

SC_Special_Emoional Recovery

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[00:00:00] Katie Wright: Welcome to Staying Connected, a podcast where I talk to people about their stories with VEDS, Marfan, Loewe's Dietz, and related vascular and aortic connective tissue conditions.

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This is your host, Katie. If you've been listening to this show a while, you know that I have VEDS or vascular Ehlers Danlos syndrome. You may also know that over the years I've dealt with some tough medical issues like recurring TIAs or many strokes, a carotid dissection, and a life threatening spleen rupture.

This past November, I had a renal artery dissection causing a kidney infarction, as well as an iliac dissection. Not long after, [00:01:00] I found out that I also have a hepatic artery dissection. The emotional recovery from medical events has always been challenging, but after I came home from the hospital in November, I dealt with my most difficult recovery yet.

This made me wonder, what was emotional recovery like for others who had been in my shoes? How did they get through this period of time? I wanted to hear from people with VEDS or conditions like it, like Marfan and Lois Dietz, who had been through a difficult medical event and were also confronted with the emotional recovery.

I wanted to hear from people who had supported loved ones through an event or lost loved ones to these conditions. What did emotional recovery look like for them? So I asked. This episode is a compilation of people with VEDS, Marfan, and Loews Dietz, or their family members, who submitted clips answering these questions.

I found the answers relatable and helpful, and if you're going through your own emotional recovery right [00:02:00] now, I hope hearing these helps you too.

Deb Kruk: My name is Deb Kruk. I was diagnosed with VEDS in August of 2022, following the death of my son, Brian, in April of 2022. He died suddenly from a dissected, ruptured aorta, and we had no idea that he had VEDS. So between him dying and Me being diagnosed, uh, it was quite paralyzing. It was difficult. Each day was difficult.

It was like wearing a lead apron, but I have grandchildren and a husband and two other children, and I needed to pull myself up on the bootstraps and, um, you know, go [00:03:00] on living, which was difficult. I've found. I have a friend who has Ehlers Danlos type 2,

and she referred me to a Facebook page, which wasn't quite for me.

And then, the VEDS page found me, and helped me out tremendously. Helped me out with education about VEDS, and support about VEDS, and, um, it was, I think, life saving, it really was. And hearing other people's stories, and how they got through, um, Their, um, journey was very helpful too. I did go to therapy. I strongly suggest therapy because it really helped me unpack things and helped me put things in perspective and, um, helped me move on with my life in spite of the VEDS, in spite of the loss of my son.

Maya Brown-Zimmerman: I'm Maya Brown Zimmerman, and I have Marfan syndrome. I had a spontaneous coronary artery dissection, or SCAD, [00:04:00] in August of 2022. The night of my dissection, my husband called 911, and the emergency personnel insisted on taking me to the closest hospital, a community hospital without much Marfan experience.

While I'm grateful that they correctly diagnosed me, I was told recovery would be one to two weeks. It actually takes several months. When I got home from the hospital, I was in shock and a little bit of denial. At first, I tried to tell myself the SCAD was no big deal, but it didn't take long to realize that it was not a small thing and that recovery would be much harder than I anticipated.

I felt overwhelmed and anxious, especially as I lost a friend to complications from Marfan about a week after my dissection, and then I started graduate school the following day. It is hard being reminded that although we can take our medications and follow activity guidelines and get our scans, aspects of these conditions are outside of our control.

I reached [00:05:00] out to a doctor friend to ask about cardiac rehab, and they made a joke about that only being helpful if I was scared. I felt like they were saying I shouldn't be scared, but I was. I worried about having another dissection. I worried whether I'd ever get my energy back. I wish that I'd been warned that it was normal to have increased chest pain, PVCs, and soul crushing fatigue during the recovery period, because those things increased my anxiety as well.

A year and a half later, I've also had two vertebral artery dissections, and the anxiety hasn't gone away, but it is more manageable. Cardiac rehab was good, and I recommend it. Talking with other SCAD survivors through the Aortopathy community and SCAD Facebook groups helped me learn my experiences were normal.

I got involved with research and I went back on anxiety medication. Reminding myself to focus on what's in my control and what I've been able to accomplish despite the [00:06:00] health setbacks helps too. None of us know how much time we have, but I want to make the most of however long that is. And that requires addressing the mental health

aspects of living with these conditions.

