

Dr. Kenneth Miller, Resources and Support for Cancer Survivors January 25, 2009 Welcome to Yale Cancer Center Answers with Dr. Ed Chu and Dr. Ken Miller, I am Bruce Barber. Dr. Chu is Deputy Director and Chief of Medical Oncology at Yale Cancer Center and an internationally recognized expert on colorectal cancer. Dr. Miller is the Director of the Connecticut Challenge Survivorship Program and is also the author of "Choices in Breast Cancer Treatment." If you would like to join the discussion, you can contact the doctors directly at canceranswers@yale.edu or 1-888-234-4YCC. This evening our guest host Ellen Matloff sits down with Ken Miller for a conversation about survivorship. Matloff Can you start by telling us, who is a cancer survivor? Miller That is a good question, and I would like to give the definition because it is a good one. A cancer survivor is someone from the moment of diagnosis for as long as they live, which we hope is a long time. Also, if you go into the National Cancer Institute it includes family and caregivers in the definition as well. So it is a big population, and I am a cancer survivor, as are my kids, from that point of view, since my wife Joanne has had cancer and is a survivor. Matloff That is very interesting. I do not think that most people would think that family would also be considered in the survivorship package. Miller On one hand you could say it's too broad a definition, and some people would say that, but you know, it reflects that cancer is a disease that affects an entire family and the people involved, in a different way than the patient, but still in a pretty profound way. Matloff Ken, can you talk a little bit about how the field of cancer survivorship has changed over the last few years and the last few decades? Miller One of the best books that I read was written about 20 years ago by Fitzhugh Mullen. He is a physician and wrote a book called "Vital Signs." He was diagnosed with cancer and talks about his treatment and the discovery of his cancer and the whole process. He also wrote a great article in the New England Journal of Medicine called Seasons of Survival talking about that process, not just focusing on the moment of diagnosis and the process of treatment where all the attention was being paid, but to the entire process. What was it like to finish treatment and then start getting back to regular life? What was it like a few years later when the cancer becomes a more distant memory? He has continued to be very active in the field, using himself as an example many times, but he is now 25 years out. For someone who has been through cancer, it really is a process; the survivorship goes on for many years. The field has come a long way; it is a topic of scientific interest and clinical interest and has really blossomed as part of oncology. 2:50 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 Matloff When I am taking family histories, it is interesting that 3 or 4 generations back did not talk about cancer, and in fact, some people will say the "C word;" they will literally not even say the word cancer. Do you find that people are more willing now to either admit to, or even embrace, the fact that they have survived cancer? Miller I think for many people that is true, they say, "I am a cancer survivor, I got through this." They really look back on it with a sense of mastery and growth and proud of that history. There are still many people though that it is something they may be ashamed of or

not sure who to discuss it with. I think some of that may be personal, some is cultural, and I think we have to respect all those peoples' rights to either talk about it or not talk about it. Matloff I heard you give a lecture yesterday Ken and you used a term that I had never heard before, post-traumatic growth, can you explain what that means? Miller We all talk about post-traumatic stress and stress syndrome such as after the Vietnam war, the Gulf War, the Iraq War, or 9/11 etc, but there can be post-traumatic growth as many cancer survivors use that experience as a springboard for other parts of their life, they become very active in supporting other people with cancer, and they become more active in their community. I will use my wife Joanne as an example, one of the things that has come out of her experience with cancer, which is now her two experiences, is her real commitment to working with children who have lost a parent. She works in children's grief in the schools, so it can be a growth experience. Matloff That is amazing. So I guess what you are saying is that some people can take what can be a very traumatic event in their life and turn it around into something positive. Miller Absolutely. Now that may not happen 6 months as a survivor, or a year, it may be 2, 3, or 4 years later. We all process this very, very tough experience in different ways; in some people the initial grief, anxiety, and the worry is the biggest part of that experience. In other people it is a year or two later after they finish treatment that they say, "Wow, that was really a tough experience." I will share my own observation, that for people where a lot of the stress and the anxiety and worry is afterwards, sometimes it is out of proportion to the actual risk so they end up becoming more worried and more concerned than people that may be at a higher risk of recurrence. The stress part of it may be out of proportion to the actual risk. Matloff As a practicing oncologist, can you advise people on how they may be able to handle their stress more effectively? 6:15 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 Miller We are all different, but I think it is useful to be an active participant in your care. People that actively engage in their treatment, that gives them a sense of mastery, and it helps people do well and have less side effects and more benefit. Now what does that mean, let me be practical about it. I talk to patients about starting chemotherapy and I say there are two ways to do it, and I say it with a smile, one is where you stick your arm out and say lets go! The other way is where someone says, "I really do not want to do this, I cannot believe I am doing this, but go ahead and do this to me," in terms of getting treated. Obviously what I would love to see is where people embrace it and say, "You know, I want to do this, but let's do it with a sense of commitment." I think that when people do that they are actively involved in the decision making process and the process of treatment is easier, it has less side effects, and personally, I think it may have more benefit. One has to engage as an active participant in their care. As much as you can in a bad situation like this, embrace the treatment and say, "This is my ally." And be sure to talk, talk to your caregivers, talk to your family and to your friends as much as you are comfortable with to share the emotional side of it so that you have a chance to vent. Matloff Do you think that there

