

In Sickness and In Health: The Critical Role Spouses Play

by Stacey Shannon

"For better or for worse." "In sickness and in health." Both phrases are often used in weddings, though the newlyweds may not completely realize just what those words mean. IC patients and their spouses are putting such vows to the test navigating this painful, chronic condition together. How they navigate the hard times can impact how they feel.

The Study

In November, researchers from Queen's University in Ontario, Loyola University Medical Center in Maywood, Ill., and the University of Rochester Medical Center in Rochester, N.Y., released their findings that a supportive spouse can improve the mental health quality of life in women suffering from IC.

"The primary finding in this study is that 'distracting' spousal responses act to 'buffer' the negative effects of pain on mental quality of life for women suffering from IC," said Dean A. Tripp, Ph.D., associate professor in the Departments of Psychology, Anesthesia & Urology at Queen's University, and one of the

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researchers conducting the study.

The study surveyed 96 women about the responses of their husbands to their pain as well as the women's quality of life, depression and their disability. Tripp said he and his colleagues found it unacceptable that no such study had yet been conducted for IC patients considering that IC clearly impacts the entire family.

Dealing with diagnosis

Many patients are not surprised by the findings. Kim Wayne*, a 32-year-old nursing home CNA in Gibson City, Ill., said she started dating her husband in 2003. Her IC symptoms started the week before Christmas in 2005. The following March she was diagnosed through a cystoscopy without any pain medicine and that horrific event showed her how much her now-husband

cared for her.

"I had gone to the appointment by myself because I was told I did not need someone to drive me home," Wayne said. *"After the procedure, I was in a hurry to get home. I was very unhappy with the way the doctor had treated me. I was in horrible pain from the procedure. I live 30 minutes from the facility where the procedure was performed. I drove home in tears due to the pain. My husband called me while I was on my way home. He was upset about the way I was treated. When I arrived at home, my heating pad was on, my blanket was on my chair and a glass of water was on the stand beside it. I was able to crawl in and do what I could to find relief from the pain."*

Wayne's husband isn't the only one who helped his wife through her diagnosis. Penney Sanders, a 50-year-old music teacher in Nashville,



Tenn., is a newlywed who has dealt with IC since getting married three years ago. In April 2008, just a few months after her wedding, Sanders began noticing her symptoms. After visiting six doctors, she was finally diagnosed in October of 2009. Her husband was relieved to have an answer; however, he also was frustrated because he wanted to help and didn't know how. He had to deal with the diagnosis himself. It was a challenging time.

"As newlyweds, you can imagine the obvious [challenge]," Sanders said. "During painful times, it can be very frustrating for both of us. There is such tremendous stress on me having to go through it, and on him seeing how hard it can be for me."

Julie Beyer, a 51-year-old registered dietician who works with IC patients in Auburn Hills, Mich., said she's talked with many patients who compare the impact of an IC diagnosis to going through the stages of grief, a lot like what Sanders described. And those stages can come at different times for each spouse.

For Beyer personally, though her symptoms started in high school and kicked up when she got married a couple of years later, she wasn't actually diagnosed until she was 38. She and her family were building a new house and the stress from it triggered her symptoms to be even worse. She wasn't the only one frustrated as she went from doctor to doctor searching for a diagnosis.

"My husband was just as worried as I was," she said. "He didn't get it. Once we got the diagnosis, we had to learn together."

In the hardest days early on, Beyer's husband would make her scrambled eggs. He wasn't sure what else to do, so scrambled eggs were his way of showing that he cared and was trying to help however he could.

Staying strong through flares

Once the initial shock of diagnosis wears off, daily life with IC begins in a marriage. The disease brings with it both mental and physical needs to be dealt with. Tripp pointed out that physical and mental health are interconnected.

"In my mind there is no difference

between pain and mental health," he said. "Pain has long been defined as a sensory and emotional event. In fact, pain signals that travel up our spinal cord to reach the higher brain centers are not only sent to areas of the brain that work to coordinate escape movements but are also sent to emotional areas of the brain as well, simultaneously."

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As such, spouses need to understand that their reactions can greatly help or hinder the IC patient's mental and physical health.

"[Spouses of IC patients] need to know that spousal support can have a huge positive or negative impact on their lives and their symptoms, which are obviously tangled together," Tripp said. "Support from a spouse that aids a patient in engaging the world and helps them be distracted from their pain and focused on wellness can make a large difference."

