

Hi, I am Bruce Barber and this is Yale Cancer Center Answers with Dr. Edward Chu and Dr. Ken Miller. Dr. Chu is the Deputy Director and Chief of Medical Oncology at Yale Cancer Center and an internationally known expert on colorectal cancer. Dr. Miller is a medical oncologist and the Director of the Connecticut Challenge Survivorship Clinic. He specializes in pain and palliative care. If you would like to submit a question about cancer, please email us at canceranswers@yale.edu or call 1888-234-4YCC. If you would like to listen to past editions of Yale Cancer Center Answers, each segment is posted on the Yale Cancer Center website at yalecancercenter.org. This evening Dr. Chu and Dr. Miller will be talking about life after cancer with Dr. Ruth McCorkle, the Florence Wald Professor of Nursing and Dr. Tish Knobf, the American Cancer Society Professor of Oncology Nursing at the Yale School of Nursing.

- Miller Tish, lets start of by talking about what happens emotionally when a patient finishes their treatment.
- Knobf I think all the transitions, the time before diagnosis, waiting for treatment and the end of treatment, are difficult times. Towards the end of treatment, patients feel pretty secure receiving treatments so when the end of treatment comes, they are uncertain and feel sort of vulnerable because the treatment has been keeping the cancer away. They can get anxious and feel a sense of abandonment because they may no longer have the support of the health care provider that they had throughout treatment. They have been coming here every week, or every two weeks, and now they will see them in three months. It is a scary time for patients when they end treatment.
- Miller Do most people vocalize that concern or is it more of an internal feeling that they have of just not feeling quite right?
- Knobf I think it is probably an internal feeling, however, it may come out in support groups when patients talk. I don't think it is something we particularly address at the last treatment either. They still have some physical side effects and so you tend to focus in on symptom management. The psychological issues don't really start to surface until after they go home. After a couple months, then I think the whole impact of the diagnosis and the treatment begins to settle in.
- Chu It is interesting because it seems to me that the patients and their families view the clinic setting, the doctors, the nurses and all support staff, as kind of their home away from home. It becomes like a family environment for them. That is what could make it so difficult once treatment ends.
- Knobf Yeah, I think so. When you are actively receiving treatment you are seeing other patients, your nurse and you are seeing your doctor. There is a great sense of, "I am doing something to keep this away." It is a very supportive environment when

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you are in the clinical situation.

- Miller We will talk about families some more because cancer is very, very hard on the whole family. What is your observation, again when treatment is finished, on the process for a family?
- McCorkle It's equally hard on families, especially if there are children involved. What is interesting is research shows that as the patient gets better, family members often become even more burdened because they are the ones that take on the roles until the patient gets back to 100%. Often they are the ones doing all of the transportation of children, or the grocery shopping, and sometimes this is role reversal. Not only do they have to do their own work, but they have to pick up the slack. It becomes very difficult for them and they also go through these sort of crises when either the disease or the treatment changes and there are changes in the person with the cancer. They are always worried about their future. Are they going to have a future with that person, and what is life going to be like?
- Miller Let me ask you a little bit more about the role reversal. Can you give an example?
- McCorkle Well often times if a woman in the family is receiving chemotherapy and she has mainly been responsible for cooking the meals, food may not look or taste very good so it is very difficult to prepare the food. The husband may have to take that on, or an older daughter. Often this will happen and it becomes very difficult.
- Chu This is interesting, following up on what Ruth was just talking about, Ken you yourself actually went through this a number of years ago.
- Miller Right.
- Chu For those listeners who may not have tuned into the show before, many years ago your wife had acute leukemia. Thank God she is doing great.
- Miller Yeah.
- Chu But in fact you have actually experienced this role reversal.
- Miller It's true. I did a lot of cooking, which I really had not done before and I must say, my family, though I love them, they were merciless. They were so critical of my cooking, but I did the best I could. But you know I made an observation and I would love to get your reactions. My wife, thank God, got better and returned to doing the normal activities, but that was a period of re-adjustment. There were a

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number of things that I was both the father and the mother and was sort of responsible for her. She wanted to return to being responsible for herself and she wanted to get back into her regular activities, but it was difficult. What is your observation, or suggestion, to other people who may experience this?

