

Peter Fraser

Age: 67

Occupation: Retired after a successful career in biotechnology Status: Married with three adult children Enjoys: Board games and golfing

A retired man who confidently advocates for himself

Peter retired after a successful career in biotechnology and science. Given his professional background, he is comfortable with technical terms and spends a significant time doing research online about pancreatitis. He is financially secure and willing to travel all across the country to receive top-notch care. Peter is not afraid to ask questions and communicate his needs to his providers.

Peter's Journey

Peter started experiencing severe abdominal pain in his 30s. He received a diagnosis of chronic pancreatitis soon thereafter but struggled to find an approach to manage the condition. He frequently visited the ER with acute episodes of pain and "I had a pretty quick diagnosis, but what to do about it was long in coming."

would be discharged with some temporary pain relief but no concrete plan. He spent all of his free time researching about pancreatitis and engaging with online support groups.

After four years and visiting 15 different gastroenterologist specialists with no clear answers, Peter was willing to try anything.

"When doctors run into a wall, they don't handle it very well."

After a particularly severe pain episode that left him debilitated for a week, Peter traveled to three different centers in search of a plan to manage his condition. He finally settled on an academic pancreatic program closest to his home and was able to find doctors who listened. The gastroenterologist (GI) connected him to a dietician and helped him put together a plan, including pancreatic enzymes and gabapentin to manage neuropathic pain.

Peter has not been to the ER in the last two years. Today, he can detect an oncoming flare-up and knows how to manage the pain. He sees his local GI twice a year and meets the specialist at the academic center once every two years.

"You feel alone as a patient. I want to develop a plan. If you have a plan, you have hope."



Caroline Fraser

Age: 64 Occupation: Retired Status: Peter's wife and caregiver, mother of three adult kids.

A partner and caregiver who fills in the gaps of expertise

"Caregiving has turned into a fulltime job...it's a lot." Caroline and Peter recently celebrated their 45th wedding anniversary. Caroline often reflects on the ups and downs that she has navigated with Peter by her side; her proudest moments were watching her three children grow into adults and having families of their own.

When her husband was diagnosed with chronic pancreatitis, Caroline's life seemed to fall apart. While she was completely shaken up, she stepped up to provide Peter her unconditional love and support, especially on days when the pain and nausea is unbearable. Caroline retired a few years ago from a mid-size company and hopes to enjoy her golden years with her family and grandkids.

Caroline's Journey

"They sometimes share his medical records between hospitals but only with heavy prompting from me." Over time, Caroline has learned to assist Peter in many aspects of his care, enabling him to be a strong advocate for himself. She travelled with him across the country as he sought a plan to manage pancreatitis. She makes time to drive Peter to his

appointments and joins the consultations to share her observations and get answers to her questions.

She often finds herself over phone fighting with insurance companies to authorize treatments that he needs or to correct erroneous charges. She manages Peter's strict diet plan and frequently asks his dietician questions about the food triggers for flare-ups. "Sleep deprivation has been a big issue for me."

Sometimes Caroline is overwhelmed with all the different aspects of care and wishes that she could access mental health support as a caregiver.