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Survivor Perspective

Guest:

Peter Debona

Glioblastoma multiforme 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 and cancer survivor Peter Lamothe continues his survivor perspective series with Peter Debona.

Lamothe Before we start to talk about your cancer diagnosis and your experience with the disease, I would be interested to know a little bit about you before you had cancer, and I think our listeners would too. So if you could spend a few minutes telling us about yourself?

Debona I was a manager of customer service for a large water utility here in the State of Connecticut. I had thirteen departments with almost 50 some odd people, and I ran around thinking of nothing but making money so I could retire early, and that is where we begin the trip.

Lamothe And are you from Connecticut?

Debona Actually, I'm from across the border in Port Chester, New York and that is where I was born.

Lamothe But you spent most of your life here in Connecticut?

Debona Yes.

Lamothe Tell us then about the transition from a life without cancer and thinking about retirement to one suddenly consumed by a cancer diagnosis.

Debona I was teaching a customer service course at one of our water plants, and the water plants are usually hidden because the public does not like to see them and it is down a long road, so I got up, got dressed, and went to do my talk for them and show them what they needed to do with customers, came back down from the plant, stopped at the bottom where there was the main road. At that point in time I knew something was wrong because my brain just stopped working. I had no idea which way to turn and I had been there at least 25 times before.

Lamothe Wow.

Debona So I called my girlfriend at that time and we set up an appointment with a psychoneurologist and he gave me three tests, each one of which I failed. So he said to me well it is either a cyst or a brain tumor, and he suggested I see a surgeon and get an MRI, and that is exactly what we did.

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And when that was over, I went to see the surgeon, and he wanted to immediately put me in the hospital and operate because it was called a glioblastoma multiforme, which in effect is a GBM, it is the highest grade of tumor, it is called a 4, and there are three other grades and most people with this live less than a year and because of where mine was located, they determined I had about three months to live.

Lamothe Wow, and how old were you?

Debona I was 51 years old.

Lamothe Tell us more.

Debona Well I had a tough time telling people that I was going into the hospital for surgery. Another fact that really upset me was that my son had asked me to be his best man and that would have been on the date of the surgery. So I went back to my surgeon, and I explained the situation to him and I said we will have somebody bring me there, the wedding was going to be in Massachusetts, and we will have somebody drive me back, and he says, Peter, you and I have different realities. I know how fast growing this tumor is, and if you care to do this, I will allow you to do it, but just be aware that it can grow exponentially every week.

Lamothe: Wow, so the clock was really ticking here?

Debona I did not want to get surgery before and have an effect on his wedding.

Lamothe So now you have this devastating diagnosis to deal with, but then added demands on top of it, so what was your decision and what happened?

Debona We decided to go. I have a daughter, but he is my only son and he was getting married. This is his first and only marriage and I decided that I needed to do this for him. So we had some good friends of ours drive us up, half of my family was there and it was nice to see them, as a kind of going away thing, I did not envision living much longer because I had not had a chance to study anything. And when we got back home I had no time either because we got home on a Sunday and the surgery was on Tuesday morning and of course on Monday night I did not sleep, trying to think of everything I needed to do. Monday we ran out and got wills and I never had a will drawn, but I needed to do something, my children I do not think would have let me go if I was a vegetable and I know my wife who was a nurse would have the foresight to say what she had to say.

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Lamothe So you were really putting your things in order and putting your faith in your doctors?

Debona Yeah, I had to. I knew nothing about this and being a businessman, the fear of not knowing was just overwhelming to me, as this was so much information to absorb and when we got back from the wedding and after I started recuperating, we had no computers, no laptops, nothing, so through research in a library I found a place called MedSpan and I wrote to them and asked them what it would cost to have everything about a glioblastoma multiforme brain tumor and they sent me about 2 inches, and I came to find out that yes, most people do not live a year. However, it is on a bell curve, so you have infants and toddlers on one end of the bell curve and we have the infirm and elderly on the other and there is this big group in the middle who does not overly live, but a good three to five years. So I decided that was what I was going to shoot for, it was the only hope I had.

Lamothe Absolutely. Tell us more about what happened as the surgery was completed, you come out from surgery and are feeling what?

Debona Well my wife said that she would be at my side and I woke up and she was not there, and the nurse was sitting by my bedside and I asked her where my wife was, and she got all upset because I started talking right away and no one knew what kind of condition I was going to be in. So she made a couple of calls and my wife came in and we had a good cry together and that was about it. Actually before the surgery, I forgot to tell you a funny story, we had a shower in my room and the nurses all brought their cups and their little decorations and stuff. So, yeah it was really something else and we were also the first wedding to ever get held in St. Raphael's chapel, which was kind of exciting.

