

Bonnie Indeck, Supportive Care for Cancer Patients March 6, 2011 Welcome to Yale Cancer Center Answers with doctors Francine Foss and Lynn Wilson. I am Bruce Barber. Dr. Foss is a Professor of Medical Oncology and Dermatology, specializing in the treatment of lymphomas. Dr. Wilson is a Professor of Therapeutic Radiology and an expert in the use of radiation to treat lung cancers and cutaneous lymphomas. If you would like to join the conversation, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1-888-234-4YCC. This evening, Lynn welcomes Bonnie Indeck. Bonnie is Director of Patient and Family Services at Yale Cancer Center and she is here to talk about support for cancer patients. Here is Lynn Wilson. Wilson Let's get started by having you tell us a little bit about what support services are and why they are important for both patients and caregivers? Indeck Support services are really a network of services that are available to patients and families to help make their life during cancer treatment a little bit easier. Often they can be of a concrete nature, including help with transportation or finances, but more often people use support services for the emotional pieces of being treated for cancer. We do support groups to help people, individual counseling. At Smilow Cancer Hospital, we actually have a fairly new boutique that sells items that are particularly helpful for cancer treatment including wigs and scarfs and items if you have had a mastectomy. We tried to put all the pieces together because we do know that medical treatment is clearly why people are there, that's number 1, but you cannot get through medical treatment unless you have the emotional component and assistance with the emotional needs to help complete the package for you. Wilson You and I have worked together for a long time, what sort of changes have you seen since you have been at Yale? What things in support services have advanced and changed, and what have you appreciated over the time here? Indeck We have increased the number of services available to patients and families and that's really a wonderful thing because we have so many people with cancer that are being treated that we need to be able to meet their needs. In fact, one of the things Smilow has available is a patient and family advisory council, and we have patients and families who actually make up the council along with a few staff people, but it is the patients and families that help to guide us and tell us what they need to get through the treatment, and we meet on a monthly basis and work on various projects, so that's one thing that has really been a huge improvement, I believe, to care because we are hearing it directly from the people who count. The other thing is with the internet, I think that many people have access to many more resources and they come in much more prepared and they ask us questions and we try to help them manage whatever the need may be. Wilson You mentioned the boutique, obviously, that's a fantastic resource that we have right here at Smilow Cancer Hospital. Indeck It's phenomenal. 3:21 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> Wilson What did patients do before we had Smilow, before we had a boutique, what were their options at that point? It seems obvious that we have got the boutique, but tell us the differences and what that provides for patients to make things a lot easier for them now, com-

pared to say two years ago before we had it.Indeck The boutique allows patients and families to have one stop shopping. They may be getting treatment, and may have to see a physician for instance, or may be having surgery, breast surgery and they do not know what they will need, they stop in the boutique and either Linda Secher who is the manager, or Lynore Aaron who is a certified fitter, help people with purchasing items that they are going to need for their surgery. It allows people to come down, and in the privacy of a small space try on wigs or try on certain lingerie that have pockets for drains for instance. It allows them to buy skin care products that have SPF in them. It allows them to buy a bathrobe if they forget that and that is something they want. It has inspirational books and items that just make you feel better. What we try to do is make you feel better emotionally, whether it be taking care of a concrete need, or whether it is actually to buy something that helps emotionally and to be able to do that where you are getting treated instead of having to go out into the community and find the correct resource is really a wonderful asset.Wilson Is there information about the boutique on our website if someone who is not on campus here at Smilow wants to ask questions about the boutique? Are they able to find their way to that online, perhaps through the website or phone numbers available.Indeck They are able to just go onto Yale Cancer Center or Smilow Cancer Hospital website and they will find the boutique there and there is a search box, they can put it in, if it does not readily come up, they can certainly call the main number and we will give them whatever information they need. Generally speaking, however, the boutique is located on the first floor of Smilow and it is typically open from 9 to 5 and we can see patients in the evening, or occasionally on the weekend if that is what is needed as well.Wilson Just a general question, is this something that's available to all patients in the community or does one have to be a patient under active treatment here at Smilow? What are the guidelines, if any exist?Indeck That's a great question. We want to be available to anybody who needs us, so certainly if you are a patient, you are welcome to come, but if you live in the community and even if you are getting treated elsewhere, we would love for you to come in and we would be happy to help you with whatever it is you may need.Wilson That's fantastic. Bonnie, tell us how you got interested in this field in the first place? Tell us a little bit about your background.Indeck I have been an oncology social worker at Yale-New Haven Hospital for many years and over that6:35 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> time I have done both inpatient and outpatient work and I think with many people your desire to work in cancer emanates from an internal force, and the same was true for me, family members who have had cancer. I have been doing this for so long now it actually seems like it is just integral to who I am and the more you do it, the more you know, that it is a wonderful place to be, to be able to help patients and families and give them what they need and just listen to their story, you benefit personally. We do not often think of it like that, but the fact that somebody will talk to you and tell you what is bothering them and what is not bothering them and what is working well and being so proud to share their stories, it makes my

