

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



Hosts

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A Survivor's Perspective: Thymoma

Guest Expert:
Pat Sclafani

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 guest host and cancer survivor Peter Lamothe sits down for a conversation with fellow survivor, Pat Sclafani. Pat was diagnosed with stage IV thymoma in 2006. Here is Peter Lamothe.

Peter Pat, we have known each other now for it seems like two or three years and we have got to know each other pretty well. Your experience with cancer is pretty inspiring and you have done quite a lot of good with it, and I never tire of hearing all of the great things that you have done and how motivated you became after your cancer experience. Let's start at the beginning with your diagnosis, can you tell us a little bit about that?

Pat I was diagnosed with stage IV thymoma back in September 2006, and it is a very rare cancer, only about a thousand cases per year in the US, so when I first got diagnosed it was a long road, it took about six months for an ultimate diagnosis to come and it was a bit of a shock. One of the things that was very-very difficult about it was that it was a rare disease and that was made known to me right from the get go, so initially, there were very few places to turn to, information about it was very difficult to get and even the initial physicians that I saw indicated to me that they had not seen the disease at all really over the past 20 or 25 years. They had seen three cases I believe. I felt pretty alone at that point and it was really difficult news to hear and to do deal with initially.

Peter Where did that occur, what facility were you in?

Pat Initially I was diagnosed up at Hartford Hospital. I had been feeling kind of, I would not say terrible, but I was dealing with fevers on and off for about two or three months and eventually I went to my GP in May 2006, and I will never forget her words when she was examining me and she listened to my chest and she said Pat, something does not sound right in there, and so from there I went through a series of diagnostics. Initially, the words were Pat, there is a little bit of inflammation in your chest and from there I went from an x-ray to a CAT scan and then from a CAT scan I had a biopsy where the procedure went through my throat because there was a feeling by those that had looked at my images and by my symptoms of having these fevers that perhaps I had lymphoma, and so the biopsy was performed in early June 2006 and it came back negative, so at the time I was told that you probably have some sort of virus, let this lay for a few months and we will see where this goes. A few months went by, I had another CAT scan and the picture was exactly the same as it was from the prior May, and at that point I was told okay now we need to do a little bit more of an invasive biopsy, so I then had a thoracoscopy which is a procedure that goes through your side, it is minimally invasive, but still an operation per se, and the initial thought after

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my thoracoscopy was that I had testicular cancer that had metastasized to my chest. After a few more days and the pathologist at Hartford Hospital really getting a good look at the cell tissue, it was determined that I had thymoma, and it was a pretty advanced form of the disease. What it actually is, is the thymus is a gland that sits in your chest, it is very involved in your immune system when you are young, but as you get older it has a tendency of slowing down, and what occurred after that in my case, was my thymus became cancerous. The thymus is encased in a fatty tissue capsule and when it is in the capsule, it is considered a benign cancer, but once it escapes from the capsule and invades the chest cavity, the various stages go from there and I was diagnosed with stage IV A. It had invaded my chest cavity, it attached itself to my left lung, it had attached itself to my aorta and it had metastasized on my diaphragm.

Peter In addition to being told you had cancer, you were told that you have a very-very rare cancer and that you had stage IV cancer?

Pat That's right.

Peter So that is like falling off a cliff three or four times Pat. How did you talk to your wife and your kids about this and then tell us the next steps were that brought you to Yale?

