

Barber I am Bruce Barber and on this week's Yale Cancer Center Answers our hosts, Dr. Edward Chu and Dr. Ken Miller, will discuss cancer survivorship. Dr. Chu is the Deputy Director and Chief of Medical Oncology at Yale Cancer Center and is a leading expert in colorectal cancer. Dr. Miller, a medical oncologist, is the Director of the Connecticut Challenge Survivorship Clinic at Yale Cancer Center. Yale Cancer Center Answers is our way providing you with the most up-to-date information on cancer care every Sunday evening on WNPR. Dr. Chu and Dr. Miller welcome some of the nation's leading oncologists and cancer specialists in the forefront of the battle to fight cancer. They wish to provide you with help and hope from the Yale Cancer Center. They are also available to answer any of your questions. If you would like to submit a question about cancer to the show, please e-mail your question to canceranswers@yale.edu or call 1888-234-4YCC. If you are interested in listening to past editions of Yale Cancer Center Answers, or if you would like to learn more about a specific kind of cancer, all of the shows are posted in audio and written format on the Yale Cancer Center website which is www.yalecancercenter.org. This evening, Dr. Chu and Dr. Miller will discuss cancer survivorship. Today, the first Sunday in June, is National Cancer Survivors' Day. A day dedicated to celebrating life and cancer survivorship. There are over 11 million cancer survivors in the United States and today we celebrate all of them. In recognition of cancer survivors' day, Dr. Chu and Dr. Miller are joined by Dr. Julia Rowland. Dr. Rowland is Director of the Office of Cancer Survivorship at the National Cancer Institute.

Miller Let's start by talking about the definition of a cancer survivor.

Rowland That is a wonderful place to start. Up until the end of the last century, the medical definition of a cancer survivor was somebody who had been disease free for five years; you couldn't consider yourself a survivor until you passed that benchmark. But as the number of individuals living long term with the disease increased, a very important thing happened. In 1986, a group of two dozen individuals met in Albuquerque, New Mexico and formed what is now called, National Coalition for Cancer Survivorship. At that very important meeting, they looked at the definition of a cancer survivor. They decided that it was not okay to have to wait five years to think of yourself as a survivor. This decision was based on two reasons; we need to provide the message of hope for individuals who are diagnosed and that they have a future ahead of them, and we need to let the medical community know that they have to think about patients' lives starting at the moment of diagnosis. They decided to reframe the definition so that individuals could call themselves cancer survivors from the day of diagnosis for the rest of their lives.

Miller Why do you feel it is important to embrace the term 'cancer survivor' from the moment of diagnosis, as opposed to five years later?

Rowland Because we know that important decisions need to be made before treatment starts. You cannot wait five years to decide, "I would love to have a family" and then realize that you have had a

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treatment that has caused you to become infertile, or you are an athlete and there is a decision about an amputation. You need to be able to make those decisions at the time of diagnosis so that you can have the same quality of life later. We need to be able to provide that dialogue right from the start of treatment.

Chu I have heard that the definition of cancer survivorship has been broadened further and includes loved ones or support caregivers, etc. Can you expand on that a bit more?

Rowland When the coalition met back in 1986, 20 years ago, they included under the umbrella of that definition family members. We know that cancer is an illness that affects not just the individual but also that person's family. They are very important in the recovery process and in the survivorship trajectory. They felt it was important to acknowledge that role and to include them in that definition.

Chu If you take that broader definition of a cancer survivor the numbers actually are much more impressive than the figure of 11 million that we started off the show with. I read on the NCI website that perhaps 3 out of every 4 individuals in this country could in fact be considered a cancer survivor.

Rowland The American Cancer Society has estimated that 3 out of every 4 families will have an effected member. If we look around a gathering of 100 people, many of those individuals will either have received a diagnosis, or know a loved one who has. You could think on an even broader scale of all the people that are important to survivors across their illness; friends, neighbors, their community. This is an illness that really does affect millions and millions of people.

Miller I want to ask you a little about the history of this movement because the council for survivorship is relatively new.

Rowland For a long time, certainly when the cancer act was passed in 1971, the picture was fairly bleak for individuals who had a diagnosis of cancer. Most individuals were not going to outlive their illness and had few treatment options. Side-effects were also poorly controlled. As we got better treatments and newer technologies to find cancers early, the population of survivors began to grow. That recognition, that life goes on after cancer, allowed the clinical community to begin to look at the impact of treating and caring for somebody with a controlled disease. This community of survivors has been incredibly articulate and vocal about their needs.

