

Yale CANCER
CENTER

answers

WNPR Connecticut Public Radio



Hosts

Anees Chagpar MD

Associate Professor of
Surgical Oncology

Francine Foss MD

Professor of Medical
Oncology

What's New in Cancer Survivorship

Guest Experts: Tara Sanft, MD

*Assistant Professor of Medicine (Medical
Oncology); Medical Director of Adult
Survivorship, Yale Cancer Center
Survivorship Clinic*

Carol Ridolfi, RN

*Registered Nurse at the Smilow Cancer
Hospital Shoreline Care Center*

Yale Cancer Center Answers

is a weekly broadcast on

WNPR Connecticut Public Radio

Sunday Evenings at 6:00 PM

Listen live online at

OR

Listen to archived podcasts at

Welcome to Yale Cancer Center Answers with doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. 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, Dr. Chagpar welcomes Dr. Tara Sanft and Carol Ridolfi. Dr. Sanft is an Assistant Professor of Medicine and Medical Oncology and Medical Director of Adult Survivorship for the Yale Cancer Center Survivorship Clinic. Carol Ridolfi is a Registered Nurse at the Smilow Cancer Hospital Shoreline Care Center. Here is Anees Chagpar.

Chagpar Why don't we start off by having both of you tell us a little bit about yourselves and about what you do at Yale and with survivorship? Tara, let's start with you.

Sanft Thanks for having me, I am a medical oncologist that specializes in the treatment of breast cancer and as Director of the Survivorship Program I see patients of all different diagnoses who have completed their initial treatment and they come through a multidisciplinary clinic with us two times and receive counseling regarding how to maximize their health after treatment. So that is my role as the Director of the Survivorship Clinic.

Chagpar Carol, tell us a little bit about what your day to day is like?

Ridolfi I started with the Survivorship Program, including work with support groups, about 9 years ago. I was working in radiation oncology as a nurse and it became very apparent that the one thing we were lacking at the Shoreline Medical Center were support groups, and the issue came up over and over again and so after some careful thought and support from my department we began two support groups, a general support group for all different kinds of cancers along with family members that might want to join them, and also a breast cancer support group and both groups have done very well. The breast cancer support group is extremely active and has been an inspiration for me. The general support group sort of waxes and wanes, right now we are on a waning stage, but I have no doubt whatsoever that it will continue to grow and will be a great comfort to people along their journey.

Chagpar Tara, why don't we start with thinking about the whole survivorship concept, every day people hear about people getting diagnosed with cancer, but how many cancer survivors are out there and when does a person become a survivor? Is it the minute that they are given a diagnosis, is it five years out, how does that work?

Sanft Currently there are an estimated 13.6 million cancer survivors in the United States and this number is expected to continue to grow. The definition of a cancer survivor has evolved over time, and at one point in the distant past there was a time point after which someone could consider themselves a cancer survivor, but a group of survivors got together in the 1980s and decided to change that definition because 65% of people are expected to live at least five years beyond their diagnosis, so

3:51 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

survivorship really starts at the time of diagnosis and we really need to pay attention to every patient who has a diagnosis of cancer because they are going to have issues after their treatment into the survivorship phase.

Chagpar Carol, do you find that in support groups you get people who are both fairly close to their diagnosis as well as long term survivors?

Ridolfi It is very individual. There are patients that come as soon as they are diagnosed and they come like deer in the headlights, they are frightened, they are overwhelmed, and I can tell you that it is the most amazing thing to watch them come into the group for the first time, just after a diagnosis when they are sobbing, they are upset, they do not what to tell their families or their friends, they don't know if they want to talk about it and they leave after conversations with group members and they are smiling and they are relaxed and they have some sort of an idea in their mind about how they are going to go on for the next days until their treatment begins. It could not be more rewarding to see those patients come through, and then we have patients that we do not see until after the treatment is finished and they have had time to think about what they have been through and they come in and start developing an understanding of the emotional aspects of their disease and how it has impacted their families, their friends, their relationships, their children, and so that is also an exciting experience. I can honestly tell you that as tired as I might be 5:30 at night when the group begins, I walk past there at the end of the day and I am elated. I have trouble sleeping that night because it has been such a wonderful, amazing experience.

Chagpar That is great. Tara you talked a little bit about the Survivorship Clinic. Can you tell us a little bit about how that works, how that is either similar or different from the support groups that Carol runs, who comes to the Survivorship Clinic and what is their experience like?