are some patients who may need to see a counselor or a social worker as they go through this process? Miller Absolutely and I think it should be part and parcel of our care. This is incredibly stressful, you are minding your own business and then all of a sudden someone says that you have cancer and your life changes in one day. It is like having a car accident, something you did not expect. Matloff Interesting analogy. Miller Many people will say, "Well, I have resources, I have my friends to talk to," but talking to a professional is different because you can say a lot of things to a social worker or counselor that you might not be able to say to your friends. I encourage people to talk. Matloff That is great, talking for a moment about cancer survivorship, up until now our focus as a medical community, and certainly as a society, has been on the treatment of cancer, and I think many of us have thought, when it is over, it is over, you never go back. Can you tell us about some of the issues, either physical or emotional, that a cancer survivor will face? Miller If we look at the broad term, from the moment of diagnosis for as long as you live, there are a number of possible issues that could come up, and I will talk about them in a second, but let me say that most people do exceptionally well. I have spent a lot of time with people that say, "I had breast cancer 20 years ago," "I had breast cancer 15 years ago," and it is 9:29 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 part of their past history, not an active thing on their mind or a big involvement in their day. But there are issues that some people will experience, for example, in the short term some people will complain of chemo-brain or chemo-fog, and they say they are not quite as sharp in terms of work and their short term memory is not as good, and usually that gets better. Some of our patients complain of neuropathy, this is more from the medical standpoint, but a little numbness or tingling, or it could be a lot of numbness or tingling in their hands or feet, again, typically it improves, but not always. There is also short and medium term recovery from surgery and from radiation, your body is different than it was. We can talk also if you like about the more long-term issues. Matloff Yes, let's do please. Miller If we look at what I would call permanent survivorship, these are people that are a number of years out from treatment. There are some people that are both free of cancer and cancer free, meaning they are not experiencing side effects, but there are some people with long-term issues, such as they have less breathing reserve than they had before. In fact, Fitzhugh Mullen who wrote that wonderful book talks about that, and it is more of an issue for him as he has gotten older; the effects of his surgery and radiation and treatment years before. Some people will develop heart problems, they are cancer free, but they are not free of cancer. There may be a predisposition to some weakening of the heart muscle because of chemotherapy. In some people there is higher risk of a second cancer because of their treatment. Matloff As we are getting better at treating the first cancer and more and more people are surviving their cancer and living a long life, what kinds of things are you seeing in those long-term survivors? Miller Again, most people do exceptionally well, but the things that we look for medically are perhaps a slightly higher risk of other cancers, some of that may be a genetic risk, some may be environmental,

and some of it may be because of our treatments. People that have had certain types of chemotherapy are at higher risk of developing blood diseases later in life. Women who have had radiation to part of the chest for Hodgkin's disease, for example, are at a much higher risk for breast cancer, and that is something that is really worth screening and paying very close attention to make an early diagnosis if they develop a breast cancer. Matloff You have already discussed the fact that cancer is really a family affair, so what kinds of fallout do you see with the whole family after a diagnosis of cancer, long-term? 12:27 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 Miller

