

# Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



## Managing the Emotional Side Effects of cancer

**Guest Expert:  
David Sells, PhD**

*Associate Research Scientist, Psychiatry, Yale School of Medicine*

## *Hosts*

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Yale Cancer Center Answers is a weekly broadcast on **WNPR** Connecticut Public Radio Sunday Evenings at 6:00PM

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*Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar, Susan Higgins and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital. Dr. Higgins is Professor of Therapeutic Radiology and of Obstetrics, Gynecology and Reproductive Sciences and Dr. Gore is Director of Hematological Malignancies at Smilow and an expert in Myelodysplastic Syndromes. Yale Cancer Center Answers features weekly conversations about the research diagnosis and treatment of cancer and if you would like to join the conversation, you can e-mail your questions and comments to [canceranswers@yale.edu](mailto:canceranswers@yale.edu) or you can leave a voicemail message at 888-234-4YCC. This week it is a conversation about the emotional and mental impact of cancer with Dr. David Sells. Dr. Sells is Associate Research Scientist in Psychiatry at Yale School of Medicine. Here is Dr. Anees Chagpar.*

**Chagpar** We talk a lot on this show about cancer, but one of the things that I think is often missed is talking about the genomics and the biology and all of these advances that we are making in terms of therapies of cancer, is the emotional impact that it has on cancer patients. Tell us more about that.

**Sells** It is such a profound experience and one that has a lot of social overtones as well that it has the ability to affect your sense of who you are, a lot of people end up adopting an identity of being a cancer survivor or cancer patient because the experience of diagnosis, rigors of treatment, the experience of the illness itself, are all so profound, that it has a transformative experience for a lot of people and along with that comes a transformative way of being, sometimes good but usually in the short term it is something that is unfamiliar and frightening where you have corresponding emotional reactions that are experienced as problematic, anxiety, fear, sense of foreshortened future, all of these things affect your way of being emotionally and they tend to infiltrate different parts of your life significantly.

**Chagpar** I think that those emotional reactions, the fear, the anxiety, would be pretty normal, you have just gone through this diagnosis, you are wondering, am I going to recur, will this happen again, what is going to happen to my children, I might die, I think that is understandable, so how do patients deal with that emotional baggage?

**Sells** People have different types of coping mechanisms in place and that can range anywhere from sharing with a loved one who sort of gets it, they get who you are, they sort of get as well as they can, not being the person who is undergoing this, what the experience is like. Some people have activities that are so profoundly engrossing for them, hobbies that could range anywhere from car repair to painting, that it serves as a sufficient distraction and even a mode of self-expression depending on what they might paint about, for example, so there is a channel of opportunity there. Other folks might reach out to a therapist or somebody in their spiritual community if they belong to one, so there are a variety of things and then of course a combination of all of these things and none of what I said is exhaustive, of course, a person's way of coping with it is about as unique as the person herself or himself.

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Chagpar Because oftentimes cancer centers have some sort of facility to help people with that emotional baggage whether it is through complementary therapy, Reiki, art therapy, massage, guided imagery, or whether it is through support groups, social work and mental health, so talk a little bit about the differences that patients have in terms of which therapies might be best for them, because as you say, what I found in my practice is that for many patients, what is good for some may not be good for others.

Sells There are certainly a variety of ways to go about getting support and guidance and saying that, you might consider for the individual what is more important to them on balance, is getting more support and feeling loved and cared for and understood the thing that makes the difference for them, or does it have something more to do with practical guidance which is another way of expressing care and love which is, I have these bad burns from radiation and somebody might suggest a remedy, either a clinical one or one that is herbal perhaps from someone that has been through the experience himself, and that is practical guidance because they receive it as a message of care, how things are offered and how they are received makes a big difference and it ends up being different for every person and that is why it is wonderful that a place like Yale Cancer Center has so many different options for support and guidance because you have so many different souls coming in for care.

Chagpar And the other way of kind of finding your way or getting emotional support, which ties into some of your research, has to do with having somebody who has gone through with themselves share their experiences. Can you talk a little bit about your findings and how that works and how some patients find that can be pretty helpful?

Sells Sure, absolutely. There is nothing like having been there and folks who have been there also have the immediate credibility with a person going through the experience now, surely they get through it in their own way but there is somebody who knows what it is like, some things you go through in this experience between diagnosis, illness, treatment are things that are very difficult to express to anybody and some of the things that we touched on earlier are part of that, so somebody who has gone through that gets it, they have that credibility, they have that understanding and if they have a sort of, I guess you could say clinical flare of sorts, they can be there for that person in a way that others cannot. They can engage them if the person is reticent to talk or express some of the experiences that they have had, keeping it in the baggage, so to speak, this provides an opportunity to unpack, an opportunity for expression which is always generally a good thing for most people, I found it to be in my research absolutely critical for people that they have that outlet with somebody who really knows what it is like.

