



Cancer Survivorship

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Welcome to Yale Cancer Answers with Drs. Anees Chagpar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists, who are on the forefront of the battle to fight cancer. This week it is a conversation about cancer survivorship with Dr. Tara Sanft. Dr. Sanft is an assistant professor of medicine in medical oncology and the Medical Director of Adult Survivorship for the Yale Cancer Center Survivorship Clinic. Dr. Chagpar is an Associate Professor of Surgery and the Assistant Director for Global Oncology at Yale Comprehensive Cancer Center.

Chagpar Tara, let's start off by talking about survivorship in general, but before we do that, let's set the stage. How many cancer survivors are there in the United States?

Sanft Currently there are over 15 million cancer survivors in the United States alone. It might be helpful to talk about the definition of cancer survivor, because historically, and to this date, patients say, I am a survivor, I was just recently diagnosed, and so looking back historically, people often thought well if you reach the 5-year mark, then you could be considered a cancer survivor, however, the National Cancer Institute, or the NCI, defines a cancer survivor as anyone who has had a diagnosis of cancer. It starts with diagnosis and the definition spans throughout his/or her lifetime and so any patient with a history of cancer is considered a survivor whether you are diagnosed today or 20 years ago.

Chagpar Perfect, and with modern therapies people are living longer, or is the number of cancer survivors growing overtime?

Sanft That is right. In 1971, I think it was, when Richard Nixon declared a war on cancer, there were 3 million cancer survivors in the United States.

Chagpar Wow!

Sanft So fast forward to today, there are nearly 16 million cancer survivors in the United States, that is an exponential growth. Part of it is early detection and another part is that patients are just living longer with better treatments. Now, this number is going to continue to grow such that by 2026, there will be over 20 million cancer survivors in the United States alone.

Chagpar That is a really great thing, right? Because oftentimes cancer survivors are people who survived a diagnosis of cancer and so, the fact that fewer people are dying of cancer and living either with their cancer or despite their cancer is a great thing, but those people have needs too, so are the needs of cancer survivors different than the needs of anybody else?

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- Sanft That is a really good point and I would like to say, before going too much further, there is a large number of people who have had cancer that do not really agree with the term survivor and so I think that is always fair to say when we are talking about these millions of people existing out there. My father for instance, has a history of prostate cancer but never once has he talked with me about his cancer survivorship for instance. I think it is important to recognize that with all these millions of survivors in the United States everyone is different. That being said, there are some unique, unifying needs that I have seen in my time working with cancer survivors and it includes things like fear of recurrence, so the normal population who may not have had a cancer diagnosis would not have a fear of having a recurrent cancer, but it is almost universal amongst people who have had a diagnosis of cancer and it really is not correlated with your actual risk of recurrence, so it is a very common emotion to have whether or not you have a 2% risk of recurrence or 70% risk of recurrence.
- Chagpar Do people tend to overestimate their risk of recurrence?
- Sanft The people who have been studied the most tend to be the breast cancer population and what patients themselves estimate as their risk does not actually correlate with their actual risk.
- Chagpar So one would anticipate that with that fear of recurrence, that might generate a lot of anxiety in someone and so what should cancer survivors do about that? Are there things that they should be thinking about or resources that they should be accessing that can help reduce that anxiety now that we have identified what as you called it, a universal phenomenon amongst cancer survivors, that is distinct from the general population, are there ways that those people can address those issues?
- Sanft I would say that the first step a cancer survivor could do who is experiencing the fear of recurrence is to recognize that it is normal and sometimes, in our survivorship clinic for instance where we see people who are recently finished with treatment, just saying that it is a very normal feeling to have, can help people cope with it better. That being said, there are patients who have become paralyzed with that fear and it is very hard to move on or to establish a new normal when all you can think about is what if this comes back or every ache and pain means that my cancer is back. For those patients, there are multiple resources. More research is needed to understand how to help this population, but certain things such as mindfulness and mindfulness based stress reduction techniques have been shown to help survivors cope with that fear or that thought about something that is going to happen in the future but has not actually happened yet.
- Chagpar I suppose talking to your doctor, your medical team, seeing if there is a survivorship clinic in your community might be helpful as well.

Sanft Right, and social workers are often very well equipped to steer patients in the right direction when these issues come up and oftentimes the most severe cases need ongoing support from either a psychiatrist or a therapist and depending on the community you live in, there are professionals who have experience with cancer survivors. There is a long list of literature out there too that helps patients that they could read books and articles and internet resources that can help frame some of these for them.