Pat My wife was with me the day we were told that I had thymoma and both of us kind of looked at each other and went, what the heck is this? We had been through a roller coaster in the previous four or five months, and initially we kept the information to ourselves pretty much because we had gone through such a roller coaster of not knowing what I had, did I have something, did I not have something, but it was pretty clear to me and my wife after hearing those words that day that we really needed to get in the hands of somebody that really knew something about this disease. The folks at Hartford Hospital were very honest and they indicated that they had not seen this disease very often, so I went on the internet, which is good and bad for finding out this information, but I had to determine where I could get treated in the geographic area that I lived, so I did a search on thoracic cancers and I got hits at Yale, Memorial Sloane Kettering in New York and Massachusetts General Hospital up in Boston and I made an appointment at all three and Yale was the first place that I came to. I ultimately followed up with a visit to Memorial Sloane and also consulted with the folks at Mass General as well. After my first visit to Yale, fortunately there was some time that was put aside to determine what would be the best way to tell our kids about something like this and it was great advice, and at the time my children were 11 years old and 5 years old, two little girls, and the advice we received was to be honest with your kids, tell them what is going on, they will figure it out, they are smart, if you start having phone conversations behind closed doors and you are whispering a lot, eventually they are going to realize what is going on. So shortly after coming to Yale, within a few days, my wife and I sat down with our kids and told them what dad had, and that he had a disease called cancer and that he was going to get treated and that it was

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going to take a long time, but there was a good chance that I was going to be fine so.

Peter How did your kids take that news?

Pat My younger one at that time who was only 5 took the word of her parents and totally believed it but my 11-year-old was clearly scared, as I was, as my wife was, but my 11-year-old put up a good front for a few weeks and realized what I was going through and probably three or four weeks into my first treatment, I remember one night taking her upstairs to go to bed and she was going to sleep and she looks at me and she said, dad, are you going to die? I think at that point it finally hit me what this was really doing to her and so I assured her that I was going to do everything in my power to get better and that I had great doctors and that everything was going to be fine, but for me personally, I think that was a signature moment that put me into the mode of, cancer is not going to do this to me and my family. I took the gloves off, so to speak, because it was one thing to come after me, but now this disease had come after my daughter and it was obviously upsetting her and so at this point I said to myself, when cancer took me on, it went after the wrong guy.

Peter I think that's a great way to look at it and a lot of people think of cancer affecting one person, but the ripple effect that the disease can have through that single person can be enormously profound and I think when it affects a child, it's a scary question to get, but I think that your response to it as a motivating aspect of this experience was terrific and you have done quite a bit of speaking about your cancer experience. You recently, maybe a year or so ago, spoke at the opening of the Smilow Cancer Hospital. Can you tell us a little bit about that?

Pat After I went through a series of treatments I decided at some point that I just wanted to get involved. It was sort of my way of fighting back against cancer and for me as a survivor, it sort of justifies, in some sense, that if I had to go through this and my family had to go through this, maybe if I can help somebody else out, maybe if I can hold their hand as others had held my hand, maybe I could make it just a little bit easier or give them a little bit of hope that being diagnosed with a stage IV cancer is not the end, maybe it is the beginning of something else, and for me it was a beginning of something else. It was a beginning of something that's very close to me now. I am very passionate about helping others that have been given a diagnosis of cancer and speaking at the dedication for Smilow cancer Hospital was another signature moment for me. It was an opportunity to not only share what we had gone through, but it was also an opportunity to share hope. With all the great things that are going on in the treatment of cancer these days I was living, breathing proof of somebody that can get through a stage IV diagnosis and to me, the Smilow Hospital at Yale really is a building of hope, and for me to get an opportunity to share my hope in an institution that's going to provide hope to others, I thought it was just a wonderful thing to be able to do.

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Peter We are going to take a break for a medical minute now, please stay tuned to hear more about Pat Sclafani's story of survivorship.

*Medical
Minute*

The American Cancer Society estimates that in 2010 over 2000 people will be diagnosed with colorectal cancer in Connecticut alone, nearly 150,000 in the US. Early detection is the key and when detected early colorectal cancer is easily treated and highly curable. Men and women over the age of 50 should have regular colonoscopies to screen for the disease. 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.

Peter Before the break we talked about when you came to Yale Cancer Center to meet the thoracic oncology team, tell us a little bit more about that?

