

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



Hosts

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Vice Chairman and Professor
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Professor of Medical Oncology

**Survivor Perspective: Linda
Yuhas**

Guest:

Linda Yuhas

Lung Cancer Survivor

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This week guest host, Peter Lamothe, speaks with fellow cancer survivor Linda Yuhas. Here is Peter Lamothe.

- Lamothe I like to start each of these survivor perspective conversations by learning a little bit about you before you had cancer. Where are you from, what your life is like, things you like to do, and then we can talk about your diagnosis and your life after that.
- Yuhas I am a Connecticut native, and I live in Southeastern Connecticut. I have a husband and two grown children and two young grandchildren, and when I was diagnosed I was already retired, but I did work for the State for 23 years as a custody mediator and evaluator and a domestic violence assessor in the Superior Court and I had been retired for four years when I was diagnosed with cancer.
- Lamothe Okay.
- Yuhas I also write and do art.
- Lamothe Excellent, what type of art work?
- Yuhas Mostly mixed media collage.
- Lamothe Excellent. Let's transition then from that to your retirement and your diagnosis, tell us about how that occurred.
- Yuhas The diagnosis took place in May. It began in May 2007 with a routine gynecological exam in which a mass was discovered on my right ovary and my doctor referred me to an OB/GYN surgeon who had an ultrasound done and decided to schedule surgery quite quickly. At that point, we feared ovarian cancer. After the surgery, we were surprised to learn that the tumor was a lymphoma, but rather than having been scattered throughout my body as often happens, I had this one discrete tumor in my abdomen, which was removed and there were no lymph nodes involved or anything.
- Lamothe Okay.
- Yuhas So the next step was to try to stage the lymphoma and I had various tests including a CT scan, a PET scan, a bone marrow biopsy, and through those tests they found

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tumors in my lungs. I had one small tumor in the upper part of each lung and I had three lung biopsies at that point.

Lamothe Okay.

Yuhas Which finally they decided were two stage I cancers.

Lamothe In your lungs?

Yuhas In my lungs, and lung cancer rather than a metastasis from the lymphoma.

Lamothe Okay, so lung cancer is the primary cancer?

Yuhas Yes, and prior to that I did not even know you could have two kinds of cancer at the same time.

Lamothe It is news to me too.

Yuhas So that was a bit of a shock. And then there was a lot of discussion. There was the referral down to Yale to talk to the doctors here and eventually a treatment plan that involved three months of chemotherapy for the lymphoma and then two months after that was completed, surgery for the lungs.

Lamothe And why was that decision made, first to have chemotherapy and then the surgery?

Yuhas It was felt that the lymphoma was curable at that point and the lung tumors were very slow growing and so the doctors at Yale advised that I get the chemotherapy first. Previously, I had contrary advise from doctors in my local area, but I decided to go with the plan that Yale offered and I did receive the chemotherapy in my local area.

Lamothe Which is important, it should be close to home.

Yuhas Yeah.

Lamothe And then you came to Yale for the lung surgery?

Yuhas And then I came to Yale for that lung surgery, correct.

Lamothe I was reading a little bit of biographical information about you and you seem to have developed a really special relationship with your care team here at Yale and I was hoping you would say something about that?

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Yuhas Well while I was still getting care in my local area I did confer with a thoracic surgeon there, whose plan was to do two separate surgeries on my lungs and that prospect was very frightening to me and about the same time my local doctor who was treating the lymphoma said, this is all getting too complicated, I am going to refer you to Yale and he sent me to Dr. Scott Gettinger who then brought in Dr. Frank Detterbeck and I felt immediately more encouraged about the outcome of the treatment. Dr. Detterbeck said that he could do the surgeries of both lungs at the same time and Dr. Gettinger was just so warm and encouraging and easy to talk to that I was immediately drawn to both of them and decided that they were the healing team that I wanted.

Lamothe Terrific.

Yuhas Yeah.

Lamothe So, it sounds like Dr. Gettinger was coordinating your care and bringing together all of the specialists at Yale, and bringing them to you in collaboration to make the best decision for the treatment course that you would take.

