

Carey Pena:

I'm Carey Pena. According to the Centers for Disease Control, the outbreak of coronavirus, COVID-19, is stressful for many. Fear and anxiety about a disease can be overwhelming and cause strong emotions in adults and children. Coping with stress will make you, the people you care about, and your community stronger.

Carey Pena:

Stress during an infectious disease outbreak can include fear and worry about your own health and the health of your loved ones, changes in sleep or eating patterns, difficulty concentrating, worsening of chronic health problems and mental health conditions, increased use of alcohol, tobacco or other drugs.

Carey Pena:

Today, we will learn how stroke survivors can improve their emotional health during this difficult time. Rachel Scanlan Henry had her stroke in 2003, followed by denial and depression. Eventually, she identified her process of recovery as the five stages of grief: denial, anger, bargaining, depression, and acceptance.

Carey Pena:

Today, she has emerged from her stroke stronger, more joyful, and as a relentless advocate for other stroke survivors. She will share how that emotional journey following her stroke has better equipped her to weather the COVID-19 pandemic. Rachel, thank you very much for being with us.

Rachel Scanlan Henry:

Thank you so much.

Carey Pena:

Rachel, go ahead and please paint the picture of what happened the day that you had your stroke. What has been your lowest point and how have you pushed forward?

Rachel Scanlan Henry:

Thank you so much for having me. It was just another day on April 4th, 2003. I was a school teacher, 30-years-old. I had been having headaches that would crack your head wide open, but nobody thought that headaches in a 30-year-old woman were anything too serious. It was before these signs of FAST: face, arms, speech, time to call 911.

Rachel Scanlan Henry:

Even my primary care physician wasn't that worried. I had a day off from school to go get my thyroid checked. It was a new condition. The nurse logged me in to the office room and took my blood pressure and went out to get the doctor, and while she was gone, I turned really, really hot. I slipped down the side of the wall. I lost 100 percent of my swallow and everything in my body sort of went numb.

Rachel Scanlan Henry:

My doctor came in the room and she knew right away what was happening and I remember her saying stroke. I remember they put me in an ambulance and the ambulance paramedic gave me a suction,

because I couldn't swallow anything. That spit in the back of your face, sorry to be disgusting, was collecting and he offered me this suction and I could breathe again. And then we went downtown with the ambulance sirens flashing and they were for me, it was totally surreal.

Rachel Scanlan Henry:

They took me right into the hospital in the ER. They had made do an MRI and they told me I'd had the stroke. They offered me TPA, which for my stroke didn't seem to be the right option at that time. I remember all of these conversations of doctors and neurologists, and I'm lying there inside of my body thinking, "This can't be me." The stroke was so silencing, everything would numb and quiet and was happening around me, and I was totally in denial of how much every single thing in me and about me had changed at 10:10 AM.

Rachel Scanlan Henry:

They took me out to the ICU and in a couple of days I was on the regular floor, and after that, for my swallow, I went to a nursing home where they had the one person who might be able to get my swallow back. Being 30-years-old in a nursing home on a floor with people who were 50 years older, most of them was very distressing. Nothing in my life made sense anymore. It was this automatic onslaught of why was I alive?

Rachel Scanlan Henry:

I spent a long time giving all the physical things back and adjusting to a lot of physical changes. I don't have any cognitive issues, people with brainstem strokes don't have that, but I have physical things. I don't have [inaudible 00:04:52] cold sensation on the entire right side of my body. I don't feel pain on that side and getting used to that was outstandingly insane.

Rachel Scanlan Henry:

So stroke silences my body. I didn't know how to communicate what I was feeling. I didn't fit in my own life. I couldn't teach. It was horrible and I spent three years honestly hoping that I wouldn't wake up one morning. It was that dark. I didn't fit into where I was and had no idea of what could come after. And one day for some reason I could never tell you. I woke up and the why me why me, why did I have a stroke? Became why not me and why did I have my stroke in my doctor's office where I could be saved receiving that immediate lifesaving care?

Rachel Scanlan Henry:

And what was that meant to do? And in that instant shift of mindset for no reason I can account for, everything changed. And from that day forward, I began practicing just like I teach my students habits that would build towards what I wanted of finding a new normal, of finding a new happiness, of finding new ways to interact, new things I loved. It's a great, very lifted to have gone through this experience and it's a great strength to survive.

Rachel Scanlan Henry:

The dark days were darker than anything and I can relate to any stroke survivor out there. And I have the gift of being able to put words to those feelings, which so many of us have and from so many different stroke-related conditions, can't express, but I can tell you they're dark. But they're not going to last forever and there is a way up and out. I promise you.

