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Survivor Perspective

Guest: Emily

Lymphoma 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 Emily shares her cancer story with Dr. Francine Foss.

Foss Emily, we first met when you were given some bad news about a cancer diagnosis. Can you go back to that point in time and tell us a little bit about what happened and how you felt about it?

Emily In retrospect, I had the disease probably for eight or nine years before I met you. I started having a couple of lesions on my lower legs two or three at a time and they would come and go and they were sort of innocuous looking. I went to a couple of dermatologists over the years and they were unimpressed and did not recommend any treatment, and because they would come and go I did not give them a tremendous amount of thought, but in the spring of 2005, I started having more and more of the lesions and the old ones did not disappear. At that point, I had a biopsy and it was a little nonspecific as I recall, but I finally saw you in August 2005 and you of course took one look at me and said, this is actually what you have, subcutaneous panniculitis-like T-cell lymphoma, which was of course a terrible shock to receive. I was 46 years old, I thought of myself as a very active, very healthy, and very physically fit person. This was a tremendous adjustment to my understanding of who I was, and I think you also said right away that I was going to need a bone marrow transplant, which was definitely something that was very hard to hear. I felt perfectly well. I could not imagine needing something so drastic as that and I had the laypersons association with it, that if had asked me to free associate on bone marrow transplantation, I would have said last ditch effort, terrible suffering, die anyway, none of that turned out to be true and some of the most helpful things that I could of known at that point was that it would be perfectly possible to lead a completely normal life after a bone marrow transplant.

Foss How many years has it been since the transplant?

Emily Tomorrow will be four years to the day.

Foss Wow.

Emily And I feel perfectly normal. I mean I am older, so I think I feel the effects of being older, but I am very active, I run four to five miles several days a week. No one looking at me would know I had been through anything like that. I lift weights; I work normally, I feel completely healthy.

Foss You work full time and you shepherd a couple of children also?

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Emily Yes, I have two daughters who were 15 and 17 at the time of my diagnosis and that was hard because one of my motivations for staying alive was feeling that they were much too young to lose a parent and that was a very strong incentive. We made the decision, at my instigation, to not share with them the dark side as much as we might have. I felt, at least in the early stages, that I had a good chance of living with the disease for a number of years since I seemed to have had it for so long, or even of being cured, and I thought, well if things get really dicey there will be time to warn them, but I wanted their lives' to be as normal as possible. Of course it is not fully possible, I mean they saw me going through the chemo and they saw me losing my hair and they saw me getting very very feeble, but I think knowing that we were going for a cure was very helpful to them and they were incredibly supportive.

Foss How did you actually break the news to them that you had cancer?

Emily I do not remember exactly. I think the initial thought after the first biopsy was it was a kind of cutaneous lymphoma and the prospects were better. We kind of just said, well I am going to need a lot of treatment and I might lose my hair but we are going to get through this. We were optimistic and very encouraging about it and I know they were very worried but I do not remember the specific moment when we actually sat down and told them.

Foss How did you break the news to them that you needed a bone marrow transplant?

Emily That again is funny. It is like the memory sort of puts a little cocoon around things like that, the specifics of that I do not know. I was very resistant to that idea from the very beginning and I think there was a moment in the illness where I started being more frightened of the disease than of the treatment and once that happened, I was very gung-ho to do whatever it took. Very shortly after finding out that I definitely needed a bone marrow transplant, we also found out that my brother was a perfect match so that was very fortunate and that made it much easier and I think that is how we presented it to the girls. We said, well I am going to need this transplant but luckily Uncle Jimmy is a perfect match and it should go fine, and I think we always presented it that way and they trusted us, but I think it must have been very unnerving for both of them. I have talked about it a lot with them since and I think it was very hard.

Foss You talk a lot about going through an emotional rollercoaster starting out with these lumps that you had for a couple of years and then all of a sudden finding out that they were cancer. What was that moment like?