Because, like I said before, there's only so much within our physical control.

Jacqui Fish: I'm Jacqui Fish, and it's my 25 year old son who has VEDS. In November 2022, he had a vertebral artery dissection, which caused a swelling in his brain called PRES, and also some bleeding. He was placed in a medically induced coma for three days, and we didn't know whether he would survive.

It has left him with a weakened left arm and hand. Then whilst recovering from this his bowel ruptured and he underwent a total colectomy followed by a massive pleural effusion which had to be drained. In all, he was in hospital for two months. Coming home from the hospital was such a relief after so long, and yet so very frightening without medical help and care on tap.

He was and [00:07:00] still is scared to sleep and very reliant on me for reassurance. We're all still suffering from PTSD, not least because we know it may well happen again at any time. We have also had to learn to live with a stoma and all that that entails both emotionally and physically. We're A good therapist is a must.

One who knows you and can support you through the trauma. There's also a grief process to go through, as our lives have been changed forever, and it's important to allow that to happen at its own pace and let go of the pressure to conform to social norms. Exercise, eating well, keeping up with our hobbies and getting back to work as much as possible have all helped with the healing process.

And linking with others in the community who understand. Also, we've learned to ask for help and to accept it and not take our anger and grief out on each other. We are now a year from that initial trauma. Reading back my diaries from those dark days, I am amazed at where we are now. Time really does [00:08:00] allow for healing and the memories to fade a little.

Kevin Kroeker: This is Kevin Kroeker. He has Loeys Dietz syndrome.

I think that would, uh, that would be after my heart attack. Mostly because it impacted my work that I thoroughly enjoyed. Because working as a healthcare aide, it wasn't so much the job itself that I kind of enjoyed the most. It was It was the fact that I, uh, really enjoyed, uh, working with seniors and getting to know them and their families.

And that was [00:09:00] basically, uh, cut off in an, in an instant where I didn't even have any like any chance for a closure. It was, it was just, uh, one, one morning I went to work, I came back home. I had, I had the heart attack. And then after that, after that, I

couldn't work as a care aid anymore. And it was, it was, it was just.

After that, emotionally, I think, I think that was, that was hard because it was, it was taken, it was taken from me, uh, just out of the blue. Like I didn't, I didn't see it coming, [00:10:00] and I enjoyed that aspect of it, and then, and then it was over.

Katie Wright: Yeah. How did you, how did you navigate that time or how did you get through that emotional period?

Kevin Kroeker:

Uh, there was a, a period of time where I actually went back and visited, uh, the nursing home where I, I worked and, and I was able to see some of, some of the residents, some of my. uh, co workers and so on, and that, uh, kind of, uh, helped a little bit, like, just to be able to, uh, see, uh, some of them again, um, but I think, I think mostly it [00:11:00] was, it was time that, uh, kind of, was more of the, of the, of like the healing, uh, kind of process.

I just have to have the time to kind of deal, uh, deal with it. And I would, uh, like in the, like in the future, like if, if an, if an opportunity kind of, uh, Uh, where, uh, like I would be able to, uh, like spend time with, uh, like seniors, uh, who are, who are like, like on their, on their own, own where they don't have a lot of, of like companionship or whatever.

Um, I would be into, [00:12:00] into doing that again, because I, I, I really enjoyed, uh, doing that as a care aide. Um, I didn't really help much after, after, after I was diagnosed with Lowery's Deeds. Uh, uh, shortly after that, the pandemic hit and, and doing that kind of thing was, uh, kind of like, uh, not, uh, not really.

uh, viable option because of the, of the threat to like, uh, seniors in place. Like, because there was so many, uh, kind of complications with that, where he would, uh, putting seniors at risk. And, uh, now I think it's, it's at a, you know, more of a, on a safer [00:13:00] place.

Dawn Marisch: This is Dawn Marisch. I have VEDS, or Vascular Ehlers Danlos Syndrome.

Before I was diagnosed with this rare condition, during the typical day at work as an elementary principal, I experienced a ruptured splenic aneurysm that nearly took my life. Over the course of the next three days, I received a remarkable 90 units of blood, and had two more surgeries. When I woke several days later, I was in an immense amount of pain, but absolutely elated to be alive.