Lamothe Excellent, and were there any others that participated, other doctor and nurses?

Yuhas Well just recently Dr. Roy Decker has become involved because I have had further treatment that involved a procedure called stereotactic radiosurgery. And I just had that last month, and that is a process by which a tumor is treated by focusing a very narrow beam of radiation on the tumor from various angles around the body.

Lamothe It sounds like you are in great hands and you feel really good about the care you got, which I would say has a very positive impact on your attitude and many people say that attitude is everything when you are dealing with cancer.

Yuhas I would say that attitude goes a long way, we're all different and sometimes what I think has been called my good attitude was simply my willingness to let go of control and let other people take over and to trust the care that they are giving.

Lamothe That is a very very good way to put it. Thank you. So let's just back up a little bit. We have talked about your treatment and the care team. What about your initial reaction? Here you were, you had your career, children were grown, you were retired and then you get this diagnosis. Were you thinking, why me?

Yuhas Not too much, I was devastated by the diagnosis. I really do not have too many thoughts about why me because I believe that the universe is relatively random and it

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just happens, people have bad luck, and focusing on why me is not productive in terms of moving yourself into the future, what will I do now, is a more useful question I think.

Lamothe Excellent, thank you. I was told once when I asked that question of a cancer survivor and the immediate reaction was, “well, why not me?” Who’s to say someone else should get it and I shouldn’t, and so I like your thought about life being more random than we think and we just have to deal with what life deals us.

Yuhas Yes.

Lamothe Was there a major impact on you life, on your thinking perhaps, or on your outlook? Tell us about changes in perspective on your life from that day forward. How has your perspective on life changed or has it been reaffirmed by this experience?

Yuhas Well, I love my life and I want to continue to live it for a long time, as long as I can. I think that I will never be able to have the same confidence in good health or the same expectation that I will have good health that I had before I was diagnosed. There is always the sense that I could be ambushed again by a different cancer or the same cancer in other places, but I do not dwell on that, it is just there.

Lamothe Is that how it felt, like an ambush when you were diagnosed?

Yuhas Yeah, at first it was quite devastating because every doctor’s visit seemed to present me with another piece of bad news, the first doctor’s visit I learn there is something on you ovary then, yes, we have removed it, but it is lymphoma, then it not just lymphoma, there is something going on in your lungs, then it’s lung cancer, and for a while there it was just continuous bad news every time I went to the doctor, but eventually, after a period of time that felt like forever, but was really only about three months, I had a treatment plan, I had doctors that I trusted, and then I was able to focus on going forward.

Lamothe It is a very difficult time period between knowing you have cancer, and knowing what you are going to do about it, so you focus your efforts on that.

Yuhas Exactly.

Lamothe How did you then, in that period of time and even afterwards, but particularly during that period of time when you did not quite know what you were going to do and the next doctor visit could have brought more bad news, how did you share this information with people? What did you tell them?

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- Yuhas I told people exactly what was happening. I told them as I got news, and I was not reluctant to tell what I knew and right after the initial diagnosis we created an e-mail list that I used and also that my husband used to send out news to all of the people that we knew had expressed an interest in keeping up with me and one of the things that sustained me then, and sustains me still, is the tremendous outpouring of love that has come to me from my family and friends.
- Lamothe And what form did that take, what were some of the things the people said or did, and what was your response?
- Yuhas People said and did conventional things like bringing flowers and meals and coming to visit me, sending me cards, and there were some things that were less conventional. For example, I have one friend who lives in Canada who has sent me, by e-mail, an image of a flower every single day since the first day I was diagnosed and still does it.
- Lamothe Since four years ago?
- Yuhas Yes.
- Lamothe Wow.
- Yuhas When I lost my hair from chemotherapy, when it was mostly gone, I had my husband shave my head because it was just easier and one of my friends got the idea of painting my head with magic marker. So, we invested in some washable magic markers and she covered my head with flowers and vines and we would wash it off every night and then the next day I would have a blank canvas for her to start with again and eventually we enlisted some more friends and they also contributed to the project and it was transformative.
- Lamothe Wonderful, very therapeutic.
- Yuhas Yes it was.
- Lamothe Well that is a great story to enter into our break with. We are going to take a short break now for a medical minute, please stay tuned to hear more about Linda' s experience.