Pat When I showed up to visit the team for the first time, all the folks were really tremendous and my wife was with me that day and the first person we met was Irene Scanlon and Irene is the Social Worker for the TOP team and I have told this story quite often, the first thing Irene asked was she looked at me and she said, how are you doing with all this? It was not how are you feeling, it was not a clinical question, it was just how you are doing with all of this? And then she looked at my wife and she said, how are you doing with all of this? We both responded the same way. We're not doing so good, we're not great, but that was the theme of the first visit that day, how are you doing with all this and we know you have a family. It was a clinical visit from the perspective of yes, you have thymoma, it is stage IV, but it was more about developing a relationship with us and really expressing their concern that we would be treated in a fair and compassionate way and that message was clear from the first day we were there.

Peter That's terrific, that's good to hear. Tell us a little bit about coming out the other side, you came into this and it was remarkably startling to be diagnosed with cancer and to be told that you had a very rare cancer and stage IV cancer at that, you went through it, you and your family fought very hard, you were fighting not only for yourself but for your kids and the people who love you, but then you are done, in a sense, with your treatments and the tether that you have to the disease and to the people that care for you is kind of broken. You have done it, you won, you have beat

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cancer, but I think as people who are listening who have experienced cancer can attest, you don't quite get back to normal right away and you are not quite able to close the door on cancer as quickly as you think you might be able to as you are going through it, and I think things change fairly profoundly for people. Could you comment a little on your experience in that area?

Pat Getting diagnosed and hearing those words is the hardest thing. Going through treatment, although it's really-really hard and in my case I went through chemo and surgery and radiation and then more chemo, it's really hard, but you are focused on that and you have this connection to the people that are treating you because they see you every week, sometimes twice a week and you have that total feeling of ultimate care but then when it is all done and you go in for your final evaluation after all your treatment is done and you hear the words Pat, there is no evidence of disease we will see in three months, if getting diagnosed is the hardest, the day after that and moving forward is a real close second. You suddenly don't have that care net around you 24/7. It is not as though your physicians and the support staff don't care about you, but they have gotten you to this point, now having to wake up every day and realize that you are not going to see your doctor next Tuesday, that you probably won't see him for three months, is a really tough thing to get through, plus after you go through a lot of treatments there are a lot of aches and pains, a lot of weird things that you feel and once you are out a couple of months and all of a sudden you get some kind of strange pain in your abdomen, you go what was that? From an anxiety perspective it is really tough dealing with it initially when you get done with your treatments.

Peter That segues nicely into something we both care a lot about based on our experiences with cancer, and that is survivorship. We hear a lot about survivorship, everyone knows about Lance Armstrong's story and the work that he is doing, the work that lots of people are doing in survivorship, but we often don't hear as much as I think should be heard about survivors themselves and the needs that they and their families have. Could you talk a little bit about those first three, six, or nine months afterwards, how you felt, what you thought, feelings you had, because I think it is a profound shift, as you said, from being in treatment and then being cancer free and then returning to your life, whatever that's supposed to look like, and feel like.

Pat Fortunately for me, the folks at Yale in TOP had warned me that this was going to be tough, but I am euphoric at that point feeling I have beat this, but I was not really quite prepared for what for me was well over a year to deal with all of that. At some point, after probably a couple of months, I realized that my clinical treatment was over, but my emotional treatment, my mental treatment, that was not over. I still had cancer. I still felt like I had cancer. I could not do the things that I wanted to do. I could not get on my bike and ride 100 miles, as I had not recovered yet from everything that I went through, but it was during that period, and I can't tell you what the moment was, but I started to realize my treatment as an individual, as a survivor, had to continue and what was I going to do to make that happen? I got very focused on taking care of myself, very focused

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on my nutrition, very focused on my after care, very focused on my ability to deal with anxiety, to deal with stress, things that I needed to manage in my life in order to start to feel better, and so in essence my treatment has never ended, but it's gone from clinical treatment to personal treatment and it is really about focusing on well being, focusing on wellness, for me it's focusing on nutrition and exercise and really doing things that keep my system, my body, as healthy as it possibly can be.

Peter And you had a fairly good support network to help you to that?

