

Jim Turner

Double Trouble — Patient's rare cancer causes heart valve damage



Jim Turner, at age 70, tried skydiving for the first time (his instructor is on his back).

Jim Turner was thoroughly enjoying retirement. He and his wife, Rhea set aside four months to cruise their boat on the South Pacific. But in the evenings, while enjoying a glass of wine and peacefully drifting on the water, his face, neck and chest would flush. At first Turner thought it was too much sun ... or sulfites in the wine. But the flushing, which had begun so suddenly, continued and progressed. So, when he returned to port, Turner made a visit to his doctor.

"My physician didn't think it was a problem, but he ran some tests. I didn't have high blood pressure or any other obvious problems," recalls Turner, who chalked the flushing up to a nuisance versus a serious medical problem ... to which he was no stranger.

Eight years prior, before retiring from his school superintendent position, Turner became severely constipated. "I was 57 and realized constipation can happen as you become less active, but I hadn't really changed my diet or activity level," recalls Turner. Subsequently, doctors discovered a cancerous tumor about the size of a grapefruit where the small and large intestines meet. "During my 1989 surgery, they removed the tumor and nine inches of intestine on either side of the mass," says Turner. "I thought I had taken action in the nick of time and it was a done deal."

Little did Turner know that he was in for "double trouble," as the cancer returned, affecting his liver and heart.

Serendipitous discoveries

While sailing, Rhea read books. One day, as she casually flipped through the pages of a medical manual, she was drawn to the word "carcinoids." It was a word she heard a doctor use, so she read about it. Turner recalls, "Rhea told me one of the telltale symptoms of carcinoids — a distinct type of liver tumor — was flushing. Furthermore, the reference material cited carcinoids as a secondary cancer resulting from the metastases of another cancer." Rhea took Jim — and the book — back to the doctor, who referred them to an oncologist.

"After an MRI and CAT scan of the liver, the oncologist confirmed that I had several liver tumors — carcinoid tumors," says Turner. "Only one of every three or four million people in the world have had this disease, so there isn't a lot of knowledge about it, or experience in treating it."

Carcinoid cancer arrived on the medical scene about a century ago. In 1907, a German pathologist by the name of Obendorfer first described a group of odd little tumors in the intestine, which looked somewhat like cancer but also somewhat like benign tumors called adenomas. So, he gave them an intermediate name. Adenoma is a benign growth; carcinoma is a malignant growth. And he applied the term "carcinoid," which means like carcinoma, but not quite the same.

Carcinoids are slow-growing neuroendocrine tumors that can cause diarrhea, flushing, asthma-like wheezing attacks and fluctuations in blood pressure. The condition is often misdiagnosed as [irritable bowel syndrome](#), [Crohn's disease](#) or colitis. Turner's doctors in Southern California didn't have experience in treating carcinoids and did not want to do surgery. Turner wasn't ready to die. He wasn't looking for any guarantees or a cure, but a treatment plan to extend his life so he could do more of the things on his retirement list.

"One of my doctors was a friend of an oncologist at Mayo Clinic and he mentioned that they had experience with carcinoids. It didn't take long to gather some clothes, my son and wife and head to Rochester," says Turner. "I was humbly looking to buy some time."

A disease with two arms

Turner saw [Joseph Rubin, M.D.](#), a medical oncologist at Mayo Clinic in Rochester, Minn. "While caring for Mr. Turner, I had him lie back on the examining table and noticed his neck pulsing or throbbing," recalls Dr. Rubin. "I recognized this as a symptom of heart disease and consulted with [Heidi Connolly, M.D.](#), a Mayo Clinic cardiologist. "She confirmed that Mr. Turner did indeed have some cardiac complications," he recalls.

"The right side of Mr. Turner's heart had developed two leaky valves," says Dr. Connolly. "This problem had to be corrected before any surgery could be done to address the carcinoid tumors in his liver," she explains, "not only for him to be strong enough to withstand the stress of liver surgery, but because back pressure from the heart goes down to the liver and could cause excessive bleeding."

The two diseases were not unrelated. "It was not as if lightening had struck twice," explains Dr. Rubin. "Carcinoid tumors produce an excessive amount of serotonin, which can damage the heart valves and restrict proper function," he explains.

"After evaluation, we excluded that carcinoid heart disease was indeed present and determined that Mr. Turner's heart problems resulted from the excess serotonin produced by his liver tumors causing heart valve injury, recalls Dr. Connolly."

A multifaceted treatment plan

Turner had [heart valve replacement](#). [Hartzell Schaff, M.D.](#), a cardiovascular surgeon at Mayo Clinic in Rochester, performed replacement of Turner's valves with tissue valves. "This meant Mr. Turner would not have to take the blood thinners required with mechanical valve replacement," explains Dr. Connolly.

The effects of excess serotonin on the heart were what Mr. Turner experienced, notes Dr. Connolly.

"After my heart surgery, I went through rehabilitation back home in California," says Turner. "I ate well and exercised so I could get strong enough to face my second surgery in December," he recalls.

The second procedure involved addressing the liver tumors. [David Nagorney, M.D.](#), a general surgeon at Mayo Clinic in Rochester, performed the complex procedure called "liver debulking." During the operation, about half of Turner's liver was removed, which eliminated about 90 percent of the carcinoid tumors present. Subsequent [radiofrequency ablation \(RFA\)](#) has further reduced the remaining tumors. Although Turner is now symptom-free, both procedures can be repeated if necessary.

"Chemotherapy has limited affects on carcinoids," notes Dr. Rubin. "It may produce side effects and the benefits may not be long-standing."

Making a list, checking it twice

"I saw two specialty physicians, two specialty surgeons and had six major tests over the course of five days. Anywhere else I've been, that would have taken two or three months at best."

After the surgeries, Turner was ready, once again, to turn his attention back to his retirement list. This time, he added a new item. "Each day I'm thankful for the specialized and integrated care I received at Mayo Clinic," he says. "I saw two specialty physicians, two specialty surgeons and had six major tests over the course of five days. Anywhere else I've been, that would have taken two or three months at best," says Turner. "I was so impressed with the efficiency of the clinic, its patient care philosophy and the camaraderie of the entire staff."

So what else was on the list? "When I turned 70, I jumped out of a perfectly good airplane," boasts Turner, who has checked off skydiving from his retirement list. "It was one of the most

exciting and exhilarating things I've ever done." And Turner and his wife plan a return visit to the Palua Islands — or Micronesia — to visit family and former students.

Turner also joined the "Southern California Carcinoid Fighters," a support group that educates carcinoid patients and their families about treatments, financial resources and other information to help patients and their families deal with the challenge of this rare disease.

Today, Turner has liver scans every three months and tests to check the serotonin levels in his blood. He takes no medications, other than a daily baby aspirin. He works out three times per week, doing both cardio and resistance training.

"Mayo Clinic doctors were successful in setting my disease way back and prolonging my life, so I could enjoy my retirement and family a little longer," says a grateful Turner. "I'm still going strong."