Medical

Minute It is estimated that nearly 200,000 men in the US will be diagnosed with prostate cancer this year, and one in six American men will develop prostate cancer in the course of his lifetime. Fortunately, major advances in the detection and treatment of prostate cancer have dramatically decreased the number of men who die from this

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disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using two simple tests; a physical exam, and a blood test. With screening, early detection and a healthy lifestyle, prostate cancer can be defeated. Clinical trials are currently underway at federally designated comprehensive cancer centers, like the one at Yale, to test innovative new treatments for prostate cancer. The da Vinci Robotic Surgical System is an option available for patients at Yale that uses three-dimensional imaging to enable the surgeon to perform a prostatectomy without the need for a large incision. This has been a medical minute and more information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

- Lamothe Welcome back to Yale Cancer Center Answers. This is Peter Lamothe and I am joined tonight by my guest Linda, who is telling us about her story of survivorship. Linda, during the break we were talking about your life and its trajectory and the new things in it and the things you are embracing since your cancer experience. Can you tell us a little bit about that? When we first started talking, you said you were a writer, and during the break you were telling me about some writing you have been doing as a result of your cancer.
- Linda Yes! I do have a blog.
- Lamothe Does it have an address?
- Linda It does. It is lindacy44.wordpress.com.
- Lamothe Excellent.
- Linda And the blog is not all about my life with cancer but there are four essays about what I call "The gifts of cancer," and I talk about the outpouring of love that I received when I was diagnosed and since, and how that supports me. I also talk about the offerings of love that came to me including several friends that put my name into a prayer circle. A couple of them were Catholic, one was Protestant, and another friend enlisted some Buddhist monks to dedicate their merit from their meditations to me. One friend burned an image of my illness in Burning Man. And what I learned was it did not really matter so much what I believed or what they believed or even what the content of the offering was, although they all were pleasing to me, but what really created the effect, the positive effect of these acts, was the love that I knew compelled them. I also wrote a piece on relinquishing control and how important it was to me to learn to let go of the things that I could not control, and then there are so many things that you can do, even though there are many things you cannot control, there are things that you can.

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- Lamothe Tell us a little bit more about relinquishing control. How did you do that? Because it sounds like a process that requires some time because it does not sound so natural to me.
- Linda It was a process of discernment, I guess you would say. I did go and learn yoga breathing at one point and I do meditate, but it was more just living my life and realizing that it was not going to serve me to try to control things, for example, I thought at first, well maybe I should try to clean out the house and make sure everything is designated where it is going to go, in case I am not here to do it, and then I suddenly realized, I do not have to do that, my children will take care of it. They might be annoyed with me a little bit if they had to, but they will forgive me, and I had an idea at one point that I wanted to write an ethical will and that is where you write down your values and your philosophy of life and so forth, and I realized there is no need for me to do that because my children and grandchildren know my values. They know what I believe makes a good life. They have rejected some of those values. They have incorporated many of them into their own lives, and there is no need for me to make a record of it.
- Lamothe It sounds a little bit too like you are saying that life is more precious when you can live life more deliberately.
- Linda More deliberately and more in the moment. I think that is something I have learned from cancer. I always knew it intellectually that we should strive to live every moment but now I feel it more deeply.
- Lamothe What type of things do you do or how do you feel it? How did you manifest it in your day?
- Linda I just try to be in the moment to have my senses alive and awake to everything that is going on and yes, I do not always succeed. There are times when I start thinking about the future and then I get all wound up in ideas about the future, but I really really strive to stay centered in the moment. Sometimes just by saying, this moment is a blessing and I am alive.
- Lamothe You definitely sound grateful to be alive.
- Linda I am. I do not want to waste the time I have here worrying about how it is all going to end.
- Lamothe I think a lot of people you hear say, gosh life is short and I have to get this done and I have to get that done, and if I am not this or that by 40 then I am really in deep trouble and all this. I hear many cancer survivors say after their experience, wow, life is a

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long time to think of all of things I can accomplish. And I can choose what I want to accomplish on a timeline established by me and with goals and objectives that will bring me satisfaction first and foremost.