McCorkle I think that the family, and whoever is helping, has to prioritize what they want to do. If the person really wants to go back to work, they may then need help only with certain things, but if they want to take on all their roles, they have to realize they are not going to be 100%. You have to decide what is most important and who is going to help you the most. It is a balance.

Knobf I think the most important thing is trying to help patients identify communication resources; who they communicate with and how they communicate, both with health care providers and their family, especially husbands and wives or partners. If there is not good open communication, the difficulty with the emotional distress and the physical recovery and changing of roles becomes all that more difficult. It is very well documented in the literature that typically as patients recover from their physical side effects, like fatigue and their hair begins to grow back, the emotional distress and the fear of recurrence does not go away. But the family wants the patient to be better, so they look better. Their hair is back, their energy is back, but psychologically they are not fully recovered and yet the family does not want to talk about it anymore. As health care providers it is important to try and get that message out to patients, about openly talking so everybody is on the same page in terms of the recovery.

Chu And yet that sometimes can be very, very difficult to have open communication amongst family members or loved ones. If there are difficulties with respect to those open lines of communication, do you have suggestions as to what patients and families can do to seek help?

Knobf There are a lot of options. Most clinical settings have nurses or social workers that can provide one-on-one counseling. The internet is a great resource for a variety of patients. There are all kinds of different support services through organizations like Cancer Care, The American Cancer Society, or The National Cancer Institute. Not all patients like the group environment, so there are also good assessment and referrals for psychotherapy on one-to-one basis which is appropriate in a lot of cases. We know that families are not perfect, and families that did not do really well before the cancer diagnosis tend to be the ones that do not do well after. Sometimes helping families who may look a little more at risk for not doing well is a good thing that nurses and doctors can help out with.

Miller Along those lines, for health care providers, is there anything that research shows us about how we can identify families or patients that are at higher risk? And for the audience, what things going into the cancer experience may predict that

it is going to be rough for them? Or perhaps easier?

- McCorkle One of the things that is coming out right now, and September brings a new report by The Institute of Medicine on the psychosocial needs of patients and families, recommends screening. Not only do you want to screen your patients, but their families as well. They look at risk as an emotional distress thermometer that goes from 0 to 10. If you score above a 4 on the thermometer, they recommend you get evaluated by a psychological health care provider like a social worker or a nurse that is trained in these specialties.
- Miller So potentially an intervention early on with a social worker or nurse will make a difference. Is that your thought?
- McCorkle The most important thing for patients and families to hear is that the reactions they are having are common among all patients. What is troublesome is whether the reaction is sustained. If it goes on for a long time and starts to affect your sleep and your ability to function, then you really need to get some assistance to help you with it.
- Miller Tish, along the lines of depression and anxiety, what would be considered uncommon? At what point might you say this is beyond what we are comfortable with and there may be a problem?
- Knobf First of all, one red flag would be if the patient has a history of depression or any kind of psychological distress, because they are at higher risk for depression after that. A basic assessment tool, like the distress thermometer, at least gives you some idea if this is above just being irritable and feeling sad. Those are normative reactions for the majority of patients and families, but if patients are really having a hard time getting up and going to work everyday, we need a psychiatrist or psychologist who can do a better assessment and intervene with these patients.
- Chu Ruth, we have been talking a lot about psycho-emotional consequences. Could you discuss a little more about some of the physical consequences that patients may have to deal with once they have completed their treatment.
- McCorkle The number one problem for patients is fatigue. It is enormously prevalent. I am a breast cancer survivor of 17 years and some of the research talks about just being bone tired. You are really just wiped out. One of the things that Tish is working on is something to help with that. She has found that exercise, just walking everyday even if you do not feel like it, really does stimulate those endorphins and helps you feel better. Fatigue affects your sleep habits and affects your appetite. It seems that there are a group of symptoms that hang together, and if the basis for them is fatigue, if you do this simple intervention of walking,

sometimes you can feel better overall.

Miller: We would like to remind you to e-mail your questions to us at canceranswers@yale.edu. We are going to take a short break for a medical minute. Please stay tuned to learn more information about life after cancer with Dr. Ruth McCorkle and Dr. Tish Knobf from the Yale Cancer Center.

