

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



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Life After Cancer

Guest Expert:
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Yale Cancer Center Answers

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Welcome to Yale Cancer Center Answers with Dr. Francine Foss and Dr. Lynn Wilson. I am Bruce Barber. 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 1888-234-4YCC. This evening Francine and Lynn are pleased to welcome Dr. Tara Sanft. Dr. Sanft is an Assistant Professor of Medicine and Medical Oncology and Medical Director of Adult Survivorship for the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Here is Francine Foss.

Foss Let us start by having you tell us a little about what you do in your role in the Survivorship Clinic?

Sanft I act as Medical Director of the Survivorship Clinic, which is working in collaboration with multiple different care providers including a social worker, registered dietician, physical therapist, and advanced practice nurse to give multidisciplinary care to cancer survivors.

Wilson Tell us a little bit more about what survivorship is and are there specific phases of cancer survivorship, short term, two years, five years, give us some details about that.

Sanft There are multiple ways that you can approach cancer survivorship. You can look at it as having no disease after the completion of treatment, or you can look at cancer survivorship as the process of living with, through, and beyond cancer. In 1985, a physician named Fitzhugh Mullan published an article in the New England Journal of Medicine titled *The Seasons of Survival*. In that article he broke down survivorship into three distinct phases including acute, extended, and permanent. I can give you a little bit more detail about each of those. The acute phase of survivorship really begins at diagnosis when the patient is told that they have cancer. At that point, they are fighting for survival, as he puts it, and undergoing treatment and tests and often times the patient is in an area that is very scary for them, and family members and caregivers can be overlooked in this phase of survivorship. Extended survivorship is really after that initial treatment is completed and the patient goes through a transition period into surveillance. This can be characterized by some feelings of uncertainty and being unsure where to go from in terms of the medical treatment after treatment is completed; what next step should be taken. At the Yale Survivorship Clinic, we focus on giving patients care and guidance in the extended survivorship phase. Permanent survivorship is characterized years after diagnosis when the risk of recurrence tends to be much lower and patients can go on and live indefinitely having a history of cancer.

Wilson Is there ever a point during the surveillance or extended phase where obviously someone is alive and surviving, where you feel like it is not necessary to follow someone any longer? Do you think it is important to have some relationship in a follow-up program with each patient for their entire life?

3:47 into mp3 file <http://valecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

- Sanft I think it is important for patients to have coordinated care for the remainder of their life in some aspect of oncology and primary medical care and I think it is critical to have a multidisciplinary approach. At our Survivorship Clinic, we follow patients over the period of several months including right after they finish their initial therapy and then two, two-month visits in follow-up. We do not assume long term care of patients so we help them with their extended survivorship phase, but we put them back into the community for their permanent survivor care.
- Foss Can you tell us a little bit about the Survivorship Clinic at Yale? You mentioned that patients start coming there when they finish their treatment, but who do they see and what is the process for the patient?
- Sanft What our goal is, is to provide guidance for patients to take the next steps in helping them live a healthy lifestyle in order to maximize their quality of life and to maximize their longevity. We see patients with all different diagnoses who have completed their initial therapy. Patients that come to visit us do not necessarily have to have completed their treatment, even at Yale, so we are open to everyone in the community.
- Foss This Survivorship Clinic at Yale, I understand, was the first one in Connecticut. Has this concept of survivorship caught on throughout the country?
- Sanft Absolutely, if you look back over time the word survivor only started to become assimilated with cancer care in the 1980s when the National Coalition for Cancer Survivorship got together and started to raise awareness, and then throughout several decades with the help of people like the Connecticut Challenge and the Lance Armstrong Foundation, the awareness increased to now where we have many dedicated clinics throughout the nation. The Yale Survivorship Clinic is just one of those, but there is a network throughout the United States. The field is still small enough that we all feel it is very important to collaborate and here at Yale where are working on multiple areas of collaboration.
- Wilson What are some of the components to excellent survivorship care? This is the two part question, so after discussing that, can you let us know what a typical visit is like for a patient after they walk in the door?
- Sanft I characterize the components to good survivorship care with four words, and I can expound on each of these, but to me, good survivorship care includes surveillance, prevention, intervention, and coordination. Surveillance focuses on monitoring for recurrence or development of a new cancer. There are specific surveillance guidelines depending on what the diagnosis has been and it is important that not only the oncologist, but the primary care physician, is aware what those surveillance recommendations are. Prevention encompasses all cancer related side effects as well as the comorbidities that having a diagnosis of cancer puts you at risk for, such as hypertension, hyperlipidemia, obesity, and metabolic syndrome, and cancer survivors are often times at increased risk for developing some of these longstanding serious comorbidities. Intervention describes the

