

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



Hosts

Lynn Wilson MD

Vice Chairman and Professor
of Therapeutic Radiology

Francine Foss MD

Professor of Medical Oncology

Survivor Perspective

Guest:
Peter Lamothe

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson. I am Bruce Barber. 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 1888-234-4YCC. This evening I will be sitting in for Lynn and Francine and my guest is Peter Lamothe, a cancer survivor from New Haven.

Barber Let's start from the beginning, tell me how you were diagnosed with cancer?

Lamothe Every cancer patient, every cancer survivor, has their own story. Mine is that on January 12, 2006, I woke up before work to go running and as I stood in front of the mirror in my bathroom I saw this large swelling about the size of a golf ball in my neck and I thought, where did that come from? Completely out of character for me, I said to myself, well if it is there tomorrow I am going to go the doctor. I am a guy that kind of waits for things to develop put them out of his mind and let them be, but this I thought, could be pretty serious. But interestingly enough, that night I applied some icy hot to it thinking maybe it was just a knotted muscle or something. That did not do anything. The next morning at 8 am, I went to see my primary care physician who is a terrific guy and I still see him till this day. I went in and he said that it looks kind of funny let's take a picture of it, I had a CAT scan and he knew immediately what it was and began to make some phone calls and he said to me, do you work locally, could you come back after a few hours when the scans are developed? I said sure, I will be happy to and I came back and he sat me down and he said we think this is cancer. We think it is lymphoma, you have this explosive swelling of your lymph node. And I sort of just blanked out then and I did not know what I was thinking or what I was going to do next. I remember then interrupting him and saying, "Wait a minute, did you say cancer, that can't be, that is impossible. I have run three marathons. I have run road races. We eat really healthy at home, this is not happening to me." And he said, it happens to people and we think it is happening to you.

Barber And this happened at what age?

Lamothe Two days short of my 36th birthday.

Barber No kidding.

Lamothe So on January 13th, a Friday, I was diagnosed with Hodgkin's lymphoma.

Barber You went from being perfectly healthy, living your life, running marathons, to cancer survivor in a day; two days?

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- Lamothe In a sense yes. I then began to connect the dots and realized that I was taking naps every weekend. I would wake up at 6 a.m. on Saturday, go for a run and by 11 o'clock when our son, who was not even 2, would go down for a nap, I'd take a nap and my wife would be like "What you are doing? We have things to do around the house, why are you so tired?" And I thought to myself at that time, over a period of several months, well I am just a new dad and working hard and doing all this and exhaustion is one of the symptoms and then we remembered that I had two episodes of very significant night sweats. Waking up completely saturated, the mattress, everything and those are some of the key symptoms.
- Barber I used the term cancer survivor for when you got your diagnosis because it is interesting that in the field now they are classifying someone as a survivor at the point of diagnosis.
- Lamothe Yeah, and I think it makes total sense, from that first day when you find out that you have cancer and then you find out what you are going to do about it, you are working to survive.
- Barber We are going to go through your story, but let me stop you at this point and talk about that flood of panic that you must have got. What would you tell someone else who may get that diagnosis some day? Was there something that would have helped you, is there just nothing you can do, or do you have to go through it or is there something that would have helped you get through it.
- Lamothe I think you just have to go through it. I mean it really does feel like you have fallen off a cliff and you have no idea when you are going to stop falling. Patients will often say that the most difficult period of time is between knowing you have cancer and finding out what you are going to do about it, which means what your treatment is going to be, what your options are, and that can take quite a long time, in some cases several weeks. So, I think it is important to ask a lot of questions of your doctors, to get a second opinion, everyone is entitled to that, and to think very carefully and plan, have a plan in place when your treatments begin. If you need coverage for your kids, if you need to talk to your employers, if you need to ask question of your insurer, put together a plan, knowing that it is not going to be perfect, things change from week to week, but be as prepared as you possibly can because you can do extraordinarily well fighting cancer.
- Barber It seems to me like it is almost like you have got a really bad job assignment now, you are going to go through potentially some difficult treatment, you are going to have an uncertain future, but it sounds like the answer to the question for someone would be to treat it as a job and go to work on being very active in your own treatment.
- Lamothe Absolutely, it is the most important thing you have to do every day for the next several months, and in some cases it is several years, but it is a job that you cannot take your eyes off, you have got to be very persistent and you need a lot of help, do not do it alone. You can't do it alone, get as

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much help as you possibly can, even from sources and places you did not think help would come from, or you did not think you should ask from, get as much help as you possibly can.