The American cancer society estimates that in 2007, there would be over 62,000 new cases of melanoma in this country; 2400 patients are diagnosed every year in Connecticut alone. Melanoma accounts for only about 4% of skin cancer cases that causes the most skin cancer deaths and when detected early, melanoma is easily treated and highly curable. New treatment options and surgical techniques are giving melanoma survivors more hope and clinical trials are currently underway at Yale Cancer Center, a federally designated comprehensive cancer center, to test innovative new treatments for melanoma. The patient enrolled in these trials are given access to newly available medicines, which have not yet been approved by the food and drug administration. This has been a medical minute brought to you as a public service by Yale Cancer Center. For more information go to yalecancercenter.org.

Miller Welcome back to Yale Cancer Center Answers. This is Dr. Ken Miller. I am here with my co-host Dr. Ed Chu and our two guests, Dr. Ruth McCorkle and Dr. Tish Knobf discussing cancer survivorship.

Chu Before the break Ruth was talking about the physical consequences patients with cancer have to face after treatment. You were talking about fatigue as a very big issue. What other physical issues might a cancer survivor have to deal with?

McCorkle What is interesting is that a lot of people fear pain and the pain associated with surgery. Most people have some kind of biopsy, especially if they have a solid tumor, and there is a little pain associated with that. Most cancers really are not painful and so if a patient does have pain with certain types of cancers it is a good warning sign that it may have metastasized, or spread to the bone. You should be seeking help if you experience pain. Mostly patients deal with nausea, lack of appetite, fatigue, insomnia and sleep disturbances. There are also some hormonal imbalances. In my own experience, I was also thrown into menopause early so I had the hot flashes. It is very disconcerting experiencing this personally, and so when you are in the middle of it, it is so difficult to talk to your family because you are trying to take care of yourself. If you are a mother and have to take care of your children too, it just drains you more. If you work and are forced to stop working for awhile, it escalates between the physical and the mental.

Chu And there is also this issue of chemo brain. Can you explain to our listeners what that means.

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- McCorkle Sometimes chemotherapy has the side effect of interfering with your ability to think. It is problematic because at the same time people are giving you information to make decisions about your treatment and during this time you are also bombarded with fatigue. Tish is also doing a cognitive study around chemo brain and the risk association with some hormones; maybe she could tell us about that.
- Knobf The major problems that patients complain about are not being able to pay attention to what they are doing and they can't concentrate. Forgetfulness is probably the single most common symptom that patients complain about. At least in the breast cancer population, as Ruth described about the abrupt menopause, that may in fact contribute to some of these memory and attention problems. We hope that we are going to be able to get some information to be able to look at this. These symptoms are really scary for patients and the more information we have that can explain why they are forgetting, and techniques to actually improve that, the better. There are now several interventions looking at ways not necessarily to improve memory, but sort of compensate for the loss. Very common sense things such as making lists, keeping a calendar, and some of these changes have been reported as particularly distressful in the work environment, more so than in the home. They are not able to perform at the same level.
- Miller Along those lines, can you tell us a little bit about what research shows on exercise for cancer survivors.
- Knobf There is really a lot of research and exercises. There is no question that exercise improves physical functioning. The majority of patient's become what we call deconditioned during treatment because they decrease their level of physical activity and then it becomes a vicious cycle with fatigue and less activity. For anybody who has had the flu and has spent two days in bed, your energy level is not the same on the third day. Exercise improves physical functioning and psychological well being along with muscle strength and the patient's outlook. One of the studies that we are doing looks at how we can improve some of the potential late effects like bone loss from being induced into menopause, or from some of the cancer treatments. I am going to be looking at resistance exercise and see if resistance exercise can prevent women from losing bone and also help them maintain their weight. We know that obesity is a risk factor for some cancers and increases risk of recurrence. If we can maintain a healthy lifetime weight, that is also going to decrease the patient's risk for not only cancer, but diabetes and heart disease as well.
- Chu With respect to exercise and physical activity, what intensity level is required in order for a cancer survivor to be able to continue to move forward?
- Knobf We should be following the national recommendations that say every adult ought

to engage in moderate exercise described as at least 30 minutes of say brisk walking on most days of the week. There have been two studies with breast cancer and colon cancer patients that have suggested walking at those recommended levels is actually associated with a decreased risk of recurrence and increase in survival. The minimum recommendation is 30 minutes of moderate activity on most days of the week.

