

Bonnie Indeck, LCSW, The Emotional Impact of Cancer September 20, 2009 Welcome to Yale Cancer Center Answers with Drs. Ed Chu and Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and he is an internationally recognized expert on colorectal cancer. Dr. Foss is a Professor of Medical Oncology and Dermatology and she is an expert in the treatment of 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 1888-234-4YCC. This evening, Ed is joined by Bonnie Indeck. Bonnie is the Director of Patient and Family Services at Yale Cancer Center. Chu Bonnie, the definition of a caregiver for cancer patients seems rather broad, can you review with us how you define a caregiver? Indeck A caregiver is anybody who participates in the care of a person with cancer. It can be a friend or family member, of course, close family, or extended family. It can be your church or your synagogue, anybody in the community who is involved is a caregiver. Chu You are head of social services for our cancer patients at Yale Cancer Center, and obviously you work very closely with caregivers, how has that experience been for you? Indeck It's always a treat to be involved in the care of a person with cancer, and I think caregivers have their own set of struggles and challenges in working with people who have cancer. Not only do they have to manage their everyday lives, they now also have to participate in the life of the family to a degree, which they may not have had to previously. Chu In many ways it really is a struggle. Indeck It can be. Depending on what the patients needs, they may be involved to a greater or lesser extent. Sometimes it may be providing emotional support, it may be providing rides to treatment, and it may be meeting with the patient and the physician to help hear what's being said. It can also be taking care of some physical needs for the person. Chu We typically think of social services supporting the cancer patient, him or herself, but are similar type of services available to caregivers, loved ones, or family members who are involved in this support effort? Indeck Absolutely, because we do believe that a person who has been diagnosed with cancer has a lot of different people involved in that care and we want to take care of everybody. If a family member is not coping well, then they won't be able to give to the person who needs their help. We do believe that it's important for us to meet with them, to help guide them, and to help them set priorities and help them figure out how they can help to the best of their abilities. 3:04 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> Chu I am just curious, at Yale Cancer Center is there sufficient support services in place to support the patients, caregivers, and loved ones? Indeck I think that like anywhere we can always use more social workers to help care for the patients and families, but the way it is now we try to meet with many of the new patients and assess what their needs may be and also meet with the families to assess what their needs may be. Chu How are caregivers in terms of accepting support? Indeck Great, they love it. All you have to do is ask somebody how they are and they are more than happy to fill you in on that. Often times they are actually surprised when we look away

from the patient for a moment and say to them, "So how are you doing? What are your needs? Is there anything I can do for you?" And they are very shocked, very surprised and say, "But I am not the patient." We tell them that we know that, but know that they need help too because this is the hardest job, or one of the hardest jobs, they will ever have. They are very happy to sit down and share with us and tell us what their situation is. Chu I can imagine that in some cases it may actually be a burden lifted off of their shoulders. Indeck Absolutely, and social workers are well aware of the resources in the community, and so if we cannot provide what they need, we can help them garner the support in other ways. Chu How does the role of a caregiver change throughout this spectrum of the treatment process? Indeck As I mentioned earlier, sometimes people need different types of help. In the beginning, particularly when a person is hearing a diagnosis, or hearing potentially of a recurrence, the friend or family member may well be there "just" and I say that in quotes, for support to listen and be there for a shoulder to cry on. That allows the person who is diagnosed to feel stronger, knowing that their worries are being heard and as the person may need more care, what the caregiver has to give will change. As I said, it could be very concrete, it could be going to the drug store to pick up prescriptions, it could be going shopping for them, and it may be going to the physician with them and taking care of physical needs. Sometimes people may need some physical help. Chu I am impressed when I see patients and their loved one, caregivers, accompanying them on the initial visit and that many of them are taking notes. Indeck Absolutely. Chu Or they bring a tape recorder. 6:02 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> Indeck Right. Chu Which I strongly recommend so that they can gather all of the information that has been communicated to them. Indeck That's right, because what happens is a person can only hear so much, so as a physician you may be giving them a lot of information, they may be struggling with something you said earlier on and their brain is not accepting the information that you are continuing to give them. The family member, which we also strongly urge people to bring with them, may be taking those notes or having the tape recorder so that they can go home and listen again. I had an incidence the other day where the patient was with her two sons and her best friend and the doctor said what was going on and I came in a few minutes later and the patient repeated it back to me and the friends said no that's not what he said and she read from her notes, exactly what was said, and the patient had heard it incorrectly. Chu Right. Indeck She was able to acknowledge it, and you can't hear it all. Chu I have heard it said that it's estimated that maybe at most 10% of what a physician or health care professional says to a patient is heard appropriately. Because I think in part the patient, especially for the first visit, is overwhelmed by the whole experience. Indeck They are overwhelmed with the experience and they are overwhelmed with emotion and you can't hear it all. 10% sounds about right, and the other thing that caregivers often do is advocate for the person because the relationship, or the dynamic, between a patient and a physician, or a nurse and a social worker, is such that they may feel the need to have somebody else

