Mark Crooks, Coping with a Diagnosis of Cancer September 5, 2010Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Francine Foss, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and Dr. Foss is a Professor of Medical Oncology and Dermatology specializing 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, I will be sitting in for Ed and France and I am joined by Mary Crooks. Mary is a Licensed Clinical Social Worker in the Head and Neck Cancer Program at Yale and she joins me this evening to talk about support for cancer patients. Barber Mary, welcome to Yale Cancer Center Answers. Let's get started by discussing how you got interested in this field? Crooks That brings me way back, Bruce, to when I was in high school actually. Back then people could work as a nurse's aide at a very young age, and I was a nurse's aide at a local nursing home. From there I went to college and decided that social work was really for me. Initially, I was introduced to social work courses at Cedar Crest College in Allentown, Pennsylvania. I had a fabulous opportunity for internship when I was a senior in college and I worked with senior citizens who were possibly abused or neglected, and at that point I realized working with seniors and trying to have them open up and talk about what was really going on with them, develop a rapport, I could then lead them to seeking help, having their needs met, and empowering them to reach out to the community and get the support they needed. After doing that internship, I was lucky to land a job with the State of Connecticut working for the Department of Income Maintenance where again, we were able to meet peoples' needs and that was a great experience because it let me know the resources in the community. Barber Let's jump forward to where you are now. Crooks I have had the opportunity to work at Yale-New Haven Hospital for over 7 years in the oncology department and I got to that area of working with oncology patients and their families because I did have past hospice experience and working with patients previously with cancer in the community, and so working at Yale I have been able to help the patients, who are inpatient, navigate and negotiate the hospital system and learn about their disease and learn how they work within the hospital as far as the hospital system, meeting the doctors, meeting the nurses, and what their disease means to them. Barber It must be very overwhelming for someone to get a cancer diagnosis, and you must be of great help to them? Crooks Thank you, I like to think so. Meeting people at a time that is so challenging for them, a3:37 into mp3 file http://yalecancercenter.org/podcast/sept0510-cancer-answers-crooks.mp3 time where they least expect to be diagnosed with cancer or any ailment of any type, and how they in turn need to take stock, learn about the diagnosis, and I reach out to them.Barber What's usually the first reaction? Crooks The first reaction people usually have is shock, disbelief that this is happening to them. Barber How do you get them to work through that, what do you find really empowers a patient once they get over that initial shock? Crooks When they have gotten over the initial shock, they are usually able to talk about it. I can give them a safe environment, a time where they can just speak with me, sit down in a

quite environment and share more about their thoughts and their feelings related to their new diagnosis. Barber Do you find that is it set up now so that you are able to spend time with them before they have to go home and go back into the world, or is it something that is a gradual process where you want to give them a little information at first, let them process it, and then let them come back and see you. Crooks I take my cues from the patient themselves, so if they are hesitant, or if they are quiet, or if I sense that they are not ready to talk at this moment, I wait until the next time they come in to see the doctor. We have a fabulous out-patient treatment area where they meet the doctor on multiple occasions to be treated or for the consult purposes, so I will visit them again on their next appointment. Barber I would imagine the emotional aspect is important to deal with first, but then there will be a lot of logistics, won't there, that you can also help with? Crooks The patient will reach out and will share what is of concern to them. They do that by me asking open ended questions, like how you are feeling today? What is going on for you? Is there anything else you would like to ask me? And they will ask what is on their mind usually that day and based upon what they share with me, I will respond accordingly. Barber This has got to be very difficult for their family as well. What kind of advice do you give patients regarding how to bring this news to their family and help their family deal with it as well? Crooks I encourage them to be open and honest with their family, and also to be patient with their family because sometimes they have this information ahead of time, before they share it with their family, and they have had time to mull it over and to process it themselves. So, when they first approach their family, I let them know that the family members may react with shock or anger or denial, 7:05 into mp3 file http://yalecancercenter.org/podcast/sept0510-canceranswers-crooks.mp3 and let them know to be patient with their family member, but to be open and honest in their communication as well. Barber How about at work? I would imagine that all of a sudden you have got this cancer diagnosis, it is probably difficult to know how much to share with people at work, and who to tell. What advice do you give for that? Crooks I also encourage them to be open and honest with their manager or their boss, because more often than not, the manager or boss will be empathetic, understanding, and will be able to guide them in their work activities. Barber And what else? Crooks When they receive the support from others around them that usually helps them cope better and go through the day and receive support and feel that support, and it gives them extra energy to move forward and to deal with and face their concerns.Barber You work with patients with head and neck cancers, what are the things that these patients are dealing with just being out and living their lives? Crooks Head and neck cancers are unique in that oftentimes you can see it when you look at person. You will often see the result of surgery or the result of radiation treatment, and their face or their neck will show signs of that treatment for a period of time, and it's difficult for people when they are out facing the community and facing people, particularly people they don't know, and they are concerned about how people are going to react to them. They look at them funny. They may feel that others are judging them based upon

