

A cancer masquerader

Potentially deadly, nine out of 10 times this slow-moving cancer is misdiagnosed

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of The Chronicle

Carcinoid tumors are rare neuroendocrin lesions midway between benign and malignant. They are considered "cancers in slow motion" because people afflicted with the tumors usually live for many years even though the carcinoids are often potentially fatal.

The condition and other neuroendocrine tumors are frequently misdiagnosed. In 2004, for example, Apple CEO Steve Jobs was diagnosed with pancreatic cancer and told he had only six months to live. He actually had a neuroendocrine tumor.

Ninety percent of carcinoid cases are misdiagnosed since cancer is usually coded by the region of the body, not the type of tumor, according to Kari Brendtro, a carcinoid cancer advocate originally from The Dalles. The three most common misdiagnoses are Crohn's disease, irritable bowel syndrome (IBS), and asthma.

The size of a carcinoid tumor when first diagnosed indicates the likelihood of the cancer already having spread. If the tumor is more than two centimeters in diameter, the chance of spread is over 50 percent. There is also a 50 percent chance of cancer resurgence when the initial tumor is 2 centimeters or greater.

Carcinoid tumors generally take anywhere from three to 10 years to grow.

According to the Carcinoid Cancer Foundation, the tumors usually originate in one of five locations:

- small intestine, 39 percent;
- appendix, 26 percent;
- rectum, 15 percent;
- bronchial system or the lungs, 10 percent;
- colon, 5-7 percent.

Dosier said that only 10 percent of carcinoid cancer patients experience one or more of the carcinoid syndromes symptoms, which are flushing, wheezing, and diarrhea. If carcinoid syndrome exists, it likely indicates that the cancer is already into the advanced stages.

She recommended testing for carcinoid cancer if sodium and potassium deficiencies are worsening.

"It won't be picked up anywhere," Dosier said. "You have to know what you're looking for and order the specific tests."

The Carcinoid Cancer Foundation agrees that the biggest impediment to diagnosis is not considering the disease because of its rarity.

A diagnosis can be confirmed using the 5-HIAA test, which measures how much Serotonin is being made through a 24 hour urine sample. With Carcinoid Syndrome, the amount of 5-HIAA is almost always above normal.

However, due to diet and drugs, the 5-HIAA test misses 50 percent of carcinoid cases. Other tests, such as chromogranin A, should be done in conjunction with the 5-HIAA.

The most accurate (though costly) way of finding carcinoid tumors is the OctreoScan. It finds 85 percent of carcinoids and consists of an injection of a radioactive isotope attracted to carcinoid tumor tissue.

A person can be cured of carcinoid cancer by removing the entire problematic tumor. However, microscopic undetected cells can remain and show up after many years. Even when the tumor has metastasized, making a cure impossible, surgery can diminish the amount of harmful hormones produced and increase life expectancy.

Octreotide injections can eliminate the symptoms of carcinoid cancer as well as inhibit or even reverse tumor growth.

- <http://www.gorgenews.com/news/2007/09/news09-02-07-02.shtml>