

Yale CANCER
CENTER
answers

WNPR Connecticut Public Radio



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**Support for Cancer
Survivors**

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Cancer Institute*

Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and he is an internationally recognized expert on colorectal cancer. Dr. Foss is a Professor of Medical Oncology and Dermatology and she is an expert in the treatment of 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 Ed and Francine welcome Dr. Ken Miller. Dr. Miller is a past host of Yale Cancer Center Answers and he is currently the Director of the Lance Armstrong Survivorship Program at the Dana-Farber Cancer Institute.

Chu Why don't we start off by defining for our listeners out there what a cancer survivor is?

Miller The definition that I like most is that a cancer survivor is someone from the moment of diagnosis for as long as they live, which obviously we hope is for years and decades. It includes the time of discovery, diagnosis, and treatment, all the way through that person's entire life, and until end of life as well.

Chu That definition has changed and evolved. The typical definition that we think about is someone who has undergone cancer treatment, survived, and then we think about the rest of their lives as being part of that cancer survivorship period, but now it's a much broader number of patients.

Miller Yeah, and this definition is a very good one because it reminds us that what we do in terms of treatment does have an impact for years and decades after that time. I am going to give you a brief example; Lance Armstrong, for example, is a cancer survivor, but his treatment that he received for testicular cancer had potential very long-term and important outcomes for him, so I think it was important for his doctors and important for all of us as oncologists as well, to look at the broad perspective.

Foss Ken, is there a change in the thinking of patients now do you think, most patients think about themselves as patients, not as potential survivors? When do they pass over that sort of magic mark and start thinking about themselves as a survivor?

Miller Well the definition is that, it is just a definition, and I think it is a process for most people after they finish treatment and then some time after that they start to say, you know what, I am going to be around, I plan on being around. So not until they actually start incorporating that kind of definition into what they live by.

Chu Can you give us a sense of how many patients are cancer survivors here in the United States?

Miller I am glad you asked, the number right now is approximately 12 million cancer survivors.

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Now, it's actually predicted by the year 2020, which is only about 10 years from now, that the number will be 20 million. Not only are more and more people living well beyond the diagnosis of cancer and hopefully are cured, but also we have better treatment. More people are long-term survivors, but also they are living longer because the life expectancy has improved in the United States. So there is a lot.

Foss When you site that number Ken, are you talking about patients who have skin cancers that are treated by local excision, as well as other more serious cancers, or are you talking about all cancer patients?

Miller Those numbers are non-skin cancers. Its people that have had breast cancer, colon cancer, or lymphoma, which you know as it's your area of expertise. It's people with very serious cancers.

Foss Real cancers that have had real treatment.

Miller Absolutely, yes.

Chu We have talked on many occasions on this show that not only is a cancer survivor the cancer patient him or herself, but it also extends beyond and includes the caregiver, the loved ones, the family members, and maybe even the neighbor who is involved in the care and support of the cancer patient.

Miller I think that's true. In fact, the National Cancer Institute's definition includes all those people. It really does have a long-term impact on an entire family and community, as you know, and I have talked about this on the show, that my wife is a cancer survivor, and my kid's at the time were 15, 11, and 7. Thankfully, we're all 10 years older then we were, but it does have an impact, some of that impact is positive I think in terms of resiliency and perhaps compassion, and some of it's negative too, a certain amount of stress that goes with having gone through that process.

Foss What about patients who never actually go into remission, who have their cancer controlled, but still have the cancer and perhaps require maintenance therapy, can they also think about themselves as cancer survivors?

Miller It's a great question. I look at cancer survivorship in terms of what we called seasons of survivorship. There is the acute survivorship when you are first diagnosed, and then what has been called extended survivorship and it's a group of different subdivisions. One of them is

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people living in remission, or living with cancer, and there are a lot of people, if you look at women with breast cancer, men with prostate cancer, people living with colon cancer, they are cancer survivors too, and the same attention to quality-of-life into both short and long term side effects and issues is just as important for them.

Foss One of the problems with that group of patients is that they come in to see us, medical oncologists, and often times all of our conversation during the visit is focused on what we are doing to control their disease and not really on the survivorship issues.

Miller I think that's true, and looking back to the journey, just for my own family and for patients I have taken care of, that's probably the biggest thing on peoples minds, but when we pole the patients here at Yale, and in my new position, cancer survivors talk about three things. One is fear of recurrence, the second is sexual health, sexuality and intimacy, and the third is how to deal with, say financial things. There is a lot more in a person's life than we typically get to know in a 15 to 20 minute visit.

Chu It's interesting because of those three things that you said, we tend to focus on number one, which is how the patient is doing in terms of their disease and their status, and I would say we rarely, if ever, talk about issues number two and three relating to sexuality and finances.