Chagpar I think for many patients it is nice to have somebody who has gone through it because then they can relate, but even though they “get it” sometimes that experience is individual to every single patient, so the emotional support, the family support, the social support, that I may have my

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particular biology, my particular cancer, my particular treatments very different from yours and while we share a common diagnosis, and yes some of things, the anxiety, the fears may be similar, they may be different as well. Have you found that can sometimes temper this peer mentorship?

Sells Absolutely. It is in the eye of the beholder to a large extent and the fact that we have both had a similar experience does not necessarily mean that we will see eye to eye or create a bridge for me to express inexpressible things, so it does not always work and when it does, it is on a continuum; for some folks it makes a lot of difference and for some, not so much, so there is a range.

Chagpar I think the other way this plays in is often when patients are given a variety of treatment options, they will say, well my...fill in the blank here with my cousin, my best friend, my brother-in-law's sister had, they chose treatment x, but the question really for me is to bring the patient back to, that may be right for them, but not for you. Have you thought about and internalized whether that is right for you? How does that dynamic of trying to take and appreciate the experience of a peer, translate into a person thinking about their own experience and how they might use that to their benefit?

Sells We all sort of pick and choose the types of things that we take from others in terms of their well-intentioned advice and gestures and some of those things are powerful and some of them, they might not be so much and that is a hallmark of peer services, what ends up being critical is a sense of match, not just along the lines of, we both had this experience, we relate to each other and that is something that I have found seems to happen fairly immediately and just like in psychotherapy, I have been trained as a psychologist, what really heals is the relationship and that common experience provides one possibility for engaging in a therapeutic type of relationship. But it does not always work and other people are going to look for other avenues to regain their sense of vitality and purpose if it has been disrupted by this experience.

Chagpar I want you to harken back to something that you mentioned a little bit in passing which is with regards to this stigma of cancer and how this transformative experience that makes patients now label themselves to be a "cancer patient" which can be either really good, I mean we have all seen cancer survivors celebrating the fact that they are a survivor and they are going to shout it at the top of the mountain tops and cheer everybody else on and raise awareness and it is a beautiful thing, and others who are in a sense burdened by that realization. But first we are sadly going to have to take a short break for a medical minute, but when we return what I would really like to do is to get your sense of how this stigma effects cancer patients and how they internalize it or not and how they can deal with that. We will be right back after we take this short break for a medical minute.

### *Medical*

*Minute This year there are over 13 million cancer survivors in the United States and over 100,000 here in Connecticut. Completing treatment is an exciting milestone, but cancer and its treatment can be a life changing experience. Following treatment, cancer survivors can face several long-term side*

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*effects of cancer including heart problems, osteoporosis, fertility issues and an increased risk of second cancers. Resources for cancer survivors are available at federally designated comprehensive cancer centers to help keep cancer survivors focused on healthy living. The survivorship clinic at Yale Cancer Center focuses on providing guidance and direction to empower survivors to maximize their health, quality of life and longevity. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale- New Haven. More information is available at [yalecancercenter.org](http://yalecancercenter.org). You are listening to WNPR, Connecticut's Public Media Source for news and ideas.*

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined tonight by my guest, Dr. David Sells. We are talking about the psychiatry of cancer and right before the break, we started to unwrap this whole idea of stigma. I will tell you a little story here, and this is a true story. My mother was recently diagnosed with breast cancer and she went through treatment and she started to tell everybody about breast cancer and the fact that they should get a mammogram and because she got a mammogram they found this really early, and she wanted to make sure that other people could learn from her experience and one of the things she told me that for her was quite curious was the fact that as she would do this people would come up to her and say, "well actually I too was diagnosed but I did not tell anyone," and my mom was really quite surprised by this because she said "I do not get why you would keep that a secret, what is the stigma behind cancer, it is not like you did anything to cause this, it is not like it is something "bad," But yet, Dr. Sells, it is something that for a lot of patients they are perhaps somewhat ashamed of, can you unpack that for us?

Sells I think that is something that perhaps was a little bit common 30, 40, 50 years ago, this stigma attached with it because it was understood to be terminal, frightening, all that stuff, so people tend to shy away from talking about frightening things, they do not know how to give support in that type of situation and the people who have been diagnosed with cancer, do not want to be a burden to others, so it becomes something that becomes through sometimes overt cues and sometimes quite subtle but also equally powerful cues, hidden, and sometimes even with some degree of shame. From that point, you get into the notion of psychological recovery from the experience, from the social overtones of the illness which have to do with redefining yourself as a person who has this, but is not this, and that is critical. I would suggest that psychological recovery from it has to do with recognition or re-recognition or reminder somehow that you are other things and perhaps primarily other things and in addition, you have this illness and from that point forward it becomes less difficult perhaps to share.