Emily It really was very terrifying and it was so discordant with what I felt about myself as a person that it was a complete identity-shattering moment. I suddenly thought, I am not in middle age, I am an old sick woman at the end of my life and that was a very hard thing to accept, but I think by my

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Nature, being an optimistic person, I knew there were always options. The initial options were not very threatening to me. I did eight or nine months of the treatment that was not terribly intrusive, I did not have a lot of side effects from it and I was able to incorporate it into the rest of my life. It became very important to me to keep my sense of who I was as I went through it and to think of all the things that matter to me that I could still do and that had to do with my relationships with my family and with my friends. I kept working for the year and half of chemotherapy and that was crucial. I actually did not tell very many people at work, I told a couple of people I had tell but in general it was easier for me to continue working and not think about being ill at work until that became impossible and I had to take a leave of absence from work for about two years, as the chemotherapy ramped up and then for the transplant itself.

Foss So, maintaining that place in reality, so to speak, helped you to adjust to this concept that you had this disease?

Emily I had to think of the disease as something that I had, something that I was experiencing but not something that defined me. It was not who I was, it was what I was doing at the moment and that was an important balancing act and I was not always successful at that but I realized that a lot of what I was experiencing was in my control in the sense of I could control my mental state, I could decide what to think about when and the mental aspects of this were much much harder than any of the physical aspects, the physical aspects do get difficult, but the really overwhelming part is the mental part, and I found that a lot of that was in my control so I could just say, well, I know what is happening next, I have made my decision, I am just not going to think about that right now, and I had to narrow my focus very much to the moment I was in and think, what am I doing now, what can I do now, and what would I like to do right this very minute and try not to think about the big picture because the big picture was very overwhelming.

Foss So you essentially took it one step at a time?

Emily Very much so, really one minute at a time, just staying very focused on the present, I would read a book or listen to music if I was up for that, or watch a DVD or talk to a friend. I had to be isolated for a lot of it, particularly right after the transplant, and I relied very heavily on E-mail and on the telephone, so I did not, in fact, feel isolated because I could still communicate with people and in some ways it was easier to communicate that way because I could be more myself if I was not worried about how people were reacting to seeing me because I know I looked very ill.

Foss You said that you worked for the beginning part of the treatment, how was it to go to work and have to kind of pretend that you were like everyone else when you were getting chemotherapy?

Emily It was actually a relief because I did not have to talk about it with anyone, I didn't have people

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coming up to me and saying, how are you, I could just act normally and my work is mentally very absorbing so I was very distracted by it, and I would go hours, days at a time, and be driving home and think, wow, I did not even think about the fact that I am sick all day and that was really a relief and it was very nice.

Foss You talk about control and I think control is a big thing that a lot of cancer patients feel that they have lost after they get the diagnosis, and certainly when they start going through chemotherapy or other treatment that is rough. Did you always feel that you had control from the beginning or did you have to figure it out as you were going through the process that you actually did have control?

Emily It is sort of an odd balancing act and in some sense you have to take the control that you cannot take and for me that involved controlling my own thoughts, but in other ways you have to give yourself up to it and just say okay, it's out of my control. I am just going to give myself over to that, I really cannot do anything right now but lie here, and that is okay I am just going to do that. I never really felt that I took control of the process. The most that I felt was that I could take control of my own thoughts and how I was processing things and I also had very wise advice from another friend of mine who was going through a similar adventure and I said, you know, every time I get bad news, I fall apart and I cannot seem to prepare myself for that and she said you have to accept that is the case, you cannot prepare yourself and you are going to fall apart when you get bad news and then you are going pull yourself together and say, okay, now I will deal with this new reality. There was a period in their early stages, when I thought oh maybe this nice drug that does not make me feel too ill is actually going to cure me, and it did do very well for a time but then it stopped working, and that was quite devastating, but I think just knowing that it was okay to fall apart when you got bad new and then to realize that I would then cope with the new reality as it became clear what that was. So I do not think I ever actually took control of the process, but I got better at sort of giving up control.