That feeling of euphoria from surviving such a serious medical crisis

propelled me through the weeks that I spent rebuilding my strength and learning what had happened to me. But after about a month, I was finally released to go home and continue my rehab there. Once again, that joy of going home lifted my spirits.

But once I got home, that joy slowly left me. I was faced with the devastation of what the rupture had done to my entire [00:14:00] body with damaged organs and arteries. My strength and stamina were diminished and I could not get back to the active lifestyle I was used to. I realize now that there was a grief that came with the acknowledgement of no longer being the healthy person I once was.

I felt vulnerable and felt fear for what could happen next. It was five months before I could return to my full time job. I made it through that period. When I reflect on that time, I see that there were some very specific things that helped me. First and foremost, the support of family and friends was critical.

Visits to lift my spirit or to assist with things around the house that I was unable to do were absolutely priceless. It also gave me an opportunity to process what had happened and what the current state of my life was. Another thing was that after several weeks, when people needed to return to their routines, I found [00:15:00] myself alone more often, and that was difficult.

During that time, music was really powerful for me. If I needed to cry, I could cry. And when uplifting songs played, I could sit with the joy of it all. I found it difficult to read or even watch television. With so much happening in my body, I couldn't focus long enough on those things. But what I could do was draw and write.

Both of those creative outlets engaged me and gave me an opportunity to express myself and my feelings. And I'm still grateful for those things today. Nature was also a huge source of comfort for me. With the summer weather, I could sit outside or go for short walks. I mean, very short walks. And I spent a good deal of time watching the birds.

They're really very interesting and captured my attention. Anytime there was an opportunity to laugh, that was a great relief. Humor really does heal the heart. And I suppose for each person it's different, [00:16:00] but those are the things that helped me, especially the people. Thank you.

Toni Harrison:

My name is Toni. I have VEDS.

In 2013, I had a hernia repair. Two weeks later, I was back in the ER. I hadn't had a bowel movement. I was having a lot of pain, having trouble breathing. I had developed an intrathoracic stomach, which

means my stomach had moved through a large hole in my abdomen and was now inside my chest cavity. Where it ruptured, spilled gastric contents onto my lungs, um, collapsed my left lung, caused a good bit of infection.

I was in the hospital for two weeks at that time. I was already diagnosed with hypermobile EDS, but After this happened, I had the genetic test and confirmed that I have vascular Ehlers Danlos Syndrome. If I had to describe the experience coming home and the long recovery from an emergency thoracotomy, where they have to spread your ribs open, uh, I would describe it [00:17:00] as isolating.

Um, nobody else in my family is diagnosed. Nobody could understand that at 27, I now had to consider my own death in a very real way. I'd been trying to get pregnant. Suddenly there was a lot of judgment around that topic. You know, the ethics of potentially passing my damaged genes to someone else. The support groups online made all the difference.

VEDS, um, It looks one way on paper, you know, when collective experiences are concentrated down into just commonalities, but we all present really differently. We come to diagnosis differently. We tackle VEDS with different approaches. And it reminded me that I'm a person, an individual, and not just a case study.

Dominga Noe:

Hello there. My name is Dominga Noe. I have Marfan syndrome. And my significant event was in 2014 when I had [00:18:00] aortic valve sparing surgery. For me, it was something that was considered fairly routine for those of us with connective tissue conditions. So leading up to the surgery, I wasn't. Too worried, the normal levels of anxiety because it is a scary thing.

But most of my emotional responses came after, after I got home from the hospital. And for me, it was really daunting to realize that my body felt completely. different than what was considered quote unquote my norm. So that was a really emotional roller coaster to go through. And also just the acceptance of the trauma that my body had gone through was definitely a, um, a mental battle that I was facing [00:19:00] pretty regularly, just trying to allow myself.

To acknowledge that my body had been through a trauma and let myself accept that. A lot of things that I did to, uh, help myself through those difficulties were talking to members of the Marfan community to just get out of my own head and the realization that I I wasn't alone in feeling this way, that this was something that others had been through as well.

That was a huge help for me. Um, another big help was going to therapy

and talking to a professional about what was going through my head and just Having that listening ear, that empathy received back from my therapist was a huge, huge help for me. Another tool that I had was really just to, to meditate.