Lamothe That's amazing.

Debona I made a deal with my wife that if I lasted a year, we would throw a party and we did, like 125 people and everybody had a great great time.

Lamothe That is terrific, so besides your surgery were there any other components to the treatment that helped you get better?

Debona Yeah, my radiologist, which is another funny story. He says, we are going to do six weeks or seven weeks of radiology and you will not get tired until towards the middle of it or so, it will cause some slight reduction in your memory and that kind of stuff. He says if you are lucky enough to reach a year, then you will have some severe memory shortage. So I said, I do not really care, let me live a year, and so we went from there and the radiation was finished in 7 weeks. I got one week off for good behavior, and then I met my oncologist and I did not like him from the start

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as he was very matter a fact, you want to live, you are going to do this. I said, okay, tell me what I have to do. He says you have to do six rounds of six weeks. Three weeks of taking pills and shots and three weeks to recuperate from pills and shots. So I said, why do you know it's six rounds, why can't it be five or seven, and he glared at me and said because we know its six, and that was the end of that but I will tell you he has gotten to be the guy I love the most.

Lamothe That is terrific.

Debona Every time he sees me he says to be very careful crossing the street.

Lamothe Good advice. So surgery, then fairly intensive chemotherapy?

Debona: Yeah, well it is not like today. The surgery was so vial that I had to take special pills, as not to get my stomach upset, and it kind of screwed up my stomach forever and I never got over it.

Lamothe Remind us again your age and in what year you were diagnosed?

Debona It was 1994 and the diagnosis was glioblastoma multiforme.

Lamothe And you were 51.

Debona So after that year, I made a promise with my god that if they let me that I will give back as much as I could. And I started doing volunteer work in the outpatient cancer center, and I am still doing it.

Lamothe What does that entail, what do you do?

Debona Talking with patients and bringing them to the MRIs, CAT scan, whatever they need we take care of it. It is a very nice place, they have puzzles and games and different things that you can do and I will probably never leave that place.

Lamothe And I'm sure you have met some pretty amazing and courageous people?

Debona Yes and too many of them are not here anymore.

Lamothe What about your return back to "a normal life" in terms of your job, dreams and aspirations?

Debona Very honestly, I had 13 eleven departments, 52 or 53 people and my brain just could not handle that anymore. I was always the go to guy and when all else failed, they would call me, and at this

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point in time, I just did not have the will to be able to manipulate all that stuff. And even with my grandchildren, I was the guy that put everything together, I cannot do that. Most of the stuff is in Japanese, so I have to rewrite it to get it in the sequence. I guess my brain has stopped random activity and it is got to be sequential only.

Lamothe So you had to relearn things, or do them in different ways in order to accomplish them?

Debona And if that's all I have to put up, that was great.

Lamothe It is not a bad deal especially after this many years now since the operation.

Debona Well technology really helps. I am always with the cell phone and when I am in my car, I always have the GPS, and God bless GPS, it has a home button so I cannot get lost.

Lamothe Were you aware in the 90s that this was a possibility that it could have this cognitive effect on you?

Debona Well, they told me if I lived long enough, it might get that way. I had five or six really great years, not good years, great years, we traveled, we did a lot of things together and then slowly I noticed that I was not as capable as I once was, I'd have the initial desire to do but, I did not have the long term stamina.

Lamothe How did family, friends, and co-workers react to this?

Debona Co-workers could not believe that I was not coming back to work.

Lamothe You were not the same guy?

Debona I told them I did not have the ability to manage everybody, and my boss agreed. For the first six months or so, he would call me once in a while and ask, what did you do with this, how do we do that, and it would make me feel good, but other than that we just parted, and I did not see much of him for a long time, and as far as what I did to replace it, I concentrated on volunteering. I ran a food bank in Branford for three years. I still work with this place called the Cancer Hope Network in Chester, New Jersey and it is a one-on-one match with people who would have things in common with what I had, and you get to talk to them on the phone, and basically they are newbies, brand new diagnosis, and I can remember that far back so I can talk to them about what they are going to go through.