talk on their behalf, somebody who can potentially explain a little bit better, who can ask for things that they may not feel comfortable with, particularly with the physician where they feel that a physician can be their lifeline and they would never want to say anything negative or anything that they think the team may hear as negative. Whereby caregivers don't have the same worries and feel very comfortable saying, this won't work, or this will work, and this is what we need from you. Chu Along those lines, I know one issue that patients, and sometimes family members, get very anxious about is the idea of perhaps seeking another opinion, a second opinion, and I know that patients are sometimes fearful that it will get their own physician upset. Indeck Right.8:51 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> Chu

What's your advice either to the patient or to the caregiver with respect to perhaps seeking additional outside opinions? Indeck I believe strongly that one deserves a second opinion, because you are fighting for your life when you have cancer and more often than not you are going to get the same answer that you have already gotten, which will allow you to feel comfortable and confident knowing very well that other places will tell you the same exact thing. So, I believe it's very important. Chu Bonnie, you are obviously a tremendous, outstanding social worker, but have you ever been on the other side, not playing the role of a social worker but playing the role of a caregiver? Indeck I have been on the other side, so I think that I know some of those challenges very personally and it can be difficult because you feel like you have to be good at everything. You feel like you need to keep up with your own family, you need to keep up with your employment responsibilities, and yet you have to take care of somebody else. There are some days where there does not seem to be enough hours in the day to do all of that and so it's very-very important to take care of yourself as a caregiver. We do give that advice to caregivers, to take some time for themselves, to take a break, to go for a walk, listen to music, to have some time to come back to a centering spot for you. If you take care of yourself, you will be better able to take care of your loved one. Chu That really is great advice, because what I have seen happen all too often is that caregivers get so focused on helping the cancer patient that they don't take care of themselves, and then they can't truly help their loved one. Indeck That's exactly right, and while it's easy to say that and caregivers are able to acknowledge that they need to take the time, sometimes you have to really sit down with them and in a very practical way, operationalize just how to do that, because often times there are feelings of guilt if you are not there all the time, and things of that nature. We sit down with people and look at a daily schedule at times and try to figure out with them what will work and what won't work. How they can take time for them self, how they can continue to get haircuts, or go to a movie, or spend time doing what they need to do, because as you say, it really does allow you to give much more to that person who you love. Chu Are there support services or resources that are available to caregivers? Indeck Yale Cancer Center does run a support group. The Department of Social Work runs a support group with nursing for caregivers of people with cancer, and we do that on a

weekly basis and it's really a drop-in kind of thing, so you don't have to call us ahead of time. It's a type of group where we just ask you to come and share your concerns and you may hear from the social workers, but12:13 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> most importantly, you hear from other caregivers, what worked and what didn't work and you also know that you are not alone, and that's the wonder of a support group. It reminds you that there is a bigger picture out there and how many of us are dealing with the same kinds of issues and the support you get from somebody who is going through it is ideal.Chu That's interesting, so as there are support groups for cancer patients who are going through the process of being treated for a particular cancer, there are similar types of services for caregivers.Indeck Correct, so even though we have a specific group for caregivers, in many of our other support groups, we run about 10 or 12 right now some of which are diagnosis related such as melanoma or multiple myeloma, but others are more general like coping with cancer and those groups are often times for patients and their family members, and sometimes we will all meet together and other times that group will be such that everybody will meet together and then they will break up. We will have two facilitators, one meeting with patients and one meeting with family members allowing everybody to get their needs met.Chu You are listening to Yale Cancer Center Answers and I am here discussing the role of caregivers and the support system in the treatment of cancer patients with my guest expert Bonnie Indeck.Chu Welcome back to Yale Cancer Center Answers. This is Dr. Ed Chu and I am here in the studio this evening with Bonnie Indeck, Director of Patient and Family Services at Yale Cancer Center. In the first part of the show we were talking about the important role of caregivers and the critical role that they play in helping a cancer patient go through their treatment, and it's quite remarkable. I came across a fact that said it's estimated that 1 in 5 adults in the United States can be defined as being a caregiver because they are actively caring for a loved one, not just with cancer, but with some type of illness.15:18 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3>Indeck Right.Chu That is pretty impressive, that at least 20% of all Americans here in the United States could be labeled as a caregiver.Indeck Absolutely, and it is impressive, that's a huge number when you think about it, and so we have to make sure to take care of caregivers as well.Chu In the first part of the show we were talking about the importance of caregivers needing to make sure that they take care of themselves, as well as making sure that the person they are taking care of is taken care of, but its critically important that they also make sure that they don't neglect themselves.Indeck Correct.Chu What are some of the tips, what is the advice that you give to caregivers who are going through this process?Indeck We try to figure out with them what works for them, what would be helpful for them to take care of themselves. We try to make a unique plan with each person and often times we suggest that the person meets with their own counselor, which we can do at Yale when they are coming with their patients, but if somebody needs more extensive work, because not every patient comes on a weekly

