

Nora Rightmer, LCSW, Building a System of Support March 15, 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 like to join the discussion, you can contact the doctors directly. The address is canceranswers@yale.edu and the phone number is 1888-234-4YCC. This evening Ed and Francine speak with Nora Rightmer. She is a Clinical Oncology Social Worker at the Yale Cancer Center and she joins us to speak about the role of caregivers in the cancer treatment process. Chu The definition of a caregiver for a cancer patient is rather broad, so let's start off by reviewing with our listeners what you think the essence of a caregiver is, and who key caregivers are. Rightmer We have to differentiate between family caregivers and paid caregivers. Often times paid caregivers are the ones who are coming into the home on a regular basis through some sort of an agency, but the real caregivers that we are talking about are the family caregivers. When I say family, that is where it gets broad. We have caregivers for our patients that run the gamut from a spouse to a neighbor and everything in between. Sons, daughters, husbands wives, friends, grandparents, and sometimes a series of people, even friends or neighbors, or a series of friends or neighbors, depending on the people resources that the patient has. Chu So it really depends upon the particular patient's own situation as to which family member or which neighbor, might be the key caregiver? Rightmer Exactly, and sometimes patients start out needing a little bit of help from a neighbor to drive them to their appointments if there is no one else in the area, and sometimes we have to look around and talk with the patient and talk with family members from across the country as their caregiving needs become greater. Foss Sometimes you actually facilitate a patient identifying who their caregivers could potentially be? Rightmer That is a very important part of our role. Very often when patients live alone, and we are seeing a lot of them, they do not realize what the course of their treatment is going to be. We know that there are going to be times when they are going to need a lot more care than they may think at the onset, and we start thinking about that very early on and try to identify people who can be helpful to them. 3:08 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 Chu Nora, I know that you and your colleagues spend a great deal of time trying to incorporate the so-called paid caregivers as part of the team, because obviously it is important to have individuals who have expertise in taking care of cancer patients. Can you say a few words about those particular paid caregivers are that are going to be involved? Rightmer Often times when patients, particularly those who have been hospitalized, go home they need additional homecare services than what they had before. It can be a real shock to patients and caregivers that mom was just driving last Wednesday, and now she cannot go home and live alone and she needs homecare services in the house. It can really be a shock to people to realize that the level of care need can change so quickly. There are many agencies out

there, usually covered by insurance, that can be tapped into to help the patient at home, and those are the paid caregivers. In addition, if people feel that they need more help, they can pay privately for additional help as well. Foss Can you tell us a little about how a patient can tap into the services of a social worker in terms of setting up this kind of caregiver system? Rightmer If they are in the hospital it is very easy. We see most of the patients and the care coordinators who set up the services and see all of the patients and assess for them their homecare needs along with physical therapy and the medical team. Any patient that is in need of any kind of homecare services would be identified and services would be set up for them if they are agreeable to that. When they come into the clinic it is a little bit different because they are more independent and more capable. If they are not in need of homecare services at that time any of the doctors can talk with the social workers at any point about becoming involved with a patient who they feel may need more service at home. In addition to the homecare agencies, there are other agencies that can help with homemaker services and different things like that if the patient qualifies. Chu Once a patient leaves the hospital, if a caregiver should have any issues, concerns, or questions, would they go back to you and your colleagues that are focused on the inpatient side of things, or are there social workers who take care of outpatient issues, if you will. Rightmer That is a good question. We have inpatient and outpatient social workers; there are outpatient social workers in the clinic, inpatient in the hospital. If, for example, we are referring to an agency like the Visiting Nurse Association and there is some additional need at home, we can refer them to the social workers in the homecare agencies, but that is all for the patients. Let's talk a little bit about the caregivers who are sometimes the ones under stress as well. We started talking about how caregivers could be a son, daughter, husband, wife, or a neighbor, and the social workers try to make a point of helping the caregivers as6:43 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 well. Often times they are the family members and the people who live with the patient, but not always. Either way, they can be under an enormous amount of stress and are in uncharted territory when it comes to taking care of a person who now has a chronic illness and is potentially becoming more and more ill. Chu Patients have support groups that help get them through the process; do caregivers have a similar type of support network or support groups that can help them through the process? Rightmer Absolutely. We see our service as being for the patient and family and we are constantly developing new support groups. One of the most important things for patients and caregivers is to be able to talk to other people that are in that same boat. Currently, there are 11 support groups running and many of them we have set up as patient and caregiver support groups. We find that that works out pretty well, because when you try to have a caregiver support group, often times the caregivers who have the most need are the ones who cannot come because they cannot leave their patient; they do not have anyone to leave their patient with. We do have a number of patient and family support groups, and we can often break it down into two separate mini groups; the patient