day, it makes my work so wonderful. Wilson Tell us in more detail about the actual support services that are available and how they are integrated into a patients' care through their treatment course and their recovery. Indeck I am going to speak mainly about social work and we often see patients based on referral by any member of the medical team whether it be the physician, or the nurse, or by any staff, or a patient and family can refer themselves. We just need to know that it is something that is needed and we'll be happy to assess and see what the needs are, so we are involved in inpatient and outpatient, we do counseling, we actually have a brand new program called PACT and it stands for Parenting at a Challenging Time, and this program was developed from a hospital in Boston because we know that parents who undergo treatment for cancer are always concerned about their children and how are their children handling it and are they telling their children the correct things and are they guiding their children correctly, so along with the child psychiatrist, the social workers see these parents because we do believe that the parents know their children the best, and we hope to guide them. They ask us questions, for instance, should I be using the word cancer and we review with them what is generally accepted from the literature and what we feel based on that is the best way to manage children and help them to cope well. In addition to that, we also have support groups. At any given time, we have about a dozen different groups going on we have groups that are for specific diagnoses like brain tumors, breast cancer, GI cancers, head and neck, lung, melanoma, myeloma, prostate cancer, and stem cell transplant, in addition to a group for caregivers as well as a general cancer support group, and the group for caregivers speaks directly to me because I believe that caregivers undergo their own sort of stress. They often are trying to balance many different roles at the same time and that can be quite difficult and they need a little added support. Wilson What sort of things do you help the caregivers with and how are they integrated into the program, give us some examples? Indeck In the caregiver support group, or even if we are meeting with them one on one, we will talk about what it is that is stressful for them. Our main advice to caregivers is to take care of yourself, because often times caregivers feel that their whole life has to be around the person with cancer. They may feel that they are not allowed to take anytime for themselves to do anything fun, they can't meet a girlfriend for lunch, or they can't go to a movie, or get their hair done, and while things like that may be true at certain times during an illness, if somebody is going through an acute phase, but generally speaking, we suggest that people take that time for themselves because11:10 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> it helps to renew them and to renew their spirit and it gives them the strength that they need to get through everyday. Wilson I see, and what sort of issues do you hear from patients with regard to these support groups? What sort of feedback do you get, I mean we have got such incredibly specialized medical care at Smilow and at Yale, it sounds like with all the support groups you just identified this aspect of care is equally specialized and there is something available for all sorts of patients regardless of their problem. What sort of feedback do you get from patients in the program

and support groups and that sort of thing?Indeck Generally speaking, we get very positive feedback because people with cancer sometimes just want a place to talk with other people who are undergoing the same kinds of things, have the same issues, the same feelings and emotions, and while it may be specialized as far as diagnosis goes, in general it allows them to share, and learn how to cope, and that is really wonderful because patients are able to give other patients things that professionals cannot. I may think I understand what a patient is going through, but until I am in that position, I really do not. And so our feedback is very-very positive, in fact we are working on a program, a new program right now, called patient-to-patient where we are hoping to set up patients one on one with another, so if somebody has been diagnosed, for instance, with breast cancer, we are hoping to set them up with the newly diagnosed patients so that they will have an opportunity to get their questions answered. Wilson In general, what is the size of the support group on average, do they meet in the evenings, and how frequently?Indeck Each group is a little bit different and the group themselves typically decide what they need. So we have some groups that meet every other week, we have groups that meet monthly, it really does depend, we meet during the daytime, we meet in the evening time, sometimes we have refreshments, more often we do not and people bring food with them and that's all fine so they tell us what they need and that's what we try to do and they come up with great ideas. I can tell you that we had a flyer for our prostate cancer support group and guys in the group decided that they needed to have the information on a small business card size paper, because they often stick it in their jacket pocket and they could not hand it out to other men if it was a large flyer, but to tell you honestly, I would have never thought of that, so it was a real improvement. Wilson Terrific. We are going to take a short break for a medical minute. Please stay tuned to learn more information about support services with Bonnie Indeck. Wilson Welcome back to Yale Cancer Center Answers. This is Dr. Lynn Wilson and I am joined by my guest Bonnie Indeck and we are discussing support services for cancer patients. Bonnie, we were talking about support groups and you were giving us some other details about when they meet and examples of some successes. How does a patient access a support group? If one of my patients, for example, has lung cancer and has heard about the support group or I have told them about it, where do we go from there to actually get them involved?Indeck What we like you to do is to have your patient call the Department of Social Work and we are happy to guide you to the appropriate support group. Many patients are told about the groups by their social workers anyhow. We have flyers that we give to patients and we also post them and we hope that people will take advantage of the groups. They are really quite helpful and sometimes people will say to me, I am a little scared to go to a group, I do not like talking in a large crowd, but to be honest about it, we always say to folks, you do not have to talk in the beginning, just come and listen and see what happens and before you know it everybody is really talking because it is peer to peer. We are there, the social workers are there, and many times nurses co-facilitate with us, but we are there as facilitators. We are not there to take over the group, we are there

