

# Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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## Support Services for Cancer Patients

### **Guest Expert:**

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## **Yale Cancer Center Answers**

is a weekly broadcast on

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*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](mailto:canceranswers@yale.edu) and the phone number is 1-888-234-4YCC. This week, Dr. Chagpar is joined by Bonnie Indeck for a conversation about support services for cancer patients. Bonnie is a Licensed Clinical Social Worker and Manager of Oncology Social Work at Smilow Cancer Hospital. Here is Anees Chagpar.*

Chagpar Bonnie, let's start off by talking about what exactly social work is within an oncology setting because I think a lot of people can get confused about what exactly a social worker does?

Indeck Social workers are all licensed clinicians. We try to see patients and families and assess what their needs may be. How they are coping with the particular disease. What areas they may need help with, and we try to help them navigate the system and get the appropriate resources for them so that they can manage this effectively.

Chagpar How does that work on a day-to-day basis? A patient comes into Smilow Cancer Hospital, or any cancer hospital, and is given a new cancer diagnosis, I can imagine that for many patients that puts them into a tailspin. Does social work see them at that point? What does that conversation look like?

Indeck Many times we will see patients on the first visit, but not all of the time and that depends on how many other people are scheduled for the day. The last thing we want to do is overwhelm our patient, so we might just make eye contact, introduce ourselves, explain our role, and then make an appointment to see them on a following visit. We will meet them and their family if they would like support people, friends whoever they would like and we go through things in detail. We do a complete psychosocial evaluation to see where they are, what their needs may be and what resources we can put in place for them. Sometimes they require supportive counseling and we will make appointments to follow up with patients while they are in clinic. Other times, it is "can you please talk to my spouse" and we will do that, or there might be questions about "how do I talk to my children about this diagnosis?" The one thing we do know about cancer is that once the patient is diagnosed it is a family disease, everybody feels its impact and so we want to be there to help that family system, whoever that may be, cope with the impact of the diagnosis.

Chagpar Do you find that some people say, I do not need a social worker, I am fine, this is enough for me to handle, I can handle it on my own, do get that a lot?

Indeck Not a lot, but it does happen on occasion and oftentimes that may be accurate, people have good support systems in place, whether it is a religious support system, friends and family, and that may work for them and they may not need somebody. But I have found the benefit of introducing myself to somebody early on is that even if they do not need me right then, I have gotten phone calls months later, years later, saying, do you remember me? I did not need you then, but..." so

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there are many times where further down the road they may need us and if they already know who you are and that you are not scary or threatening, oftentimes they are very happy that they have your phone number and that they know who to call. It may be that we are seeing them for counseling or connecting them to a community resource. It may be that we're guiding them through the system, helping them to navigate, and answering questions because if we do not know the answers ourselves, the one thing that I can say about social work is that we always know where to get the answers.

**Chagpar** Let's talk about those three pieces because I think all of them are very important and all of them are integral to what social workers do. The first one that you mentioned was counseling and part of that may have to deal with grief and the sudden impact of all of a sudden getting this diagnosis of cancer and what that does to a patient and how they handle that psychosocial distress. Talk a little bit about what that counseling process is like?

**Indeck** Everybody copes differently, so we are assessing everybody as an individual, and a lot of it may be based on their past experiences, the trauma that they have already lived through or have not lived through, and that may be prognosticative of what they will do with this diagnosis. So depending on that we will counsel them, and that is very general term and it involves a lot of active listening, a lot of feedback, some guidance support, validation of feelings, getting the patient and/or the family to where they need to be and for some people that happens sooner than others. We know the literature says that upon a new diagnosis it takes a few weeks to get accustomed to the idea and oftentimes after a few weeks we see the people are coping better. They have a medical plan and once you have a plan, even if you have not started it, you feel like you are on the road to recovery and that helps tremendously. And then it is following up with people to provide the support they need and to validate their concerns, or to be a listening ear so that if they want to know if something is normal we can let them know what is, or perhaps may not be, and it may be something they have to work on further and we will guide them in the right direction. So it is up to the individual what the counseling looks like and what the person wants from us. We do not go in with a preconceived idea or with our own agenda because it is not about us, it is about the patient. What we do know is that there is a certain amount of psychosocial distress that everyone that undergoes cancer experiences. Most recently we have started screening people for psychosocial distress. The tool that we are using is an NCCN tool called the distress thermometer and it is a simple tool that takes probably two minutes to complete and the patient puts down what number of stress between 1 and 10 they are feeling that day and for the previous week and then there are some check offs under different domains such as physical, practical, spiritual, emotional, and they check off what they are feeling and then based on that tool that helps us to prioritize who may need to be seen and if it is by us or if they are only checking off spiritual concerns, we will get the chaplain involved. We will make sure the nurse or physician is managing symptoms because psychosocial distress encompasses many domains and we want to make sure that all of the needs are being met.