Miller It's true, and one of the beauties of a Cancer Center, like Yale which is a comprehensive center, is that there is a team. The nurses tend to be fantastic and the social workers are really good. I don't know that we as oncologist have to do every thing, but what I have learned in what I call the "practice" of medicine over the years, is to sometimes ask a few questions. For example, I have learned to ask about intimacy, and I say to people, how is your sex life? Or words like that. But then if someone says, you know, we are having a problem with that or things are stressful at home, it's a chance to refer them for some help.

Foss How does a patient actually get hooked into one of those programs?

Miller It can be self referral, and sometimes people feel that if they are seeing something like the Survivorship Clinic, somehow they are not being loyal to their doctor who is their primary person, but I would like to think that their doctor will be pleased with it. So you can refer yourself, and you can also ask your oncologist. You can call Yale Cancer Center, and you guys probably know the number better than I do, and ask for the Connecticut Challenge Survivorship Clinic.

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- Foss And is it even true for patients that are say five, six, or more years out from their cancer, even ten years or more. They should still call.
- Miller I think that's the case, because the risk of recurrence at ten years out is low, but the risk of some of the late and long-term side effects of treatment are going up at that point. For example, unfortunately some people that have received chemotherapy are at risk in a delayed fashion for developing heart problems, so it's a good time at five and ten years out to be seen in the survivorship program.
- Chu Can you walk us through some of the other, short and long-term complications of cancer treatment?
- Miller The good news is that most cancer survivors are free of those late and long-term side effects. There are living busy and happy lives and cancer is a part of their history, but some cancer survivors will develop a heart problem, which could be weakening of the heart muscle. If they receive radiation therapy to the chest, they may have some problems with that, but also with the valves of the heart or with the rhythm of the heart in terms of heartbeat, or they may be at a slightly higher risk of heart attack or stroke; again, not common, but it happens. They may also have some lung problems from radiation therapy or chemotherapy. Those are the medical side effects, and there is growing expertise in that. There are also the psychosocial, posttraumatic stress syndrome is a real phenomena, or ongoing anxiety issues, or marital issues, or social issues with a partner or spouse, and economic as well.
- Foss Another major issue for patients is what they call chemobrain, not being able to think the way they could before, and other neurocognitive things that could be very subtle and perhaps lead to things like marital breakup and other social problems.
- Miller I think that a lot of people don't want to admit when they don't feel like they are functioning up to their potential, and people that have had chemotherapy sometimes say their memory is not quite as good, their ability to process things and integrate information is not as good as it was, and so yes, that does lead to all kinds of other issues. There is a study at Yale now on cognitive rehab, trying to see if you can help people regain some of that. If you find, or if someone who is a cancer survivor is having issues, testing is appropriate and then remediation. If one of us had a child in school that had those same issues, we would get help for them.
- Foss Exactly. Can you talk about standardized testing, so to speak, for cancer survivors? You

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talked about heart problems and lung problems, is there an algorithm which would tell us how frequently we test various things year after year?

Miller It's interesting, and for survivors of childhood cancer there is, and we always talk about it being evidence based so there is a lot of research behind it. For adults, we are not quite there yet. I mean, most of us as clinicians have in our mind what would be useful testing, but let me stress that very good primary care is important. You can't undo your treatment, which hopefully was curative, but you can modify other risks. Good cholesterol, exercising, good diet, and blood pressure control, all of those things about a healthy lifestyle that are important, and cancer screening for other cancers is very important too.

Foss We are talking about some very important issues here, for which sounds like a very large number of patients who are survivors.

Miller Thankfully.

Foss We need to take a break now. You are listening to Yale Cancer Center Answers and we are here discussing cancer survivorship with Dr. Ken Miller.

*Medical
Minute*

The American Cancer Society estimates that in 2009 there will be over 62,000 new cases of melanoma in this country and about 2400 patients will be diagnosed here in Connecticut alone. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths. But when detected early, melanoma is easily treated and highly curable. Clinical trials are underway at federally designated comprehensive cancer centers such as Yale Cancer Center to test innovative new treatments for melanoma. Patients enrolled in these trials are given access to newly available medicines, which have not yet been approved by the Food and Drug Administration. This has been a medical minute and you will find more information at yalecancercenter.org. You are listening to the WNPR Health Forum from Connecticut Public Radio.

Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined by my co-host Dr. Ed Chu and Dr. Ken Miller discussing the issue of cancer survivorship. Ken, can you tell us a little bit about the survivorship program at Dana-Farber?

Miller Sure, my pleasure. The Lance Armstrong Foundation has eight centers of excellence, and Dana-Farber, I think, was the first one about five years ago. It is a multidisciplinary clinic, meaning there is myself as a medical oncologist, we have two nurse practitioners, a social

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worker, we just added a nutritionist, and also an exercise specialist. We see a lot of similarities to the Yale program, but we see a large number of cancer survivors who are either just finishing treatment and/or a large group that are further out and are in need of surveillance for late and long term issues.