and the caregiver. And that works very well. Foss Are some of these so called "virtual groups," such that patients could actually call in or call other patients or other caregivers and interact with each other if they can't come to these meetings. Rightmer That is an excellent point. With the new technology that we have nowadays, anybody that has a computer can join a support group. We do not do any virtual support groups here yet, but there are a lot of virtual support groups out there online through organizations like the Leukemia and Lymphoma Society and through CancerCare. Any patient or family member that has a need for that or asks about that, we can hook them up with those kinds of support groups. They are very valuable for patients and caregivers who cannot get out. If they are not connected with us at all, they can go to their computer and Google "cancer support groups in Connecticut," and they will likely get referred to the cancer agencies that have their websites up and running with all kinds of information on them. Foss Nora, I have heard the statistic that one in five adult is caring for a sick family member, is that really true? Rightmer It is certainly true. I think there are many more caregivers out there that we do not even know about. We are just dealing with cancer here, but you have people out there taking care of relatives with Alzheimer's, stroke victims, all kinds of illnesses, and the caregivers are 10:09 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 kind of the hidden story. There has been a lot of research recently about caregivers and the fact that they tend to neglect their own health, they tend to suffer from chronic conditions at twice the rate that is normal, and they do not bother to go see their own doctors because they are too busy taking their patients or loved ones to their appointments. Chu Is there any advice that you typically give to loved ones and other caregivers as to how they can be sure not to let their own physical and emotional well-being be sacrificed in the process of helping their loved one? Rightmer That is a very, very important point, and one that we have to stress here today. If the listeners take one thing away from this show, or if any caregiver's listening take one thing away, it is that you need to take care of yourself. I have had people tell me that everybody says that but, do they do that? There are a lot of things that you can do. You need to take respite breaks, you need to be tuned in to your own needs, and you need to assess yourself as often as you assess your loved one for any kind of symptoms of depression or any other kind of illness. You have to be able to ask for help and learn how to accept it when it is offered, which can be the hardest thing. You may need to recognize that you have rights too. Finally, I think it is important to say that you have to be able to forgive yourself for not being perfect. Very often caregivers are very, very hard on themselves. They think that they are not doing enough or that maybe they got a little angry and short with the patient the other day and they feel very bad about that. They are doing a really incredible job, and the most important thing you can do for yourself is to look for a support group, talk to other caregivers, and find out that you are really doing a good job. Foss Is it harder for a patient with cancer and their caregivers to deal with the illness than say somebody with diabetes or heart disease? What are the special issues

