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## Healthline with Yale Cancer Center

*Hosts*

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WTIC Newstalk 1080

**The HERO'S Clinic for  
Survivors of Childhood Cancer**

**Guest Expert:**

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*Healthline with Yale Cancer Center is a weekly broadcast on WTIC Newstalk 1080  
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*This is Healthline, a joint venture of WTIC NewsTalk 1080 and Yale Cancer Center. Yale Cancer Center is a resource for cancer programs throughout Connecticut, developing new advances in prevention, screening, diagnosis, and treatment. On Healthline, you will hear from some of the leading doctors in the country. Healthline is not intended to provide medical advice. Yale Cancer Center urges you to consult with a qualified physician in your community for diagnosis and for answers to your medical questions. And now, our co-hosts, oncologists, Ken Miller and Ed Chu.*

- Miller Good morning and welcome to Healthline. My name is Dr. Ken Miler, and I am the Director the Survivorship Program at the Yale Cancer Center in New Haven. I am here in the WTIC studios with my colleague and co-host, Dr. Ed Chu, who is the Chief Adult Oncologist at the Yale Cancer Center. Good morning Ed.
- Chu Good morning Ken. Healthline, with the Yale Cancer Center, is our way of providing you with the most up-to-date information on cancer care every Sunday morning at 8:30 a.m. Healthline features some of the nation's leading oncologists and cancer specialists who are in the forefront of the battle to fight cancer right here in Connecticut.
- Miller Each week, Ed and I are joined by a different expert from the Yale Cancer Center. Our goal is to give you help by sharing the latest information about cancer and its treatment, and we also want to give you hope. If you would like to submit a question about cancer to Healthline, please e-mail us at [healthline@yale.edu](mailto:healthline@yale.edu) or call 1-888-234-4YCC. We will answer your questions on the air today, or in a future broadcast. If you are interested in listening to past editions of Healthline, or if you would like to learn more about a specific kind of cancer, all of our shows are posted in audio and written formats on the Yale Cancer Center website which is [www.yalecancercenter.org](http://www.yalecancercenter.org). Today, we are joined by Dr. Nina Kadan-Lottick, Assistant Professor of Pediatric Oncology at the Yale School of Medicine, and director of the HERO'S Clinic for Survivors of Childhood Cancers here at the Yale Cancer Center. Dr. Kadan-Lottick is nationally known for her research into the side-effects and risks affecting pediatric cancer survivors. Nina, thank you so much for being with us today on Healthline.
- Chu Nina, let us begin by talking a little bit about cancer survivorship. I am interested in what your definition of a cancer survivor is.
- Kadan-Lottick The Institute of Medicine would define a cancer survivor as any individual diagnosed with cancer from the point of diagnosis forward. When we generally think of cancer survivorship, we think of studying ways to decrease the physical and emotional effects of the cancer experience on the patient. We could extend the cancer survivor to those who care for patients with cancer; to the family members and friends that are also affected by the cancer diagnosis.

- Chu As we have discussed on previous shows with folks like Jeff Keith, founder of the Connecticut Challenge, there is a much broader definition of a cancer survivor. It is not as limited to just those who have physically survived the disease.
- Kadan-Lottick Especially since our research has shown that there are things we can do during the cancer treatment period as well as after the cancer treatment period to optimize wellness in someone who has had a history of cancer. Our definition is broadened both in the time period that we call a patient a cancer survivor, and also who we include in that experience.
- Miller So from that point of view, the survivorship field includes a patient's treatment as well as trying to locate ways through research to minimize side-effects. Tell us what happens after the initial phase of treatment? How is the survivorship program important for children who have been through a cancer experience?
- Kadan-Lottick It is very important because there are measures that can be taken to prevent or minimize the effects of the cancer or treatment. An example of this is that a child who has had radiation to the brain is at risk for growth problems. So, even immediately upon completion of therapy, it is good to monitor for growth hormone problems, because we can replace growth hormones and keep the normal rate of growth going before it is too late. If one waits too long, that window of opportunity is missed. Being aware of these issues during therapy will make the patient more ready to act quickly.
- Chu Nina, do you see any difference in pediatric patients who go through their treatments and survive as opposed to the types of patients that Ken and I see in adult clinics who survive their respective cancers?
- Kadan-Lottick I have found that older patients, in adolescence and adulthood, experience more psychosocial and emotional stress, and more trauma from the experience. I find the younger children, maybe because of their developmental stage or because they are sheltered by their family, do not develop as much depression, anxiety or posttraumatic stress. The definition of a survivor that includes the whole family is particularly appropriate for a child, because the whole family goes through that experience in a very direct way; especially the siblings and parents.
- Chu Are the majority of young adults and adolescents getting beyond this experience and leading happy and healthy lives, or are they left with major disabilities and depression?
- Kadan-Lottick The vast majority, I am glad you brought this up because mostly it is good news, are doing quite well. It is a wellness model of care; not a disaster model of care. Survivorship care is a strategy to keep people well and let them enjoy all that they have fought so much for in overcoming cancer. In terms of emotional issues, about 17% of adolescent cancer survivors develop major depression or

anxiety compared to about 10% in a general population. It has increased but still the majority of people are doing quite well.