I know that [00:20:00] sounds a little odd, but to focus on my breathing, focus on my body, get comfortable in my body again. I took the time to get comfortable listening to my body because what I had been used to prior to surgery was no longer there. What I was dealing with, so it really was an opportunity to just get in tune with my body again.

Tyler Farley:

My name is Tyler Farley. I have a condition called vascular Ehlers Danlos syndrome. The fall of 2023, I had a bowel perforation of my sigmoid colon that, due to me being septic, I almost lost my life. But due to my advocacy, saved my own life, doctors listened, and I now live with an ileostomy bag. This procedure is reversal.

But I chose to keep it on for the time being. My life is more important than anything. My mental health is important. Um, I learned not the hard way during my recovery process with this. I truly hated the situation I was in. [00:21:00] Uh, It degraded me. It was put me in the worst position I ever felt in my life, but I knew that life kept going and life moves forward with or without you.

So I'm not going to be stuck behind and feeling bad for myself. Uh, I was given a chance to keep going and still here. So now not only that, I push myself to the limit as much as I can, but also to help others to strive to make a difference. Um, I feel like I'm here for a reason. Because of that, I'm going to make a footprint in this world once I left.

And they're going to remember me for the things I've done, not because of my past actions or whatever they may say. It's going to be definitely something that I've done. Um, so, I definitely encourage people to not feel down. It's okay to feel that way, but definitely don't feel that way forever because you have to keep going.

Erica Baldwin:

Hi, I'm Erica and I have vascular Ehlers Danlos [00:22:00] syndrome. My most recent medical event was going to the ER and hospital when I was out of state for severe stomach pains. It ended up I had a heart attack. Partial bowel obstruction, which can be really dangerous. So they admitted me to the hospital. When they tried to place the NG tube in my nose to relieve the pressure in my intestines, I coughed and vomited so violently that it caused bruising and major hematomas in my chest and even created some pseudoaneurysms.

While the intestinal obstruction cleared up, I had to deal with a lot of follow up with the, uh, aneurysm, pseudoaneurysms in my chest. So while it wasn't a long hospital stay, it definitely was jarring and reminded me how fragile my tissues really are. [00:23:00] I had had a major medical event in my 20s with a ruptured colon before I was diagnosed.

And then in my thirties with a difficult childbirth experience and discovering multiple aneurysms finally leading to my diagnosis. So it had been over 12 years since my last major event and it made me feel really anxious and fearful and sad and exhausted and I wondered if I could do this again and fight that hard in my 40s.

When I got home, post recovery, I took a lot of rest and we found a good local provider which was a blessing out of all of this, but I did need follow up surgery on the pseudoaneurysms of my chest. And so the coping mechanisms that helped, helped me mentally and emotionally, [00:24:00] physically, spiritually were lots of love from family and friends, visits and calls and texts, uh, practical help from them, prayer with people and from people, a lot of rest, uh, talking to close friends and just seeking counsel and being reminded.

Uh, of truth and also remembering I've been through harder things before and so have a lot of other veds, zebras, and just to remind myself that we can do hard things with help and support. And I just relied a lot on my faith, um, to help me recover from this most recent medical event.

Ashton Tanner: Hi, my name is Ashton.

I have VEDS, vascular EDS. My first major event was in June of 22. I [00:25:00] had something called a SCAD. It's a spontaneous coronary artery dissection, which caused me to have a heart attack. After the heart attack, um, getting home from the hospital, emotionally I think I was all over the place. Life had changed pretty dramatically.

In the blink of an eye, I, um, I think, words to describe it, just scared, worried, anxious, angry, a lot of just raw emotion. Looking back though, on, how I've been able to work through it and get through all these changes. Um, I think most importantly, I've learned that I really do need to lean on family and friends.

There's things that we would like to try to do on our own, but we really do need help. Um, I started therapy, um, to help. Treat [00:26:00] the PTSD from everything that happened with the, with the incident and the hospital stay and that, that's super important. Um, I think people get a little bit nervous to reach out for help in that way, but we're human and, and sometimes it takes the words of somebody else to kind of help us put things into better perspective.

Another thing that I like to do. I, I try every day is to remind myself that I deserve patience for myself and to give myself grace that some days are going to be better than others and um, the days that aren't I need to just be a little bit more forgiving of myself, remind myself that it's okay. It's another day.