Chagpar What about support groups? Are those helpful or do they increase patient anxiety? I mean if you are in a support group and you see somebody whose cancer has come back, does that actually increase your anxiety or is it that if you are in a support group everybody is kind of dealing with the same thing so that reduces your anxiety?

Sanft That is a good question. There is literature, specifically in the metastatic breast cancer setting, where support groups helped patients cope better and potentially live longer. That data is now, I would say older data, but that was really the beginnings of psycho-oncology and so I think support groups can be very beneficial to certain types of patients. Now, if you feel like you can relate to a group and yet still keep emotions that happen if a patient recurs in check, that would be a very helpful setting for you and for other patients if they feel they are too different from a population, for instance the very young sometimes do not always benefit from a general support group if they feel like they are not really within the general age group of a support group, so some cancer centers have set up specific support groups that address those certain demographics, like they add a lesson in young adult population for instance.

Chagpar Many of our listeners may not be cancer survivors themselves, but they may know people who have cancer and when we think about the US statistics, one in every 2 men will be diagnosed sometime over their lifetime, one in 3 women and so most likely somebody knows somebody who has had cancer and so are there tips on how you as a friend, a neighbor, a colleague should try to be helpful in that situation? Where you have somebody who is a cancer survivor who may be having fear of recurrence or anxiety or the whole emotional rollercoaster of a cancer diagnosis? Oftentimes, the people around them do not really know what to say or how to support them. What is your advice on that?

Sanft My advice that I could give to friends and family members as well as medical professions is to meet the survivor where they are, so as I said, some patients get through their cancer and the cancer treatment and they do not want to talk about it and they just want to sort of try to get back into their regular routines. Many people have a hard time when cancer treatment ends, so the support systems that come on at the time of diagnosis are often very strong, think about the medical community for instance, we have all these resources for patients in treatment and think about neighborhood communities and signing up to bring a meal for instance while someone is on cancer treatment, oftentimes jobs and employers will take

special care of their employees while they are on cancer treatment, but when that treatment ends, people bang a gong and say congratulations and are really happy for you and oftentimes that is when the survivorship phase of struggling really starts to come out and I think it is not as obvious, so people start to look more like their old selves and because of that family members and community members and employers and even doctors can start to assume that things are okay or back to "normal" when in fact what survivors tell us in clinic all the time is that you kind of look around and say wow, what did I just go through? I have been through a lot and I am not sure that I am dealing with it as well as I thought I was and so what I would tell our general community is we need to be aware of that, we need to be sensitive to it, and we need to be supportive of this survivor who might not feel like going fulltime back to work and doing the laundry and cleaning the house and making the meals and being the end all and do all that they were before. It might take them longer to figure things out and the flipside of that of course is that survivors might want to ask for help when they need help, so that the assumption that they are back to normal can be dispelled rather quickly. It can be hard to ask for help because of all of the support that they may have received during treatment, but I think certain things that we see, some unifying things tend to be I want to get back to my physical shape, whatever that may be, I want to address some physical impairments that I have now as a result of my cancer treatment that I was not able to address during my treatment, I want to address my nutrition concerns and sometimes these are lifelong concerns, but cancer tends to be a teachable moment, so now I am ready to make those changes, how do I do that and we as medical professional should be aware of these concerns and address them appropriately, but also family members, community members, friends can be buddies, let's go for a walk together, let's figure out how to eat better, what is important now and many survivors will reprioritize things after cancer treatment, and I think being open to that as a friend or a family member is really important.

Chagpar Let's talk a little bit about the diet and nutrition part because many cancer survivors ask, was it something that I ate, was it my nutrition that caused this cancer and what can I do in terms of what can I eat or avoid eating that can prevent my cancer from coming back? They have a lot of concerns about their diet and trying to get to a healthier diet, so I hope that after we take a short break for a medical minute, you will come back and tell us more about what you would recommend in terms of diet and lifestyle, physical activity, both for our cancer survivors and their buddies in terms of the general population. We will take a short break for a medical minute. Please stay tuned to learn more information about cancer survivorship with my guest, Dr. Tara Sanft.