It is a good question and I am not sure exactly what the answer is because I'm not sure we have those answers. I'll pose it more as a question for all of us to ponder, when children have the experience of a parent with cancer, perhaps they will be more vigilant in their own life, and perhaps they will be more worried about their own health. I do not think we have that information yet, but it is important to look into. Matloff We are going to take a short break for a medical minute. We will be back with Dr. Ken Miller. Matloff I am Ellen Matloff and I am here talking to Dr. Ken Miller who is the Director of the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Welcome back Ken. Miller Thanks Ellen. Matloff Ken, in your relatively short career here at Yale you have covered a lot of new ground and it has been very exciting for me to watch. One of the many things you have accomplished has been the creation of the Connecticut Challenge Survivorship Clinic. Can you tell us about this? Miller About 3 years ago when I started at Yale I was approached by a good friend of survivorship and a cancer survivor named Jeff Keith. He is in his 40s now but had cancer of the bone as a teenager. He was an athlete at that time and ended up having an amputation of his leg many years ago. Well, thank God he has done very well medically, he is a dynamic person, and he said to me, "There are survivorship programs starting to develop, there is one in New York, there is one in Boston, we need one in Connecticut," so I was working with our 15:04 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 Cancer Center Director, Dr. Edelson, and with Dr. Chu who is my co-host many times, and said, lets do it, and so we started, with the help of the Connecticut Challenge, the Connecticut Challenge Cancer Survivorship Program. That was about 3 years ago and the program really has since flourished. Matloff Tell me what happens in this clinic, is it for survivors of all different types of cancer? What happens to a patient who walks in the door? Miller We see patients as a team which is how Yale does things in general and it works well for patients. The patient comes in as person, a cancer survivor, and comes in for pretty much a whole afternoon. They see a nutritionist to talk about nutrition and its effect on health and wellness and decreasing the risk of cancer. They also talk about physical fitness, which we think is very important. They see a physical therapist, and a social worker to talk about the emotional aspects of being a cancer survivor, and they see either advanced practitioners or myself to talk about medical issues, medical risks, and also risk assessment and care planning to look at the short and long term needs that they have. Matloff What

would you say are the most common medical side effects, or medical issues, that you see in these cancer survivors? Miller Some of them are the regular things that people have, for example, fatigue, and what we try to tease out is, is that normal fatigue that a lot of us have from busy stressful lives, or is it related to treatment? We work with people around that and around cognitive changes or chemo-fog, chemo-brain. We also have developed a very strong expertise in treating symptoms such as pain issues. That is where having a physical therapist and a social worker involved, and having more of a team approach, is very useful. We also have some alternative complimentary therapies such as Reiki and acupuncture. For cancer survivor's one of the issues is pain and symptoms like that. Matloff It is fascinating Ken because so many of our treatments are effective, for example, my mom was taking Rheumatex after a breast cancer diagnosis, and this was before we understood that a common side effect can be crippling arthritis for some people, or bone or muscle pain, and the feeling that she had, and that maybe was conveyed to her, was, hey just be lucky you do not have cancer. These debilitating symptoms were not addressed and it sounds like these are the things that you take very seriously in your clinic. Miller We do. That is the reason why we are there, to help cancer survivors. Some are dealing with physical issues and side effects of treatment, others are dealing with psychosocial issues, and some are just looking for counseling in terms of wellness. On one hand we are 18:21 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 all lucky to be alive and it is great to be cancer free, but again, that does not mean you are free of cancer. Those symptoms should be addressed and thankfully we have been able to add years of life for people that have had cancer. We need to be concerned about the quality of those years. Matloff Who would be eligible for this clinic? Miller Any cancer survivor, again, using the definition from the moment of diagnosis for as long as you live. We focus primarily on people that have completed the active part of their treatment. If a woman has had breast cancer and has chemotherapy and radiation and surgery, usually we will see them when the active part, the big part, has been finished, but we also see people 5 years out and 10 years out, who say I want to learn more. Matloff How about for listeners who have been free of cancer, let's say for 20 years or more, and they are sitting at home thinking, "Gosh, I was treated 20 years ago, should I go back in and see what is available to me?" How would you advise them? Miller We would certainly love to have them and be glad to see them. It is interesting because some people do not want to do that, they really do not, they say it was a long time ago and they are leading a happy, healthy life and really do not want to know about all that stuff, but for people that say they want to know, they want to focus on wellness, being seen in a survivorship program like ours has value. Matloff Why the Connecticut Challenge specifically? Miller It is a great organization based in Fairfield. The leadership includes Jeff Keith, who is a cancer survivor, a fellow named John Ragland, and finally, Bob Mazzone, so there are three leaders. Every year they have a bike ride, it is important to say it is not a race but it is in fact a ride, and it is either 25, 50, or 100 miles, and they added a 12.5 mile

