



Sarah Walker

Age: 38

Occupation: Software engineer

Status: Married with two young daughters

Enjoys: Lounging at the beach with her family

A hard-working engineer and mother who is worried for what is in store for her daughters

Sarah met her husband in high school and married him soon after she graduated from college. Her husband's job requires him to be on the road for extended time so she is the main caregiver for their two daughters. While she has been suffering for the last decade, she was recently diagnosed with chronic pancreatitis. Until a few months ago, she worked as a software engineer at a consumer service company. However, she recently lost her job because she was on leave for too many days. The stress is taking a toll on her mental health but she has no time to seek therapy because she has to care for her children.

Sarah's Journey

Sarah first experienced intense abdominal pain, back pain, nausea, and vomiting about 10 years ago. Her PCP diagnosed her with GERD and prescribed Zantac, which did not alleviate her symptoms. She continued to experience pain and over the next five years was in and out of the hospital, dragging her little girls along with her. One year, she had to miss multiple family celebrations because of her recurrent trips to the hospital.

Sarah saw at least seven specialists in her suburban town but they all proposed different treatments. Many also told her to quit abusing alcohol even though she had only ever had one or two glasses of wine in social settings.

“I am tired of carrying my medical records just to prove that I am not an alcoholic who is a drug addict, especially with kids in tow...”

“Every specialist you go to wants to do something else different. They don't have a protocol they follow.”

“My doctor told me that I was exaggerating the pain because I am a woman.”

“If you are having more trouble, come back to the ER.” During her visits to the hospital, ER physicians would perform scans, find nothing abnormal, and send her back home without prescribing the pain medication that she needed.

She was often labeled as a drug seeker and told that she was not presenting with the “right symptoms.” In pain and with no support, Sarah felt like giving up on some days. She imagined herself in a dark train car hurtling down bumpy tracks waiting for an inevitable fatal crash.

With no pathway in sight, she changed her insurance plan from an HMO plan to a PPO because her doctor refused to refer her to a pancreas specialist she had found through her online research. The specialist listened to her intently, asked questions, and conducted an endoscopic ultrasound. Sarah was finally diagnosed with chronic pancreatitis.

“I hope they come up with a medicine that helps treats us...I hope I dont get worse...I know this condition is only going to get worse...” Since then, the specialist has been a champion for her. He reached out to her primary care physician to share the diagnosis. His care coordinator checks in periodically with Sarah and provides referrals to tests.

Given the delay in her diagnosis, her pancreas is quite scarred and the specialist has suggested total pancreatectomy with islet auto transplantation (TPIAT) as an option to manage her pain. While her diagnosis gives her some relief, she is worried for her daughters because the results of her genetic testing show multiple risk factors.

The family is now relocating to another state because of her husband's job.

“I am worried for my daughters...I don't want them to experience this.” Sarah is optimistic and has already started searching for a specialist close to her new hometown. She has also joined a few online support groups and finds solace and advice from other patients going through similar experiences.