Miller We would like to remind you to e-mail your questions to us at [healthline@yale.edu](mailto:healthline@yale.edu). We are going to take a short break for a medical minute. Please stay tuned to learn more information about pediatric cancer survivorship with Dr. Nina Kadan-Lottick.

#### *Medical Minute*

*This is a medical minute brought to you as a public service by the Yale Cancer Center. Breast cancer is the second most common cancer in women. In Connecticut alone, approximately 3000 women will be diagnosed with breast cancer this year, but there is a new hope for these women. Earlier detection, noninvasive treatments, and novel therapies provide more options for patients to fight breast cancer. In 2006, more women are learning to live with this disease than ever before. Women should schedule an annual mammogram beginning at age 40 or earlier if they have risk factors associated with the disease. With screening, early detection, and a healthy lifestyle, breast cancer can be defeated. Clinical trials are currently underway at federally designated comprehensive cancer centers such as the Yale Cancer Center to make innovative new treatments, which have not yet been approved by the Food and Drug Administration, available to patients. For more information, visit their website at [yalecancercenter.org](http://yalecancercenter.org)*

Miller Welcome back to Healthline, this is Dr. Ken Miller. I am here with my co-host, Dr. Ed Chu, and our guest, Dr. Nina Kadan-Lottick, the director of the HERO'S Clinic at the Yale Cancer Center. I would like to ask how you decided on the name, HERO'S Clinic. It is such a great name.

Kadan-Lottick I first liked the name HERO'S because that is very much how I think of my patients and their family members so I made it work. It stands for Health, Education, Research Outcomes in Survivors, which is also very appropriate.

Chu We talked about how the large majority of pediatric patients have a very positive outcome and are cured from their cancer, but then the focus shifts towards the critical issue of quality of life and how those pediatric patients are going to live the rest of their lives.

Kadan-Lottick That is true. In fact, I have a patient in my clinic who is a Hodgkin's survivor, who was treated as an adolescent, and now has two granddaughters. We look far ahead into their lives.

Chu That is terrific. When I was in training at the NCI, Hodgkin's and non-Hodgkin's lymphoma were the two types of cancers that had positive results, and it was a very special event when our female patients would come in saying that they gave birth to children. There was actually a wall of their kids. Tell us a little bit about the HEROS Clinic, what goes on there, where is it located, and how can people access the HEROS Clinic?

Kadan-Lottick The clinic is at Yale-New Haven Hospital on the second floor of the West Pavilion. We see individuals who were diagnosed at an age younger than 21 years, and who are at least 3 years from diagnosis, because we would like to distinguish the issues of survivorship from those of toxicity or side-effects of the treatment and the decisions of what treatment they should be getting. You can make an appointment by calling (203) 785-4640. When you call for an appointment, you will be asked where you were treated so that we can send a medical release and get your medical records to review. We calculate all of the drug doses and radiation you received and put it in a summary form for you so that when we see you at the clinic, we are ready to give you individualized advice about what you need for good care.

Chu So if the family of a child who is a survivor of cancer comes and sees you, what is the visit like? How much time do they spend with you and when they leave, what information do they have and how do you decide when to follow-up?

Kadan-Lottick A typical visit lasts a couple of hours. The doctor's visit is about an hour, and then some time is spent with our nurse getting educational material and having blood drawn. You also may get x-rays or other tests that you need done. A screening history is performed with our psychologist who screens for learning problems, thinking processing problems, and problems with sadness or anxiety. That is a brief interview but is very helpful because those are often silent conditions in survivors but very important for quality of life.

Miller Tell us a little bit about what we call the end of treatment summary. How is that useful for patients?

Kadan-Lottick Well, the current recommendation among oncologists is that every individual completing therapy should receive a treatment summary, but that is an idea that is new and expanding. In our HEROS Clinic, what we do is get the medical records for each patient and create a written record of all the drugs and other therapies they received and the exact amounts. They can carry that with them like a medical passport so that even if they change doctors, they can have all their information in one place. This is very important to do in the future for everyone coming off therapy. We are doing research here at Yale to see if there is a way we can use electronic methods to help patients access that information even if they lose their form many years later.