Looking back, I'm Just a few months shy of my two year anniversary of the heart attack and It still brings up a lot of raw emotion [00:27:00] But I think looking back it also shows me that I've had two more years after that So these fears of you know, how long will I be here? When is the next event? Those are just going to be lifelong things to You work through, but I think it's just really important, that reminder to really try just to find the, the silver lining in everything.

There's a good that comes out of every situation. Um, and we might not see it at first, but keep looking because you'll find it.

Amy Jarecki: I'm Amy Jarecki and I have VEDS as well as fibromuscular dysplasia. Though I've had several undiagnosed events over the years, in 2019, a TIA from a dissected carotid artery led me down the path to my eventual diagnosis.

I didn't go to the hospital right away because I'd had a similar event about eight years prior. [00:28:00] At that time, I did go to the hospital where I was given no tests. I was told I had a migraine and was sent home with Benadryl and Tylenol. However, this time I went completely blind for about a minute and was very shaky for days afterward.

Two days after the TIA, I went to the urgent care and was given only a CT scan of my head and was once again told I had. A migraine. A week later, my daughter was in a car accident and had carotid and vertebral dissections and it was her neurologist who urged me to have a CT scan of my neck. I went to urgent care where the doctor tried to talk me out of getting the scan.

However, after I persisted, he made a show of rolling his eyes and said if it would give me peace of mind, he would order the test. Subsequently, the neck CT scan showed a dissected right carotid, as well as twisted and tortuous carotid and vertebral arteries indicating fibromuscular [00:29:00] dysplasia. The VEDS genetics test result actually came in three years later.

My carotid dissection never healed and is now referred to as chronic. An aneurysm has popped up just above the carotid splice site. I also have several other aneurysms throughout my vascular system that are being watched by my cardiologist. I would be lying if I didn't say I feel that through the years of having VEDS events, including nearly

bleeding out during a cesarean, I have felt unheard, misdiagnosed, and treated as though I was a hypochondriac, which in turn made me abhor going to any doctor for any reason.

Fortunately, since my diagnosis, I have found doctors who are familiar with my condition, and that has made a world of difference. One thing I'd like to stress through this process, I have learned that it is important for individuals to take charge of their health, to thoroughly research everything and gain as much [00:30:00] information as possible.

VEDS is a rare disease and most doctors have a sketchy understanding of it, if any. I have found meditation and moderate exercise helpful, especially walking and Tai Chi.

Lauren Atherton: hi, my name is Lauren Atherton and I have Loays Dietz Syndrome. I actually found out I had Loays Dietz Syndrome, um, after an emergency aortic dissection.

And so when I first got home from the hospital, I really thought, Oh, I've been through this. done, check, we fixed everything, good to go. And then, as you know, if you've been through a heart surgery two weeks after your procedure and after a traumatic event, you go back for a post op appointment with your surgeon.

And it was actually at that appointment that I found out I have Lowey's Dietz Syndrome. I tested positive from a genetic, uh, genetic test. test and it really threw me through a [00:31:00] loop. I thought, okay, this open heart surgery thing was just a fluke and we fixed it and done and now we can get back to normal.

Um, and Loays-Dietz syndrome along with finding out I had the condition, I also found out that I, uh, probably would need another open heart surgery in the next six months. So it was a very, um, yeah. Heavy time to be processing all that information. And I think what was most impactful for me was over the next few months, I actually found myself, um, really just seeking control in little things, little ways.

Um, with, I own my own business, so like with my business, I really wanted control over the process, what we were doing, winning business, just being more hands on, um, and then I would find myself, uh, you know, crying randomly, having, um, some dissociation where I [00:32:00] just felt like I'm not really here, um, just feeling like a lot of things were taken away that weren't fair.

And I'll say. When I was going through it at the time, I didn't know how to express all of that in words, um, but after experiencing a few episodes, um, I realized, you know, my body is processing this grief that I can't quite put into words. So I sought a psychiatrist to work through a lot of that, um, Unexpected, uh, one, the trauma, but then,

like, the unexpected diagnosis, feeling like this is not fair, like, oh, all of this is being taken away from me, this future I thought that I was going to have and what it was going to look like, um, and it was a multi year process to work through that.