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- Chagpar If you have a patient who is having emotional, psychosocial distress, having issues with coping with this diagnosis, do you provide for patients different coping strategies individualized to that patient? Could you give our audience some idea of what those coping strategies might be?
- Indeck I think initially your world is turned upside down, and you are faced with own mortality, even if your diagnosis is not such that that is an issue, but people feel that and that is a normal feeling. So it depends on what a person needs, again. We may start with some simple breathing exercises, guided imagery. We might do Reiki, or send them to complimentary services, they may need a massage to decrease some of the anxiety and stress that they are feeling. Other times it may be that supportive counseling or in other instances it may be longer term psychotherapy that is needed and then we will make appropriate referrals for that. In addition, we have many support groups at Smilow Cancer Hospital, and most of them are based on diagnosis, but we do have several that are very general for any patient and/or family to attend and we do evaluations of our groups and they are quite successful and the feedback we have is that they should continue and that patients love talking to other patients who have been there, patients who can identify with them. Along those lines, most recently we started a new mentoring program, patient for patient. It is for people who have been through certain diagnoses and have lived through treatment, have come out the other end, who are willing then to share their experience with people who are newly diagnosed. That has started in breast cancer and soon it will be in many other diagnoses. We train the volunteers about how to talk to patients and more importantly how to listen to patients and see what their concerns may be and to help them see that in fact what is going on is quite normal.
- Chagpar I would imagine that it is therapeutic to the mentor as much as it is to the mentees.
- Indeck It can very much be, and the mentors love doing it because they feel like they are giving back. They feel like they are being helpful, that this cancer, this disease has a place in their life, they have learned something. They are using it. They are helping others and that is a wonderful feeling. You are absolutely right Dr. Chagpar.
- Chagpar The other thing you mentioned Bonnie, when we were talking a little bit about coping strategies, was breathing exercises and Reiki, and people may need a massage and you mentioned complimentary therapy, are these free for patients?
- Indeck The wonderful thing about Smilow Cancer Hospital is that our complementary therapy is complimentary. You have to use both spellings of the word, but we do not charge for people to attend the sessions that we have. In addition to the Reiki and massage, and guided imagery, we have yoga classes, and we have a very large art expression program that patients are just loving and if you have seen recently on the first floor of Smilow, that huge cornucopia, that was done by patients and also by some staff and it has gotten a lot of positive feedback. It is a wonderful way to use your energy and to do something constructive with what is inside of you.

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Chagpar I think that for a lot of patients that must be incredibly therapeutic as you say to take what could initially be seen as negative energy and put it into something positive.

Indeck Absolutely.

Chagpar The second area that you mentioned briefly when we were talking about social work after the counseling piece was connecting patients to resources in their community. Can you talk a little bit about what kinds of resources are in the community and how community is defined, is it just around the hospital or is it around the state, around the nation?

Indeck We would like to use community in the largest sense, in its most global definition. So of course it is around the nation, you are absolutely right. Although people often take advantage of resources that are closest to home first, so we may refer somebody as I mentioned before let's say for long term counseling because that may be what they need, but we may also refer somebody who needs transportation, so we would refer them to the cancer society for their volunteer ride program. We may refer somebody for financial assistance to the state and things of that nature.

Chagpar Bonnie, we are going to pick up on this conversation because I think it is extraordinarily important to our audience to know about resources in their community, but first we are going to take a break for a medical minute. Please stay tuned to learn more information about support services for cancer patients with Bonnie Indeck.

