

Dr. James Lord's Story
(Seattle, WA)



As a gastroenterologist, my patients do not often die because of the reason they came to see me. And if they do, it usually is not from inflammatory bowel disease (IBD), so Carol's death hit me hard. Her death was preventable, and it motivated me to become an advocate for Medicare reform.

As part of my research work, I recently opened the chart of a woman I took care of for a four-year period, ending a few years ago. Carol (not her real name) had ulcerative colitis, a chronic, incurable IBD. She had been on a lot of steroids before I met her. While steroids can relieve symptoms, they don't slow disease progression and they pose other risk factors if used long-term. So, we looked for better options. She temporarily got her colitis under control with an immunosuppressive drug, but it stopped working after a year. We tried another medication, but it did not work either, and Carol remained dependent on steroids to control flare-ups. Finally, we did find an immunosuppressant that Carol said was "wonderful" at eliminating her symptoms.

Five months into her newfound remission Carol turned 65 and went on Medicare. She was no longer eligible for copay assistance, and Medicare Part D has no out of pocket cap for pharmaceuticals. Carol simply could not afford the medication that was working so well to control her disease, so she stopped taking it.

I never saw Carol again, as she went back to getting her care from our affiliate hospital closer to her home. But recently when I opened her chart, I learned she had died. In the years since I last saw Carol, her doctors had tried again with the medications that had previously failed, predictably with no benefit. With no relief, she had to continue to take high dose steroids pretty much incessantly for years. Her gastroenterologist had prescribed a new immunosuppressant, but she never filled that prescription, again due to cost. Carol had another flare this year, prompting her admission to the hospital, where five days later her colon ruptured. She had an emergency colectomy and went into septic shock after the operation. She was transferred to the ICU on life support and died of multisystem failure within a month.

Carol and her doctors had found medication capable of controlling her colitis. But without affordable access to it, she had to resort to long-term steroid use. The steroids, in combination with ongoing inflammation, weakened her colon to the point of spontaneous, fatal perforation. Preventable deaths are inexcusable. That is why I am advocating alongside the Crohn's & Colitis Foundation as they call on Congress to establish an out-of-pocket cap for Medicare Part D.

Join us in advocating for patient access to care by visiting crohnscolitisfoundation.org/advocacy.