Miller Along those lines, what are cancer survivors telling us?

Rowland Cancer survivors are telling us several things. First and foremost, looking at all the literature

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combined with the research that has been done to date, I would highlight the fact that we would not have this information if literally thousands of survivors had not been willing to take the time to talk about their experience and share it with the medical community. They made sure to fill out the questionnaires and forms. So if somebody asks you to please fill out a form, I hope you will volunteer to do it because it is a making a difference in people's lives. Most individuals, despite the demands of treatment and toxicities of some therapies and arduous courses, are incredibly resilient. They must have the resources they need to get through this. It is a very impressive time and survivors can tell us how they got through it. They are telling us that when treatment is over, the illness experience is not over. We are hearing time and again that cancer can affect all aspects of an individual's life from physical to emotional, social to the existential and it is those issues that they struggle with. The medical community is still lagging behind in helping systematically address these issues.

- Chu When I was a fellow and trained at the National Cancer Institute many-many moons ago, we focused on the treatment aspects and I have to say we didn't really focus on what would happen once the individual completed therapy, or the consequences of that therapy. It is nice to see now that in our own fellowship program we will be developing programs that incorporate that aspect of survivorship.
- Rowland Our growing population of survivors is a wonderful testament to all of the research that individuals like you have done to help us advance our ability to cure and control cancer, but it is also a challenge to us. They want to know what they are being returned to after treatment and what their life is going to be like. They need to be ensured that they are going to return to a life of value in the context of having had this illness. That is a very important message to the medical community.
- Chu One of the good things about all of the large clinical trials now being conducted is that quality of life indices are now being incorporated.
- Rowland Absolutely, and that is in part the focus of why we created the office of cancer survivorship; to increase the visibility of science in that area and to promote recognition of the need to have not just recurrence and disease indicators, but also personal indicators of the impact of this illness on an individual's life.
- Miller Later on in the program we can talk about some of the challenges that survivors face; physical, emotional, etc. What are some of the positive things that cancer survivors report?
- Rowland For so long we were focused on all the ways that we had damaged individuals, caused them disability, disfigurement, distress, and all of our research was focused on that. But as researchers stood back and began to listen to survivors, they learned about the problems they had, things they

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were surprised to learn they could do, that they are proud of the fact they were able to get through this disease and they appreciate life much more now. There is a sense of what researchers call posttraumatic growth. It is a way that we are wired to make sense of traumatic experiences in our lives and find that silver lining that makes us stop and smell the roses. We appreciate the people who have been there for us and begin to live each day more fully and more deeply. For many individuals it has been incredible and for some a surprise, but it is a sort of gift that comes with a serious illness like cancer.

Miller Is this the same for the family or the caregivers?

Rowland The processes are different but the responses of family members are comparable to those of their loved one who is the actual patient. Sometimes family members have an even more difficult time because, of course, all of our intent in the medical community is to help the individuals in active treatment. Sometimes we take for granted that the family members are there, and we don't offer consistent help to them. They are going through the same kind of experience with less support. We need more research to help us identify critical information as to the needs of family members so that they can be there for their loved one and do as well as them.

Miller You mentioned challenges that people face; physical, social, emotional and existential. Tell us about existential. That is an interesting concept.

Rowland As you know, those words "you have cancer" are probably some of the most terrifying words that an individual will hear in their lifetime. A question that often arises is "Am I going to live?" For many individuals this is not something they have thought about, and it causes people to do a life review. They begin to think about what they want to do differently going forward with life after treatment.

Miller Tell us a little about some of the physical challenges people face.

Rowland The physical challenges of cancer are vast. It depends on the nature of the treatment and the type of cancer, but they can literally affect every organ system. Some people have very few effects and some people have many. It is very difficult for us to predict who is going to have what kinds of problems. We know that if you have surgery there is going to be surgical scarring, changes in body image, and based on the nature of the surgery, you may not have the same capacity to do thing you once did. We are beginning to learn about persistently chronic problems as we listen to survivors; most commonly fatigue. They don't have the energy they used to have, and want to know when it will be come back.

Lymphedema is a common problem for breast cancer survivors and survivors of other kinds of dissections of the lymph node system. They endure cognitive problems where they cannot

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remember anything. This is called chemo brain or chemo fog, and many of our patients talk to us about how they cannot concentrate. Sexual dysfunction is another physical challenge that is very common but often goes unaddressed. If the medical team doesn't ask about a specific problem, the patient is reluctant to bring it up themselves so important issues can go unnoticed. The final category deals with depression, anxiety and fear of recurrence, which may lead to physiological manifestations and pain syndromes.