Barber We are speaking with Peter Lamothe, who is a cancer survivor, about his diagnosis. Let's continue, you had that initial shock, you obviously took your own advice and started to get organized.

Lamothe Yes, absolutely. And it was not me exclusively of course. I had a strong network of friends, I have a terrific wife who was there with me for every appointment, every infusion, every weekend after chemotherapy treatments when you are really low, she ran the household, answered questions of family and friends that they would not ask me such as how I was feeling, so she deserves a terrific amount of credit. I also had two friends who prior to my diagnosis I did not know had cancer, but as soon as they learned that I did, they came forward and told me about their experience and I remember in particular saying to them, this is going to sound terrible, but I am so glad you had cancer because this is going to help me a lot.

Barber Interesting, and that's something to stop and think about for a second, the fact that there were friends of yours that had had cancer, and had not talked about it. Talk about the way you deal with your diagnosis, I mean obviously you are on the radio now talking about it, so it is something you are comfortable talking about. Does it depend on each person, or is it important to share that?

Lamothe I think it depends on each person. I know people who treat this as a chapter in their life and when it is over, it is over; they do not go back to it. They keep moving forward. And I know other people who get incredibly energized and mobilized by it, and do lots of things, fundraisers and advocacy and are very much upfront about their cancer and talking about it. I think it also has to do with your personality. I feel very comfortable talking about it. I felt comfortable talking about how I felt when I was going through the treatment. I think each person has to determine how they want to, in a sense, have a relationship with their cancer diagnosis and with their survivorship, knowing too that that relationship may wane over time, or may grow over time. Not many people I know have been diagnosed since I have had my experience, but I am guessing that should a family member or close friend of mine, or a neighbor, be diagnosed, I would be there for them. But at the same time, it is a result of my diagnosis and my experience that I chose to switch careers and leave museum management and move into fundraising at Yale Cancer Center. I was living in New Haven, I am from New Haven, and I felt after my experience, which was so profound, that I wanted to do something to help people going through a similar experience as mine, and what I can do best is fundraising. That is what you do as a director of a museum, and that is what I am doing now for Yale Cancer Center.

Barber And how long was it before you started actual treatment?

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- Lamothe I started treatment on February 9, 2006. It was a little less than a month after that Friday the 13th diagnosis.
- Barber Just to fill in that gap there, what is that time spent doing? What you have described is doctors' appointments, research, and deciding on a plan of treatment.
- Lamothe Absolutely right. I had my second opinion, I had some stress tests and other tests to determine the potential effects that the chemotherapy drug could have on me. I certainly spoke to my employer, I contacted my health insurance plan, my wife and I made a plan at home for how we were going to deal with this, and so then we hit the ground running on February 9th with my first chemotherapy treatment, still not quite knowing what to expect, but we felt we had some things planned that would make it a little bit easier going into it.
- Barber Is there kind of a constant fear during this time?
- Lamothe For me anyway, there was a fairly constant fear, my prognosis was good, it was stage II of IV stages, and I was young, I was otherwise healthy and my doctor felt that I would handle the chemotherapy very well and I was able to do other things during my six months of chemotherapy, running, exercising, going to work, and eating well. You have checkpoints along the way and you hope you meet the marks. You hope that the tumor begins to shrink, you hope that you respond well to chemotherapy, you hope that your white blood cell counts do not plummet, and that you do not get sick which may interrupt your chemotherapy treatments. So there is a lot of fear, it is not always at the forefront of how you are feeling, you try to live the rest of your life and enjoy the good things in your life and have this be a part of it, a critically important part of it, but the fear is always there. The fear for me, anyways, was replaced by hope because I did respond really well, and things did go very well. I was able to tolerate the chemotherapy as best as I could. I did not have much nausea, I did not have much pain and again, I could go out running three or four days after I had an infusion of chemotherapy, and then as I got towards the end, and we will discuss this later in our conversation, but you are not necessarily done with cancer once cancer leaves your body. You are still dealing with the experience and so you often hear people say, well I am cancer free, but I don't quite feel free from cancer. That is a whole other component of having to deal with the trauma of a cancer diagnosis and a cancer experience.
- Barber When did the fear start to wane? Was it when you started getting reports back that your counts were good?
- Lamothe Yeah, the markers started to look good. The tumor was shrinking and at one point before I ended my treatment, it was clear that the cancer was no longer showing up on PET scans and so to be

