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Stages of survival: Facing the future with ovarian cancer

Jayne Solinger

The first time Patty Hennessy Dunn heard the words "ovarian cancer" from her physician, she didn't apply it to herself. The second time, when her surgeon described her condition as "cancer, stage II," she thought, "How rude."

Dunn, 34, of Minneapolis, looks back at her diagnosis three years ago as a time when "intricate denial mechanisms" operated at full tilt. "I did not equate that I had cancer."

Given the statistics facing women diagnosed with ovarian cancer, it's easy to understand Dunn's reluctance to accept it. A disease in which cells in a woman's ovaries become abnormal, multiply and can spread, ovarian cancer is the most deadly gynecological cancer and the fourth leading cause of cancer-related deaths in women ages 35-74.

At the time Dunn was diagnosed, an extreme case of toxemia had landed her in the hospital when she was eight months' pregnant with twins. Her physician performed an emergency Cesarean section and noticed her ovary didn't look right. He removed it, tested it for cancer, and was using words like "chemotherapy" and "hysterectomy" before Dunn even knew what ovarian cancer was. Fortunately her husband was able to ask questions and her family quickly congregated to offer support when she needed to make treatment decisions.

Dunn was also motivated by her two infant sons. "When I was sick, I just wanted to be there for their kindergarten," she remembered.

When Rep. Karen Clark of Minneapolis was diagnosed with ovarian cancer nearly two years ago, she knew it was a horrible diagnosis for a woman to have. A public health nurse by training, Clark, 55, considered herself healthy and had followed a vegetarian diet for years. "When I got sick, I couldn't have been more shocked at the potential diagnosis, because I do things that are supposed to prevent these kinds of things from happening."

Like Dunn, Clark happened to be in the hospital for symptoms that may or may not have been related to her diagnosis. Clark was having abdominal pain, and an x-ray showed a mass on her right ovary. Over the following days



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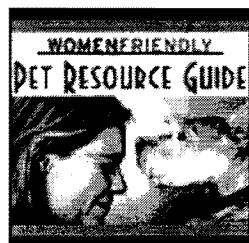
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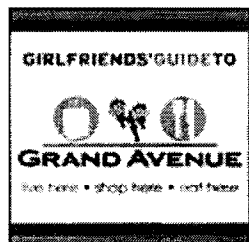


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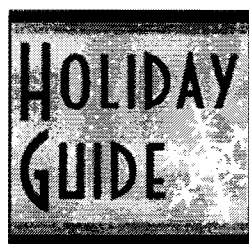


she had more tests and quickly learned to rely on her partner and a cadre of friends who joined her for every medical appointment.

Symptoms of this insidious disease, if they're present at all, are "nondescript," said Linda Carson, M.D., a gynecological oncologist at the University of Minnesota. "Ovarian cancer usually doesn't have symptoms until it's advanced." Even then, it doesn't present like a palpable lump or pain women can feel. Possible signs include stomach swelling or discomfort, loss of appetite, weight gain or loss and anxiety (see accompanying sidebar).



The causes of ovarian cancer are equally vague. Doctors do know women over 50 and Caucasian women are at greater risk. They know that a woman with a family or personal history of breast or colon cancer has a greater chance of developing ovarian cancer, and women who've never had children or never taken birth control pills are more vulnerable to the disease. Fertility drugs, if taken over a long period of time, can also increase the risk. While Dunn took them briefly, she had no other obvious risk factors.



Also disturbing is that no consistently reliable, accurate screening test to detect ovarian cancer exists. Doctors use a combination of diagnostic tools, including pelvic exams, ultrasound, and a CA 125 blood test to detect that ovarian cancer may be present, but no method is conclusive. Surgery is the only way to know for certain. At that point, the extent of the cancer can be assessed and doctors can determine whether the disease has spread from the ovaries to other parts of the body.

Clark's surgery was scheduled two weeks after her initial diagnosis. She sought out homeopathic providers for natural remedies. She drew on spiritual resources, including a healing ceremony and a sweat lodge ceremony performed by an American Indian medicine man, as well as Christian healing circles with members of her family. "It was a period of time during which I received just an incredible outpouring of love from the people who were there. And affirmations in terms of my being able to heal and survive.

Dunn didn't hesitate to embrace every treatment available to her, either. Between January and April 1998, she had three rounds of chemotherapy. While it wasn't difficult, she wasn't crazy about losing her hair. "It's like a kick in the gut when you're down. They can put a man on the moon, you'd think they could figure out a way to do chemo without having to lose your hair."

By April, Dunn had a hysterectomy. "I wanted it gone and done. I thought, 'If this helps me live, it's what I'm gonna do.'" The oncologist returned a week later with good news: The cancer hadn't spread.

