. And within a year, she could automatically take control of any negative thoughts.



Elysa Lanz, diagnosed with MS in 1989, gained control over her emotions thanks to cognitive behavioral therapy. Photo courtesy of Elysa Lanz

The same CBT exercises that deal with pain can also help with fatigue or sleeplessness. “By removing unhelpful thoughts, you can trigger the parasympathetic nervous system that brings the body to relaxation,” Ehde says. “And relaxation can improve fatigue.”

Lanz says this is particularly helpful when she wakes up in the middle of the night worrying about something and can’t get back to sleep.

“You can’t just take away the thought — you have to add something back in to fill the void, something that makes you feel calm,” Lanz says. “I say an affirmation over and over again. Or, something like a prayer, which I say one time: ‘Peace to my mind; let all my thoughts be still.’ It really works. It’s like putting your fingers in your ears and saying, ‘La la la la.’”

Dealing with the uncertainty of MS

It wasn’t until the third time a doctor told her she had MS that Robyn Roberts finally accepted her diagnosis. By then, she was having cognitive symptoms like not being able to find the right words or forgetting where she parked her car. She envisioned a future where she

couldn't work at her job as an insurance counselor in Lexington Park, Maryland, and would become a burden on society and her family.

And then her worst fears came true.



Robyn Roberts, diagnosed with MS in 2013, benefited from acceptance and commitment therapy (ACT). Photo courtesy of Robyn Roberts

In 2015, two years after Roberts finally accepted her diagnosis, her doctor suggested that because of her cognitive issues and chronic fatigue, she should quit her job. "My work was my life," says Roberts, who was only 34 at the time. "Without it, I felt like I was worthless."

Traditional CBT is based on examining negative or obsessive thoughts and figuring out whether they're valid. Often, they're not. But for people with MS, those thoughts may very well turn out to be true in the future.

For instance, the uncertainty of MS means someday you might not be able to walk without assistance or remember a friend's name. That's where more recent approaches to CBT, like ACT, can be useful.

"ACT works especially well with thoughts you can't prove or disprove," Molton says. "Your brain is trying to warn you of something bad in your future, but you need to examine whether that's useful information; whether you can act on it. If not, you may be better off just gently accepting the presence of that thought without trying to change it."

Molton is conducting a National MS Society-funded study on whether a form of CBT can help people who are newly diagnosed with MS cope with the uncertainty of the disease. He says the key when you have these types of thoughts is to compassionately accept them. “Thank your brain for warning you, acknowledge that you’re going to worry about the future and uncertainty of your disease, and then just let the thought pass.”

When fears about her disease get stuck in her mind, Roberts uses CBT-based coping skills that Beier taught her. “I’ve learned how to literally envision a stop sign and then take five deep breaths. It helps me stop when my brain won’t shut off.”

Roberts has also found that CBT helps her family. “No one’s walking on eggshells around me now that I can look at things from different angles,” she says. “I thought maybe my husband and son would be happier if I just left. I assumed that my husband was thinking the same way that I was — that I was too needy because of my disease. But then I asked him, and he said that wasn’t true. That made me think about my disease’s effect on my family in a whole new way.”

Roberts knows she can’t control her disease. But she can control how she thinks and feels about it and how she behaves. “CBT gave me a different perspective,” she says. “I think it’s a beneficial but under-recommended tool for people with MS.”

Additional CBT resources

If you’d like to try CBT on your own, psychologists Meghan Beier and Ivan Molton recommend the following books and apps.

Books:

- Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy by Steven C. Hayes (New Harbinger Publications, 2005)
- Solve for Happy: Engineer Your Path to Joy by Mo Gawdat (Gallery Books, 2017)
- The Stress and Mood Management Program for Individuals with Multiple Sclerosis (Oxford Press, 2010)
- Cognitive Therapy for Chronic Pain: A Step-by-Step Guide, Second Edition by Beverly E. Thorn (Guilford Press, 2017)

Apps:

- Woebot (woebot.io): This free CBT app developed by Stanford University psychologists offers daily lessons and check-ins for people with depression or anxiety.
- Curable (curablehealth.com): This online CBT pain psychology program features Clara, a virtual pain coach with lessons and exercises to manage pain. You can try it for free, but then you’ll need to pay anywhere from \$5.99 to \$14.99 a month.

Vicky Uhland is a writer and editor in Lafayette, Colorado.