*Medical
Minute*

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This is a medical minute about genetic testing which can be useful for people with certain types of cancer that seem to run in their families. Patients that are considered at risk receive genetic counseling and testing, so informed medical decisions can be based on their own personal risk assessment. Resources for genetic counseling and testing are available at federally designated comprehensive cancer centers. Interdisciplinary teams include geneticists, genetic counselors, physicians, and nurses who work together to provide risk assessment and steps to prevent the development of cancer. More information is available at YaleCancerCenter.org. You are listening to Connecticut Public Radio.

Chagpar This is Dr. Anees Chagpar and I am joined tonight by my guest, Dr. Tara Sanft. We are talking about cancer survivorship. Before the break, we talked about how one of the concerns of cancer survivors is often the fear of recurrence, but then Tara, you also mentioned that sometimes cancer survivors have a lot of concerns about what do I eat, did I eat something wrong that caused this cancer, how can I prevent the cancer from coming back, should I be taking dietary supplements, what should I do to alter my diet, what about physical activity, can I lift weights, should I not lift weights? What advice do you give to cancer survivors with regards to all of those things?

Sanft I think that is a very good point. We asked over 300 survivors who came to our clinic, what their top 2 concerns were and the majority of them fell into the fear and coping which we have already talked about a little bit and then the others were nutrition, physical activity and weight in addition to symptoms and side effects. So this is another unifying theme amongst cancer survivors. I think it is hard not to reflect on life at the time of the diagnosis and think if there was something that could have been done to prevent this or if there was something that led to this happening. The truth is we know very little about diet and exercise as it directly relates to cancer occurrence except that there is an association between obesity and multiple types of cancers. That being said, there is a growing body of literature showing that people who maintain a healthier lifestyle throughout their life have lower rates of cancer or cancer recurrence for instance. So the focus on life after cancer I think is very important. Another reason why it is important to focus on this is because many early stage cancers such as breast cancer, their biggest threat to their health after the cancer treatment is actually cardiovascular disease, just like the rest of the general population and I think that is often overlooked after a cancer diagnosis,

Chagpar So this is a teachable moment after diagnosis where people can take stock of their life and say, thank you, I had cancer and now, I want to change for the better.

Sanft That is right. I think as an adult it is very hard for us to change behaviors and cancer can be one of those times where we are ready to overhaul some major things and we see this all the time in our cancer survivorship clinic where patients have come in and they are ready. Now the thing to keep in mind from a medical standpoint is that less than 25% of oncologists talk about health promotion with their patients. We all feel like you should be healthy, but I think

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we do not always have the vocabulary or know exactly how to talk to our patients about it and it often gets kind of bumped down on the list of things that need to be addressed, but it is very important. Survivors are much more likely to make changes if they have discussed it with a healthcare professional like their medical doctor and so I think what is important to know again is to meet the survivor where they are at. There is no sense in saying, you should go out and run a half marathon if you cannot walk a block. So the recommendation is 150 minutes per week of exercise or about 30 minutes per day, but that should not be the thing that you start off with, but you can certainly counsel your survivors to start off at much lower increments. A 10-minute walk is better than nothing at all and this is where the buddy system can really come into play. We often feel as loved ones, I want to do something, maybe instead of making a batch of chocolate chip cookies, offer to go on a walk and we really do think that some of that matters. It matters what you eat and it matters what you do, both during treatment and afterwards.

Chagpar A lot of cancer patients, however, might say, I know that I want to get healthy and I know that I want to incorporate more physical activity but I am just so tired or I gained weight. In some cancers, you gain weight and in some cancers, you lose weight, but getting that motivation either because of physical fatigue or just mental exhaustion because you have been through so much, how do you overcome that?

Sanft Fatigue is a real issue. It is again almost universal with cancer and cancer treatment that patients report fatigue. What we know is that patients who are physically active and survivors who are physically active have less fatigue than those who are not and so it is strange, but if you think about it, getting off the couch and doing something will actually help the fatigue more than taking naps or resting, that is the interesting part of cancer fatigue. Now, that is a hard obstacle to overcome, just getting up off the couch. So again, I have a physical therapist that I work with in my clinic who is a survivor himself and counsels on nothing but how to do this and I picked up a few tips from him, starting small is one of them, engaging a buddy is another, but other things like setting goals, deciding, I want to walk a 5K in 3 months and getting that on your calendar can be very helpful. Many survivors say, I do not have time, I have no time in my day and what his skill is, is to go through your schedule and actually find that time, so he gave an example recently that he dropped his car off for an oil change and went for a run while his oil was being changed. It does not have to be perfect and certainly we shouldn't feel like we need to be in a gym, sweating it out at 5 o'clock every morning in order to see these benefits. It could be just parking farther away and trying to get those few more steps and taking the stairs down instead of the elevator for instance. Every little thing does matter and you should reward yourself when you reach those little milestones and realize you are doing something good for yourself.