*Medical  
Minute*

*The American Cancer Society estimates that over 1000 patients are 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 hope 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 problems of research excellence and skin cancer grant at Yale also known as the SPORE grant will help to establish national guidelines on modifying behavior and on prevention as well as identification of new drug targets. This has been a medial minute, brought to you as a public service by Yale Cancer Center. More information is available at [yalecancercenter.org](http://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 tonight by my guest Bonnie Indeck. We are discussing support services for cancer patients and right before the break Bonnie, you were telling us many of the roles of social workers. The first was counseling, but the second was really connecting people to resources in the community and you were telling us a little bit about some of those resources. I want to really start to understand

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what those resources are. You had mentioned, for example, transportation, because I would think that a lot of people have issues with, how do I get to a doctor's appointment, I live alone, I do not have any friends, or family. I think most people have friends, but I do not have friends who can drive me and who would think that a social worker could help them with that. Tell us more about that.

Indeck You are absolutely correct, not everybody has somebody who can take them to treatment, particularly, if somebody is undergoing, for instance, radiation therapy, which can be daily for weeks and it is hard to find somebody who can take you back and forth even though the treatment itself may be over within just a few moments. So we will look at the resources in the area. Does your town have transportation? Is there senior transportation, and senior also includes disabled, and when I say disabled, I do not mean that you have to be officially social security eligible disabled, but many towns will take who are undergoing treatment to a cancer center, and then there are other area agencies that focus on this and that will help somebody get there. So I do suggest that if somebody has difficulty that they contact the local social worker in the area where they are being treated and see what resources are available to them. Along those same lines, globally if somebody is having difficulty, for instance with social security disability, not to say that everybody who has cancer needs disability by any stretch of the imagination, but sometimes when a disease becomes more advanced, that may be an appropriate referral. We help people access that, or if somebody has a question about insurance, we will try to help them, we will get the appropriate staff members at the hospital to try to help them, but sometimes it is a question of legality. Did my company do well by me? Do they have the right to do this to me? And there are a couple of organizations that we work with regularly that can help. There is an organization, for instance, the National Coalition for Cancer Survivors who are experts on these things. There is an agency called Cancer and Careers. They are experts at these things as well and will make those contacts for the patient to make sure that they are been treated correctly.

Chagpar I would imagine that there are patients with whom these two areas intersect. They may come to you Bonnie and say, how do I tell my employer that I have cancer? Is there a possibility that they may discriminate against me and I may lose my job as a result of this diagnosis? What do you tell the people who ask you those questions?

Indeck There are certain regulations in place and we as individual social workers do not know the answers and that is when we would contact that particular agency. Because everybody's situation is a little bit different I cannot really tell you exactly what I would say, because I would really have to hear the individual circumstance. We know most things about what the laws are and we are able to help people, but if there is a trick question, we are not attorneys and so we will use the resources that are most appropriate to guide that patient through that particular dilemma.

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- Chagpar Do you get a lot of people who come to your social work saying, I have issues paying my medical bills. Because this is an expensive diagnosis, and if they do not have insurance or if they are under insured, are there resources that social work have that connects them to help with that?
- Indeck There are some, usually we work first within the hospital resources. So we have an office of patient and financial admitting services who help to financially counsel people and work with us as a team approach, to see if somebody is eligible for certain insurances that they may not know they are eligible for. Is somebody eligible for HUSKY? Can they purchase individual plans? Is COBRA a possibility? Or if they are underinsured can the state help with the spend down? Again, everybody is individual, there is not one answer out there, but there are some community resources that do have a little bit of financial assistance available, and I say it like that because in these financial times, obviously all budgets have become a little tighter and the resources are not what they were 10 to 15 years ago, but we will connect people to those resources if we think that they can be of help.
- Chagpar And the good news is that at least there are some possibilities, granted financial times being what they are, but that is really a valuable resource that you provide the patients to be able to say, there may be some help for you.
- Indeck Yes, that is exactly right and we want to make sure that no needs go on met. We do not have a magic wand so we cannot make sure that every need is fulfilled, but we will do our best to scour every resource to make sure that if there is anything we can do, we do it.
- Chagpar What about other resources, we have heard about things like Look Good, Feel Better, getting bras and prosthetics after mastectomies, those kinds of things. If people aren't sure about where to go for those kinds of programs, is that something that social work helps with as well?
- Indeck Absolutely and in fact at the hospital we run a very successful Look Good, Feel Better program that we co-sponsor with the American Cancer Society. We have many-many people who attend one of our most successful programs and it is a positive one. Women connecting with each other, women bonding, and laughing, and just working together to make the most out of the situation. There are ways to get prosthesis if that is what somebody needs, we have a wonderful boutique at the hospital that sells some of these items, and also some people may be eligible for some assistance for it and there are many kinds of resources. For instance, if you want to be careful of the sun, there is clothing that has SPF in it so that you can be protected a bit more. There is sunscreen that we sell, nutritional supplements, and one area that people do not always like to talk about is sexuality and intimacy, the boutique sells certain items that may be of help for those issues, also some hats, scarves, whatever it might be to help somebody just feel better during this whole process.