With so little known about ovarian cancer, resources like the Minnesota Ovarian Cancer Alliance (MOCA) are all the more important. "So much is out there for breast cancer," said co-founder Kristin Warn. "We wanted those diagnosed with ovarian cancer to have tools to help them make decisions." Formed just over a year ago, the organization is also committed to spreading the word about symptoms of ovarian cancer and increasing awareness within the medical community about warning signs. Its first annual "Silent No More" run/walk held last September raised over \$100,000, which will be distributed for research grants in June.

Clark, whose follow-up tests have indicated that her cancer has not returned, wants to improve the odds for other women. Last session she sponsored a bill that would require insurance companies to pay for a woman's CA 125 test when it is recommended by her physician. While the test is far from perfect, it's the only diagnostic test for ovarian cancer. However, the bill did not even get a hearing because the committee chair said it would raise insurance costs. Clark believes it's an issue of fairness, as insurance is required to pay



for the test that detects prostate cancer in men. She plans to introduce the bill again this session, with language stipulating payment for "current diagnostic tests" for ovarian cancer. That way, if research develops better tests than CA 125, they would be covered.

Clark is also interested in the causes of cancer. She's long advocated a cancer registry, which would not only keep track of cancer cases, but would document possible toxic exposures in individuals and populations. While cancer cases are registered in the state of Minnesota, epidemiological studies have not yet been funded. Some research has shown a child's exposure to talc powders can increase chances of developing ovarian cancer later in life. Clark believes her own exposure to DDT, a pesticide used on her parents' farm, may have increased her risk. Studies have also shown high-fat diets can contribute to the development of ovarian cancer.

Such information may eventually be helpful in prevention, but scientists still don't know enough about why the disease occurs. Statistics indicate that birth control pills, pregnancy and breast feeding offer protection against ovarian cancer. And while having a hysterectomy can reduce the risk, doctors don't recommend it unless it's indicated for another condition.

The good news is that ovarian cancer research is not only ongoing, it's on the rise. Carson is involved in several trials at the University of Minnesota, including new blood tests that may be more accurate, treatments that stimulate the immune system and vaccines to prevent recurrence. She believes research has already shown results.

"Over the past 20 years, the survival rate has gone from a 20 percent five-year survival rate to 50 percent," Carson said. While ovarian cancer tends to recur—half of those diagnosed will experience recurrence within the first three years—treatments have improved. "Patients can live with cancer, and cancer doctors work to ensure that the quality of life can remain high. Chemotherapy agents are effective and well-tolerated," Carson said. "It's not a secondary part of what we do."

"We need to de-mystify cancer, because I think that will help us overcome it," Clark said. "Most people get the scary information and start going downhill. 'Cancer' is such a powerful word, such a scary word in our culture. Truth is, cancer is something that goes in and out of most of our lives and our body takes care of it."

The key is early detection, and that requires women know their own bodies and take the initiative if any symptom concerns them. "Don't blow it off," Dunn advised. "If your doctor doesn't take it seriously, find another doctor."

While recurrence isn't a constant worry for Dunn, it's always in the back of her mind. "You lose that freedom of just having a stomach ache. My doctor indulges every cramp," she said.

Carson agrees it's important to be vigilant, no matter what your particular risk factors. "A lot of people do have changes as they get older. If they feel their body is distinctly different than it has been, or their health has deteriorated, they should see a doctor." It's also a good idea to maintain a relationship with a physician over time; that way, if changes occur, he or she will be able to detect them earlier.

Both Clark and Dunn have learned that living well is about far more than physical health. "I've never been so clear about the importance of friendship and family and a loving partner, and what difference it makes for people to really care about each other," Clark said. Perhaps most important to Dunn are her two sons, Ryan and Patrick, now 3. Had her cancer been detected

earlier, she may have never had them. And without their birth, her cancer may never have been detected. "I think about that all the time," she said. "It's been a web of miracles."

Living through the experience has given Dunn "the mentality of an old woman." Even so, she said, "I'm excited to see what happens in my lifetime. By the time I'm 80, will women even worry about this? I hope not."

Jayne Solinger is a senior producer for the public television series "Health Diary," which airs locally Sundays at 5:30 p.m. on TPT-2, and Fridays at 8 p.m. on TPT-17.

Sidebar: For more information:

Minnesota Ovarian Cancer Alliance

1-877-569-7612

www.mnovarian.org

Women's Cancer Resource Center

612-729-0491

www.givingvoice.org

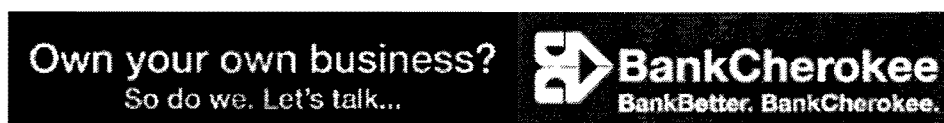
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