

Welcome to Yale Cancer Answers with your hosts, doctors Anees Chagpar and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital. Dr. Gore is Director of Hematologic Malignancies at Smilow Cancer Hospital and an expert at myelodysplastic syndromes. Yale Cancer Answers features weekly conversations about the research diagnosis and treatment of cancer and if you like to join in, you can e-mail your questions and comments to canceranswers@yale.edu or you can leave a voice mail message at 888-234-4ycc. This week it is a conversation about Edward Cantor's book, chronicling his wife's battle with ovarian cancer. Here is Dr. Steven Gore.

Gore Tell us about your wife and her diagnosis.

Cantor Nikki was in her early 60s when she was diagnosed. She had retired about 5 years before that and had begun to take courses at Yale and was enrolled in graduate school when she was diagnosed. In the beginning, there were no typical symptoms and that is one of the problems with ovarian cancer. They say you may feel some bloating in your stomach, she had none of that. There were some earlier situations which had we been more aware, I think would have kindled some interest in us to pursue that may have helped the situation, but we didn't.

Gore How did she come to medical attention?

Cantor Well she had some pain in her back, but she had had chronic back problems, so her doctor, at that time her gynecologist, ordered an ultrasound and the ultrasound by was taken by an independent physician, a radiologist and he said that there was some oxygenation that was apparent, which meant that there could have been some cellular growth that was being fed by oxygen and said that we should follow it for 90 days. At the end of 90 days, he followed through and said that this requires surgery. Had we been more alert, had the doctor suggested it, a possibility that would have occurred would have been a hysterectomy in the beginning because obviously my wife's ovaries at the age, in her early 60s and 63, were not something that she needed.

Gore But it sounds like perhaps on the ultrasound he did not really see a tumor, right?

Cantor It was not a tumor, there was just increased vascularization.

Gore I see, okay.

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Cantor And soon thereafter we were sent to Yale Cancer Center and were told that Nikki was going to be operated on very quickly. She was operated on by Dr. Tom Rutherford, who we did not have a chance to meet before the surgery. Her gynecologist up to that time told her that it was nothing that progressed to something on one ovary. Then, her statement to us was that if it is something on one ovary, it is obviously encapsulated which meant that it had not spread.

Gore Did she indicate that something meant cancer or you understood that something was cancer?

Cantor That's what we assumed, although she told us in the beginning that she did not think it was anything. When they operated, they found that she had cancer on both ovaries on the omentum which is located between the 2 ovaries and in the fallopian tubes and all that was removed.

Gore Was that very shocking?

Cantor Totally, we were not ready for that diagnosis. Nikki was in the hospital. I decided that I needed to tell her right away what had happened and she was not

prepared for it, I was not prepared for it. I told her about the diagnosis. My reaction was shock, anger, disappointment, and I then found out that within the next 2 days that she really did not comprehend what I had told her, she was still feeling the effect of the surgery and that when she next saw her doctor, who was not Dr. Rutherford, it was a doctor covering, he told her about the cancer and the spread of the cancer, so that when I saw her the next day and she no longer felt the effects of surgery, she was crying, very emotional, and very upset. Gore The diagnosis of cancer with patients and families is always a difficult one, it is one of the hardest jobs we have as oncologists, but it certainly sounds like in retrospect this whole series of events was not managed in a way that was really optimal for you guys, given that there was going to be bad news?Cantor That was before we got to the Cancer Center, particularly we dismissed the gynecologist at the time. You always think back and think what if, what if you had been aware of certain things. Well, there were 2 things, when Nikki reached menopause, she was given hormone replacement drugs as many women are, consisting of progesterone and Premarin and she was on it for quite some time and the general medical feeling is, don't stay on it forever, that it presents certain dangers. She was aware of the danger, she chose to stay on it because she reacted very badly to postmenopausal discomfort, but when she switched gynecologists, there was a mistake and the gynecologist, who eventually told us that her initial diagnosis was nothing, kept 7:13 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3her on Premarin, but forgot to put her on progesterone. Premarin stimulates cell growth, it thickens the uterine lining, that is the last thing you want, progesterone contracts that, so there were periods of months in which she was only on Premarin and not on progesterone, now we can't say that caused or accelerated anything, but it is still something that certainly wasn't good for her in her situation. So the early management before anything was diagnosed is certainly something that was questionable.Gore But it sounds like even in the hospital, the primary surgeon, again that casts dispersion in any directions, was not as available as one might like either in terms of preop meeting and postop debriefing for the two of you together?Cantor He would come at 6 o'clock in the morning and I didn't know that and Nikki was in a daze, she didn't know who he was because she had never met him and so there were several days in which I was very frustrated because I had not had a chance to meet him and talk to and see who he was. There were other people on staff, there was another oncologist, who also was a surgeon who was very nice and talked to us during that time and explained things. We were in a storm. We were taken up in a whirlwind and were carried along by the system. That was very upsetting, particularly for me who in my life had always been in control of what I was doing and what was happening and now we were part of the system and there was not a lot of personal contact in the beginning, that was remedied as her treatment progressed.Gore This was in 2003, so certainly before the advent of our Smilow Hospital, where I believe and having come from another great institution, John Hopkins, I do really believe that the patient and family