Carey Pena:

You've been so incredibly brave about sharing your journey openly through the months. And as we are talking here today on this show, can you talk a little bit more about the feelings that you experienced following your stroke?

Rachel Scanlan Henry:

Helpless, hopeless, ugly, untrustworthy, 100% fear all the time. My body completely betrayed me. People go along through their life sort of taking for granted simple things like breathing, swallowing, walking, whatever it is that we do in our daily lives that we're not grateful for in that moment that are aware of how complex and gifted this. All of that became where I lived and it was totally inhuman for me not to be able to break bread, to be able to eat with my family. So I felt not human and I felt no way of communicating and sharing with others.

Rachel Scanlan Henry:

I felt isolated beyond belief. I didn't know how I was feeling. I thought people were afraid of me like stroke was somehow contagious. It's sort of your worst nightmare to be well and have a life one second and have something catch you so off guard as a stroke does, it's a brain attack. It happens without warning and comes and takes your life and who you think you are from you. And that is terrifying. So living in that amount of fear, leading to the anger, leading to depression and being isolated physically and emotionally, not a good combination.

Carey Pena:

And Rachel, you've talked about how your recovery followed the five stages of grief. How do the stages parallel what you and other stroke survivors and really all of us right now are experiencing during the COVID pandemic?

Rachel Scanlan Henry:

I love that way of looking at it. Thank you. You start off COVID, the pandemic that we're all experiencing now. A couple of days ago, I celebrated my 17th year stroke anniversary and 17 years out from my stroke, and you look back and you think at that total state of denial of having had a stroke and so many people around us were in that stage of denial that the pandemic was really going to get as bad as it is, and affect us as much, and people get angry and that anger is based in fear.

Rachel Scanlan Henry:

It's fear of the unknown. It's fear of a loss of control. It's the bargaining and grabbing at straws. And that's something that stroke survivors have been through. What a gift to know that we never really had that kind of control, that there is a new life to be had. That we can follow doctor and scientist and our church people and whoever our spiritual advisors are to find a way through this. That we already know we already have this strength is to recreate and relearn a life that's new. We have that to build on and that you can share with others.

Carey Pena:

And Rachel, you've already shared a little bit of this, but I'd like because your answers are so insightful. If you would just talk a little bit more about how you personally are staying emotionally well during this pandemic.

Rachel Scanlan Henry:

Emotionally well now. I'm a school teacher and so part of being emotionally well as a schoolteacher is connecting with kids and I'd say staying emotionally well is connecting with people that you care about in some fashion and it's new. 25 years of teaching and I'm Zooming a class online. So that's new. For a stroke survivor, we know how to find new ways of handling situations.

Rachel Scanlan Henry:

So I get up every morning and I have that first cup of coffee and I enjoy that sip of coffee. I enjoy the little things that mean everything. Being able to have time with my son and my husband here at home, that's a gift. We never thought we'd have this much time together. I spend a lot of time in meditation, taking care of myself. I consider cooking a meditation because I didn't swallow for 10 weeks. So now food's a big part of my life where I'm food and interacting with every little part of my day.

Rachel Scanlan Henry:

You make it fun. You practice a routine that's the new normal and find the littlest thing that makes you smile and do it all day long. If it's gardening one day, if it's just making a bowl of popcorn, whatever it is, but we have to practice those good habits to train our body and our mind to do healthy, to ride this out, to stay safe and to feed that spiritual part of ourselves.

Carey Pena:

Rachel, I want to thank you so much for sharing your story and I know that your strength can inspire so many people right now who need the strength. So thank you so much.

Carey Pena:

I want to turn now to Kimberly Mcguire, a clinical psychologist at Kessler Institute for rehabilitation in New Jersey. Dr. Mcguire, thank you very much for being here.

Kimberly Mcguire:

Thank you for having me.

Carey Pena:

Are the things to look for that would signal heightened emotional stress or anxiety during this time? Can you kind of take us through what those things are?

Kimberly Mcguire:

Sure, absolutely. And Rachel really did a wonderful job of explaining some of the symptoms as well as some of the strategies that folks can use. But I think it's important to first recognize that the health threat that's occurring and the disruption of usual schedules and activities, and the lack of control over rapidly changing life events. These all have the potential to undermine anyone of us, right? Our sense of safety and self-confidence.

Kimberly Mcguire:

And then we have folks already who are living with emotional illness that are reporting exacerbations of their symptoms and even individuals that are typically calm, right? They're reporting this elevated

experience of stress, anxiety and fear. And then when we come back to individuals living with stroke, there is the fact that depression and anxiety are common post-stroke. So Rachel shared some of her story about that. And depression is affecting approximately one to two-thirds of stroke survivors and anxiety about one fourth of stroke survivors.