to help you to talk, to categorize and label what we are hearing and to make sure that people in the group are really hearing what other folks are saying, perhaps learning how to cope based on ideas that have developed in the group and things of that nature. So it is really a wonderful way to meet with other people in a little bit of a more formal setting. Wilson Obviously a cancer diagnosis and treatment is a deeply personal experience and very different for every patient. In your experience Bonnie, do you find that most patients are familiar with the support group concept, but are a little afraid to get involved, or is it something that most people want to do or feel they need to be pushed because they may not be interested? What have you done to try to get them involved if they are afraid? Indeck We always tell people directly what's involved. So we lay the ground rules, so to speak, to begin with, and we encourage people to try it at least once or twice. Many people do want to come but what I find as a reason that they can't come often is because of the care the patient is getting. The timing may not be great for everybody and that is part of the reason that we have various times for groups, so that if you can't make an evening group, perhaps you can make a daytime group, but it is more because of concrete reasons that folks do not always come then any other reason, but at Smilow Cancer Hospital we continue to run a Look Good, Feel Better program which is a program 18:39 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> that we co-sponsor with the American Cancer Society. The objective of the program is to help women cope and deal, and learn how to manage skin and hair changes during cancer treatment. We have complimentary makeup that women get and we show them tricks about how to put it on, how to make eyebrows when you have lost your eyebrows. We give out scarves, we have wigs available for women, and this is a group that we ran on a monthly basis for many years, but what we found is that our waiting list for the group was so long that we have now recently increased the group to twice a month and we are filled each time. Women walk away saying thank you so much because it is so gratifying to them to learn that they are not alone, and they know that intellectually, but it is very different when you are sitting around the table and women pull off wigs and take off the makeup they have on, they learn how to put on new eyebrows, how to put on blush or something of that nature, and actually many women share phone numbers and talk afterward because they bonded so much in a program like that. Wilson I was going to ask you, after patients are finished with their actual treatment experience and they are in the recovery phase and months to years go on, have you witnessed patients forming strong bonds during the actual treatment process and that these folks stay in touch with each other long term? Indeck I think that is true many times. It all depends what else is going on in people's lives, obviously. We do have a Survivorship Clinic at Smilow Cancer Hospital and we run groups through that clinic as well, so it is also a way to connect with other people who are in that phase of their illness. Wilson Tell us a little bit more about the Complimentary Therapy Program. Indeck We do have complimentary therapies and we are one of the only cancer centers that provide it free of charge. We provide massage, Reiki, guided imagery, yoga, and art expressions. This is also