their appearance and it's hard for them to face the world that way versus if you have cancer in another part of the body, a part of the body that is often covered with clothing, and people might not be aware, so this is particularly difficult when we think of head and neck cancer. Barber What strategies do you advise them to use, to again just be open about it? Crooks Yes, absolutely. The patient needs to work on how they are going to relate to others and how they want to respond to others. How do they feel comfortable? If they want to pass over it so to speak or have a very short limited conversation with someone, that's fine. If they want to elaborate on their situation, tell about their diagnosis, tell about their treatment, that's fine too. It's for them to find what they are most comfortable with, giving more or less information based upon their needs.10:36 into mp3 file http://yalecancercenter.org/podcast/sept0510-canceranswers-crooks.mp3Barber And do you find that it varies widely from patient to patient, or are there some things that are fairly common? Crooks I find it varies widely from patient to patient because we are all individuals, Bruce, and we all relate to others in our own unique ways with our own unique personality. We need to honor those ways and honor that personality and go forward and be comfortable in who we are relating to. Barber How are patients referred to you? Crooks Patients are referred to me as a consult service by the doctor, and specific to the head and neck cancer area, the oncologist or the surgeon would refer a patient to me who they feel has expressed the need, an emotional need, a social need, a need that the other interdisciplinary team members are not equipped to address. A need such as concerns about finances, concerns about relationship issues, concerns possibly with their relationship with God and others around them.Barber These are all very important issues and I would like to speak with you some more about them. Let's take a quick break for a medical minute and then come back to speak some more about support for cancer patients with Mary Crooks.Barber Welcome back, we are speaking with Mary Crooks about support for cancer patients. Mary, take me through your average day. Are you working at Smilow Cancer Hospital? Crooks Yes, I am. A typical day starts out early, I arrive at work around 7 because I need to be on time for our early morning disciplinary rounds. They begin at 7:30, and the interdisciplinary team includes the doctor, the nurse, our care coordinator, which is also considered the discharge planner, and 14:03 into mp3 file http://yalecancercenter.org/podcast/sept 0510cancer-answers-crooks.mp3 residents and internists. And what we do in our early morning rounds is we go from room to room to check on each individual patient on the floor, the hematology/oncology floor at Smilow Cancer Hospital and the team goes in to see the patient to determine what their needs are for the day and the doctor reports what the treatment plan will be. When I go into the room in the morning with the team, I am assessing just by observation how the person may be coping that day or feeling emotionally. If I sense that the person is stressed in any manner, I will make a mental note to return later at the end of completion of rounds to check in with that person and see how they are feeling. Barber So, after you have done your rounds, is there then a meeting of the team? Crooks Yes, the meeting of the team happens first thing in the morning with the completion of seeing each patient. We do a little

check in at the time when we are seeing each patient, prior to going into the room and prior to coming out of the room. Barber What do those meetings entail? Crooks The meetings entail the doctors sharing the medical information, test results, and setting up, again as I said, what the plan of treatment will be for that day. At that moment in time, if there is what we call a psychosocial concern, I raise it at that time and let the team know what I am thinking about for my plan for the day with that particular patient. Barber Then you will go back in and see that patient if you feel it's important to speak with the patient? Crooks Absolutely, I will go back in, I will see the patient and I will determine if they had any unmet needs or any concerns that they did not have a chance to voice to the team earlier, and then what I will do is I will report back to the team later that day, usually by phone call or if I see them on the floor later when they are visiting the patient, and that is how we keep the communication open and let the patient and family members know that we are working in their best interest and serving them. Barber Sometimes do the patients not want to talk about it? Crooks Yes, sometimes the particular patient does not want to talk about what is upsetting them or what is concerning them, so I sense that based upon cues they give me, usually nonverbal cues but sometimes verbal cues, and I will approach them sometimes that same day or the next day based upon how they are feeling and the cues I am getting from them.17:24 into mp3 file http://yalecancercenter.org/podcast/sept0510-canceranswers-crooks.mp3Barber In head and neck cancer, what kind of side effects are they facing and how do you help them deal with the side effects of their treatment? Crooks The side effects they are facing could be a whole range of side effects, based mostly upon the treatment they received. Most head and neck cancer patients receive both radiation therapy and chemotherapy. Based upon the treatment they received, they will have certain symptoms. Symptoms that we often see with radiation therapy, depending upon where it is directed on the head or on the neck, can affect the person's swallowing. It can affect a person's speech. It can affect their skin, so what I do is when I meet with the individual patient, by my communication to them I give them permission to be able to talk about these symptoms openly and honestly and to be able to address the feelings they may have about these symptoms. Barber What are some of the techniques you use to get through these difficult times? Crooks The technique that I often use is to let them know, through my nonverbal and verbal actions, that they can open up, that they can feel safe with me, that I understand not as a person who has had a head and neck cancer, but as a person who has worked with many head and neck cancer patients. I let them know that other people have expressed their concerns to me and that I know that these concerns often exist; they may or may not exist for them, but that I know that these are common concerns that others have shared. Barber Are there actual techniques they can use such as say guided imagery to mentally cope with what they are going through? Crooks Absolutely, there are many techniques that some people already employ themselves, and they are not aware of it. Some people actually have routines that they do, at home or they do it at work to reduce stress. Some of those routines are listening to music, exercising, or meditating. Some people