experience is a central focus of the Smilow experience now, we have a really wonderful administration, but at least back then, you didn't have that kind of experience. So here you are, she is crying, you are feeling lost, what happened after that?Cantor She was told that she would need to have chemotherapy and we gradually realized how grave the situation was. We learned that 50% of ovarian cancer patients with her level which was level 3, only 50% survive for 5 years. I tend to look at things with a glass half full, Nikki tended to look at things more with a glass half empty. So I was in a position of telling her "well, you are going to be part of the good 50%" and she wasn't so sure about that. About 3 weeks later, we began chemotherapy and the chemotherapy consisted of 6 sessions 3 weeks apart. She tolerated the chemotherapy very well. At the end of each session, she was given Neulasta.Gore It is a growth factor to stimulate her white blood cells.11:35 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3Cantor Right and that was the hardest thing for her to handle.Gore A lot of bony pain?Cantor A lot of pain in her bones. We planned things for after the chemotherapy she was going to be okay for 24 hours, then we would have the Neulasta and she would have a lot of pain for about 2 days and then that would subside so we got a period of about 10 days or 2 weeks in which she was weak and then gathered her strength and we could carry on and then she would have the next treatment.Gore Did you think about discussing with the physicians or any of the physician extenders, the nurse practitioners or whatever about the Neulasta and whether that could be adjusted or changed to something else or you just assumed this was the price of admission?Cantor We tried to ameliorate the pain and they were giving her things to do that but they did not always work.Gore So 6 cycles of this, that is over 4 months it sounds like?Cantor That's correct.Gore And then what happened? Cantor Well it's very interesting because a patient does what she is told to do and that is to follow the medical instructions and she was doing very well at the end of 18 weeks. There is a marker to show you what your levels are, called the CA125 and about 10% or 15% of people who have cancer don't register on that standard and she did not. So we couldn't tell objectively how she was doing but she felt good. Physical examinations were all positive and she was told that now, we shouldn't wait and by that time, we had gotten to know her surgical-oncologist, Dr. Tom Rutherford, who turned out to be a wonderful, wonderful guy and she was actually given her treatment by Arthur Levy, who is a terrific oncologist, a local oncologist and we waited, we sat and waited to see what would happen over the next 2 years which was going to be a marker we were looking for because if patients have recurrence, they generally happen in the next 2 years.Gore Well we are going to have to take a short break for medical minute. Please stay tuned to hear more of Ed and Nikki Cantor's story.14:22 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3 This year over 200,000 Americans will be diagnosed with lung cancer. More than 85% of lung cancer diagnosis are related to smoking and quitting even after decades of use can significantly