Chu Once a patient has come to you for an initial consultation, what is the follow-up like? How frequently might you see that individual?

Kadan-Lottick For high-risk patients, or patients whose treatment exposures mean that they are at a higher risk for having problems later on, they visit yearly. We work in cooperation with their primary care doctor and primary oncologist. We want them to maintain their medical home and have those close connections with their doctors, so we partner with their doctors and share information for recommendations on the tests and evaluations that need to be done to keep them healthy, and we

are available as a resource. Some of our patients see us once because they live far away, and some come back yearly. It depends on their medical needs, and it depends on what is available locally for them. Our goal is to get them the bulk of that care after their visit with their primary care doctor with updates from us if any recommendations change.

Chu Are there any other clinics that are similar to the HEROS Clinic here in the state of Connecticut, and do they have similar types of clinics and cancer centers around the country?

Kadan-Lottick When I started this clinic 4 years ago it was the first clinic in the State of Connecticut, and it remains the only clinic in the State of Connecticut. We are fortunate that HEROS Clinic is now partnered with the Connecticut Challenge Survivorship Clinic at Yale Cancer Center in meeting the needs of cancer survivors in Connecticut across the entire age spectrum. There are other programs in the country. We were one of the first to establish one 4 years ago, and were ahead of the times. Now, according to the NIH, and the general consensus among the oncologists in the country, every center for treating cancer patients should have a program such as this. It is very difficult to have that expertise in every location, so we are committed to building a center of excellence here, both in clinical care and research, so that we can be a regional resource for primary oncologists. They can send their patients here on a consult basis, and then, they resume their care with the very specialized advice we give them.

Chu The Yale Cancer Center is very-very excited to have you and Ken partner together and have pediatric and adult medical oncology survivors being part of the same experience. A lot of this would not be possible without the amazing efforts of Jeff Keith and his colleagues at the Connecticut Challenge. They have really done an amazing job within the last couple of years raising very important funds that have gone to help support your efforts.

Kadan-Lottick Absolutely, Jeff Keith is a man with a vision and is also way ahead of his time. He has created opportunities for Yale to build both clinical and research programs that will help generations of Connecticut survivors.

Miller Personally, what is that experience like for you as a clinician seeing young children who have moved beyond the cancer experience?

Kadan-Lottick Well, frankly, I was attracted to this field because it is very uplifting and hopeful, and while I find great joy in taking care of patients who are just diagnosed, it really is an uplifting experience and important for me to see these individuals thrive and live productive lives and come back with their children and husbands and wives.

Miller That is wonderful. We would like remind you to e-mail your questions to us [healthline@yale.edu](mailto:healthline@yale.edu). We are going to take a short break to listen to a survivor's story, which is very appropriate for this

discussion, Please stay tuned to learn more about pediatric cancer survivorship with Dr. Nina Kadan-Lottick.

### *Survivor Story*

*A few years ago, the diagnosis of cancer was a death sentence for many patients, but today, thanks to advances in clinical research, we are turning the corner in the battle against cancer. There are over 10 million cancer survivors now living in the US. They are the true heroes in the war against cancer. Here is the story of a hero from Fairfield*

*I visited a walk-in clinic on Christmas Eve in 1999, because I thought I had the flu. The doctor there suspected that it was something more serious, and thus, he examined my belly, and he found a mass. I was referred to Dr. Tom Rutherford, a gynecologic oncologist and researcher at Yale Cancer Center, where I had surgery and received chemotherapy for stage II ovarian cancer. Because of early detection, excellent treatment, and the benefit of the latest research, I recently celebrated 6 years as a cancer survivor. Today, I am a fervent believer that women should pay attention to changes in their bodies and should not be reluctant to tell their physicians any concerns they have, even those they feel might sound trivial. Early detection is the best way to cure cancer.*

*This survivor's story has been brought to you by Yale Cancer Center.*

Miller Welcome back to Healthline. This is Dr. Ken Miller, and I am here with Dr. Ed Chu and our guest, Dr. Nina Kadan-Lottick, who is the director of the HERO'S Clinic at the Yale Cancer Center. Nina, you are actively involved in research. You just had the honor of being published in the New England Journal of Medicine, which is very exciting. Congratulations! Talking about some of the chronic health problems found in childhood cancer survivors, can you tell us a little bit about your findings?