7:46 into mp3 file <http://valecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

treatment and symptom management that the patients will come up with sometimes years after diagnosis and it is important to be aware of these things and then act appropriately to maximize their quality of life. Perhaps one of the most important components of survivorship care is coordination, again, many patients are living beyond their cancer diagnosis for years and sometimes decades, and they will be seeing multiple providers and in survivorship care, it is really important to delineate all involved with the care of the patient and who is responsible for which aspects of that care.

Wilson Take us through a typical visit.

Sanft At the Survivorship Clinic at Yale, we see patients once weekly in a half-day session and when the patient comes through they will see four different providers, they will see a social worker, a registered dietician, a physical therapist, and either myself or an advanced practitioner. With each of these consultations, the patient will receive individualized counseling regarding their diet, their exercise, again focusing someone on the coordination of their follow-up medical care, and then they also get a chance to talk about the nonmedical and nonphysical aspects of how the cancer diagnosis has impacted their life. They also may be referred to other types of clinics as needed, such as genetic counseling. We also have a sexuality, intimacy, and menopause clinic at Yale. We also have a Complementary Medicine Clinic at Yale and so there are multiple different avenues that patients could be plugged into, and different services that they could be referred to. After that initial visit, we will follow-up with patients two months later to see how they are doing, make adjustments to their individualized care plan and then another two months after that we will make a final visit, and at that point we usually see some behavior changes and very positive effects that the clinic has had on patients. If they need to be seen again down the road, we do not turn anyone away.

Foss Do you include family members in these visits? Do family members generally come and is there counseling available for them as well?

Sanft There is, but the majority of patients that we have seen historically come through by themselves, but when they do bring significant others we incorporate them into the visits, and actually the definition of a cancer survivor includes family members and caregivers and anyone who is impacted by that diagnosis of cancer and so it is important to keep the supportive people in mind when you are offering these types of services.

Wilson Your background is in oncology and palliative care, tell us a bit about how palliative care integrates into survivorship.

Sanft Like survivorship, palliative care should be introduced upon diagnosis, so I believe that the concept of survivorship care should be introduced early and I also believe that palliative care should be introduced early, and what I mean by that is all patients should have the chance to have aggressive symptom management. They should all have the chance to be offered spiritual support,

11:19 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

counseling, and financial services, and so at Yale I feel like the philosophy is to take care of the whole patient, that includes a palliative care, it includes survivorship care, and it really means multidisciplinary care that begins at diagnosis and continues throughout the remainder of the patient's life, regardless of whether they go into a permanent survivorship phase, or into end of life issues and hospice care.

Foss Tara, can you tell us what kind of cancers they are seeing in the survivorship clinic?

Sanft To be honest we have seen all different tumor types and patients with multiple different diagnoses and looking through the history, it seems that we have seen at least one of everything, and so patients should feel reassured that we are happy to see anyone with any particular diagnosis. The most common patient that comes to our clinic tends to be the breast cancer survivors, but we have also seen multiple patients with a history of lung cancer, lymphomas, and stem cell transplant patient recipients, so we have run the gamut in terms of the types of patients we have seen.

Foss Do you include children as well in your clinic?

Sanft Survivors of childhood cancer are often referred to our HEROS Clinic, which is also offered at Smilow Cancer Hospital and that is a program that is offered through the Childrens Hospital as well and the Medical Director of that is Dr. Nina Kadan-Lottick.

Foss Can you tell us a little bit about the interaction as you move forward with patients? You are starting with a patient who comes in probably with lots of issues, as you move forward do the issues change?

