

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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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 discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening Ed welcomes Dr. Thomas Quinn. Dr. Quinn is the Director of the Connecticut Challenge Survivorship Clinic at Yale Cancer Center.

Chu Why don't we go ahead and start off by defining a cancer survivor.

Quinn That's a little difficult, as there is no official definition that everybody agrees on. For a long time, when so many patient's were dying of their cancer, we thought of anybody who had survived beyond five years of their treatment as being a survivor, but now, we pretty much recognize that, that definition is both inadequate and very narrow. Actually, way back in 1986, the founders of the National Correlation for Cancer Survivorship decided to establish an organization that would change the common parlance of cancer victim to cancer survivor. They envisioned an organization that would deal with the full spectrum of survivorship issues and they came up with the definition of a survivor as anyone from the time of diagnosis for the balance of their life, and later they added family, friends, and caregivers to that because when a patient is diagnosed with cancer it affects everyone around them.

Chu Tom, can you give us a sense of the magnitude of the problem. What are the numbers in terms of cancer survivors that are currently living in the United States in 2009?

Quinn Yes, and that's very important because as I implied earlier, more and more patients are living well beyond diagnosis and treatment. Currently, we can estimate that about 12 million people in the United States are cancer survivors and about 14% of them are long-term survivors, meaning 20 years or more according to the National Cancer Institute. In Connecticut that probably translates to around 120,000 people just based on population estimates, I am not aware of anybody who has actually surveyed people in Connecticut, but compare that to, for example, 30 years ago, there were only about 2-1/2 million survivors in the country, and 10 years ago there were probably about 9-1/2 million. We can see that there is a significant long-term trend towards increasing numbers of cancer survivors because we have continually improving treatments, and because of our aging population; more people are susceptible to cancer as they age.

Chu It's interesting because in the New York Times and in the Washington Post, there are always these articles on the front page that say the "War on Cancer" has failed and we haven't made

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progress and that we haven't seen the increase in the number of survivors from various cancers.

Quinn Right.

Chu Yet, these quick numbers that you talk about really do suggest a very different picture.

Quinn I think it is different. Around the beginning of this century we saw the trend, which was already reversing, to now, where most of the people who have a diagnosis of cancer are going to survive for a significant period of time. When I say most of them, I am statistically saying more than 50%, which is a dramatic difference from 30 years ago, but if we look just at the numbers of people who get cancer, yes, we still have a ways to go on prevention, early diagnosis, and so forth, but our treatments are so much better both in terms of attacking the disease itself, and supporting the person who has cancer, that we are able to have successful long-term outcomes.

Chu I was reading somewhere recently, and I forget where, but they were defining cancer survivorship, and by this definition, which was a very broad definition, they estimated that 3 out of every 4 individuals in this country is a cancer survivor of some kind.

Quinn When you include, as you say, the very broad definition, which includes family and friends, yes, you could say that, because almost everybody is affected by cancer either because of their own diagnosis or because of a family member.

Chu It is really remarkable how much and how deeply cancer does involve everyone.

Quinn It's a life changing experience, and I think it's safe to say that and very few people would argue with that comment. We will probably get to this a little bit later, but the whole idea of having cancer and then getting back to something that we would call "normal life" really doesn't happen. What is considered "normal" gets changed over the course of the disease and treatment.

Chu Obviously a cancer experience is a very profound experience, what are some of the consequences, both short term and long term, that cancer patients may experience?

Quinn We think of these kinds of things, the side effects of the disease and the treatment, as being in 3 overlapping categories. We refer to residual effects, long-term effects, and secondary effects. The residual effects are the symptoms or the conditions that continue for a fairly short period of time after treatment ends. For example, fatigue, or perhaps pain for some

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patients, and it may continue for some months and gradually dissipate, sometimes with some interventions on our part. The long-term effects are the symptoms that don't go away, the two that I just mentioned, pain and fatigue, are sometimes things that people have to experience for a very long time and we have limited ways of dealing with those. There are some permanent effects such as infertility that would also fall under this category. The third category is secondary effects, which are conditions that are caused by the treatment itself; that would include second cancers that might be caused by radiation therapy or chemotherapy, it might also be diseases like heart disease or pulmonary disease, that again, are caused by the treatments that may not show up for years or even decades after the treatment is finished.