Sanft Just as a little bit of history, we were founded in 2006 and we are the first comprehensive multidisciplinary Survivorship Clinic in the State of Connecticut, and the way that we approach survivorship is with a multidisciplinary approach. Patients find us in a myriad of ways and once they come to our clinic, they are usually finished with initial treatment. They might be on anti-hormonal therapy or have some maintenance therapy but the bulk of their initial treatment is over and what they get when they come to the clinic is a 2-hour visit. They meet with four different providers. These providers include myself as a medical oncologist and my nurse practitioner, a registered dietician, a physical therapist, and a social worker and they leave with a personalized survivorship care plan, which is a document that not only summarizes what they have just been through including their diagnosis and the treatments that they received but also information about potential side effects, things to expect in future surveillance, recommendations, and identifying who will be in-charge of what going forward. We also spend the majority of our visit focused on addressing their identified concerns, which typically center around the fear of recurrence and also issues regarding their health now, so that means changes in their diet and changes in their physical activity to help get them back to where they want to be.

8:00 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

- Chagpar Carol, do you find that those are the same kinds of issues that come up in your support groups and do people who come through the support group then get access to the kind of personalized care plans that Tara is talking about? How do those two avenues for survivors intertwine?
- Ridolfi I would say that the Survivorship Clinic is talked about quite frequently in our support groups as are many other therapies that might be interesting to the group. There is a lot of educational information that is shared between group members along with support, just emotional support for each other, so yes I would say that if new people who have come into the group have not heard about the Survivorship Clinic then by the time they leave they will know about it and are almost always very concerned about getting there and being evaluated and getting the help that they think they need after the treatment has been completed. Often times they do not think about all of those needs until they have gotten through the storm really. So I would say that our way of integrating our care with them is just through education.
- Chagpar I would think that when you get that diagnosis initially, it is very much like you were saying Carol, that deer in the headlights, oh my gosh my world has just been turned upside down, but I would anticipate Tara, that when they get to you, they are back into, how do I get on with my life? When is it too early or too late to access the Survivorship Clinic, because it sounds like it is remarkable resource?
- Sanft It is and I will tell you just as a follow-up to what Carol was saying, that when people come through our clinic they see us twice and they walk away with their care plan and many of them want more support and want more ongoing long-term opportunities to talk with others about the experience and that is how we interact with the support group. People out there who are listening and think that this might be a resource themselves or someone they love could benefit from, I would say to you that there is really no time that is too late or too early to think about us. There are times when we would say, call us when you are done with your initial treatment because really the needs that are happening during that time are best handled by the active treating medical team, but when they are all done, while some of them do want to regroup and get on with their lives, like Carol said, many times there is a period of time, and sometimes it can last for years, when people look back and think, wow I am really devastated by what just happened to me, or, this has touched me I want to grow and become a better person than I was before cancer, and so that is the time when we try to capture patients, after that initial treatment is over. And who we really want to help are the patients who have a lot of uncertainty and feel sort of lost in transition. They have been in treatment, have seen their doctor every other week for months, and now they are going into surveillance and that is a scary word for many, even though it should be very happy time, they do not know how to expect, what might happen and we feel like we can do a good service to those patients, especially because we can help guide them to what to think about in the future.
- Chagpar It sounds like you would give them that survivorship care plan, that package that says okay, here is the road map that brought you to this point, here is the road map going forward, so that they have something tangible that they can hold on to when you are not there between visits.

12:13 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

Sanft Exactly, and to dispel myths and to answer questions that may not have come up until now.

Chagpar Speaking of myths Carol, one of the things that I think a lot of people may have experienced and certainly on the provider side some of us have found as well, is that when you are diagnosed with cancer, particularly a cancer like breast cancer, there are a lot of people that have a similar diagnosis and they all have an experience and they all have a story to tell, and I would anticipate that would be really exaggerated perhaps in support groups. How do you mitigate against people taking other people stories, which may not be their own and personalizing them?

Ridolfi That is the one good thing about the support group, there is every kind of breast cancer, there is every different diagnosis of breast cancer that the patient can relate to whatever cancer is being promoted or discussed. They now begin to understand that every breast cancer is not the same and then they begin to understand and learn about their own specific cancer, which can be a sense of relief depending on the kind of cancer that they have and the prognosis of each cancer, most people live very long healthy life after breast cancer and so having a group where you have the whole spectrum of cancers and the whole spectrum of longevity is a source of strength for them.