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- Lamothe If you had returned to work as you had been before and stepped right back into that life, do you think you would have felt this compelled or become as involved as you are now in the cancer community, the population of people dealing with this?
- Debona No, absolutely not, I found many organizations. There are two organizations, one in Illinois and one in the San Francisco, that do nothing but research and hold seminars on different aspects of brain cancer. And I have spoken at those many times, and I still like the people in Chester because you get a one-on-one.
- Lamothe Tell us little bit about the one-on-one, how do you prepare, what is the experience like, and how does it make you feel, what you are doing for other people?
- Debona They used to call me, but since I have been moving around they email me and they give me all the stats on this person, and they give me a time to call which I do, and I introduce myself and we talk for a while and I can find out just from listening to them what their fears are, the fear of the unknown, and that is the worst fear you can have, the unknown. So I try to ease into what is going on, but before we go any further I have been out now over 17 years with a disease that was supposed to give me three months. So for the most part, when I tell them that there are all kinds of oohs and aahs and oh I wish I could do that what did you do, how did you do it? And I tell them that I tried to continue to live my life as I did before cancer. There are things that you are not supposed to eat, and I am of Italian background and I am used to having a glass of wine two or three nights a week with my dinner and that was a no, no, but I said, I will try it and let me see what happens and nothing happened, so I decided that it was okay. I was also a lover of very dark chocolate, and the tyramine, I think it is called, in the chocolate gave me a terrible headache, so I do not eat any more chocolate. It is like compromising, and if you do that, you do not feel like you are missing anything.
- Lamothe There are some cancer survivors that feel this obligation to give back and I know some that I have spoken to who do similar work as you are, dealing with patients who are beginning their journey, and oftentimes they feel a real guilt from having survived this disease when they work with so many people that they know are not going to survive this disease. What would you say about that perspective?
- Debona It is always going to be there, it is never going to go away because I talk to these people and I try to give them as much hope as I can and it is not false, I mean I am doing it and there are numbers of other people that have lived a long time with this disease, but when I find out that they have gone I feel bad, I really do feel guilty because I say to myself why me? And I do not know how to resolve that, I really do not know how to resolve that, but I will keep going.

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Lamothe That is all we can do, that is great. We are going to take a break now for a medical minute. Please stay tuned to hear more about Peter's experience with cancer.

*Medical
Minute*

There are over 12 million cancer survivors in the United States right now and the numbers keep growing. Completing treatment for cancer is a very exciting milestone, but cancer and its treatment can be a life changing experience. The return to normal activities and relationships may be difficult and cancer survivors face other long term side effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers such as the one at Yale Cancer Center to keep cancer survivors well and focused on healthy living. This has been a medical minute brought to as public service by Yale Cancer Center 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 today by my guest Peter Debona who is sharing his story of survivorship. Peter, before we went to the break we were talking a little about the one-on-one counseling that you do and what that means to you and what it means to the individual that you work with, which is quite a lot and I congratulate you on taking that step. A lot of people that survive cancer want to get as far away from it as possible and I think that you have touched hundreds of lives through that work. We have hundreds and thousands of listeners listening to this on the radio on Sunday evening and we have many more who listen to this as a podcast, lots of them are cancer survivors, a lot of them are cancer patients and a lot of them are people who know cancer survivors and want to help. What would you say to those groups of people? What should they do at this point in their lives to give back, like you have, to respond positively to a cancer experience?

Debona I tried to live my life as normally as I could, my feeling was that if I did everything that the doctors asked me to do, it would not feel normal, so what I try to tell people is if the cancer patient wants to go on vacation, certainly check with your doctor where are they are in their treatment, but if they really want to do something, let them do it. I also tell them that when you are in treatment, and mine lasted almost a full year, there is not much you can expect. The hope is that for a couple of hours you can maybe go out to dinner or go see some family, but other than that you really can't expect a whole lot.

Lamothe So, have realistic expectations to stay focused on your disease and your plan to treat it.

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Debona A couple of years after I was out of treatment and I was feeling better, we travelled all the way through Europe and had a wonderful time and once my year was over and I had no other medications to take, and we even did a little up scale trip to Maine, while I was taking chemo pills, and it was wonderful, all I had to do was take a nap during the day because I was tired from walking and I would be great the rest of the time.

Lamothe So, you learned how to manage this disease and take control of it?

Debona Exactly, you learn how to compromise. I always loved the water and I learned that I had to wear a life jacket, and I learned I had to stay close to shore, and that is also a compromise. As I was telling you, I lived in Arizona for a while and that is a strange state and if I did not have a GPS to take me home, I think I would never have gotten home sometimes, I mean I do not have that kind of cognitive ability.

Lamothe So it sounds like that measured approach of compromise is a whole heck of lot better than feeling dejected that you cannot do something?

Debona Yes and I also said to myself I am not going to let anybody get into my life to tell me things that are negative and I will try to eliminate as much negativity and interference or arguments as I possibly can.

