

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Survivor Perspective

Guest:

Gregory Walsh

Lymphoma Cancer Survivor

Yale Cancer Center Answers is a weekly broadcast on **WNPR** Connecticut Public Radio Sunday evenings at 6:00 PM.

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Welcome to Yale Cancer Center Answers with your hosts doctors

Gore. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at the Yale Cancer Center. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital and Dr. Gore is Director of Hematological Malignancies at Smilow. Yale Cancer Center Answers features weekly conversations about the research diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about lymphoma with survivor Greg Walsh. Here is Dr. Steven Gore.

Gore Can you tell us a little bit about your story, what kind of cancer you had and when you were diagnosed? How did you find out about it?

Walsh Sure, it was lymphoma, B-cell lymphoma and it was in 2008. I had just begun my second year of teaching and the summer before that I had bought a rental property, so I was working all summer on that and I think in June I started experiencing lower back pain and sciatica symptoms and in my early days I had recovered from something called reflex sympathetic disorder and I have been through a whole process of surgery and all these other treatments and the only thing that worked was a mind-body technique that I had learned. It was the mind-body connection idea and I cured myself of that pain disorder. So when this happened, I thought it was the same thing coming back. So the whole summer I practiced my psychological techniques on this pain that was progressively getting worse. I had all the classic symptoms of lymphoma, although I did not know what they were at the time, the swollen ankles and loss of energy and all those things and somewhat foolishly looking back on it, I just delayed, and delayed, and delayed until I finally went to see my doctor and he pretty much knew what it was right away. He had a good sense but he was very gentle. He did not want to make any calls right then in terms of what it was, but he said, this could be serious. And from there one thing led to another, I went to Bridgeport Hospital initially and they suspected that it was lymphoma. Scans were done and I got the call. I believe it was in early October that I heard from the doctor there. The first thing he said is that it was a “good cancer” to have because prognosis is usually pretty good, even if you are at high stage of diagnosis. So that was a relief, and we went from there to a couple different doctors and then I ended up at Yale Cancer Center, and Smilow.

Gore And did you have to have a biopsy done of the tumor somewhere?

Walsh I did, they took bone marrow out. It was at the base of my spine. It was hard to get into that area without destructing nerves, but they did do a biopsy as I remember, and it took a long time to identify and that was challenging to deal with. They finally identified it and nailed it down to the particular type of lymphoma and at that point, I was getting ready for treatment and ready for the challenge. I was very gung ho in the beginning. I thought I had a great fighting attitude at the start. That did not last forever, but it came back later on in my treatment, which was good.

Gore How old were you at that time?

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Walsh I was a very active 38-year-old.

Gore What was the treatment like? How were you treated?

Walsh Because the location of the tumor was at the base of my spine and there was a potential for it to enter the spinal canal, and I did not know anything about lymphoma at the time, that it was this cancer that could spread and they were very much concerned about that and that there could be some kind of infiltration into the brain. So they were very aggressive. It was a very dose-dense treatment and I took off work, I think I left work the last day just before Thanksgiving and I did not come back until June. I responded very well to the chemotherapy and so after the first scan showed that there were no longer any cancer cells alive, I was very much encouraged, but as a cancer patient you know that you are going to go through the course and that is two or three or four more treatments. I think they were scheduled for every two weeks but a couple were delayed so it averaged out to every two to three weeks, but I think I finished treatment around January and then I went for radiation a few months later.

Gore And the radiation, was that to the original area of the tumor?

Walsh Yes, very localized to the pelvic area.

Gore You said that there was a time when you were gung ho, but your fighting self was getting a little tired, what was that like? When did that happen?

Walsh I approached the whole idea of being treated for cancer with equal parts of fear and positive attitude, it was a little strange I guess. I was more afraid of the treatment than the cancer itself. As I said, I was a very active 38-year-old. I did not know what I was going to be like physically after treatment. I did not have a sense for that and I was really concerned about coming out of treatment so I was going to do everything I could on my end. I consulted with a Chinese medicine specialist and she put me on a diet to support me through chemotherapy and I had a great attitude, I was going to do everything I could. I was not just going to rely on the treatment and I was positive and then just prior to the first chemotherapy treatment at the latest scan, they had scanned my entire upper body, and it came through and the results came in while I was in the waiting room ready for treatment, and it turned out the cancer had spread and I hadn't accounted for that possibility.