Sanft Absolutely, there are lots of different ways to look at issues or side effects. Right after treatment, almost all patients experience some degree of fatigue, and I think that it is very important to be mindful of that. They may also be dealing with hair loss, physical limitations such as maybe a decreased range of motion in their shoulders, especially in women who have had an axillary lymph node dissection after breast cancer surgery. Patients may require intensive rehabilitative services, for instance, patients with sarcoma who have undergone limb-sparing surgery may have some physical limitations after their diagnosis and also many patients report a reduced capacity for exercise, and a decreased tolerance to complete a work day and those are often times symptoms and issues that come up right after initial treatment is completed. In the long term phase of care, other issues that come up include chronic numbness, pain, or swelling that can be associated with either surgery, radiation, or chemotherapy. Other issues that are important to pay attention to that often surface years after therapy are those revolving around reproductive health and infertility.

Wilson We are going to take a short break for a medical minute. Please stay tuned to learn more information about survivorship with Dr. Tara Sanft.

15:13 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

*Medical
Minute*

The American Cancer society estimates that in 2010 over 2000 people will be diagnosed with colorectal cancer in Connecticut alone and nearly 150,000 in the U.S. Early detection is the key and when detected early colorectal cancer is easily treated and highly curable. Men and women over the age of 50 should have regular colonoscopy to screen for the disease. Patients with colorectal cancer have more help than ever before. Each day more patients are surviving the disease due to increased access to advanced therapies and specialized care. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for colorectal cancer. New options include a Chinese Herbal Medicine being used in combination with chemotherapy to reduce side effects of treatment and help cancer drugs work more effectively. This has been a medical minute and more information is available at yalecancercenter.org. You are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.

Wilson Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my co-host Dr. Francine Foss. Today, we are joined by Dr. Tara Sanft and we are discussing survivorship. Dr. Sanft, can you talk to us a little bit about some of the nonphysical effects of a cancer diagnosis and how that is addressed both in the short term and the long term?

Sanft The nonphysical effects include issues with uncertainty or the inability to determine the meaning of the illness. Patients can have a lot of issues regarding ‘why me’ or ‘did I do something to cause this’, or going forward ‘how can I prevent my cancer from coming back’. At the survivorship clinic, we address these issues and try to use the best evidence that we have to instill healthy life style behaviors in patients in order to maximize their longevity and decrease the risk that they may have a recurrence. Other issues in the short term that can spill over into the long term include feelings of anxiety, depression, and distress. At Yale, we have a multidisciplinary approach and there are multiple people who specialize in these sort of psycho-oncology outcome measures and we are looking at integrating interventions and screening tools throughout the cancer continuum including survivorship to address some of these distress levels or signs of depression and maximize our intervention to help these patients move forward.

Wilson It sounds like what happens in the Survivorship Clinic is that there is really a vast array of things that can be provided for a patient. Tell us how a patient can get to the Survivorship Clinic, how can they find out about it, how can they get an appointment, do they need their doctor to refer them or can they call themselves?

Sanft I am glad that you brought that up. There are multiple ways that a patient can find us. First of all, they can call us at the clinic. This number is (203)785-CARE, or numerically, it is (203)785-2273. Any patient can call us and they will talk to our clinic coordinator and we can determine when the best time is to see that patient. Alternatively, we also get multiple referrals from oncologists, not only that, but other critical members of the care team including physical therapists and social

19:13 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

workers, and we have even had women that work at the check-out desk at Smilow Cancer Hospital help refer a patient to our clinic, so there is no one way that a patient can find us, there are multiple ways. You can find us on the Web at yalecancercenter.org or a patient can Google us at Yale Survivorship Clinic.