Chu Can you talk to us a little about the assessment tools and how you determine what the needs are of an individual patient?

Miller A survivorship visit, which part of that, is a comprehensive visit usually with the nurse practitioner going through in detail the person's medical history, but also in real detail what treatment they had, including surgery, radiation, and chemotherapy, and then based on that, we have a computerized tool, plus our own knowledge and what the issues are that person is facing. For example, if someone had radiation therapy to the head and neck area, they are at a slightly high risk of problems with the carotid artery, and so our clinicians are aware that that person should have a Doppler, an ultrasound of the carotid artery after a certain number of years. If they have had radiation for Hodgkin disease, for example, that allows us to say for a woman for example, she should have mammograms and breast MRI a number of years later. There is an algorithm both on the computer and also just based on our knowledge. The other thing I am excited about is hopefully we are going to be able to add to the body of knowledge through what we call an onco-cardiologist, a cardiologist interested in oncology and an onco-nephrologist, a kidney specialist. We are really trying to learn more and contribute to the field of survivorship.

Chu These computer algorithms that you talk about, were they developed by the folks of Dana-Farber, or are they readily available to anyone out in the community?

Miller We have a tool that was developed at Dana-Farber that we are using with our patients and at a number of our satellite clinics. At this point it is not really online, but I do want to encourage people listening to go to LIVESTRONG, actually look up LIVESTRONG Care Plan and that is a survivorship care plan that a cancer survivor can do themselves online. You do have to tell the program what chemotherapy you had, or what radiation, and how long ago, but it is very simple to use and it gives you a lot of information about healthy cancer survivorship.

Foss Ken, I imagine that a big part of your program going forward is going to be educating other physicians about cancer survivorship, particularly the primary care doctors who are following a lot of these patients, can you talk a little bit about that?

Miller Yes, and great question, I am glad you asked it because there does come a time that it's

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important to leave your oncologist after a certain number of years, people are healthy and should go back to primary care, and I want to encourage people to see their primary care doctor throughout their entire course, because all that is important. Primary care doctors, I think, will become more and more comfortable seeing cancer survivors, because there are a lot of them, and one benefit of these care plans that we're discussing, whether its the Dana-Farber one or the Lance Armstrong one, is that they give good information for the patient and for the primary care provider about when there should be screening test done, what screening test should be done, and its also a reminder if, unfortunately, someone has had one cancer, they are not immune from another. Having ongoing screening for a woman who has had breast cancer, screening for colon cancer is important, as one example.

Chu You have also been part of this whole education process and have been very active in putting together seminars and symposiums, and you have also recently written a book about the whole process of being a cancer survivor, can you tell us a little bit about that?

Miller Thank you. The book is a nice collection of very well written chapters on important issues and survivorship. In fact, a lot of the faculty who wrote are friends and colleagues from Yale from my days here. It has all the important highlights, its got the medical issues such as heart, lung, and kidney problems and hearing and vision, its got the psychosocial issues such as posttraumatic stress and depression and posttraumatic growth. It also has epidemiology issues, such as who is at risk of second cancers or secondary cancers? I have written a number of chapters myself, looking at survivorship as a process.

Foss You talked about your own personal experience with cancer and your wife. Can you talk a little bit about how that influenced you to move forward and develop a career in survivorship, and to write the book?

Miller I have been a practicing oncologist for about 20 years and after Joan was sick ten years ago, it was a time of personal reflection, realizing that in our careers and in our lives we only go around this one time, and I said I would like to go back to academics, which is what I did and came to the Yale faculty, but the other thing I realized too ten years later, after Joan was sick, is that treatment for cancer is often, thankfully, a relatively short period of time, it feels like a long time because you are so enmeshed in it as a patient and as a clinician, but then it has been ten years since then and just to share also, Joan had breast cancer about a year and half ago. As a cancer survivor there are all the other issues that people face. Treatment is a short time, survivorship hopefully is a long time, and it has put it into a different perspective for me.

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Chu Being a medical oncologist, did that help you to get through that experience with your wife, did it make it easier or perhaps more difficult?

Miller It's a combination of both. Just as a reflection back on it, we were down in Maryland at that time and being a clinician I had a lot of understanding of some of the medical issues, but that also gave me a lot more anxiety. I was not naïve to the real chance that Joan might die of cancer. I also think it's hard for clinicians to care for a doctor's family. I think it's a tense situation and so initially we didn't get quite as much support as we could have used, and with the help of a social worker I was able to say that we needed someone to come in and say to Joan, you are going to be okay, you are going to make it, and I did that. I actually went to Joan's doctor, I did not pound my fist, but I said this is what Joan needs. Being a patient I equated to being a visitor in a foreign land, even if you are in the medical field, you are a foreigner.