Foss And you also allowed yourself to fall apart because that is an important part. Everybody has to allow themselves to do that.

Emily That was very hard for me because I am a controlled person, I am not particularly spontaneous and I do not really like unexpected adventures. I had tremendous help in all of this from not only my family and friends, but I must say, the people at Yale were absolutely extraordinary, the doctors, the nurses, one of the fringe benefits of this whole experience was seeing the absolute best side of human nature, that is the kindness and the compassion and the generosity that I received from the nurses and doctors at the hospital and these were people that I had only ever met as a patient, so they did not even know me and they were just so incredibly kind and I am extremely grateful. I would not be here if it weren't for you and all the people who work with you, so I am very grateful for that.

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Foss Emily, we are going to have to take a break right now for medical minute. We will be back to hear more about your story, and particularly more about your transplant.

*Medical
Minute*

The American Cancer Society estimates that last year there were over 65,000 new cases of melanoma in this country and over 1,000 patients are diagnosed annually in Connecticut alone. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths. Early detection is the key. When detected early, melanoma is easily treated and highly curable and new treatment options and surgical techniques are giving melanoma survivors more hope than they have ever had before. Clinical trials are currently underway at Yale Cancer Center, Connecticut's federally designated comprehensive cancer center, to test innovative new treatments for melanoma. The Specialized Programs of Research Excellence and Skin Cancer Grant at Yale, also known as the SPORE grant, will help establish national guidelines on modifying behavior and on prevention as well as identification of new drug targets. This has been a medical minute brought to you as a public service by Yale Cancer Center. More information is available at YaleCancerCenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined today by my guest Emily who is a patient who has experienced lymphoma, had a bone marrow transplant and is now a long-term survivor. We were talking a little bit at the beginning of the show about the whole diagnosis of cancer and how you felt and the process you went through in order to accept all of what was happening to you, and certainly it was one thing to have to accept the diagnosis and then the treatment, but the other part for you was that you had to undergo a bone marrow transplant. Can you tell us what you thought when that was first mentioned to you?

Emily My first reaction, because it came on the same day that I was diagnosed with the disease, was just sort of shock, horror and disbelief, it seemed like such a drastic approach to what I had been living with for eight or nine years and had not thought of as life threatening. So it was a gradual adjustment and I think I had to get to the point where I was more frightened of the disease than of the treatment and once I got to that point then I really understood that in order to eradicate the disease, I needed the transplant, and then I really was enthusiastic and eagerly awaiting the moment when you told me that I was in remission and that I could in fact go forward with the transplant.

Foss Most people think about the bone marrow transplant as being the absolute last thing and I think that is what you thought as well, or you were scared that a transplant would be something that may kill you.

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Emily You know, it is funny. At that point, I was so clear that the disease was going to kill me that I did not really allow myself to think that I could die during the transplant. What I was afraid of was that it would leave me a complete invalid, and that I would have no quality of life after it. But what I recognized going through the whole process, and since, is that quality of life is largely dependent on mental attitude, and some of that is in my control, not all of it, but some of it. It was only about a year after the transplant that I thought, I could have died just going through the process, but I was so fixed on the goal and that is one of the mental images that helped me a lot, thinking of myself as freight train that I was just going to barrel down the tracks and I was not going to let anything deflect me, nothing was going to me knock me over, so I think I went for the transplant without allowing myself to think about the risks of actually dying during it.

Foss Can you talk about how hard the transplant was compared to the chemotherapy?

Emily As difficult as the chemotherapy was, and I had five day inpatient treatments separated by 16 days at home, and I had eight of those, and that was quite challenging. The transplant made that seem like a vacation at the beach. I have to say that the transplant was unimaginably more difficult, but I had no idea. I do not know that any one could have told me in advance. The big thing was the fatigue, the weakness. I was in the hospital for three weeks, and when I came home I spent six weeks on the sofa and literally could not get off the sofa except to go to the Day Hospital for the blood tests and support treatment that I definitely needed. I literally lay still for six months and I was not prepared for that, it was very difficult.

