Husband Follows Wife’s Lead to Support Scleroderma Patients As She Fights Her Own Battle

Facing scleroderma takes courage.

The kind we name awards after. The kind we honor with ovations. The kind we make movies about.

I say this as an outsider. I’ve only spent the last couple months discovering this disease and hearing the stories of its impact.

To see the courage of many scleroderma patients is to see a pure, humble, enduring bravery – a life that’s willing to accept its own frailty and at the same time refuse to let that define its strength.

When a person is diagnosed with this autoimmune disease, their future is largely unpredictable. Each patient’s battle is unique.
“It can kill you slow. It can kill you fast. Or it can make you really, really miserable for the rest of your life.”

Michael Maas has seen it all over the last six years. His wife Sandee was diagnosed in May 2011 and together they’ve been facing the disease head on – first for Sandee, and then for others.

It was early winter in 2010, and Sandee was ecstatic to be starting nursing school. She had worked in the family business for 31 years, but something had changed and now she wanted to work with those in hospice care. After spending two years on a waitlist for enrollment, the time had come.

“Sandee had her plans to become a nurse to do noble things to help people. And it’s like God said, ‘That’s good, Sandee, I like that. But I’ve got something else for you.’”

All of a sudden, a wave of “devastating” and “indescribable” exhaustion, swelling in her extremities, Raynaud’s syndrome, and other symptoms enveloped and suffocated her plans. Doctors didn’t know what was happening.

In the meantime, she did her best to manage, hiding her symptoms during school and asking fellow students to cover for her. Soon, it became clear whatever this was attacking her from the inside would not let her continue.

It was crushing.

When the diagnosis was made, the couple tried to keep their minds on whatever was next. Immediately, Sandee searched the internet for more information or a support group.

That’s when she found the Scleroderma Foundation.

“Just looking back now,” Michael said, “the whole way has been filled with blessings that we couldn’t possibly have imagined – between people and situations and Sandee being able to help others. I know I’m skipping a whole bunch but just to compare where we are now to where we were then, it was a big life-changer.”
What Michael was skipping was years of uncertainty and pain as Sandee’s scleroderma came on very aggressively – her case was one that could kill her quickly. In addition to two rounds of chemo, kidney failure, two years of daily dialysis, and an eventual kidney transplant, Sandee went into respiratory failure twice, once with a 50/50 chance at surviving.

“I was pretty darn frantic,” Michael recounted. “At one point the doctor was kicking us out, but she mouthed to me ‘I’ll always be with you.’” Michael said, briefly pausing to collect his emotions. “She thought she was dying, too.”

Very thankfully, Sandee survived all of it. And the couple fought through it together – not without fear, but in the face of it, keeping their faith and pushing ahead.

*Courage.*

Back when Sandee first found the Scleroderma Foundation, she and Michael began regularly attending a support group. It would become a haven for them, but not right away. First, they had to witness the range of ailments the other patients were suffering: skin hardening, unmanageable pain, physical deformities, some loss of mobility, and others.

“It told us things we didn’t want to hear. I made it through the meeting without breaking down,” Sandee said.

As difficult as it was, they kept attending.

“I got a lot out of the first one,” she continued. “Even though it was scary, I learned so much information and I could see the camaraderie. I knew I needed that.”

Neither Sandee nor Michael believes her survival is by chance. With each passing support group and as her disease stabilized, a deep responsibility developed to help her fellow patients who were suffering.

“It’s in my heart to do that. I want to help whoever I can,” Sandee said.
She’s now a member of the Board of Directors of the Scleroderma Foundation-Rocky Mountain Chapter, helping to spread awareness and guide the organization. In addition, she’s leading the Mile High Support Group here in Denver, offering the understanding and support others offered her – so much so, in fact, that she won the National Support Group Leader of the Year Award at the 2016 National Patient Education Conference.

As a guest attendee of her support group a few weeks ago, I can tell you these two people are pillars in that room, along with some others who are quick to welcome and meet patients with warmth, joy, and hope, no matter where the patients may be on the journey.

But as much as this is a celebration of Sandee – and Michael’s – efforts, they’re just two people. For every story of hope like Sandee’s, I’ve heard another that’s full of despair. Scleroderma patients need us to join the fight.

Michael would be the first to admit that watching his wife’s determination to not let this disease control her attitude has caused him to evaluate his own focus.
“I'm just proud of her. Her heart, her servant heart. How she looks outside of herself to help others who are afflicted... It's helped me to look beyond my own personal issues and be more sympathetic to others. And helpful, hopefully.”

Courage necessitates a battle. Sandee and Michael didn’t get to choose theirs, but did get to choose their response. We get to choose both.

You’re needed.

By supporting the Scleroderma Foundation on Colorado Gives Day, you’re facing the battle. Schedule your donation and share Sandee’s story on social media. Let’s make this disease famous to make it history.

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