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- Chagpar To get back to feeling better and getting normal, one thing that I do not want to lose sight of is something that you started with at the very beginning, which was that this is a family disease. It is a family diagnosis and it affects entire families or units of people. What are the resources that are available for spouses or significant others or children, for them to get through this as well?
- Indeck Always with the patient's permission we are very happy to talk to family, and family is defined any way that the patient wants to, so that may be friends, it may not be a blood relation. Whoever the patient decides is family, is family. We will work with them the same way we work with the patient. Children are one of the things that I think that we help with very much. We have a program called PACT, which stands for parenting at a challenging time because when somebody gets diagnosed they are very worried and often as a parent your first worry may be, how do I tell my children, and so we help guide the parents with how to tell their children. First we find out what are the ages of the children, because we believe and the literature supports it, that children should know what is going on, but it has to be an age appropriate truth because you are not going to tell a 5-year-old the same thing you are going to tell a 15-year-old. So we will make sure that parents know how to talk with their children, and get their questions answered. They may need support, they may need reassurance, they may say, am I going about this the right way? We will suggest speaking with the school, does the teacher know, any little hint that could help because we are only with our children a certain amount of hours a day and if they are school-aged, teachers may see them 8 hours a day. So we want to alert the teachers as well so that they know what to be on the lookout for. Oftentimes, children may act fine at home but at school is where they may act out. We will help guide the parent and many times it could be a grandparent because now-a-days grandparents can have custody of young children or even if they do not have custody if in fact they are very close to their grandchildren we are going to make sure that the grandparent is explaining things correctly. One of the worst things that can happen is not telling the children the truth because when they find out they will be angry that you lied to them and again you are going to say it in a way that they can understand, you are going to watch their behavior. You are going to see if they are coping okay, we are going to help with that. We are going to give you books and pamphlets as appropriate to what you might need, we do not want children guessing because oftentimes what they are thinking in their minds and not verbalizing is far worse than the reality of the situation and the other thing is that oftentimes children overhear things, so you think you are protecting your children by not telling them but they may hear you on the telephone say, I am going to the doctor again and they may not feel comfortable talking to you about it. We really try to help support the parent in this challenge.
- Chagpar The other thing too Bonnie is that we have been talking for the most part about adult cancers, which are the majority of cancers that we see, but I would imagine that social work must play an incredible role when a child gets cancer as well.
- Indeck Absolutely, we have three very skilled pediatric oncology social workers who know every child who has been diagnosed with cancer. Oftentimes they are working with the parents and the family

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more than the child. It depends on the age of the child at the time of diagnosis and it is a team approach in pediatrics just as it is in adults where they are working with the nurse practitioners or physicians whoever might be involved in that child's care.

Chagpar One of the issues that comes to mind and that you mentioned earlier in the show before the break was that sometimes people contact you months later, years later and say, do you remember me? What that makes me think about is that these days with advanced therapies there are a lot of people who are not dying from cancer, but living with it. So there is this whole survivorship movement because the number of survivors of cancer in this country is sky rocketing. Does survivorship have a role intertwined with social work? Can you talk a little bit about the role of the social worker in that long range survivorship care?

Indeck When somebody has completed their treatment that is the time when their anxiety rises, they are used to coming for medical care quite frequently, and all of a sudden we're saying to them, you do not need to return for three months and so many people are thinking, my arm hurts, my leg hurts what does this mean, has my cancer returned? So we try to normalize for them some of the things that they may feel during that period of time. We have a very active survivorship clinic and so social work is a large part of that clinic and what we are trying to do is help people figure out what purpose the cancer has served in their life and I know that may sound weird, but what have you learned from that cancer, how do you put that into place and where do you go from here? How do you rationalize this, can you move forward in a better way or are you still traumatized by it? What other help may you need and prefer if that is the case?

*Bonnie Indeck is a Licensed Clinical Social Worker and Manger of Oncology Social Work at Smilow Cancer Hospital. If you have questions or would like to add your comments, visit [yalecancercenter.org](http://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.*