Foss When did you actually feel like you were better?

Emily I was able to drag myself off the sofa at six months and I discovered that I had two frozen shoulders and I went to the physical therapist at that point, it was the first time I was really able to do that and I discovered that I had lost 80% of the range of motion in my left shoulder and 90% of the range of motion in my right shoulder, and the thing that was most shocking was when the therapist said to me, how long has your mobility been impaired, and I realized that I had no idea. I had been too ill to notice that I could not move my arms, that's how weak I was, and I did pretty intensive physical therapy to get my mobility back, and I did regain all of it. I would say it was a year out. I remember the nurses made a big deal about the 100 days, because I had to go to the hospital I think three times a week for the first 100 hundred days, and that was a huge milestone and I remembered looking at my mother and thinking, wow I still feel terrible and it was 100 days out, but I tried to be active during the chemo and during the transplant, and it was important to me both physically and mentally to stay active. So even when I was on the sofa, I would drag myself off the sofa for five minutes to just walk around the living room and that was crucial.

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- Foss That is a really important point for patients who do not feel good, as you know, when do you decide, yeah I do not feel good, but I really need to get up and do something and when do you say, well gee, I do not feel good, I need to rest?
- Emily It is sort of trial and error. I think for me if I pushed myself to do something, and I remember there was a period where I could just walk once around the backyard, and then when I lay down again, did I feel better or worse. If I felt a little better, then I thought it was a good move, if I felt worse, then I thought, okay maybe that was too much.
- Foss Now you are survivor, you have been for four years, you have been cancer free for that long, but you have had to come in and get the scans done and I know you have been anxious about the scans. Can you tell us how you felt when you had that first scan after the transplant and how do you feel now when you have your scans?
- Emily I think because my disease was always visible, or at least part of it always visible, when I did not see any of the lesions on my skin, it gave me some confidence to think, well maybe it had not come back and as time went on I still did not see them, but I mean I had a mosquito bite last week and I was freaking out about because that's how innocuous these lesions looked, so until that went away, and I knew it was a mosquito bite, I could see it, it itched, but just seeing a lump on my skin was a very alarming thing. The scans are hard, just waiting for test results is very very hard and I just have to use that technique that I am not going to think about it right now, I am going through it, I will do it and I will cope with the results.
- Foss Is it hard to come back into the hospital? Is it hard to go up to the transplant floor, does that bring back memories?
- Emily I want to go back and thank all the nurses and I have not yet been able to do that and it has been four years. I do have sort of a post traumatic stress response to the hospital, just walking into the hospital I feel nauseous, so that is hard, and there are certain aisles in the supermarket where I will see foods that I had to use when I was sick and I get that same sort of visceral reaction. In some sense you do feel more vulnerable after an experience like this, so I think it has made me somewhat more fragile.
- Foss Do you think about yourself as a cancer survivor, is that something that is on your mind day-to-day?
- Emily No, I really do not. I think that was something I experienced and went through. I try not to frame it that way. That is not helpful for me; maybe it is for some people, but for me that is not helpful.