Beyer learned that firsthand early on. When her symptoms were at their worst, she was helping her husband wallpaper the kitchen. He got cross with her about something and she immediately doubled over in pain, feeling as if someone had just stuck a knife into her bladder. Her husband struggled to understand how she could have been fine five minutes before and struck so severely so quickly.

"That was something I didn't quite understand at the time," she said. "But, that's how quickly stress can affect the body."

Like so many other couples dealing with IC, Beyer and her husband have learned how to navigate flares to stay strong in their marriage.

These days her symptoms are more under control, but her husband does extra things for her such as buying a car with heated seats to help her on car trips to visit their children.

"It's almost like you're renegotiating your marriage contract because neither one of you signed up for this," Beyer said.

For Wayne and her husband, the IC diagnosis changed their wedding plans. They were going to get married in 2006, but after Wayne was diagnosed with IC and her husband got a new job, they decided to wait another year instead.

"We both ended up being very happy with our decision," she said. "By the time of our wedding in 2007, I had my IC under control, and he was established at his new job."

Even after walking down the aisle, her husband continues to be supportive of Wayne whenever her IC does flare.

"My husband is very good about allowing me to relax and take it easy," she said. "He will ask if I need my heating pad, water or meds. He will rub my back. He's a very good listener and allows me to cry on him if I need to. Crying is my way of dealing with pain and stress."

Sanders' husband has been similar. She said he is very sympathetic which helps her most. He's willing to try anything to help ease her pain. Recently, the couple has been trying to use distraction to help with pain management.

"He never acts like it's no big deal and takes it very seriously," she said. "That can do a world of good – just to [have him] understand as much as anybody can that doesn't have it."

Sanders mentioned that her husband has also learned there are times when he needs to just leave her alone to deal with her anger and frustration about IC.

Kathleen Hancock, an office manager in Vancouver, Canada, has been married for 12 years. Her IC symptoms started in 1999 after having a miscarriage, though she wasn't officially diagnosed until 2004.

"My husband is awesome," she said. "If not for him, I'd have been admitted to the loony bin by now."

When she flares, he helps her settle into the couch with her heating pad, medicines and snacks – whatever she needs. And he works to ease her mental anxieties as well.

"He is so funny," Hancock said. "He has a great sense of humor. He will do anything to ease the pain. Just knowing he is there helps. He always says if he could switch places with me and take my pain away he would."

Hancock has other chronic conditions as well, including vulvadynia, vestibulitis, IBS and endometriosis. Combined together, her conditions can make intimacy with her husband a challenge.

"There have been times when we couldn't do anything for weeks," she said. "I got assurances and love like hugs and massages to make me feel better. I feel so blessed to have him in my life and by my side. It takes a special kind of man to stand beside and help his wife who has IC."

Dealing with unsupportive spouses

And while some spouses have risen to the challenge of supporting their IC patients, not all spouses have reacted the same way. Tripp said the best thing for patients to do is talk openly and honestly with their spouses, even though that can be difficult.

"This may be very challenging for many patients because they are fatigued, feel the spouse will not listen or feel that they do not have all the answers they need to address this issue with those they love in a meaningful way," he said. "BUT, patients need to know that if they do not try to speak and collect positive support, they will only be further isolating themselves with their pain and symptoms."

He also suggested seeking out counseling with a provider who has expertise in pain if necessary. Tripp and his colleagues concluded through their study that some spousal training may be needed in the future for treating IC patients.

Beyer has seen IC patients facing such challenges and the impact they've had.

"If you're constantly living under the stress of when you first get diagnosed with an illness and you've got somebody who doesn't understand, it isn't just one more thing [to deal with]," she said. "It almost doubles everything."

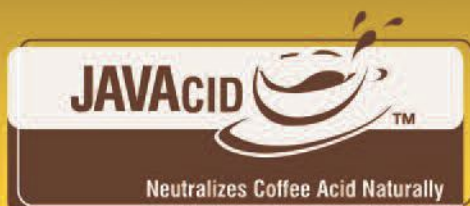
She also cautioned, however, for patients to not assume that just because someone is unsupportive in the beginning that he/she will remain that way.

"They're going through stuff, too," Beyer said. "Give people a chance to go through that period. It's not going to happen overnight."

Above all, Sanders, Wayne, Beyer and Hancock all agreed that patience is important for both sides.

"As much as we want to ask them for patience, we need to be patient with them, too," said Beyer. "This is what they mean 'for better or for worse.'"

* Some names have been changed in part to protect identity.



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