Lamothe Not sweating the small stuff or tolerating other people's problems.

Debona You have to do that or otherwise it is not worth living because none of us know how long we are going to live. So why not do something for yourself every day and that is what I try to do.

Lamothe So what do you say then to the people who have a friend or loved one, a neighbor, coworker who they learn is fighting this disease?

Debona I tell them that there are many people that survive and I am going to be one of them, I don't want to listen to it, and if they do not want to respond positively, I will tell them flat out, I do not need negative feelings, I want to be positive.

Lamothe I recall after my diagnosis of Hodgkin's disease five years ago, the first thing someone said to me when they find out was, O my goodness, I know someone who had cancer and they died so quickly, and at that point I said to myself like you did, that I am cutting out the negativity, it won't be a part of this process.

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- Debona Exactly, we do not need it as patients, and the family has the same obligation. I know one family that wanted to take pictures and that is probably the worst thing you can do, line up your kids with the patient and want to take a picture of them, it is like you put him in the grave already and it is just not right, it takes away your feeling of hope. So my wife helped me because she also made sure that people were not that way.
- Lamothe As a patient, you would suggest that you are certainly entitled to say exactly what you are feeling, how you are feeling, what you want, what you do not want because for that period of time really you and your health are all that matters.
- Debona And quite honestly if this person is your real friend, then they will respect it and honor it.
- Lamothe Let's transition into things like support groups and staying involved, many people start doing marathons, bike riding, but you have done this one-on-one coaching. There are a lot of people who want to get involved in some way, you often hear it referred to as the obligation of the cured, what are your thoughts on the importance of that to the people who receive the benefit of their involvement?
- Debona Many people just go back to work, and they get absorbed in their lives and work. For me I made a decision that I was old enough and I was in management, so I was able to retire and then I had to figure out after 25 years of service to one company, what do I do now and I was always involved. So I had this tremendous urge to continue to be involved, and I found the first support group was here at Yale, they had a specific brain tumor support group, so I started attending and the hospital where I was had general support groups. I was attending two different ones. From these people I found out about the National Brain Tumor Societies, and they hold conferences every year. So I asked to be invited and I talked to someone who is in charge and after the first year they asked me if I would do spots on survivorship, and I did that for four or five years running. Lots of them are held in California, and that kind of stuff is too far away for me to go, so when they happen anywhere in New England, I try to attend, but what you have to understand is that if you are not busy that is when the thoughts come, so I try to keep as busy as I possibly can. I always want to do something.
- Lamothe In general terms, how do you look at your life as having changed? You have this opportunity now to reflect on the last fifteen years, you have got plenty of years in front of you, and I think a lot of cancer survivors shift their perspective from life is short, to life is a long time and I really want to do a lot of living, so how has your perspective on life changed and what do you want to do with the rest of it? Compared to that guy who was probably working 70 hours a week hoping to earn enough to retire and do something entirely different.

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Debona You know, everything is different. First of all, I think you tend to look inward more. Family becomes much-much more important, I do not spent a lot of time with them, but know where they are, what they are doing. Whenever we get together, it is just a real happy occasion as both my wife's and my families are blended families, we have a lot of children and grandchildren, so I really love seeing them and being with them. We take a lot of vacations, even if they are just weekends. We have been to Europe two times, Mexico two or three times, all over the United States and it's just something that I wanted to do all my life and we are doing it and we thank God we have enough funds to do it, and some people just do not, and I think that is a sad thing because there is not enough to do if you cannot plan to do some thing, you know, the plans are sometimes, better than the journey or the actual doing, so if you get a good journey going, it keeps your mind occupied.

Lamothe I often hear people say that cancer has had a profound impact on their lives and I guess that would be anyone who has had a cancer experience that you can be free of cancer but not free from cancer. You do not have cancer in your body any longer, but the impact of that experience, of the disease, of the trauma, of the journey, is such that it will always be a part of who you are.

Debona For the first seven or eight years of my cancer life, I was doing MRIs every six months and when it came time for that MRI I was just jelly, you know, just nothing was working and so after a couple of years of this, I asked my wife to schedule it and not tell me till the day, and that is how I got through it, and I really feel that the time has to pass, you have to understand that you are not going to die, things are looking really good and for whatever reason somebody has given me the ability to survive and help others, and that is what pushes me a lot. I want to contribute to this life of mine.

Lamothe Peter, let us end with this, what are you most grateful for?

Debona God has given me life and I am going to give back as much I can.

Peter Debona is a cancer survivor. 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.