Pat I ultimately reached out to a nutritionist and worked with that person to figure out what I needed to maintain nutritionally in order to keep my immune system at a high level. I actually visited the survivorship clinic at Yale, where I had an opportunity to speak with a nutrition person there, as well as I saw an additional oncologist to get some additional feedback on things that I might be dealing with after my chemotherapy. I was also able to meet with a counselor to discuss some of these things, so I think over time the more and more you network as survivor, the more people you get to see what they're going through, how they are dealing with it, whether it's from an emotional perspective or physical perspective, as your network grows you get to know more things and you can sort of put that in a package that's good for you.

Peter It sounds great, so in some ways you are kind of an elder statesman of survivorship now, you have gone through the experience, you have passed from the clinical into the survivorship period, and now you have been in that for a considerable period of time reaching out and helping other people. What would you say to someone who has a favorable clinical outcome, is approaching survivorship and preparing for that tether, that link to the clinical side, to end? What you tell them, some things that they should be thinking about or planning to do in the coming weeks and months?

Pat I think the first thing is to realize that as it is handed over to you as a survivor from your clinical folks, there are things that you can do to take control and for me it was becoming my own clinician if you will. It's important to focus on keeping healthy, on preparing yourself for the future from a health perspective and anything that you could do to feel like you are in control, because cancer tries to take control away from you and then you rely on this clinical team to help you get to that other point, and so then you have to take control back, you have to take control back of your life and be able to make decisions based on your health and not cancer dictating those decisions. It is a tough transition, but once you do something for yourself once or twice, for your own health and well being, be it nutrition, looking into taking a yoga class, or doing something for fitness, even just going out for a walk on a regular basis, it becomes easier.

Peter I remember after my experience when the clinical side of cancer ended and then moving through

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survivorship, a close friend of mine said to me, it is okay to grieve for yourself, and I am wondering what you think about that and if there was an episode for you after your clinical experience where you said, now that I am not fighting this day in and day out, and I have some time to step back from it, whether you could grieve a little bit, you and your family?

Pat I think the grieving aspect, when you are getting treated you don't have time for it, you just focus on trying to get well. I think when you get diagnosed you get hit over the head and you grieve for a short period of time, but then you think okay I've got to get after this, I've got to get to people that can help me and let me get focused on this and let me get through my treatments and let me do what I have to do. Afterwards, I think for me it was over the course of probably a year, every time I did not feel right, when there was a pain, and I had all sorts of health issues afterwards due to my treatments, I think when those things happened, yeah I did feel sorry for myself and there were times that it was why me, why me, but until you start to turn it around, until you can try to take from it what it wants to do to you, which is beat you down, and turn it on its back and try to do something positive with it, I think those moments become less and less.

Peter That is terrific. Pat, we have just a minute left. We will end on a very positive note. We are both very knowledgeable about lots of the things that are happening in the cancer field now in prevention and in research. Tell me what really inspires about what is happening at Yale Cancer Center and Smilow Cancer Hospital?

Pat I had my first appointment at Smilow Cancer Hospital just about three weeks ago and three or four years ago when I was first diagnosed it was just a hole in the ground, it was not yet even framed out, but the thought was gee, how great is it going to be when all the facilities for cancer patients and their families are in one building, and as I went through my treatment here I was all over New Haven getting various aspects of my treatment or testing, so I had the opportunity as a patient to go into Smilow for the first time a few weeks ago and I cannot tell you how much easier it is having all of the facilities in one building and to just go from the fourth floor to the second floor and from the second floor to the fourth floor as opposed to going to a building down by Long Wharf to a building in the middle New Haven. The facility to me just expresses hope. There is a feeling of hope in the building, it's a bright beautiful building and I think when you have a world class facility, you will have world class people, and I think there is great opportunity here for doing some wonderful things.

Pat Sclafani and Peter Lamothe are cancer survivors. If you have questions or would like to share your comments, visit yalecancercenter.org where you can also subscribe to our podcast 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.