Miller We would like to remind you to e-mail your questions to yalecanceranswers@yale.edu or you can call 1888-234-4YCC. We are going to take a short break for a medical minute. Please stay tuned to learn more information about cancer survivorship with Dr. Julia Rowland from the National Cancer Institute.

Medical Minute

The American Cancer Society estimates that in 2007, there will be over 62,000 new cases of melanoma in this country, 2400 patients diagnosed annually right here in Connecticut alone. While melanoma accounts for only 4% of skin cancer cases, it causes the most skin cancer deaths. Early detection is the key. When detected early, melanoma is easily treated and highly curable. However, patients with advanced melanoma now have more hope than ever before. Each day patients are surviving the disease due to increased access to advanced therapies and specialized care. New treatment options and surgical techniques are giving melanoma survivors more hope than they ever had before. Clinical trials are currently underway at Yale Cancer Center, Connecticut's only federally designated comprehensive cancer center to test the innovative new treatments for melanoma. Patients 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, on the web at yalecancercenter.org.

Miller Julia, what does your office of cancer survivorship do?

Rowland I'm so glad you asked that. It is very important for everybody who is listening today to know about this office because this is their public entity. It is an office that was established within the National Cancer Institute in 1996 in specific recognition of the growing population of survivors, who at that time were poorly understood. The office was designed in direct response to articulate and compelling advocacy from survivors who were saying that yes, it is wonderful that we have all of these medical advances that allow people to live longer with cancer, but we also need to deal with the lives of those individuals once treatment is over. The office's main mission is to enhance the quality of life of individuals, and also educate the scientific communities about their role.

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- Miller What resources are available through your office to the public? How will they learn more about survivorship?
- Rowland We have a website that individuals can visit, www.survivorship.cancer.gov. Here people can learn about what we are funding, the kind of research we have and resources available to patients and family members. In collaboration with our educational partners at the National Cancer Institute, we have put out a publication series called Facing Forward. These are wonderful booklets that talk about the issues that individuals face as they are finishing cancer treatment and resuming their normal lives. One booklet deals with life after cancer treatment and is available in English and in Spanish. We have another that is specifically for caregivers when their loved one is finishing treatment. A third book is designed to help people who have been through this experience and want to get involved on another level of their cancer experience. Many survivors have told us that they want to help others and reach out to those who may be struggling.
- Chu How did you get involved in this field of cancer survivorship?
- Rowland That is an interesting question and kind of a funny journey. In some ways I have been in the cancer arena since early on. I started out in a field called cytology and was interested in cellular biology and trained in cytotechnology. Simply, I am trained in doing Pap smears, among other things, and looking at the cellular diagnosis of cancer. As I worked in cytology, I realized that I was much more interested in people and decided to go back to school and do graduate work in psychology. I was doing some of my doctorate work at Columbia University and took a course taught by a visiting faculty member from Harvard, who was very interested in what we call psychosomatic disorders; workers stress and its impact on an individual's health. I fell into literature from the 1950s and 1960s looking for a type C, or cancer personality. I will tell you right away that there is no such thing as a cancer personality. It is a very egalitarian disease, I am sorry to say. We are all potential candidates for developing cancer so there isn't a particular risk profile in that regard. However, that course lead me to work being done by a woman in New York City named Jimmy Holland. She was really the pioneer of what we now call psycho-oncology or psychosocial oncology. I ended up doing research work with her, and that was really the beginning of my career.
- Chu And as we talked about in the last segment, much of cancer survivorship really does deal with psychosocial, emotional, cognitive, and existential issues.
- Rowland I would say that is true. It is not that we aren't attentive to those long-term medical or physiologic sequelae. We are an integrated system, if you have a physiologic problem, it is going to have an emotional, cognitive and social impact; even vice versa. For example, if you are depressed, it has physiologic ramifications and we have to be dealing with both of these. Sometimes it is easier to access and change things on the psychosocial level than it is on the physical. Yet we could

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probably affect change on the physical level by doing things on the behavioral. It is an interesting area in that we are functioning in right now.

Miller In terms of mind and body connections in survivorship, what is research telling us?