So, I'll say, if you, um, You know, after you go through, whether it's an emergency or a dissection, or it's just a normal open heart surgery, and I know that sounds silly, normal open heart surgery, um, you know, [00:33:00] really giving yourself the space and the grace and, um, The time to process and just pay attention to how your body is handling this reaction, this news, as well as, uh, you know, getting help if you need it.

And I totally understand I'm in a very privileged position to be able to afford therapy, um, you know, once a week at the time. Um, but, you know, really getting mental health or even using the Calm app or an app to help meditate and just kind of process these emotions. is super, super helpful. So you are not alone.

Um, this is a normal process. I think that everyone who's had surgery goes through and, um, I hope that just my perspective has helped you, uh, just kind of find those next steps of what could help you.

Roe Nania: So my name is Rosemary Nania. Um, I am part of the VEDS community. I am A VEDS. Sister [00:34:00] daughter. My dad passed in 1995 for suspected VEDS I have a brother Angelo who passed in 2019 due to VEDS.

So the most emotional experience I've ever had with VEDS for Angelo was his passing. What got me through Angelo's passing is actually the VEDS community. But it also woke up the fact that my father passed from veds That became a real reality after angelo's death And that one I needed professional help for that one.

I needed to process because I felt So angry at the veds community. I felt angry at veds itself And it wasn't so much that I was angry at the community I was angry at the fact that we all had to face this and watching everybody's stories unfold Made it more real and more unavoidable. [00:35:00] And. It just put up a mirror in front of my face that I can't ignore this and that made me angry So I don't know that I was angry at the community as much as myself for not accepting the diagnosis But when it comes out, that's how I

wasn't a realistic fear It wasn't a realistic emotion at that point, but it felt really real and I was angry and then When my other brother was diagnosed and my three nieces got diagnosed, I became re angry at VEDS and I realized that I needed to be a part of this to be on the changing team. I needed to get front and center involved.

I needed to be a part of the change and the distribution of our voice.

Because I was never a person who sat on the [00:36:00] sidelines and watched things go by. I wanted to be on the change committee. And I just think in the future I would love to have a viable treatment for this condition.

Katie Wright: My name is Katie and I have vascular Ehlers Danlos Syndrome.

After I came home from the hospital from my renal artery dissection and iliac dissection, I experienced an intense depression. I found myself ruminating on the hospital stay where my pain was not managed adequately. I struggled with the loss of not only part of my kidney, but the loss of the meaningful use of my left leg.

I agonized over whether I would be around to see my grandson grow up, and I went through an intense baby fever and sadness around my inability to care for a child of my own. I was so depressed that I considered moving away from the city and away from medical care entirely. I withdrew from my friends, and I lost touch with how to interact with them.

[00:37:00] During this time I also found out about another dissection and pseudoaneurysm in my hepatic artery which contributed to an emotional crisis around my 35th birthday. During this time I realized I needed help and I reached out to my primary care doctor to increase the dosage of antidepressants that I had already been taking.

I talked to a therapist who I still continue to see and I found comfort in revisiting old hobbies. I alleviated my baby fever by adopting an eight week old kitten, who I absolutely adore. I allowed myself to look at houses and properties out of the city, and I daydreamed about moving away from medical care, knowing that I wouldn't ever do it.

I received help from my friends and family in the form of DoorDash gift cards, phone calls, visits, and financial help to hire a temporary house cleaner. I allowed myself to rest when I needed it. I read books and I spent time in nature when I felt up to it, and I still do this. And when I finally felt up to [00:38:00] it, I re engaged with my friends in the community.

All of these things allowed me the mental space to process my emotions, and while I am still on an emotional rollercoaster and deal with significant levels of fatigue and exhaustion, the lows have gotten more manageable. I continue to be gentle with myself and my recovery, and I am incredibly grateful for my friends, family, and community that have helped me get through this time.

Thank you. If you're dealing with an emotional recovery of your own, or are dealing with a diagnosis of Marfan, VEDS, Loeys-Dietz, another

condition like it, a major medical event, a loss of a loved one, my heart is with you. I hope that this episode was able to provide you advice and experiences to relate to.

And I want you to know that there are resources in the episode show notes for where you can reach out to get more support, all the love I'll see you [00:39:00] soon.