Gore That was before you started treatment?

Walsh It was the day of treatment, and nobody knew that at the time, I had been scanned a couple of times I believe, and went through the biopsies. None of that was known. So, the idea that the cancer could spread was a new thing and it pretty much crashed my attitude. I was terrified. I am not afraid to admit that I was terrified by that and it became very real that this was a life or death_

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situation potentially, and that really changed my view for a while. I realized that this was not going to be just me. This was going to be very seriously relying on other people to save my life potentially, and all of a sudden the relationships in my life became very, very important, much more than I realized before because it is not just you. You have to rely on other people and thankfully I have an incredible family. My work family was just incredibly supportive. They donated personal days. I did not have enough personal days to take the time off so Bridgeport City teachers donated about 60 personal days. My students sent me, I have piles of letters, they made videos, my parents, and my brothers and sisters, there was at least one person at every doctor's visit. I think the first doctor's visit, they did not have enough chairs in the doctor's office, they had to bring in more. That sort of thing, and that really affects you on multiple levels. Especially someone like me because I have always been very much of an individual and did my own thing and to realize all those people in your life, show up at your doorstep the moment you need them and it was a big change for me to rely on the people of my support system.

Gore That is great, and how rough was the chemotherapy for you? How difficult was the treatment?

Walsh You know, five years later, it is hard to remember exactly to be accurate. I almost think that it was not that bad. It certainly was not as bad as I feared it would be. My energy level never got that low. I lost the hair on top of my head, but I was never nauseous and I ate really well, and I do not think it was that trying of ordeal and the same went for the radiation. It was not that bad.

Gore And you seem to have liked the bald look so much that you have maintained it. For the studio audience, Greg has shaved his head.

Walsh Yeah and I get a lot of comments now from my students. You look good Mr. Walsh, but you need to grow your hair back. Actually one of the things I did was I joined a support group. Dr. Bernie Siegel runs a support group and a page I took out of his book was that he shaved his head as a reminder of the importance of the work he does and so I kind of did the same thing as a reminder to take care of myself, because it is very easy to get unbalanced and to work harder than you really need to and to forget about taking care of yourself in terms of your health and it is a constant reminder to take care of me, so I do not end up in the same position again.

Gore That is really fascinating. I heard Dr. Siegel talk when I was a medical student here, which is quite a long time ago, and I got a lot of jewels or pearls out of that talk, but the most important thing to me was at that time, this is around 1980 or so, I was not using my seatbelt regularly and Dr. Siegel started out his talk to a bunch of students and nurses and doctors by asking us how many people wanted to live, and everyone raised their hands. He then said, how many of you always wear your seatbelt and everyone's hands went down, and I have these patients who are struggling, exceptional patients, who are surviving cancer and they have got real problems and you have got something you can do to save your life every day and you are not doing it and that was just profound for me, but he also talked about the shaving of the head and why he does that so it is pretty interesting.

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Walsh Yeah and attending those meetings, the support group meetings, there was a lot of what you just described. He really brings things down to a very concrete level. He is very pointed and he does not sugar-coat anything. You know, this is real life. This is real life and death and he will ask you certain questions that make you question, where am I at in this decision, whatever that decision may be, where am I at in my treatment? What am I doing? The thing that I remember most from those meetings is, I was struggling with fear and he knew it and he said, well can you look beyond the fear and ask yourself very simply, what is your potential? And I really thought about it and that really hit me hard. I thought about, assuming I come out of this, what is my potential? What am I going to do with this at the other end, what is your potential as a human being and that has really stuck with me. It has made me become a better teacher, a better family member, and just to live life like there is no tomorrow. Every single day, be as present as possible.

Gore How long were you in the support group for?

Walsh I think it was about five or six months during treatment.

Gore We are going to want to speak more about the support group and your experience with your treatment and what has happened since then, but right now, we are going to take a short break for a medical minute. Please stay tuned to learn more about Greg Walsh's journey through the treatment of lymphoma.