Chu The development of these complications, the side effects of therapy, also depends upon the age the individual patient was treated.

Quinn Certainly to an extent that is true. So, childhood cancer survivors have somewhat of a different trajectory than adult survivors and that all depends on where they are developmentally at the time of their disease. So, for example a young woman, a teenager for example who gets Hodgkin's disease has chemotherapy and radiation therapy. There is going to be a significant risk for breast cancer for example from the radiation therapy that she might have to the chest, and perhaps, depending upon the chemotherapy to cardiac disease, you know, 30-40 years later, you know, one of the things that we have seen as major accomplishments over the years is the improvement, the reduction in intensity of treatments, but still having good effect from those treatments. So, we are hoping overtime that some of those secondary effects will diminish.

Chu There is this term called chemo-brain, where a lot of patients during therapy, and even after they have completed therapy, say that the brain feels kind of fuzzy and they just can't concentrate and their memory is not so good, and sometimes there is a bit of confusion. Why is that happening?

Quinn That's an excellent question, and we don't know that for sure, but the vast majority of research that has been done on that so far has been done in women with breast cancer and of course one of the things that happens with the chemotherapy, related to breast cancer and the hormone therapy related to breast cancer, is that many of these women go into a chemically-induced menopause. So, there is a dramatic reduction in estrogen. Whether the effect that we're seeing is directly related to the chemotherapy or something in combination with changes in estrogen and other hormones, we simply don't know at this point. It is clearly not something that is experienced only by women with breast cancer; we certainly have other

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patients who report it as well. But another difficulty is that we do not have very good instruments for measuring exactly what it is that's happening. People will present these subjective experiences of having come into the cancer experience with a very sharp mind, sharp memory, and now they find they can't find their keys, they have to write notes to remind themselves of everything, and they have a hard time making a decision, but some of those things are hard to measure with the standard instruments that are used for determining what cognitive function is. We are having a hard time with the research and essentially we are in the infancy of that research, and at this point, we really don't have any interventions that are supported by research.

Chu It is hard to think of someone being diagnosed with cancer and that diagnosis experience having a positive effect on an individual, but we do hear that in fact there can be a positive effect, I think we have seen that in many of the patients we have treated.

Quinn Sure.

Chu How do patients turn that very serious, very significant experience with cancer into a very positive, beneficial outcome?

Quinn That's a very good question, but it's also a delicate one. I have been impressed over my career with both how fragile and how resilient human beings are when it comes to something like cancer. When a patient is first diagnosed, they almost always are going to be frightened, confused, and overwhelmed, but then they adjust to the diagnosis and the rigors of the treatment and some people have what has been referred to as a transcended kind of experience. It's a spiritual or psychological growth where they begin to see the world differently, and say, "Well, I changed from the person that I was, to seeing things that are actually important." I think the delicate part of that is that we try not to put expectations onto individuals based on these remarkable stories that we see in some patients or that have been written in books, movies, and newspaper articles. Every person comes into this with their own individual contacts, their needs, their strengths, their family support, and so forth; we need to approach this for people as individuals. One of those remarkable stories in a mini-fashion occurred just last week at the Cancer Center where a patient who had lost her hair to chemotherapy came in and someone had painted a clown face on the back of her skull, and everybody had a good laugh and it was uplifting. That sort of thing is great, humor, and the strength and resilience demonstrated is important for everybody in that microenvironment, and is indicative of healthy coping.

Chu Obviously to help with that coping it is critically important to have a very supportive team

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environment, if you will, family members, loved ones, close friends, who really are there to support the cancer patient.

Quinn Exactly, a part of our ongoing assessment with patients is to look at that support system and to make sure that it's in place and that the support system in itself is able to cope. Often the longer a person is in treatment, or the more intense the treatment is, the family becomes fatigued and begins to have difficulty coping, whether it's a spouse, the children, the parents, all depending upon the situation. The same holds true for the work environment, some patients are supported very well at work and others are not, or the children in school. Schools now have programs that help both the child who has the diagnosis and the classmates and teachers so that they can be part of that support system. Our supportive care antennae are up whenever we see patients have a significant change in mood or capacities when we see them. For example, if they begin to dwindle in terms of their energy, we may have our nurses and social workers and perhaps the chaplain get involved and see if there is something else that we can do to support the patient in their home environment.