Chagpar That is terrific, we are going to continue this conversation, but first we are going to take a break for a Medical Minute. Please stay tuned to learn more information about cancer survivorship with Dr. Tara Sanft and Carol Ridolfi.

Medical Minute

The American Cancer Society estimates that over a thousand patients will be diagnosed with melanoma in Connecticut each year. 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 help than they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers like the one at Yale to test innovative new treatments for melanoma. The specialized programs of research excellence in skin cancer grant at Yale, also known as the SPORÉ grant, will help establish national guidelines and 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.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guest Dr. Tara Sanft and Carol Ridolfi and we are discussing cancer survivorship. Tara, before the break you were telling us about millions of survivors in this country and how the Survivorship Clinic here at Yale has a multidisciplinary approach to survivorship. Can you tell us about survivorship programs in general, are these all over the place, do they have different flavors

and should every cancer survivor be in a survivorship program or get this personalized care plan that you were talking about?

16:01 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

Sanft To answer the first part in terms of what is happening across the nation, survivorship is really evolving and I would say that over the past five years or so it has received a lot of attention and comprehensive cancer centers across the nation have been charged to address this and I would say that we are one of the institutions trying a multidisciplinary model, but we are not the only one. There are other models out there that include disease specific survivorship clinics in which let us say a breast cancer survivor or a colon cancer survivor would be seen within their own clinic and given a survivorship care plan and those are models that are happening as well as entire centers dedicated to counseling survivors within an academic institution, and there are many different ways to give survivorship care and I think that there is no one right way. I think that everybody is different and everyone may want their information given a little bit differently. That being said, there are many national institutions like the Institute of Medicine who believe that every patient deserves and should receive a survivorship care plan and the reason why this is important is not only are 65% of all cancer patients expected to live beyond five years, but a significant number are going to live decades, and with our mobile society there will be times when patients need to report their own cancer history. A survivorship care plan at the least should include information about the diagnosis and treatments received in order to aid that person in their journey going forward to help give their future providers accurate information. Does every patient need reams and reams of information about potential side effects and long term effects and things like that? No, but every patient should know about the recommended surveillance because that will be important for them going forward to make sure that we catch any recurrence early and that a second cancer can either be prevented or caught and treated.

Chagpar One of the things that I thought was really amazing and intriguing and really great about the model that you had embraced, is this multidisciplinary approach with a dietician and a physical therapist and a social worker. Carol, do you find that survivors are interested in talking about what they should be eating and how they should exercise. Do you find that those are questions and comments that come up in your support groups?

Ridolfi Yes, we talk about those almost at every meeting, the fact that they feel guilty about perhaps not eating as nutritiously as they should have and they blame themselves for their cancer diagnosis and to the other extreme, where they have always been very active, had been very concerned about making sure that they ate proper foods and can't understand how they could have gotten cancer, so we do see people on the entire spectrum and I would agree that probably the time for patients to be seen in Tara's clinic is after they have finished treatment and they have had time to figure out what their needs are and sometimes that happens through support groups, things that they had not even concern themselves with, come up in support groups and suddenly a light bulb goes off, it is certainly after they have been in group for a short period of time, they understand the intricacies of their breast cancer, they come in embarrassed, not knowing whether they are ER or PR positive, and suddenly that is information that they find important. We sometimes find people that are on

the Internet way too much and come in so overwhelmed with misinformation from the Internet or from friends and family and we are able to sway those fears as well. We are talking about all the

20:34 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

issues that Tara is able to address in her clinic and then often times they will come back from her clinic and report back to the group which will stimulate more participants so it is really a nice marriage.

Chagpar And so it seems to me that when we have people who are going to support groups and thinking about, what should I be eating, how active should I be and all of the psychological concerns that are there, they may be very interested in accessing a survivorship program like this one. Do people who want to access a survivorship care clinic like yours, do they need a physician's order or referral, can people simply look up your phone number and say I am a cancer survivor?

Sanft Certainly every survivor should look in their own community for resources that are available to them and I can't speak for the other survivorship clinics, but at the Yale Survivorship Clinic anyone can refer themselves to us and while we have physician champions and nurse champions and even people in the check out booth who refer people to us on a regular basis, I would say the majority of people who find us see us on the web, Google survivorship services at Yale and find us that way and call us and get in to see us and we will always talk to anyone who is interested and help navigate the system and get them to us if appropriate.

Chagpar Carol, I want to come back to you and talk about support groups because just like there are survivorship programs potentially all over the place, there are also support groups all over the place and so does every cancer patient need to be plugged into a support group or are there some people who do better with some support groups than others? How do people figure out what support group is right for them and are there things that people should be looking for in finding a support group that might be appropriate for their particular diagnosis in their particular case?