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absolutely certain, we completed all six cycles of chemotherapy and then I had 13 radiation treatments to mop up anything that might not be picked up by PET scan. And then new work began, the work of dealing with the trauma of grieving for yourself. While at the same time knowing that you should feel incredibly happy that you do not have cancer, you do not quite always feel happy because you have gone through this really horrible experience.

Barber What was the timeframe between diagnosis and when you finished up the actual treatments?

Lamothe Basically, early February to early September 2006.

Barber And then after that, that started what sounds like a very profound change in your life as a human being.

Lamothe Absolutely, it was only a matter of weeks before in my mind I began to think that I wanted to do something in cancer, and so it really involved a lot of changes in our life and in the life of my family. We had only recently moved out of state to pursue a new job opportunity for me and very shortly after beginning that, I realized that it was something that meant more to the person I was before I had cancer than to the person I was going to become post cancer, and that was very difficult for me and my family. While we respected those decisions and understood them, it is still difficult to act on them, but we did it and I will be eternally grateful to my wife for supporting me during that particular time.

Barber Peter Lamothe, cancer survivor, let us talk some more about your odyssey after your treatment for cancer when we come back from this break.

*Medical
Minute*

The American Cancer society estimates that in 2010 over 2000 people will be diagnosed with colorectal cancer in Connecticut alone and nearly 150,000 in the US. Early detection is the key and when detected early, colorectal cancers are easily treated and highly curable. Men and women over the age of fifty should have regular colonoscopies to screen for the disease. The patients with colorectal cancer have more hope than ever before. Each day more patients are surviving the disease due to increased access to advanced therapies and specialized care. Clinical trials are currently underway at Federally Designated Comprehensive Cancer Centers like the one at Yale to test innovative new treatments for colorectal cancer. New options include a Chinese herbal medicine being used in combination with chemotherapy to reduce side effects of treatment and help cancer drugs work more effectively. 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.

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- Barber We are back with Peter Lamothe, cancer survivor. Peter, when we left off you were describing what happened from diagnosis to treatment, and then you described an amazing period of change after treatment, describe that for us.
- Lamothe The first thing is that I realized soon after treatment that cancer would always in some way be a part of who I was. I thought how, if that is the case, I can make that as much of a positive as possible. I thought well, I can use this experience to potentially make an impact, a positive impact on the lives of the people I don't know who, someday, will face that word cancer, will be told you have cancer and have to come home and tell their spouse, their loved ones, their family, and go through all the things that we had to go through, in many cases probably with a worse prognosis, so I decided that professionally I wanted to do something, and my background had been in museum management which is predominantly fundraising for the institution, and so I came to Yale Cancer Center to apply those skills in the development office and raise money for research and programs so that treatments are improved, patient care is continuously enhanced, and that there are more people like me who survive cancer.
- Barber How long was it after your treatments were over that you started at Yale?
- Lamothe I think it was about seven months, so I wrapped up treatment in late September 2006, and I began mid April 2007 at Yale.
- Barber It has got to be something that's amazing to bring to that job.
- Lamothe I think it gives me a lot of credibility with people who are interested in funding the things that we do, particularly if they have had a cancer experience. During our conversation I will share some information about myself when it's appropriate and you can see in a person's body language and in the things that they say that it changes when they learn that I have had cancer. When they know that we have had a similar shared experience to some degree and that I understand some of the things that they went through or their loved ones went through, it becomes a very different conversation and quite a deeper conversation, which is what I hoped would happen. That is one of the intangibles I hoped to bring to the job, which has been effective so far.
- Barber What would you say if you, as a cancer survivor, could pick an area where you would love to see more money channeled?
- Lamothe Into cancer research. We have made remarkable breakthroughs and I am not a clinician, I am not a researcher, I am not on the medical side of things, but what I do know as a cancer survivor and a person who now works in this environment is that we cannot conduct enough research, we cannot