Chu Interesting.

Foss Ken, this whole survivorship area has just recently come to the forefront in medical oncology and your stories are tremendously inspirational. I remember when you first came to Yale, you gave us a Grand Rounds where you talked a lot about your experiences and that really changed the way a lot of us think about what we do everyday as medical oncologists. Just another point in terms of where survivorship is now, I am on the program committee for the American Society of Clinical Oncology, and for our annual meeting this year the major focus of the meeting is survivorship and that cuts across all of the different disciplines that we are talking about. The major goal is to build survivorship into the entire program this year, and I think that's a tremendous testament to the work that you and others like you have done to make us aware of this area.

Miller Absolutely. I didn't know that, that's very-very exciting. You know survivorship, the word cancer survivor as we think about it now started to be used around 1986. So, it's been a long-long time, but most things due to our process in terms of people getting interested and excited about it, so I am glad that in 2009 and 2010 that this is becoming a real important focus for oncology. In a sense it's a type of celebration, we have made a lot of progress in our careers and people are doing well, and now lets focus on the whole process of survivorship, its great.

Chu There is no question that someone like Lance Armstrong, who is a true testament to being the ultimate cancer survivor, right.

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Miller Yeah.

Chu He has got the most aggressive, most advanced stage of testicular cancer, survives that and then goes on to win seven Tour de Frances later. And I think he finished third this year.

Miller I think that was pretty good.

Chu It was amazing.

Miller Yes it is.

Chu He is probably the strongest advocate and supporter for pushing this whole field of survivorship forward, which really is terrific.

Miller Absolutely. There have been many people that have been visible in the field of survivorship, such as a very wonderful women named Ellen Stovall, who has been President of the National Coalition for Cancer Survivors, and others because cancer is so common, but Lance Armstrong really has propelled the field, and ten years ago when Joan was being treated for leukemia the two of us sat there watching TV that summer as he won his first tour and it was pretty inspirational.

Foss Can you talk about information for the lay public, you know websites, support groups, and other reading material for patients in this area?

Miller I want to encourage people, there are great resources at Yale Cancer Center's website, and it has some great information on survivorship. Dana-Farber, our website is good, and also the Lance Armstrong Foundation, livestrong.com, has got great information. I want to encourage people to look at those, because it is a reminder, it's a testimony to the fact that more and more people are living beyond cancer, with cancer, and through cancer, so focusing on healthy survivorship is a great opportunity for people.

Chu I would imagine that the book you recently published also might be of help to cancer patients and cancer survivors. If anyone wants to get a copy of the book, can you give the name and how they can get a copy?

Miller It's a long title, but it is called *Medical and Psychosocial Care of the Cancer Survivor* and it's published by Jones and Bartlett Publishers. It's got a lot of medical information, but I think it's a good resource. I just want to mention too my other book called *Choices In Breast Cancer*, it's on a different topic, but it's about how women make choices when faced with

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breast cancer. What I have learned from that process is how people face the initial diagnosis, how they make choices, how they get through that, actually does have reflections later on. For those people out there that are just going through diagnosis and finding out they have cancer, I think part of survivorship is becoming an active participant in that process, asking questions, learning, and I think it makes the later process of being a cancer survivor easier; you're more empowered.

Foss What about support groups for family members?

Miller Again, each cancer center, each area has its own, but there are some that are online too. For example, the Wellness Community, I think its thewellnesscommunity.org, has online cancer support groups that are really good, and so that's a way for people that may not want to travel to evening meetings, to participate online and learn a lot. My father-in-law just had an unusual cancer of the stomach, and he is on medicine called Gleevec and has been on it for years, he is 87 and is an active participant in an outline support group and loves it.

Chu Great. Any last thoughts to our listeners out there in the last minute or so that we have for the show?

Miller I would summarize in terms of my own belief system, we do not have a cure for every type of cancer, but thankfully, many people are cured or are long-term cancer survivors. And I am going to throw this out there, just a personal belief, I don't think cure is a dirty word, I think cure is a great word and I hope for the day, as we work on our careers, where more and more people will be long-term survivors. A big set of good words for the people out there that are cancer survivors, and their families, and very best wishes.

Chu It has been great having you back on the show and we look forward to having you back and hearing more about the developments of the Dana-Farber Cancer Center.

Miller Thank you.

Chu You have been listening to Yale Cancer Center Answers and we would like to thank our guest Dr. Ken Miller for joining us this evening. From Yale Cancer Center, this is Ed Chu wishing you a safe and healthy week.

If you have questions or would like to share your comments, you can go to yalecancercenter.org where you can also subscribe to our podcast and find written transcripts of past program. I am Bruce Barber and you are listening to the WNPR Health Forum from Connecticut Public Radio.