are not used to thinking about what their routines are or the natural ways they employ to reduce stress. I talk to them about that and we review how they have dealt with stress in the past and then based upon what they share with me, I ask them questions and I say to them, I heard you say to me that you have exercised to reduce stress or you listen to music to reduce stress. So we go back to the techniques that they are most familiar with first and foremost, then if they are interested in learning new techniques, based upon what they share with me, I will introduce those to them. There are many different techniques one can use to relax and I ask them which one's they think they would like to try and we start off with something simple. Barber Give me a couple of examples. Give me your top favorite relaxation techniques. Crooks The easiest and the most simple, and one that people can relate to often, is just simply breathing. 21:52 into mp3 file http://yalecancercenter.org/podcast/sept0510-canceranswers-crooks.mp3We all breathe, obviously, and we all take it for granted, we are not aware of it. We do not pay attention to our breathes and one way that a person can relax very quickly is just simply breathing in through the nose and then out through the nose, and to be mindful as they are doing that they are breathing in from a space in their abdomen, breathing up through their chest, and then hold the breath for a minute and then breathe out, again all the way down to their abdomen. And this is a very very simple relaxation technique that I practice with them and I encourage them to try that and then once they have mastered that, we can look at other techniques. Barber Are there support groups available? Crooks Yes, absolutely at Smilow Cancer Hospital we have multiple oncology support groups. Some are disease based, such as the head and neck cancer support group, there is a multiple myeloma group, and we have other support groups that are more generally based such as a patient and family support group that meets at the hospital. We have another patient and family support group that meets at the Shoreline for people who live out that way. It is easier for them to get to. We have a brain tumor support group, and I encourage people to try support groups, see if they like it and they are open ended groups, so you can come as you wish and if you miss a meeting or two that is fine, you can always come back. Barber And I would imagine that is very powerful for a lot of people to know, and you alluded to this earlier, that they are not alone in this. Crooks Absolutely, people when they come to support groups often talk about the other people in the group and how they know exactly what they are going through, and they are right. All of us medical professionals, unless we have had cancer ourselves, we do not exactly know what the other person is feeling. We can imagine it, we can be empathetic, but we do not know exactly. The people in the support group know exactly how it feels to have cancer, and how it feels to have the treatment that they have received.Barber I think the thing with cancer is it is something that we all worry about. we are a cancer survivor we have dealt with it, if not, it is certainly something that is there. What would you say to someone who has not dealt with cancer, but is thinking about the possibility that they might one day hear that diagnosis? Crooks We all worry about certain things and we can become anxious about something. Certainly many people are anxious about the economy and fear of

loss of jobs, many people can be anxious about receiving a diagnosis, and not knowing how that would be for them and how they will respond to it. I think that when we think of our loved ones and we think of the people around us who truly25:23 into mp3 file http://yalecancercenter.org/podcast/sept0510-canceranswers-crooks.mp3care about us and who are there for us, we have a built in support system, people who we can lean on if we are ever diagnosed. A lot of things can happen in life and life is filled with adversity and one thing we know about is that there will be changes in our lives and when that happens we need to know who is there for us, who we can reach out to, who we can lean on and call and speak with to share our concerns. Barber That is a wonderful way to close, to underline how important it is for all of us to have strong relationships in our lives. Crooks Absolutely, the theme here is a strong relationships in our lives, building relationships with our loved ones and keeping them strong, building relationships with the doctors, the nurses, people we come in contact with when we are ill, and remembering to keep open communication with everyone who touches our lives, everyone who we work with in our day-to-day living. Barber Mary Crooks is a Licensed Clinical Social Worker in the Head and Neck Cancer Program at Yale. If you have questions or would like to share your comments, visit yalecancecenter.org where you can also subscribe to our pod cast 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.