- Miller Ruth I wanted to ask you, based on your own personal experience with cancer many years ago, how does that experience change you as you look at the longterm?
- McCorkle Initially I thought it was a huge interruption in my life because my treatment lasted about nine months with chemotherapy and radiation. It was a rough time because I had small children; they were 7 and 8 at that time. I was fortunate because I was able to get child care and transportation and other things, but at that time you are sort of in limbo. Once I got through the treatment, and about a year after that, I realized how very lucky I was in receiving an early diagnosis. It gave me a new lease on life and made me change my priorities and enjoy my family more and set goals. Gilda Ratner said in one of her books that you really have to be a cancer survivor in order to help people. I always took offence to that when I read it early on and was teaching students, but after you have this experience it makes you humble and gives you great insight to the struggles that some patients experience.
- Miller Based on your experience, is there a lot of resiliency in cancer survivors?
- McCorkle They are phenomenal; the courage that they have and the efforts that they make. Everyday that I walk through the clinics I see people getting there, they are still able to get out and are doing a terrific job and people recognize what a good job they are doing. Getting on the other side of it, it is worth it.
- Chu And again, this is true not only for the patient, but also for the caregivers and the loved ones who have all been a part of the treatment aspects and then the recovery.
- McCorkle It is important to make them understand that they are all part of the team to help the person get well and they have played a key role. It is critically important to have children understand that they are helping their mother or father or sibling during this time and that this helps make them feel better.
- Miller In many ways it can be a strengthening experience for the family as well.
- McCorkle Absolutely.

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- Miller It is not uncommon to see a patient who had cancer 10 to 15 years ago and when we ask them what stage it was and what treatment they received, they really do not know anything about it. What are some ways that we can share that information with patients so that they have the information, which hopefully is empowering?
- Knobf One of the recommendations now, and it certainly makes sense, is to provide the patient with a summary of their treatment once treatment is completed. This way they have a personal history of what their diagnosis was, what the stage was, and the treatment they received. This will also help them in followup care to understand why they need certain tests, or tell them to look out for a long-term effect of treatment that may occur 10 or 15 years later. Having this information decreases that sense of uncertainty and a lot of the fears that patients have can really be decreased by providing them with accurate information.
- Chu In fact, a great deal of interest right now is being focussed on developing these cancer survivorship clinics to really address the issue that you just highlighted Ken.
- Miller The Connecticut Challenge Cancer Survivorship Program is one of about 13 or 14 survivorship programs in the country and it puts an emphasis on a holistic approach. Each patient sees a nurse practitioner or a doctor as well as a physical therapist, a nutritionist and a social worker, to try to address some of these issues. Several of the major universities have programs. What have you seen in regards to their contribution?
- McCorkle The survivorship programs actually started in the pediatric area and they have done a terrific job. We have a HERO'S Clinic here at Yale run by Nina Kadan - Lottick and they do a fantastic job. They do such a good job, the people that were young that now are older do not want to leave the clinic. I think the oldest patient in the clinic is 40. It just shows you what a good job they do. We have transported that into the adult population. Anna Meadows, who started at the Children's Hospital in Philadelphia, was on the panel that earmarked this at the National Cancer Institute and it sort of broke loose like flood waters from a dam. There are so many survivors, over 10 million survivors now, so it is long overdue. It is exciting that we are part of that. A lot of the citizens of Connecticut, even our governor, are all cancer survivors; it is so prevalent that this is a very good thing.
- Miller It is exciting the growing number of cancer survivors. It is a testimony to many things including medicines and also the strength of people getting through this. I would like to thank Dr. Ruth McCorkle and Dr. Tish Knobf for joining us on Yale Cancer Center Answers.

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Chu

Ruth and Tish, this has been great and we look forward to having you both come back for a future show. Until next week, this is Dr. Ed Chu and Dr. Ken Miller from the Yale Cancer Center wishing you safe and healthy week.

If you have questions, comments, or would like to subscribe to our podcast, go to yalecancercenter.org where you will also find past broadcasts in written form. Next week we will discuss ovarian cancer with Dr. Thomas Rutherford.