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- Foss What has been the most important thing for you in your recovery phase, post having been through all of this as you are recovering, now to go back to your life? What are the important things?
- Emily This surprising realization that in some ways life can be much better after an experience like that, it certainly does help me to keep my priorities straight, I can be stuck in a terrible traffic jam and think, I do not have to worry about this and I do not have to be upset about this, I survived a bone marrow transplant. And being able to laugh about something like that can be very helpful, so it's a little bit like trying to hold water in your hand, you have to keep trying, but it does give me a frame of reference so that I try to make sure that I concentrate on what is really worth concentrating on and I do not sweat the small stuff as much as I used to, that is definitely true.
- Foss Can you talk about how your life has changed as a result of this, how things have changed at work, how things have changed at home?
- Emily I am one of those that like my routine, so I have come back to a lot of my normal life, I think I am a better friend and a better parent and wife because of what I went through and I think I am empathetic and more sensitive to other peoples needs. I had a wonderful life before I got sick and I am very fortunate to have a wonderful life now. I love my family, I love my work, so to be able to resume that has been a tremendous gift. I do not think every day, I am a cancer survivor, I am a cancer survivor, but it is definitely on some level in my mind. Every moment is really precious, every moment is a gift, and I won't take anything for granted.
- Foss Do you ever not worry about relapsing, or is that something that a cancer survivor always has at the back of their mind?
- Emily I was always an anxious person, and I think I was always afraid of illness, but there is a big difference between being diffusely anxious and having a very clear and specific idea of what there is to be anxious about. That is the constant challenge and when I find myself having these sorts of circular anxious thoughts, I just say no, I am not going to think about that now. I think the way I framed it to myself is that I have a good chance of getting some new cancer, so why fear the old one? There does not seem to be any benefit in worrying about that.
- Foss Did you every go to support groups or are there specific books that you read that helped you along the way?
- Emily No, I never did support groups; that is not something that I find helpful. I do read a lot and I find reading in general very helpful. As far as specific things, individual quotes from different people I found very helpful and kept in my mind as sort of mantras, so for me reading was either a distraction or a way to focus my energies.

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- Foss You had the unique opportunity to get bone marrow from your brother, how that did change your relationship with him?
- Emily My brother and I were very close but when we were children we fought a lot and I remember telling a friend that I have had since high school that it was the strangest thing that Jimmy and I were a perfect match, and she looked at me and she said, yeah, and you were hoping you were not even related. We were able to laugh about it, and it definitely brought us closer, but we were already close by the time we were in college. It was an incredibly generous thing that he did and we were just at my younger daughter's graduation from college and my brother was there and I was next to him and I thought, I am only here because of you.
- Foss I remember initially he was a little apprehensive just because he did not understand the process, but after he went through it, he felt it was pretty easy?
- Emily Yeah, that was sort of nice. I was not asking him for a kidney, I think it would have been harder for me to ask for a kidney, but this was something that I understood was not going to compromise the quality of his life and he was willing to do whatever it took, but I was glad that it did not require anything, especially now that you do not need bone marrow per se, it was just stem cells, so it was a couple of days of discomfort for him, but that is all.
- Foss And one of the issues we face is that a lot of our patients still do not actually have family donors and we have to go to the unrelated bone marrow transplant registry. Would you have felt the same way if you had an unrelated donor, would that have made any difference to you?
- Emily Well I was glad that a full sibling donor was a good match, but I think a donor where there is a good match is a good match and that is the issue, and I would not even feel that it was a great imposition on a donor. If I were someone whose marrow was desirable, I would have no qualms about donating because it seems that it is not a particular invasive process.
- Foss And I think your story will reach to people in the community who have not thought about donating yet, that donating bone marrow can really lead to success stories like yours?
- Emily If you have not been tested please do so, because it is a minor imposition on you and you can save somebody's life.
- Foss Are there pros and tidbits that you would like to throw out there for people that are going through what you are going through, or people that are just getting a diagnosis of cancer?

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Emily I would just say, remember who you are and try to be that person as you are going through it, try to find humor whenever you can, humor is very helpful, and try to stay physically active as much as you can. I was lifting weights in between chemo cycles and walking, so do what you can to keep your identity.

Foss And you are doing some other things. Emily was very physically active and did a few things that her doctor told her not to do while she was getting chemotherapy, but we ended up making it through.

Emily Yes, I am a horse back rider and I remember my horse took advantage of my frailty at one point and tossed me and I ended up with three fractured ribs and a punctured lung and I remember how thrilled you were with that.

Foss And that wasn't long after the transplant.

Emily But it was important for me to stay me. That was a part of my identity that I was not ready to give up and being able to connect with my horse even on the days when I would just go up and visit with him and not actually ride, that was very important to my mental wellbeing.

That is Emily and we would like to thank her for sharing her cancer story with Dr. Francine Foss. 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.