that the caregivers of cancer patients have to face? Rightmer I think that in some ways it is harder. Cancer is a very devastating illness and it can be a very long drawn out illness where the caregivers get very worn out. They are not sure how it is going to go when they first get into it, and then as the patient has more and more needs, they get in deeper and deeper and they are not prepared and have not been asking for the help that they need. At those points they need to recognize that they are in need of help, and that is where support groups can come in, and where social workers can come in. Caregivers need to speak up, they are dealing with a devastating illness in a loved one and it can really sink the boat. They need to know that there are people out there that can help them, that can steer them in the right direction and get them the support that they need. Chu Nora, what are your general recommendations for say, end of life issues? I know a lot of 14:06 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 family members and friends that have had loved ones who have had cancer at the end stages and there is always this very intense discussion about whether or not to keep mom or dad home for homecare, or send them to inpatient hospice such as what we have at Branford Connecticut Hospice, which is a terrific facility. It's always a struggle for family members to decide what to do, and to have a discussion with the patient. What are your thoughts as to how to approach that discussion? Rightmer My thoughts are that the discussion does not happen soon enough. It is, as you say, a very difficult discussion to have and is one that people tend to avoid, but in the end they often wind up feeling very regretful that they did not have the discussion earlier on, because now they do not know what mom or dad would have wanted, or what their spouse or partner would have wanted. It needs to be a discussion you have early on. We try now to get all patients to participate in making and discussing advanced directives and letting their loved ones know what their wishes would be. At that same time, and it is especially true for the caregivers who are not an immediate relative, the patient needs to speak up and say who they want their surrogate decision-maker to be if it comes down to the fact that they can no longer make decisions for themselves. The caregiver can be empowered, especially if they are not a relative. Situations come up where the person that they wanted to be their surrogate decision-maker is trumped by a family member who comes in from out of town, and it is not the person that the patient would have wanted. Having those discussions earlier is one way to do that. Foss We are making a lot of very important points here and I would like to get back to a couple of these issues after the break. You are listening to Yale Cancer Center Answers. We are discussing the patient support system with Nora Rightmer. 17:30 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 Foss Welcome back to Yale Cancer Center Answers. This is Dr. Francine Foss and I am joined by my co-host Dr. Ed Chu and Nora Rightmer, a Clinical Oncology Social Worker at Yale Cancer Center. Nora, we were talking about end-of-life decisions and directives and about interactions between caregivers and patients, but I would like to switch gears a little bit and talk about the relationship between the caregiver and the physician. The physician

obviously interacts with the patient, but I am wondering, should the physician also be interacting directly with the caregiver, or should that communication go directly from the caregiver to the patient and vice-versa? Rightmer That is a very important question and it is a very individual answer. There are some patients who really do not want their caregivers to be too involved, at least initially, and if they are fine and healthy and able to interact with their physician and make decisions they should be able to do that. However, there are some patients who are really not able to do that, in which case the physician has to interact mostly with the caregiver. Probably the best way to do it is to have the physician interacting with the caregiver and the patient at the same time. If the patient allows it, the caregiver should be with the patient if at all possible at most appointments. It is always good to have a second set of ears, and we encourage patients to bring their caregivers with them to appointments to talk with the doctor, so that when they leave they can discuss it and one can remember what the other one does not. They say it is very effective to do it this way, and many times patients and caregivers find that they remembered or heard different things. If that is the case, they can check back with the physician, because it is very, very important information that they are trying to understand. Chu That is a key point that you just raised because there have been some studies looking at how much information a patient will retain after they see their physician. Some estimates are at most 10% or 15% of the conversation actually is retained and understood. I know a lot of patients who come with their caregivers to see me in the clinic and their caregiver will either bring a tape recorder or a notebook and take down notes, as well as perhaps have questions that they thought about beforehand, and I think that is very important to try to enhance communication between patient, caregiver, and physician. Rightmer It is an important role for the caregiver to be the backup guy. Foss How does the physician know what the status of the caregiver is, and how do we know whether a caregiver might be getting overwhelmed or depressed? Are there signals that we should be looking for? How would you advise that we go about counseling the caregiver? I know that I have run into situations where I have had family members come in and I have talked to them about some of these issues like depression and anxiety. 20:58 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 Rightmer It is very wonderful that the doctors are looking out for the caregivers too, and yes, there are certainly signs and symptoms just like you would notice in your patient. If a caregiver is seemingly overwhelmed they tend to be disheveled, forgetful, having difficulty, or they may start talking with you and start crying. Sometimes it is pretty easy to see that the caregiver is stressed. Other things that you might do is ask them a few questions about how it is going at home, and how they are talking care of themselves, have they been eating and sleeping. Which is something we cant use to judge depression in oncology patients because none of them can either sleep nor eat, but the caregivers are able to do that and if they say they are not doing those things, or if they look like they are pretty grim and do not smile and cannot look you in the eye, I would start to get worried and ask them if perhaps they might want