Rowland This is a growing area of interest; looking at the mind body connection. Taking depression as an example, if you are depressed, what is the impact of that on your survival? There is certainly data to suggest that if you are hopeless and helpless and giving up, that is a risk factor for having a poor disease outcome. We are concerned about how we should intervene. It becomes a biologic question; if you alter the depression, what are you altering biochemically for that individual? Sometimes our own behavioral changes, the way we help people think about their illness, may help. We can help them realize that yes, this is a challenge, but it is one you can overcome. There is help to be had. Thinking about the things that might benefit them in recovery, can help patients get through this challenging situation.

Chu Going back to some of the overall missions of your office, does the National Cancer Institute have special expectations for the designated comprehensive cancer centers? I am proud to say that the Yale Cancer Center was just recently re-approved for a five-year term as a National Cancer Institute Designated Comprehensive Cancer Center.

Rowland Yale has been a designated comprehensive cancer center for 33 years; a remarkable record. It is an important resource for the larger Connecticut population and the cancer institute is very committed to this area. The fact that there is an office of cancer survivorship here that just celebrated its decennial says something right away. Remarkable progress has been made in our capacity to grow the science in this arena. Through the National Cancer Institutes leadership, there has been an emphasis put on the incorporation of the comprehensive centers and what we call the cancer control arena. We are now looking to the comprehensive centers to take on this area of research and care as one that they need to own and champion. Very recently, in fact, the cancer center directors from across the United States put together a report detailing what they were doing in regards to survivorship. It is quite a remarkable document that lists all the different services, programs and research that they are now pursuing to address cancer survivorship.

Miller Overall, what types of services are being provided throughout the United States?

Rowland That is a good question Ken. The emphasis is now on developing programs for individuals that are making that transition into post treatment. There are a new set of initiatives, which are in part supported by the Lance Armstrong Foundation, which has been very instrumental in bringing attention to this area of need and care. There are now a growing number of comprehensive cancer centers that have survivorship programs; programs that are designed like the one you are leading

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Ken. They are designed to help individuals map out the course of their health and their well being after the active treatment period. These are fairly new activities, at least in the adult arena. In the pediatric arena, we actually have seen much more activity because pediatric cancer survivors have really been in the vanguard of our understanding of long-term survivorship issues. Some of the most dramatic successes we have had in curing cancer have come from these younger survivors.

Chu I am proud to say that we here at Yale Cancer Center are very committed to the entire issue of cancer survivorship. For those of you who are not aware my co-host, Dr. Ken Miller, is in fact the Director of Connecticut Challenge Survivorship Clinic here at Yale. Ken, can you tell our listeners out there a little about what this survivorship clinic is all about and also let people know what the Connecticut Challenge represents.

Miller Sure it's my pleasure. We started the program approximately 6 months ago to offer cancer survivors an opportunity to, in a sense, process the experience and start moving on to the next phase of survivorship beyond active treatment. There are certain needs that people have when they are first diagnosed and when they are being treated, but were really want to meet their needs afterwards. Cancer survivors come and meet with a nurse practitioner who talks about wellness and screening and being healthy; they see a nutritionist who talks about a healthy diet and healthy lifestyles; they meet with a physical therapist who talks about exercise and fitness and how that may possibly have an impact on doing well in the future and they also see a social worker to give them a chance to process the experience. It is a wonderful opportunity that is available to patients who are treated at Yale and people anywhere in the community.

Chu This clinic should be viewed as a resource. Not only patients treated here at Yale can go, but any patient in the state of Connecticut and perhaps local regional areas as well.

Miller Absolutely. In a sense we are part of those programs throughout the United States trying to learn the best way to provide this care and hopefully send out a positive message of hope to cancer survivors.

Chu For those listening out there, how can they access some of the resources available?

Miller They can call 203-785-CARE or visit Yale Cancer Center website, www.yalecancercenter.org. More globally, Julia you can tell us.

Rowland If individuals are interested in pursuing more information about the office of cancer survivorship, they can go to the website www.survivorship.cancer.gov. If they want more information on the vast educational materials that are available through the National Cancer Institute, they can pursue this by going online to <http://www.cancer.gov/> or calling the helpline, that is manned by the

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National Cancer Institute, at 1800-4-CANCER.

Barber Thank you Dr. Rowland and of course, thank you Dr. Ed Chu and Dr. Ken Miller. If you have questions for Dr. Rowland, Dr. Chu or Dr. Miller, we encourage you to go to www.yalecancercenter.org. You can listen to past editions of Yale Cancer Center Answers in audio and written formats here as well.