reduce your risk of developing lung cancer. Clinical trials are currently underway at Federally designated comprehensive cancer center such as Yale Cancer Center and at Smilow Cancer Hospital to test innovative new treatments for lung cancers. Advances are being made by utilizing targeted therapies and immunotherapies. The battle 2 trial at Yale aims to learn if a drug or a combination of drugs based on personal biomarkers can help to control non-small cell lung cancer. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital. More information is available at YaleCancerCenter.org. You're listening to WNPR Connecticut's Public Media Source for News and Ideas. Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore and I am talking tonight with my guest, Edward Cantor, about his journey through his wife's cancer diagnosis of ovarian cancer over 10 years ago. Ed, I want to make sure we have time to talk about your book and your journey, but perhaps you can summarize what happened when I left you before the break, you mentioned that she had received her chemotherapy, she was being monitored, you were hoping for good news at a 2-year mark? Cantor Everything went well. We reached 2 years without any further incident and then the next goal was 5 years and we continued to have physical examinations by both Dr. Rutherford and Dr. Levy and Nikki did well. She gathered her strength, she went back to school, she was at that time the oldest graduate student at Yale and proceeding toward a master's degree and at the end of 5 years, generally the standard is that means you are cured. Gore 2008 this would be or so? Cantor That would be 2008 and 6 months later she had a recurrence. Gore And how did you find out about that? Cantor She felt a lump in her stomach and we had had a previous appointment scheduled with Dr. Rutherford 3 days later and she went to see him and you could tell by the look on his face that it was back and so he did an immediate CAT scan, said we have to operate, this is really very unusual and very unfortunate and they opened her up and they found more tumors, a very large tumor pressing against her lung and another one near her liver, so they knew about it through the CAT scans before they went in and 2 doctors operated on her at that time. Gore Were they able to remove most of the cancer then? 17:45 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3 Cantor They removed everything that was visible, but they did not know then obviously they did not remove it all because over the next 2-3 years, she at that point began to register on the CEA-125 tests and the numbers did not come down sufficiently and it was steadily downhill. There were some really bad incidents, we did a trial with Avastin which was a drug that was being used. Gore This was a clinical trial? Cantor A clinical trial she was in, she ended up with very high blood pressure, being rushed to the hospital, having a seizure, being in a coma for about 4 or 5 days, so there were a series of misfortunes and at one point, in 2011, at the end of 2010, we were basically told, I was told, that nothing else was going to work and we had to decide whether to continue to look for the needle in the haystack without much optimism or to go for quality of life

which is the decision that we made. Gore And was hospice involved at that point? Cantor There was an early hospice program when we weren't actually in because we were still in chemotherapy when Nikki needed help at home and during that time, they came a couple of days a week, then at the end of 2010, we went into a full hospice program as an outpatient. Gore And then, when did she pass away? Cantor She passed away on July 7, 2011. Gore And did she have some reasonable quality of life in those last months? Cantor She did, and her attitude was terrific because she did not want people to look on her as Nikki, the patient; she wanted to be looked on as a real person. What held her back is that because there was an increased tumor again at the base of her lung, her lung was compressed, so she needed to be on oxygen all time, that meant that basically she was confined home, but she did the best under the circumstances and she never complained, that's what I wrote about. Gore What led you to write a book about this? Cantor Well in the beginning when she was in the hospital back in 2003, I started to keep a journal just out of my own frustration to write about what was going on and I did that during until she finished her first part of chemotherapy. Then when she died, I looked 20:33 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3 at my notes and I said, you know I think there is something here that other caregivers could use, I was the primary caregiver, and I have never written a book before, so I began to put everything together and put together, made a script, and wrote about it. When I was done, I was a friend of Dr. Sherwin Nuland, who wrote an award-winning book called "How We Die" and I asked him if he would look at this book and he said he was going away for a vacation for a few weeks but would read it when he came back. Well the next morning, on my e-mail was a message from Dr. Nuland, it said I was done packing, I was going to read the first few pages and instead I read the whole book, I couldn't put it down, you need to publish it, it's very important. Gore Wow! Cantor And that just was a great incentive and impetuous to me that carried me through refining the book, expanding the book. In the beginning, it was really too clinical, I was relying on the journal, later on I added several thousand words and made it much more personal, so it became a personal story. It became a story for caregivers, I think, but it also became a love story. Gore And when did you publish it? Cantor The book was published about a little over a year ago. Gore And how would people get a hold of it, is it? Cantor You can get it at Barnes Noble, at Amazon, at independent book stores. But it is important, the name of the book is Remember Me Living With Cancer, it is important to use the whole title, because I found out later that there are several Remember Me's, so you need to go a little further than that or you need to use my name. Gore Got it. So you say that this is really a book for caregivers, what are some of the learning points or take home points or is that just a question of knowing that there is other people out there who have been undergoing similar experiences and get validation from reading this experience of yours, what do you see as the message for the caregiver. Cantor I recall 2 questions that were put to me by friends of mine, close friends, one of them was are you afraid of Nikki dying, that was the question that I was