Ridolfi When I am speaking about my own support group, I am a nurse facilitator and maybe because of that, the people that come to my support group are really looking for educational information and they receive emotional support not only from me, but from each other. So we do not have the luxury of a social worker in the breast cancer support group that I facilitate, but the focus has always been on information sharing, educational sharing, and it is a very strong healthy group so that is what has really worked for us in Guilford. And I think that some people come, they are in crisis, they are falling apart and we think this is going to be a long term person, but we never see them again. So, they came to us in crisis, somehow we got them through that moment of fear and they never felt that they needed to come back. We have people that have been coming for nine years. I mention that to almost every patient that comes through our department, there are no hard feelings, but if they think it is something that they need, we would love to have you. If you do not think that you are interested in something like this, then that is fine. Sometimes they need one-on-one, a nurse or social worker and themselves. Some people do not want to discuss it at all. They

want to put it behind them and people just need to know that whatever their need is that we are there for them.

24:40 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

Chagpar Tara, when people come to the Survivorship Clinic and they are past their first treatment and you were addressing some of their fears and you said that one of the fears was recurrence, and I can imagine that might be something that many cancer survivors often think about, are survivorship clinics designed to be the surveillance module, do they come through your clinic and get a mammogram every year or is this really giving them the tools to look for that recurrence, how does that work?

Sanft There are a few issues with the point that you have brought up that deserve attention. First of all the fear of recurrence is a very real palpable issue for almost every single patient coming into the clinic, regardless of their disease, stage, diagnosis, where they are in their treatments, or in their life and I think coping with that fear is necessary to move past the diagnosis and that is why the multidisciplinary approach becomes very important. So the real fear of recurrence, regardless of how realistic it is that the cancer could come back, there are certain techniques, mindfulness techniques and guided imagery and ways to cope with that fear that we spend a lot of time talking about that in the multidisciplinary clinic. That being said, we also do provide tools to help them understand what the surveillance schedule should be and send them back generally to their treating oncologist to discuss that and to set up those schedules and many of them are already very well informed about this, but some of them are not and so we reinforce based upon comprehensive cancer center guidelines what should be the general expected schedule of surveillance. Also at Yale we are trying something new, we're adding on another model which is a Long Term Survivorship Clinic in the Breast Center where patients who are five years out of their diagnosis have a choice to be followed in a long term survivorship clinic where we would be the ones who are ordering their surveillance and monitoring them for late effects or recurrence.

Chagpar I would think that for some people that would be nice because just as you say, that lost in transition, some people want to hang on to coming back and being seen every year.

Sanft They do and there has been some research on this topic and ultimately as a person who gets further and further way from the diagnosis, the risk of recurrence goes down, and primary care providers and oncologists are able to provide equivalent care, very high level care, if they know exactly what to do. When you survey patients though, at least in the breast cancer community, the majority of them do want to hold on to their oncologist for emotional reasons and for that psychosocial support that they get from getting a clean bill of health from their oncologist every year.

Chagpar I think that the relationship it sounds like the Survivorship Clinic has with both the treating providers and the family physician is really very robust and Carol I would think that the same thing occurs in support groups. One of the things that you mentioned was that sometimes you have

people who come in that are in crisis. Tell me a little bit about how you as a nurse facilitator are able to not only get that patient through that moment in the group setting, but the relationship of how you can tie them back to that treatment model if that is what they need. What is the relationship there?

28:49 into mp3 file <http://yalecancercenter.org/podcasts/2013%200512%20YCC%20Answers%20-%20Sanft%20and%20Ridolfi.mp3>

Ridolfi Thankfully, I do not have to do that by myself. I usually have about 15 other people in our support group that are able to manage that themselves. So, we are able to try to relieve some of their anxiety over just the diagnosis, get them through that period of anxiety, let them know that we are here for them and often times they will take phone numbers of other support members and have a relationship with them outside of the group and that sort of ties it all up for them and usually gives them the reassurance that they need, knowing that other patients have been through this and have gotten through it and they get that reassurance that they are going to get through it too.

Dr. Tara Sanft is Assistant Professor of Medicine and Medical Oncology and Director of Adult Survivorship for the Yale Cancer Center Survivorship Clinic and Carol Ridolfi is a Registered Nurse at the Smilow Cancer Hospital Shoreline Care Center. 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.