Chu Great. You are listening to Yale Cancer Center Answers, and I am here this evening in the studio with my guest Dr. Thomas Quinn discussing the importance of supportive care and supportive network for cancer survivors.

*Medical
Minute*

Breast cancer is the second most common cancer in women. About 3000 women in Connecticut will be diagnosed with breast cancer this year, but earlier detection, noninvasive treatments and new therapies are providing more options for breast cancer patients and more women are able to live with breast cancer than ever before. Beginning at age 40, every woman should schedule an annual mammogram and you should start even sooner if you have a risk factor associated with breast cancer. Screening, early detection, and a healthy lifestyle are the most important factors in defeating breast cancer. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center to make new treatments not yet approved by the Food and Drug Administration available to patients. 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.

Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu and I am pleased to be joined by Dr. Thomas Quinn, Director of the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Tom, in the first segment we were talking about the whole concept of cancer survivorship, what I thought would be important to do in the second segment is to

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focus a bit more on the services that are provided at the Connecticut Challenge Survivorship Clinic. Before we get into that, what is the Connecticut Challenge Survivorship Clinic?

Quinn Well, the clinic has been open for 2-1/2 years and it was originally designed to serve patients who had just completed primary or acute treatment for their cancer. Whenever an organization determines what services they want to provide they have to identify the target population, and for them that becomes the definition of a survivor, or survivorship, that we were talking about earlier. Our target population is those people who have just completed treatment, people who fall into that though are people who are on what we would think of as maintenance or preventative therapies; the aromatase inhibitors that a breast cancer patient would be on, or the hormones that a prostate cancer patient might be on. Those folks are part of our target population and what we hope to do in the survivorship clinic is to help patients to become as healthy as possible within the context of their current medical condition.

Chu What are the different types of services that are offered in your survivorship clinic?

Quinn The services are divided into two broad categories. The first would be screening and surveillance and the second would be rehabilitation and wellness. Screening and surveillance includes monitoring for a recurrence of the cancer, secondary cancers, and the development of secondary effects such as heart or lung disorders. To an extent, it also includes making sure patients understand that just because they have had cancer, they are still susceptible to all other gender and age-related disorders that everybody else is related to. In our model, we don't do extensive screening, but we teach the patients and make sure that they understand the importance of their followup schedule with their oncologist, make sure that they are tied in with their primary care provider, their dentist, and any specialist that they may also be seeing for rheumatology or cardiac disease or any of the other conditions that might come along with that. The other part, rehabilitation and wellness, includes symptom management, a fitness evaluation and recommendations, nutrition evaluation, and a psychosocial evaluation. Then we build recommendations around each of those depending upon what the assessment for that individual turns out to be, and we invite people to come back two more times at two months intervals, essentially for tune up, coaching, or just a pat on the back when they have done well and to answer questions that arose in the interim.

Chu How do people access your services?

Quinn Most of the patients that we see are referred by their medical oncologist at Yale, but we are happy to see patients from any place, or who are self-referred. For example, we occasionally have patients who are very long-term survivors, including childhood survivors of cancer, people who have heard about us from Yale Cancer Center radio broadcast and publications,

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some from distant parts of the state, young and old. People access us through multiple sources and some are referred by people who have come through the clinic in the past.

Chu It may also be important to emphasize that even when a patient goes to your survivorship clinic to seek additional services, they are still hooked in with their primary medical oncologist.

Quinn That's absolutely correct, and I emphasize that with every single patient. The intent of our clinic is not to take over the care of the patient after they have completed treatment, but to help coordinate and enhance that care by providing them with information, tools, and coaching so that they can follow through on the recommendations from their oncologists for followup, and also be able to interact as good consumers with their other providers out in the community.

Chu Tom, for those listening who may not be aware what the Connecticut Challenge is, how did the Connecticut Challenge get to be on the Survivorship Clinic name?

Quinn It's actually a great story. Jeff Keith, who is a childhood cancer survivor, had experienced, intentionally, looking for survivorship support at a couple of clinics and other institutions outside the State of Connecticut, and on his way back from one of those, he thought that we should be able to do this in Connecticut. So, he and a buddy of his sat down and mapped out a business plan for the Connecticut Challenge, which is a private philanthropic organization and its primary means of raising funds for survivorship is an annual bicycle ride in Fairfield, Connecticut. The mission of the challenge is to encourage and support survivorship services around the state. The Connecticut Challenge Survivorship Clinic at Yale Cancer Center was the first of those efforts to support survivorship, the second was also here at Yale, the HERO'S Pediatric Survivorship Clinic, and they are now reaching out to other institutions in other parts of the state.