ride, that one sounds good to me. Matloff Absolutely. Miller This is a great organization, they do other fundraising to support cancer survivorship and with their help we have been able to start this program, and also learn more about survivorship through research grants. Matloff If some of our listeners are interested in the Connecticut Challenge, either being a part of the bike ride or perhaps a sponsor, or giving a donation to the Connecticut Challenge 21:07 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 maybe in lieu of a gift for a family member or to honor a family member, how do they do that? Miller I encourage them to go to the Connecticut Challenge website. Matloff So they can Google that? Miller I would Google Connecticut Challenge, and they will find a great website and learn more about it. I encourage people to ride if they can ride a bike, in general it is healthy for you to get to do a little bit of practicing and training before you get out there. It is truly a wonderful event with a lot of celebration to it, because it is all about survivorship and healthy living. Go to their website, Google it, and do make a contribution or even better, get on your bike and ride. Matloff That is fantastic. Raising another issue, people do these kinds of things now, they come out for a bike ride for cancer survivors, or they walk in a breast cancer walk, in your view, in terms of survivorship we have talked about how it has changed for the survivor and for the family in the last decade or so, but how has it changed for the community as a whole in terms of supporting cancer survivors instead of ignoring them or even shunning them? Miller A very good question. The term cancer survivorship includes many different aspects so let me say a word or two about that. It is not just people that are cancer free, it is people that are living with cancer, and for many people cancer has become a chronic disease that they live with like diabetes or high blood pressure, a little bit different, but nonetheless, chronic. There are people that are in remission from cancer but are on medication to maintain that, so they are long-term survivors, and there are people that had cancer 20 years ago that live long enough and, unfortunately, develop another cancer, so that is a large group of people. It is estimated that there are 11 million cancer survivors now and it is also estimated that by the year 2020, a little more than 10 years from now, there will be 20 million cancer survivors; the number is going to double. What it means is that people are being diagnosed and, thankfully, are doing well. You are in a sense a cancer survivor because your mom has had cancer, and as am I. All of us have been affected by cancer in one way or another and the term survivorship and cancer survival has affected the community and created more acceptance and support for people. That may lead to an earlier diagnosis or to better reintegration after treatment is over too. Matloff That is really interesting. I want to sort of veer off into a different subject, you have been treating cancer patients for a long time now, and I am wondering if you can tell us firsthand 24:19 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 how caregivers can recover along with their patients. This has got to be a draining, and a debilitating area for you in some ways, how do you do it? Miller I will talk both as an oncologist and as a husband as well. The cancer

experience is a very difficult one, sometimes more difficult for family than for the patient themselves. Patients who are actively being treated thankfully have tremendous amounts of attention from the medical professionals involved, and by other support services. The caregivers are frequently doing a lot of different things, trying to keep a household going, trying to take care of the person who has been treated, trying to take care of themselves, take care of children, and relationships change. When my wife was sick I had to do a lot and I had to make a lot of decisions when she could not. Afterwards my wife Joanne got better, and as people get better they want to take that back, they are very independent adults, so relationships have to shift and then shift again, that is difficult too. What I would encourage people to do is to communicate, which is difficult for all of us at different times, but talk about the experience to identify what is going on, use professionals, counselors, and healthcare providers. A counselor could be your nurse in the oncology center. And vice versa, I encourage healthcare professionals to do the following; when Joanne was in the hospital it was always nice when someone would turn their head to me and ask how I was doing; I loved that. Matloff Absolutely. Miller It is a small thing, but I do try to do that with my own patient's families now; it identifies that they are there, that they are an active participant, and usually people say they are fine, but just having identified them as being present is useful. Matloff Would you like to speak a little bit about it from the healthcare provider point of view? What is it like for you to treat so many patients with cancer, how do you stay fresh? Miller It is nice to reflect on this a little bit. I love being an oncologist in many ways, and pretty much all the time. It is in a sense invigorating to meet a new person, a person just diagnosed who has been dealing with cancer, and say, this is what has happened, I wish it had not, I wish he did not have cancer, but this is what we are going to try to do about it. I try to share a prescription for hope and I think part of the treatment is hope, hope to get you better, hope to get rid of the cancer, hope that you will be able to live longer with a good quality life, all those different things. We have many goals at the same time, so in many ways it is invigorating. 27:26 into mp3 file http://www.yalecancercenter.org/podcast/Answers_Jan-25-09.mp3 Matloff That is wonderful to hear, so you get something back from your patients. Miller Absolutely. There is a strong bond that develops between doctor and patient. It is different with each person, sometimes it is humor that people relate to, other times it may be more on a scientific basis, but with each of my patients I try to have something that we can both relate to on some level that pulls us together above and beyond treatment of the cancer itself. Matloff Thank you Ken, and thank you for all the work you have done here at Yale. You have been listening to Yale Cancer Center Answers and I would like to thank my guest Dr. Ken Miller for joining me. From Yale Cancer Center this is Ellen Matloff 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.