basis so we can't possibly meet with every patient and every family member every time they come, and if people have a lot of different things going on we may suggest that they see a counselor in the community. We may suggest that they talk to somebody that they know, that they go to a support group in the community, that they have friends that they talk to, or that they go walking, because we also believe that physical exercise is key in managing a lot of emotions, particularly depression. It gets the right energy going and helps you feel better both physically and mentally.

Chu On the subject of depression, do you see that as common sequelae of having such an intense involvement in taking care of a cancer patient?

Indeck It can be, there are often patterns that patient's experience, but also the caregiver's experience when they are hearing of a loved ones diagnosis. They can be just as overwhelmed and just as upset. They are doing what we sometimes call anticipatory grieving, thinking about the losses that they will suffer, and sometimes when we say loss, people think people have died, but losses are far greater than that. It could be the loss of employment. It could be loss of life as you had anticipated it. It can be many different things, even if you can't go out as frequently because you're so busy.

Chu How often do you see that?

Indeck 18:13 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> may be more fatigued from treatment, that can be a loss. Caregivers often are dealing with all of those issues and it is like a grieving process. Depression can occur and we treat depression as you are well aware with talk therapy, but also sometimes with medication, cognitive behavioral therapy, all sorts of different modalities that we feel will help the person manage their emotions and therefore take better care of people with cancer.

Chu Will there ever be a need for these caregivers to seek counseling from either a psychologist or psychiatrist if the symptoms became so serious?

Indeck We may refer to a psychiatrist, if medication management is necessary, because as social workers we cannot prescribe. We will ask for a psychiatrist in the community to manage some of this with us and we may be the hands on people who are monitoring it on a regular basis, but we can't do it without our colleagues.

Chu And I guess one other thought is what's the recommendation for trying to have a team approach, multiple caregivers being a part of the care of a cancer patient as opposed to the burden being placed solely on one individual?

Indeck As you can imagine teams are always great, because everybody comes from their own perspectives and their own discipline, and their experts in that particular field, so the more experts we have together, the better off the patient is. We certainly would advocate for that and it's a very good idea. Additionally, sometimes we will suggest that family members as well as patients take advantage of Yale's Complementary Therapy Program, where we provide guided imagery, Reiki, massage, and gentle yoga. There are a lot of ways to manage some of the emotions that are going on. Some of the clinical trials have shown that complementary therapies can in fact reduce symptomology, and so we strongly urge people to take advantage of those sessions.

Chu Bonnie, could you tell us a little bit more about what guided imagery or Reiki is?

Indeck Guided imagery is where we play a tape and help you to imagine different kinds of things in your own healing, whether you are