to talk to somebody about what is going on or get some support. Coming from the physician, it can be a very important thing because they would take it seriously. Obviously taking care of a loved one with cancer can be a pretty intense experience. Do you give any tips to caregivers as to how they can stay upbeat and remain positive throughout this whole process? Rightmer I think we are back to taking care of themselves again. That is the most important thing, and the other thing that they can do is they can write things down. They can write down their worries, write down tasks that they have to accomplish, and I used to tell caregivers to keep a list by the phone so when people call up and say, "What can I do?," you can say, oh you can take my car out and get me some gas, I am on empty. I had a caregiver one time that really got to me when she said, "If only I had someone who could come over on Monday nights and put my garbage out." I thought, bingo, its little things that put people over the edge because they have all these things to attend to and if they could start portioning them out to their friends and relatives, if each friend or relative could do one of those things, it would be really helpful. Foss That is a very good point and what we are talking about here is the caregiver developing their own network; just like they have developed a network for the patient, they also need to develop a network for themselves. Rightmer Absolutely. They have to be able to accept the help, and sometimes, people out there mean very well but they do not know what to offer. I would suggest to people who know families who have cancer, that they try to come up with things to offer, but if they are not able to, as many are not, if the caregiver writes down the list and keeps it by the phone that can help. Chu As you said, one of the real challenges that we have all seen in our daily practice is that caregivers sometimes find it very difficult to say they need help. They view that as a weakness on their part, but in fact, that is probably the most important thing they can do if they feel overwhelmed. If they need help, they need to seek help. Rightmer It is actually a strength to recognize that you need some help and to be able to organize yourself to find the things that you can get help with, but I agree, they feel like, "How can I need help? Here is my loved one who is suffering so much and I am perfectly fine and healthy, I can deal." But you will not be able to deal for very long if you do not make sure that you take care of yourself as well. Foss One of the unique issues with being a caretaker for a cancer patient is that after the patient passes on, the issues for the caregiver continue, and in many instances, the caregiver may feel guilty about things that they did not do. I think it is really important for us to continue to think about the caregiver even after the patient has passed on. Can you talk a little bit about some of those special issues that those caretakers may have? Rightmer There are special issues. You are talking about a person who has had a lot of their life taken up with taking care of their loved one, and now their loved one is gone and they are just completely at loose ends, in addition to being in really heavy bereavement. I would recommend groups as a solution. There are bereavement groups for people who are having an extremely difficult time with the bereavement, which is not at all unusual if you have been living

with cancer for a number of years. It is also important to realize that you are going to have to take some time before life starts to feel "new normal" again; it is not going to be back to normal ever, but it will be a "new normal." You will be able to get your life back together and sometimes have a greater appreciation for life. You have been through a traumatic experience that leaves you with some existential questions, some sense of meaning in life that perhaps if you had not gone through that experience that would not be the case. Chu It is not just the patient who survives cancer, but now it also includes the loved ones and the caregivers who have been in some way touched by taking care of a patient with cancer. Rightmer That is very interesting. Yes, I agree 100%. Chu Are there any situations where you might recommend, in addition to obviously seeking group counseling, perhaps therapy with a psychiatrist or psychologist, and perhaps seek out medical help if you will for those issues? Rightmer Yes, it depends. There are certainly people who go into the experience of being a cancer caregiver more vulnerable than other people, just by virtue of where they were in their life. If they start to have symptoms of depression and anxiety that is unrelenting, it is certainly a28:08 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Mar-15-09.mp3 good idea that they seek help. Psychiatrists can provide medication. Psychologists, social workers, and nurses can provide counseling. It is never a bad idea to have that kind of service available to you if you are going through a difficult time and you are feeling particularly vulnerable. Chu You have been listening to Yale Cancer Center Answers and we would like to thank our guest Nora Rightmer for joining us this evening. Until next time, I am Ed Chu from the Yale Cancer Center wishing you a safe and healthy week. If you have questions or would like to share your comments, go to 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.