Medical

Minute It is estimated that over 200,000 men in the United States will be diagnosed with prostate cancer this year, with almost 3000 of these diagnoses here in Connecticut. One in six American men will develop prostate cancer in the course of his lifetime. Major advances in the detection and treatment of prostate cancer have dramatically decreased the numbers of men who die from the 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. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for prostate cancer. The Artemis machine is a new technology being used at Smilow that enables targeted biopsies to be performed as opposed to removing multiple cores from the prostate for examination, which may not be necessary. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. More information is available at yalecancercenter.org. You are listening to the WNPR, Connecticut's public media source for news and ideas.

Gore Welcome back to Yale Cancer Center Answers. This is Dr. Steven Gore and we have a special guest tonight, Greg Walsh, who is a survivor of lymphoma. Greg, before the break you were telling us about your experience with what sounds like a very wonderful support group run by Dr.

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Bernie Siegel who many people will know of as the surgeon who has written things like *Love Medicine and Miracles*. He is very interested in the mind-body connection and people's ability to take some control over their cancers, correct?

Walsh Yeah, in fact I read that book years before, so it is familiar and luckily Dr. Siegel lives here in the state and the support group was only about a half an hour from where I live. So, showing up on a Tuesday night was very easy and I think that it really opened my eyes to a lot of things. There is this whole other spiritual side when we are going through cancer treatment and it is an opportunity for learning where you are along life's path and Bernie Siegel talks a lot about the unconscious mind and trying to use your understanding of where you are at on different levels to support your journey through treatment. So, he talked a lot about meditation. There was meditation every meeting and I used meditation throughout my treatment as well for anxiety and also to think about my connection with everything around me, and what is my place here? What does it all mean? One of the things that Bernie Siegel said to me at some point, I do not remember exactly when in the course of treatment, but it was a time where I was pretty low, he just said, he looked me right in the eye and he said, ask yourself what your potential is and he let it go at that and that hung with me and I thought well, there is a good chance I am going to make it through this and what is my potential? Who am I? What am I doing with my life? And how can I be of service to others? And I think going forward through treatment it made me a much better teacher. It made me care a lot more about my students and the people around me and their experience within my classroom. It made me care a lot more about my family, the people I am close to. I spend a lot more time now than I did then with my family and friends. What your potential is can mean any number of things.

Gore It sounds like in some way, and not that anybody ever wants to have cancer, but it sounds like it has played a very important part in self-actualization and moving you to the next level as a person. It was not completely a negative experience in some ways.

Walsh It forces you to look into the mirror and ask a lot of questions, and absolutely I could not agree more, maybe not self-actualization yet, I am only 43, but hopefully I am on the road, but yeah it makes you look at how you are spending your time, how you are taking care of yourself. That was a big change for me. I was pretty healthy other than having lymphoma prior to that.

Gore Oh, there is that.

Walsh Yeah, there was that, but I was not really putting the effort that I felt I needed to into diet and exercise and all that changed afterwards, because again it forces you to look and see, and say, it is impossible to say why this happened exactly, biologically, but what are the things that I can do to put me in that segment of the population that does not get as sick or does not have to go through this again and I was very much willing to do all of those things and continue to do things now. So, yeah it does. It definitely wakes you up in a lot of ways.

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Gore I am interested in the lifestyle changes that you made at this point, five or six years later, do you feel like you are maintaining those lifestyle changes because they have just become the norm for you or is it really a conscious effort in the same way that shaving your head reminds you of cancer, your experience with cancer, and how is that working for you, these changes and that you are sustaining them, which I think is unusual.

Walsh I think it is easy to slip. We live very busy lives in our culture and it is hard to make that time to stay focused on that. I am not perfect but I do spend a lot of time, I follow a macrobiotic diet, which is a lot of grains and vegetables, plenty of protein to, but it is a lot of work to be prepared. I spend a lot of time in the kitchen and I get a lot of exercise and am much more active than I was, even though I was fairly active before. I do a lot of running and hiking, a lot of cardio exercise and the exercise is easy, because it is very enjoyable and I know I am missing it when I have not done it for a few days. So that is a constant reminder. With the food, like I said, it is easy to slip, but in the back of my mind it is always very important and actually if I go off my diet for too long I notice it, I do not feel as well, and I think that after going through recovery from cancer, I am much more tuned to that feeling of, I am not feeling as well. So as soon as I get that feeling, there is kind of a switch that goes off in my head and tells me to get back on track. So, it is much more of a norm than it was before. I am much more conscious of my diet than I was prior to starting macrobiotics. So, it is a norm, but it is easy to slip too.