the patient or the family. We will do breathing exercises, we will do body relaxation and we will end often times with a particular scene that will allow people to put themselves in a good spot visually. Reiki is a light, typically hands on, but it does not have to be, old Asian art of energy movement that helps to relax folks. It really can be an amazing experience, people get off the table, as we often do it on a massage table although it can be done in a chair, and they just feel better, so it is wonderful. Often times at Yale Cancer Center we do educational programs where we will talk about these approaches on a much broader level and help people to experience various strategies so that they can choose the one that may be best for them.22:09 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3>Chu While these services are obviously being provided at Yale Cancer Center, I suspect that similar types of services are provided out in the community as well?Indeck Absolutely yes, that is true, right now our program is complementary to patients and families and in the community typically you do have to pay for them, some insurances may pay but that's typically very limited. Patients who come to Yale are very happy that we provide these services.Chu Yeah, it's a terrific service.Indeck It really is, and I am very happy that we have been able to do that for people.Chu Bonnie, can you review again for our listeners how caregivers can work to create a balance in their lives between caring for themselves and their own family, as well as caring for the loved one, the cancer patient who is ill?Indeck As we have alluded to its not always easy, it's very difficult to manage everything because you take on a workload and it all depends on your particular circumstance; are you living with that person? Are you at a distance? And all of that will impact how well you can balance it. When somebody has cancer many times neighbors will ask what can they do to help, because they don't know what they can do and I always tell people to take advantage of that. Even if they don't know themselves, just say, you know what I would love you to make us dinner, if I could count on you for dinner one night a week that would be terrific. Many times neighbors or friends, or parents of your children friend's have to go shopping anyhow, so if it helps give them a short list so that they can pick it up for you. Anything that you can do to help lighten your own load can be very very helpful. Take advantage of those offers for help. People mean well and they just don't always know what to do, they are looking to you for guidance, please tell them.Chu It's interesting, at least from my vantage point, I get the sense that all to often caregivers tend to feel like they cant accept or seek out help, and that they have to shoulder all of the responsibility, which I think then makes it more difficult for them.Indeck Absolutely, you are right. Many times they feel like, well I am the caregiver, I have to do it all, but none of us can do it all.Chu Right.Indeck We really do have to ask for help, even as a caregiver it is okay to ask for help.24:53 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3>Chu That really is an important message for those of you who are caregivers and listening to the show, that it is okay to ask for help, to go ahead and seek advice, seek help from others.Indeck And not only is

it okay, it really is recommended. Chu You really do need to do that. Indeck Absolutely. Chu As I think many people out there know, the Cancer Center is soon going to be moving into the Smilow Cancer Hospital, which I think we are all extremely excited about. Indeck Absolutely. Chu From your vantage point, how do you see things changing, evolving, as we move into the new Cancer Hospital? Indeck Some of the things that we are going to be adding to our Smilow Cancer Hospital will be just terrific, and an added advantage for patients and families. For instance, we will have a boutique that will be one stop shopping, so that you will be able to pick up prosthesis, or be fitted, I shouldn't say pick up, be fitted for prosthesis and then pick it up. We will have wigs available and we will continue to work with the American Cancer Society to take advantage of their wig bank, which offers wigs to patients at no charge. We may have clothing available that has SPF in it, which a lot of people with melanoma use regularly to avoid extra sun exposure. We will have cards and particular items, skin care items, for people with cancer. So the fact that you can come and go for your treatment, stop at the boutique, pick up what your need, I think will be really terrific, and a real bonus for folks. We will continue with our complementary therapies, we will continue with our educational programs. This is a very exciting time not only for the staff, but for patients and families to have an NCI designated cancer center in their backyard. Chu I think also a new addition to the hospital will be a patient resource center. Indeck Yes. Chu Again, where patients and family members and caregivers can get information and education materials. 27:11 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> Indeck Absolutely. Chu Which obviously is huge? Indeck Right, because education is key to coping, if you know what is coming up, if you can anticipate then you can cope with it, you can manage it. If you do not know what's going to happen to you then it can be much more difficult. The educational piece is very large and we are so glad to be able to provide it. Chu Can you say a quick word about some of the evening programs that I know you are so actively involved with and have done a tremendous job in coordinating these educational programs for the community. Indeck Well thank you. Yes, we have monthly programs, and in fact our September program will be on September 23, 2009, and it is on genetics. We will be talking about the genetics of cancer, what makes certain people at high risk, and I suggest that if you are at all interested you should come, and this is a topic that we usually get a full house for because it's so important. So many of the cancers we have identifying genes, and you can certainly speak to that better than I, but to learn about it, to know what puts you at high risk, to know if there is anything you can do and a proactive preventative stands is great. Of course we will continue with other monthly programs and if you would like a listing of that, we would be happy to get that to anybody who is interested. Chu Is there a website that the listeners could access? Indeck www.yalecancercenter.org has a listing of all our upcoming programs, at 6 o'clock, we have our light supper, it is an evening program and at 6:30 the lecture begins and it does not take long and we provide free parking in the Air Rights garage. It is great and we hope to be

able to do these programs at Smilow a few months down the road. Chu Bonnie, it's been great as always to have you on the show and I look forward to having you on a future show. Indeck Thanks so much, it's been a pleasure to be here today. Chu You have been listening to Yale Cancer Center Answers and I would like to thank my guest Bonnie Indeck for joining me this evening. Until next time, I am Ed Chu from Yale Cancer Center wishing you a safe and healthy week. 29:22 into mp3 file <http://www.yalecancercenter.org/podcast/sept2009-emotional-impact-cancer.mp3> If you have questions or would like to share your comments, go [yalecancercenter.org](http://www.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 from Connecticut Public Radio.