Kimberly Mcguire:

And some of the symptoms or behaviors that we can see at this time and the COVID-19 situation that might increase during this time our isolation, right? Withdrawing, appetite changes, sleep changes, a flattening of one's affect. They kind of have a distant stare. Persistent, negative thinking, right? A pessimistic approach, increased sense of hopelessness and helplessness, anger, agitation, irritability, increased depressed mood. Some people will have thoughts of self harm.

Kimberly Mcguire:

And as you can hear in that, a lot of these symptoms are similar to what Rachel was saying that she experienced and the time right after her stroke.

Carey Pena:

Dr. Maguire, what can stroke survivors do to improve their emotional health during this difficult situation?

Kimberly Mcguire:

Yes. So there are several important strategies that an individual can implement. So here are some ideas. So the first would be to please consider limiting news to five minutes daily. And I put five minutes on it, but give or take. You will be able to get all the updates in that short amount of time without overloading your system. And try to remember that gathering information is helpful and sensationalism can be very counterproductive and have an adverse effect on one's health.

Kimberly Mcguire:

A number two thing that would be very important is keeping a schedule. So this will provide necessary predictability. And a time of decreased control. I would say number three is to breathe. Rachel talked about this as well. Try mindful breathing throughout the day. Paced breathing sends calming signals to the body and can help with concentration, relaxation and have positive impacts on the nervous system and immune functioning.

Kimberly Mcguire:

Next I would say to please stay connected. So spend quality time with family you're already live with. Maybe get creative, try a new game, painting, read a new book. You can have virtual gatherings or phone calls. The American Heart Association has the support network. They also have the warm line.

Kimberly Mcguire:

The next one would be sleep. Very important for a healthy immune system and our overall mental health wellbeing. So you can do this for example, by keeping a nighttime routine. Maybe have a cup of decaf tea, chamomile tea about an hour before bedtime. Watch or read something that's lighthearted and get into bed the same time every night. And do not watch the news right before going to bed. So this is very important for to calm the nervous system.

Kimberly Mcguire:

And then next, I would say get outside if it's for five minutes. If you can sit outside, get some sunshine, some vitamin D. For those who are able to exercise outside, if you're able to go for a walk or a bike ride depends on the ability level. This is a great time to do that. For those that have worked with physical or occupational therapists, they can engage in 10 to 15 minutes a day of those specific exercises in their home.

Kimberly Mcguire:

For individuals with cognitive challenges, right? A lot of stroke survivors do live with cognitive challenges. If they have a computer and can access it, they can consider trying online games or take an online course and something that's of interest to them. This will help to keep the brain challenged and active during this time when the outside activities are not available.

Kimberly Mcguire:

Another idea is to laugh it up, right? So laughter makes us feel good. Don't be afraid to laugh out loud even when you're alone. You can rewatch your favorite comedy or take and share a post with an embarrassing photo of yourself. You might even get others to laugh as well.

Kimberly Mcguire:

Another idea I would say is with regards to releasing your emotions. So there's something called expressive writing. Some people might call it journaling. And this is when somebody writes about their emotions and thoughts and it's a really great cathartic release. There's something out there called the five-minute journal and there are other things like this that can help guide you through the process of getting to those emotions and thoughts.

Kimberly Mcguire:

And another idea is called the to-do list. So we all know about these to-do lists, but the to-do list can help you focus on your most important tasks or things you'd like to accomplish during this time. So house projects, et cetera. And lastly, I would like to say under this area of strategies it would be under the topic of increasing resilience. So consider the importance of this idea of increasing your resilience.

Kimberly Mcguire:

You can practice meditation or just a straightforward breathing relaxation daily, even when you're feeling well. And the idea is that the more you practice these strategies, the stronger that neural networking pattern develops and that you're really setting up your nervous system and your overall wellbeing for success. So it's more of a preventative approach versus a reactive approach to wellbeing.

Carey Pena:

Dr. Mcguire, some incredible points you made there. I'm just wondering as people try to sort this out day by day and they feel a lot of folks feel like it's Groundhog's Day one thing after another. How do you know when you might be reaching your breaking point? When should you seek professional help for depression or anxiety and what treatments can health professionals offer?

Kimberly Mcguire:

So right off the bat I would say please don't wait to seek professional support. So these are very stressful times and everyone that I've interacted with is feeling some level of distress and will benefit from additional support. Specifically though, if you or a loved one begins to have expressed suicidal thoughts, again, it would be fairly normal during this period of time. You want to reach out to a professional right away.

Kimberly Mcguire:

There is no need to suffer with these thoughts. Even if the thoughts seem to ebb and flow, they are distressing and they do need to have some attention to them. And in today's COVID-19 crisis, insurance companies have approved coverage for telemental health. So it's also called telebehavioral health telepsychology. But these sessions can occur via video format for those that own a smartphone or a computer or a laptop, and also by audio for those without that type of technology.