Chagpar I think that it is so right on the mark. My mom bounced back, had her surgery, we were out shopping the next day and people were shocked, and she was like, what it was a bump in the road, so

I had cancer, I had my surgery, I am done now, she is a remarkable individual and I think that for her this was just a thing, like any other thing, an ailment like a cold, okay cancer is much worse than a cold, but like many of the medical conditions that we deal with that does not define us and

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so I think that was really important. I guess the other thing too that ties into this feeling of shame is for some cancers there may be more baggage associated with it because of its etiology, so for example in patients who have lung cancer who smoked for 40 years, do you find that they have more guilt because they feel like they caused this or people who have HIV associated malignancies that they feel that somehow this was a shameful thing, how do we get beyond that, how do we get to empowering patients to say, yes I had cancer, I am a survivor but I am much more than that?

**Sells** It is a matter of encouraging and reconnecting them with their other ways of defining themselves and that could be their jobs, their families, as a father or a mother, their professions sometimes are a big deal, a lot of people will double up in their professional life if they are feeling up to it and to sort of reinforce that kind of identity. There is always a question of where did this come from, why has this happened to me and sometimes they suspect it was a past behavior and there might be some guilt and shame tied to the experience as well, not that they ever know definitively, but we all want to know so badly that that is one of the directions that can go in when this storm erupts around them.

**Chagpar** And it must be difficult to get into the headspace of whatever was in the past that led up to this, I am here now, I am dealing with this cancer now but I am going to move forward in the future in a productive way regardless of the past and I think that perhaps getting to that headspace in the whirlwind of cancer therapy and diagnosis and all of the psychology that goes into what caused this and why me, might be difficult.

**Sells** You are saying that it would be difficult to get to that point?

**Chagpar** To get to that point, I am going to put this behind me because that is essentially where they need to get to is, it does not matter what caused it we are here now.

**Sells** Absolutely, that is such an important point, it is nothing short of an epic journey through the storm of diagnosis and treatments and the illness itself of course and communicating it to loved ones and it is an epic quest. I had this idea in my mind after doing a number of interviews with people that it was not unlike a mythical quest that Psyche who was a mortal in Greek mythology, she was looking for her love, Eros, Eros was a God who had fallen in love with her but they had a falling out that had to do with a number of things, but she went on this quest to regain her Eros. Everybody goes on this quest differently and of course upon this quest she was faced with what felt like insurmountable types of challenges and tasks and it was all quite harrowing; unlike a lot of Greek myths it has a

happy ending because she did regain her Eros, but I use that in part I guess to remind myself, lest I forget, what a profound challenge it is to regain one's sense of self and vitality for a lot of people after these experiences.

Chagpar The story kind of made me think about another element of this whole situation which is that as we are individuals in relationships, in families, in communities, in societies, how do those

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relationships also vary either with just the knowledge of the diagnosis or with ramifications of the treatments. For example, women who undergo mastectomies, one of the questions always is how does this affect your body image, your sense of femininity, your sense of sexuality this whole concept of will my husband, lover, whatever still care for me, how much does that play into the whole psychology of cancer in the sense of I am more than my cancer?

Sells Our bodies are perhaps our greatest personal possession and if they are changed in a matter that is visible or otherwise demands a psychological adjustment, usually a stage of grief and everybody again, given all our differences personally, can go through that differently. Some people bounce back very quickly, I imagine perhaps your mom went through a stage of grief maybe it was very short and maybe she is built differently.

Chagpar I do think it is so individual. It has been my experience. My mom is remarkable. So mom if you are listening to the show, you are, I have said it to the world, just an incredible remarkable woman and she bounced back and she really did take it like a bump in the road but so many patients even if there is no physical insult, even just the mental cognition of I am now a cancer survivor changes in some way those relationships and I find that it often is patients who have very strong support who have families who say, you know what, we are here for you no matter what, we love you no matter what, that is one situation, but there are situations where people end up as they go through this cancer diagnosis having relationships fall apart and so I think it all speaks to both how cancer has an impact on that individual's psyche and their relationships, but also I find that it is a truth telling of the relationship itself as to how it is enduring or not.

Sells A litmus test of sorts, yeah and lot of people find that their social networks shift and rearrange after something like this which is profound but it is all part of that storm and some people come through as angels that you would not have expected whereas others that you sort of expected to stand right by you have not quite lived up to that expectation and of course it changes the relationship and since to a large extent we also understand ourselves in reference to our relationships, it changes our identity in those ways as well meaning, I am close to this person and not that person anymore and it feels like a different world.

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Chagpar I think one of the things just as we are wrapping up that I would like you to speak to fairly quickly is that I have also found that patients sometimes celebrate and they transform into people who can actually do things that they never thought they would do because of this experience, have you found the same?

Sells Yes, definitely, I mean that is the positive and the transformative type of experience of it, they end up feeling more connected with others more invested in a particular type of activity, I will just say my father has become an award winning artist since his diagnosis in 2005, speaking of parents and that is a new type of identity.

*Dr. David Sells is Associate Research Scientist in Psychiatry at Yale School of Medicine. We invite you to share your questions and comments, you can send them to [canceranswers@yale.edu](mailto:canceranswers@yale.edu) or you can leave a voicemail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written form at [yalecancercenter.org](http://yalecancercenter.org). I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.*