- Foss Tara, when you see a patient, do you interact with their treating physician, say with their referring oncologist? And what is the relationship that develops between the referring physician and the Survivorship Clinic staff?
- Sanft We make every effort to coordinate care and that includes very detailed communication with the primary oncologist and other identified members so if the patient tells us that they will see a surgeon, a radiation oncologist, a primary care physician, or a cardiologist going forward, what we do at the Survivorship Clinic is make a detailed plan regarding not only lifestyle interventions, but medical follow-up and then we communicate this plan to the providers that the patient specifies.
- Foss Can you tell us a little bit about some of the things that you have learned? You have been working in survivorship now for a number of years, what are some of the things that you have learned about patients and what patients gain from their experience with cancer?
- Sanft I feel that cancer patients teach us a lot on multiple different levels and in the realm of survivorship, something I have learned recently is how patients can take a diagnosis that can otherwise be very devastating, and turn it into something life changing and very positive, and I can share a story about that with you. Jeff Keith was diagnosed at age 12 with an osteogenic sarcoma, or cancer involving the bone, and this required removal of his right leg, including the knee and below. He continued from age 12 forward playing sports and doing multiple things in high school and through college. After college Jeff Keith became the first amputee to run across the United States. He raised 1 million dollars and donated that money to the American Cancer Society. Jeff Keith went on to found the Connecticut Challenge bike ride and has been the founder and very big supporter of the Survivorship Clinic at Yale. I think that examples like this really are inspiring and show us how a cancer diagnosis can shape a patient's life. Not every cancer survivor has major life altering changes that happen, but I think this shows us how a cancer diagnosis in one patient affects countless people going forward.
- Foss Do you feel that most patients develop a closer relationship with their family members after going through a cancer experience?
- Sanft I do, from my personal experience seeing patients who have had a diagnosis of cancer, I think it bring things to the forefront and helps put into perspective what is important to that patient, whether it be their family members, their significant others, their friends, maybe decreasing stress in their life, changing their job, these are all different things that patients have reported back to us coming through the Survivorship Clinic.

23:02 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

- Foss Another question I had is in reference to a number of patients that I have treated within lymphoma, and we have people coming frequently for chemotherapy week after week after week, and then when they are all finished and they are cured, they do not come in to see us anymore, they come every three months or so and a number of patients have expressed feelings of loss for the caregivers, the nurses, and the staff that they were used to seeing all the time. I wonder if you have seen that as well and how you deal with that?
- Sanft Yes, I have seen that and it has also been described in literature, and one article was looking at focus groups of this exact same scenario and the patients reported feeling like a warrior without a war, and so what the Survivorship Clinic at Yale helps to do is to transition those patients who have gone from very intense, sometimes very rewarding medical management and have built very deep relationships with their nurses and ancillary staff and their oncologists, and we help them transition from that intense monitoring to the longer term follow-up and I think the Survivorship Clinic at Yale really helps answer some of those unmet needs in that period of time.
- Wilson Here at Yale, we have a great variety of cutting edge clinical trials and research that patients can participate in and be a part of, typically at first diagnosis, what sort of opportunities are there for the survivor to participate in research, are there any opportunities?
- Sanft Yale actually has a longstanding history of conducting research focusing on survivorship and we have had a number of groundbreaking trials that have investigated specifically exercise and lifestyle interventions in the survivorship population, and looking at outcomes such as obesity, different levels that may be associated with tumor markers, and other things such as body composition and bone health. Currently, we have several studies going on in different populations looking at exercise as an intervention and its effect on things such as joint pain and women with aromatase inhibitor induced arthralgias, which is a very common side effect in this population, and also the effects of exercising women with a history of ovarian cancer. This tends to be a population that has had high risk for problems with weight and obesity and we also have studies going on looking at cardiovascular fitness and bone health in the breast cancer survivorship population as well.
- Foss Can you tell us a little bit about how cancer survivorship has changed over the last five years? I remember going to American Society of Clinical Oncology meetings year after year and it seems like it has only been recently that we have even talked about survivorship and things have really changed. Such as at the last meeting I went to last year, I think it must have been about 20% to 25% of the meeting was devoted to the issue of survivorship.
- Sanft Last year they had an entire track that was devoted to survivorship and I believe that was probably the first of its kind. Again, I think that survivorship really started to get some attention as far back as the 1980s, but if you look in the literature the topic has exploded in the past five years, and again, this has been with the support of people like Jeff Keith who started the Connecticut Challenge and of course Lance Armstrong who started LIVESTRONG or the Lance Armstrong

26:58 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

Foundation. They have really helped lay the groundwork to start things like survivorship clinics and survivorship programs, and also there has been an enhancement in terms of the education of providers like us. In the future, I think what should happen is survivorship should be introduced as an integral part of cancer care so that every cancer patient has exposure to survivorship care and I believe in order to make this happen, we have to think big in terms of all different types of services offered to cancer survivors and focus also on educating physicians in terms of giving that specialized care and making things like fellowship programs including these sorts of tracks at meetings such as ASCO and really enhancing community awareness and training within the medical field.