asked early on and I said I'm not afraid of her dying, I'm afraid of getting there and it was this torturous journey that is important to keep in mind that I wrote about. Second was do you have any advice that you take out of the experience that you can repeat to other caregivers 23:29 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3and I thought about that and the first one is to be there, to be there for your spouse or the person you are giving care to be physically and emotionally be present, even if it is just holding hands. The second is to be an advocate, because you are in a situation that you cannot control and the patient just has to follow the doctor's instructions but you need to speak up to question the doctor to ask questions to talk to friends, to tell them what is appropriate and what isn't and I think those are 2 important things that I carried forward and the other one is that a cancer death is not like dying from a heart attack, it goes on generally over a period of time. If there is a good thing about a cancer death, it's that you have time to say goodbye and I tell my friends now frequently don't wait too long to tell someone you love them, it is really important. Gore A couple of things you mentioned earlier really struck me, one that the doctors sort of took you aside it sounds like to talk to about the pathologic diagnosis or surgical diagnosis while your wife was still recovering and subsequently, later on you were told that there was nothing meaningful that could be done and at least looking at it from 2016 perspective or from my personal perspective, we really believe the patient needs to be the center of the drama and the information and it feels to me like perhaps you were put in a situation of knowing something she did not know and what was like that or am I misinterpreting the story?Cantor I think I encouraged the conversation. Early on when she had her recurrence, I talked to Dr. Schwartz and I was asking the questions, Nikki was not, and I said when you have a recurrence, what are the chances of recovery and he said, well it depends on how early you catch the recurrence and whether the treatment that you try in the early stages works, because the further out she goes, the more likely it isn't going to work and so I listened to him and I followed what he said after going through the trial with Avastin and with the number of the drugs, it appeared to me that we were just going downhill and it was not going to change. So I sought out one of the doctors and I said what is going on, where are we and he was very honest with me and he said I think at some point soon we have to talk about palliative care.Gore And how did Nikki deal with that conversation?Cantor After I spoke to the doctor, within 24 hours they spoke to her in isolative care.Gore I see, so it wasn't put in your hands.Cantor No, it wasn't and after I knew that they had spoken with her, she and I discussed and all the decisions about her treatment were made by her but we talked about them together, that was part of our journey.27:00 into mp3 file https://cdn1.medicine.yale.edu/cancer/2016%200529%20YCC%20Answers%20-%20Edward%20Cantor_254741_5_v1.mp3Gore I am glad to hear that as hard it had must have been. I think you raise really important attention to the important role that the caregiver plays but also in some ways the kind of loneliness of that position and the burden of the responsibility that many

caregivers feel or take upon themselves for better, for worse, and I wonder what kind of support you received as a caregiver, who were your caregivers during the time, did you have any, were there support groups for family? Cantor I was really very fortunate, I had a son, who lived in the next town and he was at our house continually, his fiancée was there with him, his former wife came to our house continually and our grandchildren were there and they were my primary support and my grandchildren began confronting the disease when they were 7 and 9 and we didn't know how they would react to it, but they were wonderful. By the time Nikki had died, they were 15 and 17 and they were a great source of support for me as were friends and you learn during the situation that some friends stand up for you and some disappear and that is what happens during life, but the support was very helpful. On the other hand, they all come during the day and at night, they all go home and what's left is the caregiver and the patient and it is a lonely existence but an existence that the caregiver takes on. We invite you to share your question and comments. You can send them to canceranswers@yale.edu or you can leave a voice mail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written form at YaleCancerCenter.org. I am Bruce Barber.