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do enough inquiry, and the more that we ask the more that we learn, the greater the benefit to the patient and to our population. Not only for those people who have cancer or will be diagnosed with cancer, but the general population in terms of prevention and cancer control, those things are critically important and research is being done in those areas.

Barber You talked about when you were going through chemotherapy, not being really sick, is that one of the things that has come from this research; that there are better drugs now to manage the symptoms?

Lamothe I think that is certainly the case and it is not only the drugs themselves, but diet and exercise and all of these other things that a person can do. I do feel that my particular journey through treatment was certainly helped by the drugs, there is absolutely no doubt, but I think exercise, family support, positive attitude, in some cases spirituality, religion, all those things are components in getting yourself better.

Barber Let us talk about the family part of this, it must have been difficult to both be managing your emotions and your fears along with theirs and incorporating their needs.

Lamothe I am enormously fortunate because my wife let me be a cancer patient first and foremost and it was all about me getting better and so she took care of a lot of things at home that needed to be taken care of and kept a stiff upper lip when she had to, which was quite often, but in many ways her cancer experience was similar to mine. As the spouse of someone who has potentially a deadly disease, it was difficult and I think that in terms of survivorship, when you think of survivorship being broader than just the patient including loved ones and families, there are needs there for that survivorship population that often go unaddressed, and so that is a critically important area too.

Barber Did you or any members of your family avail yourself of any support groups or any extra help to get through that?

Lamothe In our particular case, we did not avail ourselves to any particular support groups, although they were there, because I had two friends who had a cancer experience and I sort of leaned on them and talked to them a lot and they were terrific. If it was not for them I think I would have joined a support group either for men with cancer, people with lymphoma, or young cancer patients, something like that to just have that community of people who understand how you are feeling that are there for you on a fairly regular basis. That are also very well managed by clinicians or social worker or people in the medical field.

Barber What do you need to do for follow-up now? You stay in good physical shape but I would imagine that you were already on that path before you were diagnosed.

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Lamothe I have a terrific doctor at Yale, Stuart Seropian, and I see him about twice a year, although I see him more often now through the course of work, bumping into him here and there, but I am basically cancer free. I am almost at five years and feeling terrific. It is kind of ironic that we are talking today, just a few days after Labor Day, because it was really Labor Day of 2005, about five months before my diagnosis that I finished a 5K, it was the first time I had run a 5K, the 5 previous years I ran the 20K. I was not up to running the 20K distance that particular year and I had a horrible race, my breathing was bad, I just knew something was wrong with me but I could not pinpoint it and never in my mind did I think I should be checked for cancer, so I finished the race and I almost passed out, but I had a decent time I would say, I was pretty happy with that, but just a few days ago I returned and ran the 20K and had an absolutely terrific race. I feel like I have come full circle.

Barber Wow! Congratulations. Let's go back to where we started which was the diagnosis which you said you had felt a little off leading up to this, but then seeing the fact that you needed to have something checked out, having gone through this, is there any way that someone listening could prepare themselves better than you were prepared. To wake up one morning, see that, go to the doctor and then pretty soon after you are being told you have cancer.