one of our programs that has a waiting list because it helps people to revitalize, it helps people to get a half hour or an hour to themselves to renew their spirit and to continue to go on. So men and women love this program. Wilson For this program, does someone have to be under care currently? Indeck Yes, generally speaking it is for people who are in active treatment. Wilson And this is at Smilow as well? Indeck It is. Wilson Okay. Indeck We have a room for it on the first floor of Smilow, where appointments are made and we can send people up for that. We also have a therapist that goes to the inpatient and outpatient unit to 22:04 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> provide some of the care in a decentralized fashion and all of our therapist are either certified or licensed depending on what it is and what their requirements are. Wilson Terrific, there is a program that is under development and almost ready to open up called the Resource Room. Can you tell us about that? Indeck The Resource Room is still, as you are mentioning, under development. We have a spot that will have computers available, there will be somebody manning the room and we want it to be a 'soft place the fall'. While we want to help you educationally, books, pamphlets, whatever it is you may need, we are thinking that we also want to help you take care of yourself. So come in, stop and have a cup of coffee or tea, and we are trying to figure out with patients and families right now if they would even like it to be more diversionary than that. So whether they want to have a knitting class, for instance, or come speak to the social worker on a certain day or come speak with a Chaplin, or come with questions about bills. We hope to do many different kinds of things, but again it is the patients and families who will be telling us exactly what they want to see in the resource room. Wilson When will it be available and where it will be located? Indeck Again, in Smilow, on the first floor. That first floor is very big, we have a lot of programming that goes on there and we are hoping that it will be open in the spring time. Wilson That is terrific. Bonnie, tell us some other things that you have seen people gain from their cancer experience, relationships with family members, new perspectives on life, as we said in the beginning. You have been at this a long time and have a tremendous amount of experience. Share some other stories with us. Indeck You are absolutely right. It gives people the ability to have a different perspective of life, and I remember I had one gentleman who had a lymphoma and he was really struggling with it initially. This was several years back, and he just did not realize the best way to cope for him and he finally came to the conclusion that even though the treatment was difficult for him, without treatment he was not going to be here at all, and I remember during a particular support group session he said to another new patient, while it is not easy to go through treatment, if you do not have it there are no options available to you, even though you may struggle here and there with some of the symptoms and side effects of treatment, it is far better than not having it and he was then able to turn to his life around in a way that was pretty amazing to watch. He was able to take a lot of things in stride that otherwise he would not have been able to and his family mentioned to me the change in him. So I knew that it was a long lasting kind of change and something that other people were noticing as well. Wilson That is

interesting. We have talked a fair amount about groups, and the programs that are available, but I want to point out and have you expand a little bit on some of the other very25:38 into mp3 file <http://yalecancercenter.org/podcast/mar0611-cancer-answers-indek.mp3> individualized services that you are offering all the time for patients, dealing with financial issues, housing for patients who may come from a far distance, and transportation. I had two patients this morning that I saw who had transportation issues and we needed to get our social worker involved immediately to help these folks. Tell us about some of those things. How does that work?Indeck Patients and families will tell us what they need and in fact, very recently, we have new lodging that opened up and it is called The Suites at Yale-New Haven and it is just a couple of blocks from the hospital. There are 24 private suites that are three rooms, they are fully furnished, so up to, I believe four or six people, can be in any given room. There is a kitchenette so you can make your own food if you shop, and it really is an asset. We find that they have been filled already even though they have recently opened.Wilson Oh that is right.Indeck People come in and they go out, so we always suggest that you call, again it is called Suites at Yale-New Haven and it is on the internet and people can absolutely access it and make a reservation like a hotel, and it has been a great asset for us because people have felt calmer knowing that they are close to us. In fact, I had a patient a couple of weeks ago when we had that big snow storm and she called The Suites and got a room and was able to be at our facility at 8 o'clock the next morning and she said to us, I did not want to have to worry about driving. Now that was quite wonderful that she had the ability to do that and previously she could have stayed in New Haven, but it would not have been as convenient. Our security will drive you back and forth, if that is what you need, the parking is free there. It really is a great resource to have.Wilson That is excellent, and do you help patients with transportation needs, interpretation of medical bills, and help with insurance and things like that?Indeck Yes and no. We will be happy to help people with insurance and figure out what their questions may be. We do have a department call PFAS which is Patient Financial and Admitting Services and we work with them. They are the experts in insurance and finance as far as what is covered, what benefits you may have and things of that nature. We are more the expert in helping you get other resources if you should need those. The one nice thing about Smilow is that you can really see teams working together. You no longer ever hear, that is not my job, I do not do that, but rather, let's work on it together and even with transportation, for instance, we will absolutely help patients find transportation by using our community resources. The American Cancer Society does have a Road to Recovery Program and we use them quite frequently to help our patients come to the hospital.Bonnie Indeck is Director of Patient and Family Services at Yale Cancer Center. If you have questions or would like to share your comments, visit yalecancercenter.org, where you can also subscribe to our podcast and find written transcripts of past programs. I am Bruce Barber and you are listening to the WNPR Health Forum on the Connecticut Public Broadcasting Network.