Chagpar What about in terms of diet? You said the other thing that people often talk about is nutrition. So I think there may still be some questions as to what kind of diet should I be

eating as a cancer survivor? Should I avoid all meats, should I avoid all alcohol, should I avoid all carbs, what do you recommend?

Sanft Nutrition is a very hot topic, not just amongst cancer survivors, but I think in the population as a whole. I do work with a registered dietician who is a certified specialist in oncology, so she has helped me learn some tips to tell our survivors and the truth is the recommendations put forth by the American Cancer Society and the American Society of Clinical Oncology are the very same recommendations that all of us should be following, which is plant based diet, so that means predominantly fruits and vegetables, about two and a half cups per day is the recommended serving and avoiding red meats or eating is sparingly and the alcohol debate, drinking alcohol less than 1 drink per day for women and I think less than 2 or 3 drinks per day for men, but if you are not a drinker, do not start and if you want to be a teetotaler about it, you could cut alcohol out.

Chagpar Then the question is, what about supplements, because a lot of cancer survivors ask, should I be going to the health store and buying supplements, should I be taking a vitamin, should I be using the latest alternative supplement? How do you feel about supplements in the survivorship period?

Sanft I think the official stance on supplements is to not use supplements to prevent cancer recurrence, we really have no good data that shows any one supplement is able to prevent cancer from coming back. That being said, most cancer survivors take some supplements. We just do not ask about it a lot but when we have in the studies that are published the fact is that people are just doing this and so I think as a medical community we need to ask them and then we need to talk about it and in those cases, my personal philosophy is first do no harm, we know that in certain types of cancers, for instance, breast cancer, women can be on pills for a very long time after their cancer to prevent it from recurring and those pills can interact with a lot of supplements and so in those cases, I think it is really important to bring to attention to your doctor the types of supplements that you are using to make sure that you are not harming yourself. The truth is that if you eat a variety of foods you are going to obtain most of the things that you need in your diet and that tends to be what we tell our patients to do.

Chagpar Beyond diet and exercise, there are other things that I think could really affect cancer survivors and I want to touch just a little bit on some of those. One is you mentioned the side effects of treatment. How long do those side effects last and what do cancer patients say about that? I mean presumably they are different for different kinds of cancer and different kinds of treatment, but how do they cope with that, I mean do those side effects last forever, do they just have to deal?

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Sanft Again I think when you are talking about millions of cancer survivors in any given time it is hard to lump all of this together. I would say that for each type of cancer that you have had, there is a long list of potential, what we call late side effects which could happen years after your treatment is over or long-term, that means things that you have acquired during the treatment process that may stick with you or sometimes never go away and so that can be different depending on who you are and the types of treatment that you have had and it is important that you do talk to your oncologist and your primary care provider who is navigating your care going forward about these specific treatments. We have strategies on how to help people involve specialists like physical therapists who may help with lets say postsurgical mobility issues, for instance we are getting better at addressing things like neuropathy which is numbness and tingling in your hands and your feet that you can get with certain types of chemotherapy. There are other side effects that are a little bit harder to address and sometimes harder to bring up which include sexual side effects for instance in men and women and without talking about it, we certainly cannot treat it, but the treatments are becoming more diverse and more encompassing I think to try to help survivors achieve an intimate lifestyle that they had before or that they want to get more out of their relationship going forward.

Chagpar And I would imagine that the whole cancer diagnosis and treatment has quite an impact on relationships even without the physical side effects right, because now this relationship, this family has gone through what is really a major life event which can either strengthen a relationship or make it disintegrate. What do you think about that?

Sanft Cancer is not often in anybody's plans and so it is often not in a caregiver's plans and so when this happens, I think it affects much more than just the patient himself or herself, it affects their loved ones including their partner and I think the caregiver stress and the caregiver burden is really not well understood and certainly not well addressed within the medical community and I think it is a real issue that needs to be supported, so that people can maintain their relationships rather than have them derail.

Dr. Tara Sanft is an Assistant Professor of Medicine in Medical Oncology and the Medical Director of the Yale Cancer Center Survivorship Clinic. If you have questions, the address is canceranswers@yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.