- Linda And it is alright to be a little bit self centered about this because there are things that I want to experience and I have less patience for empty social obligations and that sort of thing.
- Lamothe You belong to a really special support group here at Yale, and you are smiling as I mentioned it, and I know it means a lot to you. Let us spend some time talking about that group. What does it do for you and why do you feel it so valuable?
- Linda I attend a thoracic oncology support group that is led by Irene Scanlon, the social worker, and nurse Linda David, and it meets every other week and the people in the group all have lung cancer. People of all different stages and have had all sorts of different kinds of treatments, and I find it very uplifting to spend time with them and talk to them. Irene and Linda do an excellent job facilitating the group, and it has grown a great deal over the time that I have been involved with it. The attendance fluctuates, but I would say the average is maybe 20 to 25 people every session.
- Lamothe And what do you talk about?
- Linda We talk about what has been happening with us lately; anybody that is having new issues or new treatments. We talk about what is going on in the world of lung cancer therapies. The last meeting I was at, Irene had the head of clinical oncology, and he is fairly new.
- Lamothe Dr. Roy Herbst?
- Linda Yes.
- Lamothe He is a terrific guy.
- Linda Yes, and he talked about things that are going on in research and very exciting things.
- Lamothe One of Roy's primary charges beyond leading medical oncology is serving as Associate Director for Translational Research, and taking those findings in the laboratory and making them applicable in the clinic at the bedside for a patient.
- Linda Yes! And he talked about that. That was all very encouraging and very exciting.

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Lamothe And Roy, much like our Director of the Cancer Center, Thomas Lynch, he is one of the world's leading experts in lung cancer and in translational research and personalized medicine looking at the genetic makeup of a tumor, so that the treatment the patient would receive, whenever possible, is specific to their type of genetic tumor as opposed to saying, "you have lung cancer," so this is what you will have for treatment. It is a whole new frontier in cancer research and the development of therapeutics to target those gene markers and deliver ever more effective care. Outside of the support groups, outside of your blog, what new things have you added to your life that you think maybe you would not have if you had not had this profound experience with cancer?

Linda I do not think there is anything that I have really added more to my life. Just that I approach what is in my life and what has been in my life all along with greater intensity, greater appreciation. My family is very important to me. My friends are very important to me, my church community is very important to me, and I think I just engage with them on a deeper level now.

Lamothe With, thankfully, more cancer survivors in America each year and by extension, their families and friends, how is it that you would define survivorship? I think it does go beyond just the patient to their families and friends and loved ones. We hear about the obligation of the cured people feeling compelled to give back. What are your thoughts on folks who are listening now, who may have just survived a cancer experience or who have been motivated by someone else's experience, maybe it is the death of a loved one or neighbor who have said to themselves, you know, now is the time I am going to do something. What would you say to them to direct that or to encourage it, and what you think the benefit of all that is to patients?

Linda For anyone who feels the need to take action, there are groups devoted to research and fundraising for all different kinds of cancer and I would say get involved in one of those groups, organize a vigil, organize a call in campaign to your Congress persons for the lung cancer mortality reduction act, which is a piece of legislation that is coming before the national congress.

Lamothe And what it is that intended to do?

Linda Put money for research into lung cancer. As I said, there are other kinds of cancer and each one seems to have its own organization. So there are things you can do that way concretely or on a more diffuse level. One thing that I did after I had completed my surgeries, my initial surgeries, and I was feeling a need to give something back, was I got involved as a volunteer at my local

hospital doing a gentle touch massage, they called it, and the hospital provided training and I did that for myself and for other people. It was a rather remarkable experience.

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Linda Yuhas and Peter Lamothe are cancer survivors. If you have questions or would like to add your comments, visit yalecancercenter.org, where you can also get the podcast and find written transcripts of past programs. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.