Lamothe Generally speaking people should be very tuned in to their bodies, listen to what their bodies are telling them, try not to ignore pain or anything that they think is out of the ordinary. Things of course do come and go, we get colds, little bumps and bruises and things like that, but if there is anything that in the back of your mind that is making you think twice, you should go to a doctor and have it checked out. For men and women preventive measures, whether in field of cancer or other disease areas are things that should be taken seriously. People should take their health really seriously. I felt after my diagnosis that my life was pretty short, and now I feel life is pretty long and it feels a lot better to think that life is long than life is short.

Barber How would you advise people to speak with children about cancer?

Lamothe It is hard, my son knows I had cancer, he was not quite 2 when I was diagnosed, but after when I came to Yale Cancer Center we began to talk about my work and some of the doctors and things that I do and he understands what I do and he knows why I do it and understands that I had cancer. There are obviously, as in anything, lighter moments and there were some lighter moments in our cancer experience and many of them associated with our son, who did not quite understand the gravity of the situation, but he was terrific and it is hard. I would say talk to your doctor or talk to your social worker, someone at the medical center where you are being treated if you are currently under treatment, about how to talk to your children.

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- Barber And now in your role at Yale, what is it that's most exciting? What is the great part of your job?
- Lamothe There are actually two parts that are great in my job, one is the people that I work with, the clinicians, the doctors, the researchers, all the people associated with the Cancer Center who collectively are all focused on defeating cancer in a thousand different ways or preventing cancer in the first place. The other part of my job which is terrific are the people who choose to support cancer research and programs that help people with cancer, because to see the positive feeling that they get when they decide that they are going to make a gift or they are going to do something to help the work that we do, it is really remarkable and many of them say, it I knew I was going to feel this good, I would have given money sooner.
- Barber What percentages of donors have had a cancer experience?
- Lamothe Those that I work with, if I think about it, probably all of them. In some degree or another we all have been affected by cancer. I would say that roughly half of the people that I talk to have had cancer themselves, or a loved one had cancer.
- Barber Coming back to your story, talk a little more about how you feel you are a different person now than before your diagnosis?
- Lamothe This will sound a little cliché but I certainly do not sweat as much of the small stuff anymore as I used to. I try to look at life both as a long time, a long stretch, and as a short period of time, so rather than just living life you take joy in living and you should live with some purpose and try to do new things, do not wait, do not say I will get to that when I retire, or I will try that at some other point in time. Just try it now, repair friendships or relationships, start new ones, talk to your neighbors, things that just generally make you feel good.
- Barber I would imagine you formed some pretty special bonds with your caregivers during the experience as well?
- Lamothe Absolutely, they were definitely terrific and they have really hard jobs, particularly those that deal with patients whose prognosis is not good and who face a really difficult road. I do not know how they do it, but I am glad that they are doing it because they are the right people.
- Barber Did you find there was an appropriate way to say thanks at the conclusion of your treatment to your doctor and to your nurses?
- Lamothe I don't know if there is an appropriate way other than just to be enormously sincere because that is

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how I felt and now when I see my doctors it just brings a smile to my face to see that here are people that returned me back to life.

Barber Any thought in closing that you think would help someone who has not had this conversation yet and does not think they are going to have it, or is worried that they might have it?

Lamothe Take care of yourself now, do as much as you can now to take care of yourself, take preventive measures, eat well, exercise, common sense things that often we are too busy to do or we overlook and we think we will get to it at some other point in time. I think that if you have had cancer or you have experienced cancer in one degree or another, get involved, and it does not necessarily mean donating money or going out and fundraising or running a road race, all those things are terrific, but if someone down your street has cancer, or is going through a cancer experience, cook them a few meals, shovel their driveway, offer to drive them to the hospital, take the spouse out for a drink or go to a movie, something that has nothing to do with cancer and feel free to talk to them about anything other than cancer. Just get involved in those ways that builds stronger relationships between people, stronger and healthier communities.

Barber Peter Lamothe is a cancer survivor from New Haven, Connecticut.

If you have questions or would like to share your comments, visit yalecancercenter.org where you can also subscribe to our pod cast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.