Kadan-Lottick That study was an eye-opener for us. We studied 10,000 childhood cancer survivors to see what their rate was of developing serious medical conditions later in life, and we are very surprised to realize that two-thirds of survivors will have at least one serious medical condition, and that these survivors are four times as likely as their siblings of developing serious medical conditions. This study was the first in a large population to quantify what the experience for survivors is like 10 to 25 years after diagnosis as a child. It really reiterated that programs like our Connecticut Challenge Survivorship Clinic and HERO'S Clinic need to take care of our survivors and need to do research that prevent problems and make problems that do occur better.

Chu What were some of the medical consequences that you found to be increased in the pediatric survivor population?

Kadan-Lottick We found problems from developing new cancers in a different location to heart failure, lung scarring, need for organ transplant later in life, depression, the need for having an assisted living condition at a younger age, osteoporosis, and infertility. Those are some of the examples.

Chu It is important to emphasize to the listeners out there that a lot of medical consequences are related to the types of specific treatments that the patient received.

Kadan-Lottick Thank you for pointing that out. The numbers I just quoted are for the whole group, but that is the other reason why we need a specialized center such as ours because each survivor has very unique needs. One person may be at risk for heart failure, and another person just needs to focus on a healthy life like other people, without any increased need for these tests, but that in itself is reassuring. Every cancer survivor thinks they are at risk for everything until they know; until they have the chance to get an individualized evaluation. In many ways, patients who come to our clinic feel reassured afterwards, because they know exactly what they should be thinking about, what symptoms in themselves they should watch for, and what things they don't have to worry about.

Miller In terms of developing another cancer, that is out of our control. It is something that just develops; we don't know the cause for it. In a sense, the things that you are developing allows patients and doctors to bring these things back into control, to understand them, and try to work with these problems and make them as minimal as possible.

Kadan-Lottick Exactly, it is an empowering experience rather than an illness model. It is that you are well and have to stay well.

Chu Which is very, very important and an uplifting message to our listeners. Nina, what is the childhood cancer survivor study?

Kadan-Lottick That is the study that was used in the New England journal article. This is a cohort of approximately 12,000 childhood cancer survivors who are being followed forward in time every two years. This study is particularly helpful because there is an over 70% participation rate, so we feel like this group is fairly representative of this survivorship experience. We have been following them for a little over 10 years, and they will be continued to be followed into the future.

Chu That is terrific.

Kadan-Lottick I am an investigator in that accord as are other individuals here at Yale.

Miller Tell us a little bit about your research; what are the things that you are looking into that you are excited about?

Kadan-Lottick I am very interested in studying the effects of chemotherapy on the brain and on memory and concentration and executive function, or the ability to organize ones thoughts. I am struck by the fact that for both adults and for children, there can be subtle problems that if you are not aware of, can keep individuals from meeting their full potential. We have realized that adult survivors of childhood cancer are more likely to live with their parents as adults. They are 3 times more likely not to complete high school, and they are more likely to be underemployed. Understanding how chemotherapy can affect the brain can invite preventive measures, like perhaps using protectants for the brain at the time of therapy or later on; trying to develop strategies that could help restore function.

Chu It is interesting, certainly in the adult world, these kinds of effects that we call chemo-brain. It clearly spans the pediatric and adult world.

Kadan-Lottick I have studied it extensively in leukemia, and realized, about 3 years ago, that there was emerging literature for women with breast cancer in the same area. I think it is very important in childhood cancer, and breast cancer and other cancers, because they have high survival rates. We expect these individuals to live a long life, and we want them to be productive and important contributors to society, to their family, and for themselves.

Miller Are there any positive side-effects of the cancer experience?

Kadan-Lottick You know, there are. The, “That which will not kill you, will make you stronger” approach. It is called posttraumatic growth. It is this idea that you would never choose something so hard as a cancer diagnosis or this trauma, but having gone through it you are stronger. Studies have shown over and over again that about one-third of patients will actually report a higher quality of life than a non-cancer population. There is the idea that this enhanced life shows what is truly important. We wouldn’t choose it for anyone, but many of our most amazing people in society, like Jeff Keith, are those who have overcome cancer.

Miller If you have questions for Dr. Nina Kadan-Lottick, or for Healthline, I encourage you to go to our website, [yalecancercenter.org](http://yalecancercenter.org) for more information on cancer and the resources available to you. Nina, I want to thank you for joining us on Healthline.

Chu Nina, thanks again, it has been terrific having you and we look forward to hearing more in the future. Remember, tune in to WTIC NewsTalk 1080 every Sunday morning at 8:30 a.m. for Healthline with the Yale Cancer Center. Our next program will feature a discussion of disparities in breast cancer treatment with Dr. Lyndsay Harris and Dr. Shon Black. Until then, this is Dr. Ed Chu and Dr. Ken Miller, from the Yale Cancer Center, wishing you a safe and healthy week.