Foss At this point, is cancer survivorship a specialty within oncology?

Sanft It is becoming a specialty within oncology, but it is not its own dedicated training track as of yet. There is definitely room for that and I think that in the next five years we may see that be a part of our medical training.

Wilson You had mentioned how a patient or a physician can get in touch with the Survivorship Clinic. Where is the clinic? Is it in Smilow? What sort of proximity is it to the clinicians taking care of patients in their therapeutic phase?

Sanft It is right in the same area that patients receive their treatments so we are located on the fourth floor of Smilow Cancer Hospital. We meet once a week, right now on Wednesday afternoons, and any patient can find us by coming up there or giving us a call, again at (203) 785-2273. We feel it is important to be a part of the Cancer Hospital so that patients are able to see us and aspire to come to our clinic when they are finished with their treatment.

Wilson What do you think are some of the important things that a cancer survivor should know, or be thinking about?

Sanft In my opinion, I think that for cancer survivors the most important thing that they should know is who is involved in their care. And while this may seem like an obvious aspect of what a patient might know, there has actually been some literature that shows patients are often unsure about who is responsible for monitoring them going forward and so I think it is our job as providers to help patients know who is responsible. With such a mobile society, and patients living decades after diagnosis, the chances are that they will move around and possibly have multiple different providers, and I think it is really important for them to keep track of what is recommended in terms of surveillance and follow-up care and who is going to be providing that care for them.

Foss Tara, if there is a patient listening out there who had a cancer diagnosis say many years ago, 5, 10 or 15 years ago, would that patient still be eligible to come to the Survivorship Clinic?

30:30 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

- Sanft Absolutely, actually a couple of weeks ago we saw a patient who had had a diagnosis of testicular cancer 38 years prior, and he had just now heard about us and he came to our clinic and found it very beneficial.
- Wilson Is the clinic always available, you mentioned you have a meeting on Wednesday, but can patients come in on any day, how does the schedule work?
- Sanft We would love to be available to patients all day every day, but as it stands right now we meet once weekly and we will work with the patient to help them find a time that is best for them to come and visit us, but we have a half-day session weekly and we would hope to expand that and we are talking about that in the future.
- Foss Are there any programs that are planned at this point to educate the physicians in Connecticut about the survivorship program, and I think that includes not only the medical oncologist, but all the community physicians out there as well that are seeing these cancer survivors in their practices?
- Sanft Once yearly we at Yale support a Survivorship Summit that provides education to all different types of providers and we have a different focus every year, so last year we focused on sexuality but other topics that we might cover include nutrition and psychosocial support, and this is a conference that is meant to enhance the education of all different types of providers. There are other programs like this offered throughout the state and I think it is important that healthcare providers take the time to learn about these issues because there are some very specific things that we need to know going forward and taking care of this population.
- Wilson Does your group get into the community, or are there survivorship programs around the United States that do that sort of thing?
- Sanft There are programs like this out there for survivors, and interestingly, there are often open invitations for survivors to attend these types of conferences and they will be sitting in the breakout sessions and participating in small groups, and so beyond attendance at some of these professional research or educational programs that are offered, there are multiple support groups and intervention specific for survivors that are offered throughout the state and then of course throughout the nation as well.
- Foss It sounds like most of your patients have a positive experience and actually benefit significantly from coming to the clinic.
- Sanft Absolutely, I firmly believe that and I believe that we have something to offer everyone at Yale and I believe that the Survivorship Clinic is a very valuable experience that all patients should partake in.

33:39 into mp3 file <http://yalecancercenter.org/podcast/oct3110-cancer-answers-sanft.mp3>

Dr. Tara Sanft is an Assistant Professor of Medicine in Medical Oncology and Medical Director of Adult Survivorship for the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. If you have questions for the doctors or would like to share your comments, visit yalecancecenter.org or you can also subscribe to our pod cast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.