Chu It really is a remarkable group and in the three years since they actually started the Connecticut Challenge, I think they have raised over 2 million dollars, and all of the proceeds have gone to promote and support cancer survivorship, initially here at Yale Cancer Center, but now they are looking more broadly to support survivorship programs throughout the State of Connecticut.

Quinn And that's clearly good for people around the state to be able to access survivorship services. It's also an opportunity for us in the survivorship field, which is a pretty new field, to be able

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to see how different models are put together and designed where we can collaborate with each other, where we can share resources, and perhaps do joint educational programs or consortia; the more that we essentially share the wealth in terms of our clinical expertise, the better for everybody concerned.

Chu In fact, for the last couple of years, you and Ken Miller, who was my former co-host on the show who is now at Harvard, have organized an annual symposium focusing on cancer survivorship that is open to all of the people involved in supporting cancer survivorship throughout the State of Connecticut.

Quinn Yes, those have been exciting, and they have been very well received. I think all of them have been essentially sold out. The proceedings from last year's conference are actually available on CD for free and you can go to the Connecticut Challenge website or to our website and you can access the content from that symposium. People who want continuing medical education credits can pay a very nominal fee and get a whole lot of credits for viewing those CDs.

Chu Now, the CT Challenge Bike Event is coming up, can you give our listeners some information as to when the event is taking place, and how they can get involved?

Quinn It's just a month away on Saturday, July 25, 2009. It is the Fifth Annual Connecticut Challenge Bike Ride. It starts and ends at Greenfield Hill in Fairfield and the course runs up through the beautiful countryside, North of Fairfield. There are lots of opportunities for people to get involved as volunteers, riders, or fundraisers, and obviously as donors. There are opportunities for people who are well conditioned and others who are not. There are 12, 25, 50, 75, and 100 mile rides. I have done the 100-mile ride twice.

Chu Wow, that's pretty impressive.

Quinn Well, I was pretty impressed. Unfortunately, I didn't have as much time to train this year, so I will only be doing the 50, and this will be my second time doing the 50. I can testify that the nickname, the toughest century in New England, is correct, the 100 mile is a very hard ride and shouldn't be attempted by people who aren't in good condition, and haven't done a lot of training. The 12-mile ride is accessible to just about anybody. I would encourage people to get involved and sign up for that ride, and if you do not feel like you can get in condition for even that ride, there are lots of volunteer opportunities that are available both on the day of the ride and prior to that.

Chu I should note that there also is a kiddy ride.

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- Quinn Yes. Thank you.
- Chu Yours truly may actually do the kiddy ride with my 4 and 5 year olds.
- Quinn Yes, there are parents that do the kiddy ride. Some of them then peel off and do the larger one, or families have done the 12 and 25 mile rides. It's a great family event and lots of families with kids ranging from toddlers up to teenagers have participated in the past.
- Chu For those who are interested in coming out and supporting the bike event you can either go to the yalecancercenter.org website or you can also go to the ctchallenge.org website to get further information. Tom, in the minute or so that we have remaining, are there any key messages that you would like our listeners, who may be cancer survivors, to know? What are take home messages that they should take away from this show?
- Quinn For better or worse, after cancer treatment ends and cancer is gone, there are still things to pay attention to, what Ken Miller used to call being cancer free, but not free of cancer, and that can be both positive and negative perspectives. Some people will spend a lot of time worrying about recurrence, which would be a negative side. The positive side is, okay it is looks like I will beat this thing, what can I do to make sure that I stay healthy for the rest of the time that I have?
- Chu Tom, it has been great having you on the show, it's amazing how quickly time has gone and we would love to have you come back on a future show to hear more about what's going on in the CT Challenge Survivorship Clinic.
- Quinn I would love to be able to talk further about how it's grown and how we have further developed it.
- Chu You have been listening to Yale Cancer Center Answers, and I would like thank our guest this evening Dr. Thomas Quinn for joining me. Until next time, I am Ed Chu from Yale Cancer Center wishing you a safe and healthy week.

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