Gore What was that like sort of re-entering the world, once you were done with your treatment? Tell us about that.

Walsh I noticed there were some symptoms physically, the first thing that comes to mind are the physical symptoms. My eyesight was a little blurry. I was a little shaky, my balance was a little shaky and teaching physical science is a very active job, I am rarely behind my desk and there are a lot of physical experiments the kids do with forces and motion, and that sort of thing, so if I am teaching forces and motion as a teacher and I am off balance physically it can be a little embarrassing, but I noticed that, so I was not feeling like my normal self. I did have a little lack of energy, but it did not take long for that to come back and my sense of balance came back really quickly. I did notice that people treated me differently, not in a bad way at all, but they were more attentive to me, how are you doing and that question that all cancer survivors get, when was your last scan, and some other questions, are you doing okay, and it is not just how are you doing today, are you doing okay? It is *how* are you doing? Basically, are you doing alright in terms of your recovery without saying it. And of course none of that bothered me. Again, my work environment, the people there were super supportive all the way through and still are. So you are treated a little bit differently I suppose, but as time has gone on a lot of that kind of melts away, and I do not feel that much different than I did I think before in terms of re-entering the world. You feel like you have an obligation, at least I did, to teach health, even though it is not part of my curriculum. And not just with my students, with people. I talk about my diet a lot and I am asked a lot because I bring very

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strange food to school and they ask, what is that Mr. Walsh? What you are eating? That is very strange. Why do you do that? And I always have the discussion and I am very up front with my students, even those that were in second or third grade when I was out of school for treatment. I think it is very important for them to learn about health. So, you do feel an obligation to share what you learned about living a healthy lifestyle.

Gore Do you worry about your cancer coming back?

Walsh Not on regular basis, I do not worry too much. It has been five years and five years is a pretty good milestone for that, and with the things that I do to take care of myself in my back pocket, I think there is more of a barrier between me and it coming back, but you never know, anything can happen. So the answer to your question is, I do not worry much about the cancer coming back and the other thing about that too is the worry going through this process, and practicing living in the present moment, I do not want to spend any time worrying. So that is another switch that goes off as soon as I get into that worrying, and if I do, I remember what I learned from Bernie Siegel and all the other things that I read is, "it is your right not to live in that space of fear, it is your right to soak up everything that is around you, every single day, every single moment" and that is not something that comes easily for anybody. Cancer certainly propels it and I am very grateful for having that outlook and that ability to kind of come back to right now and just enjoy it because, again, you do not know how long you have. Another great thing that Bernie said was, some people have lives that are like a long tall candle, and some are really short ones. You have no idea what it is going to be like, just be here now.

Gore You were mentioning to me before we started that you have been involved with some survivorship groups.

Walsh Yale has a lot of great programs for people going through treatment from yoga to meditation, exercise classes. So I took advantage of every single one I could and met some wonderful people. They were very helpful. I found that everything about my treatment and my experience at Yale was just a very warm environment all the way through and I am grateful, I actually credit my brother because initially he got on the internet and found who the top oncologists were in the particular cancer that I had and he found Dr. Foss here at Yale and I think it made a world of difference for me and then being here at Yale, again these survivorship classes, a nutritionist, everything that I was able to avail myself of was very, very helpful.

Gore That is great. I am wondering, in your experience with these support groups you likely met some people who did not do as well as you, is that true?

Walsh It is true, and especially Bernie Siegel's group, I remember one guy I became friends with who passed away before I finished treatment and he was a young guy very successful, beautiful family,

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and it was really hard. I saw him in the ICU shortly before he passed, it is a very difficult thing to be a part of but, you are part of it. When you attend those meetings, you are right there with people on the edge of life and that is a very special place to be. Again, like I said, it opens your eyes, but it can be very emotionally draining and it really puts things in perspective when you look at somebody who is on that edge and who has such a great life and does not make it and oftentimes the spouses, my brother came with me to several meetings, you meet the families, and it is a hard thing to see, but you also want to be there for those people. That is part of your recovery too.

Greg Walsh is a lymphoma survivor. We invite you to share your questions and comments and you can send them to canceranswers@yale.edu or you can leave a voicemail 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 hoping you will join us again next Sunday evening at 6:00 for another addition of Yale Cancer Center Answers here on WNPR Connecticut's Public Media Source for news and ideas.