Kimberly Mcguire:

And when individuals are reaching out to and working with mental health professionals, these professionals can provide support, guidance, information, and coping strategies. And I guess if I were to bottom line it, they can help you to learn how to feel and be empowered and improve your daily quality of life during this very stressful time. Because fear is normal and it is nature's response to a threat. So it's about learning how to work with the fear.

Carey Pena:

And I guess we're all looking for some bright spots. So if I could touch on one of those, and that would be having a pet. Can you talk about how a pet might provide some emotional comfort for all of us right now?

Kimberly Mcguire:

Yes, I would love to talk about. Pets are wonderful, you might not be able to hug your grandkids or children that live outside the home or friends or neighbors right now, but you can hug away with your pet. And so if you have a pet at home, enjoy this extra time with them. Research has shown historically that time with your pet can encourage the release of endorphins, which help our mood.

Kimberly Mcguire:

And sometimes I work with individuals that say, "Well, I I don't have a pet." So what I would say to that is if you don't want to have a pet, consider grabbing a pillow or a stuffed animal and that the actual act of hugging can also produce a sense of relaxation.

Carey Pena:

So what resources does the ASA have to provide emotional support right now to stroke survivors and to caregivers when they are isolated?

Kimberly Mcguire:

So some of the resources available are through the website. They can go to supportnetwork.heart.org and its purpose is to give stroke survivors and caregivers an opportunity to share experiences and to get guidance from other patients and caregivers, as well as some of the clinical experts. And having these

types of online connections are a great reminder that we are all in this together during this very difficult time.

Kimberly Mcguire:

Additionally, the American Stroke Association's toll-free stroke warm line connects stroke survivors and their families with an ASA team member who can provide support, helpful information or just a listening ear and the warm line number is 1-884-STROKE. So that's 1-888-478-7653.

Carey Pena:

Dr. Mcguire, what can family members do to support their stroke survivors from a distance if they're at a facility where visitors are not allowed or are sheltering at home alone? This is obviously of great concern to a lot of people right now.

Kimberly Mcguire:

Yeah, so let me speak first to family members that are in hospital settings, nursing facilities, rehab facilities. This has been an extremely stressful experience for these individuals that are in these types of facilities. So I had actually worked with a patient earlier this week I think it was just yesterday. And it was a great idea that their family, they live pretty far away and their family drove up to the parking lot and the patient could see them from the window. And so they talk to one another on the phone, but yet they could still see each other.

Kimberly Mcguire:

I thought this was a great idea. And then a lot of facilities are helping patients that don't have the ability to make phone calls on their own. So they're actually scheduling when to call family or friends. People are using technology, family members, caregivers are bringing food to the front doors of the facilities and leaving cards or sending cards.

Kimberly Mcguire:

So there are many ways to kind of get creative and still facilitate that type of support. And some of that would pertain to people who are alone, living alone and in the house. I think a lot of the strategies that we talked about earlier would still pertain to individuals that are living alone, but also for those folks if they at least have a landline, a phone to reach out to the American Heart Association's support network and really start to engage with some people to decrease that sense of isolation.

Carey Pena:

Rachel, I know you're standing by here. I want to bring you back into this part of the conversation because you are a survivor and you know how important it is to reach out to support groups. Can you talk about that?

Rachel Scanlan Henry:

Yes. It's so very important to realize you're not alone. There are so many opportunities to reach out now, whether through support groups you're involved in, through rehabilitation, call them. Find out ways to connect, but I know for myself on Facebook and Twitter, there are survivors just like us all over the world and one word from them picks up my day. 17 years later, I know I'm not alone and somebody feels just like me and we're together and seriously, it saves the whole day.

Carey Pena:

And Dr. Mcguire, I'd like to leave you with the final word. Everyone is looking for a little bit of information and inspiration and I would love for you to just share with your audience what they want to take away from your overview today.

Kimberly Mcguire:

Yes. I would say that my message would be pretty simple. You want to practice the best self care you can and show yourself and others compassion. It's really important in this time where fear and anxiety are elevated, so self compassion and compassion for others.

Carey Pena:

Dr. Mcguire, thank you very much. And Rachel, thank you so much for bravely sharing your story and I know in doing so you are inspiring thousands of folks who are in a similar situation and just those of us day by day trying to make it through this pandemic. Rachel, thank you very much and we wish you and your family all the best.

Carey Pena:

And thank you all for joining us and remember to share this show with someone who needs it, learn more at stroke.org or call our stroke warm line at 1-888-4-STROKE. That's 1-888-478-7653. I'm Carey Pena. Thank you very much for joining us.