

Yale CANCER CENTER *answers*

WNPR Connecticut Public Radio



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Survivors Perspective/House of Heros

Guest:

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Yale Cancer Center Answers is a weekly broadcast on **WNPR** Connecticut Public Radio Sunday Evenings at 6:00PM

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Welcome to Yale Cancer Center Answers with your hosts doctors Anees Chagpar, Susan Higgins and Steven Gore. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital. Dr. Higgins is Professor of Therapeutic Radiology and of Obstetrics, Gynecology and Reproductive Sciences and Dr. Gore is Director of Hematological Malignancies at Smilow and an expert on myelodysplastic syndromes. Yale Cancer Center Answers features weekly conversations about the research, diagnosis and treatment of cancer and if you would like to join in, you can e-mail your questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week it is a survivor story from Bill May and here is Dr. Steven Gore.

- Gore Tell us a little bit about your cancer story.
- May Well my story started in 2014 and I had an abdominal pain that I had ignored for about 3 months and when I finally went in, they discovered that it was a cancer of the cecum.
- Gore Wow and that is part of the colon?
- May Right and we proceeded with right hemicolectomy in December 2014. From there it was determined that it had metastasized to the liver and abdominal cavity and for the last 14-15 months, I have been undergoing chemotherapy in various forms.
- Gore Tell us about that diagnosis, it must have really been a shocker I would think?
- May It hit me pretty hard and in retrospect, I had a family history of things going wrong in colonoscopies and it kind of dissuaded me from getting my colonoscopy.
- Gore You mean people had bad experiences with colonoscopy?
- May Yes, I had several family members that had tears during the procedure.
- Gore Really?
- May And it really frightened me going in and getting things done and in retrospect that was a bad decision on my part and so when I did finally have the colonoscopy, the cancer was discovered.
- Gore Was there a family history of colon cancer?
- May No, not all.

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Gore How old were you when this happened?

May I was 56 when diagnosed.

Gore Very young.

May Yes.

Gore That is a little bit of kick yourself moment.

May Yeah, it really opened my eyes as to, we are all here on a limited basis and so what I have been doing is my best to try and make a difference in the world by giving back to others, selfless service and quite frankly, it might have been the best year of my life, this last year.

Gore I am definitely going to want to hear and talk to you more about your service work but just back to your story, how are things going with the chemotherapies and how are you feeling?

May The initial treatment was with FOLFOX therapy for six months.

Gore That is a multiple agent chemotherapy regimen, for our audience.

May It was a little caustic to me and I came off that and it was successful in reducing the tumor size. Then, I went on to Xeloda, the maintenance drug.

Gore That is an oral chemotherapy drug right?

May Yes and that was about a four month course of treatment. There was some minor growth associated with that treatment and I moved to FOLFIRI.

Gore Another multi-agent chemotherapy regimen?

May Right and that had some mixed results, both tumor growth and tumor reduction and now I am back to the FOLFOX regimen for the last month.

Gore You look fantastic. How are you feeling?

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- May I am feeling good. I get up every day, and thank God that I am still able to get up and do what I do best and I get inspired by my work and hope to inspire others to go out and help each other.
- Gore Tell us about your work.
- May I was a career Army officer, I was a Black Hawk helicopter pilot for 24 years. I served proudly both in the active Army and the National Guard. I took a brief 12-year stint as a brand strategist here in Connecticut and then really when I was diagnosed, I decided to go full time with a charity that I had started here in Connecticut in 2012 and that is called House of Heroes. Our mission is to recognize and honor service military and public safety veterans and their spouses for their sacrificial service to our country, so over the last 4 years in Connecticut, we have helped 61 veterans with more than \$500,000 worth of no cost home improvement and I have done that with organizing teams of volunteers, over 500 volunteers, over 100 contractors and the generosity of many great companies and businesses here in the State of Connecticut. On a national basis, we have helped over 900 veterans in 20 different states, so I am extremely proud of our work with House of Heroes.
- Gore So it is a little bit like habitat for humanity for veterans?
- May Yes, it is a little bit different though. It is one-day home improvements, we call it making a difference in a day, so we identify veterans that own their home, have a physical or financial need and are honorably discharged. We put together a team of 20-30 people, 5-10 contractors, mechanics that are licensed to do code work for electrical, plumbing and such and we hit their house in one 8-hour day and we transform veterans lives and about one-third of the recipients have been surviving spouses, so there are quite a few 90-year-old World War II surviving spouses out there that need a little help and it has been the most rewarding work.
- Gore Can you give us some examples of the kind of scope of work they can get done in a day, are you redoing kitchens, are you fixing the electricity or air-conditioning?
- May We have done a great amount of projects. We have built decks, we have painted houses, we have renewed electrical systems, and we have redone plumbing. Actually, in the town of Westbrook, we encountered a veteran that had lived for 8 years without water and heat. In the course of a several months project and in conjunction with many different organizations, we were able to restore this Vietnam veteran to a livable household with heat and water and she is now doing great. We have helped many different veterans, a 95-year-old World War II veteran that was a bomb disposal expert. He had some great stories.

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Gore Were they not called sappers or something like that, something with an S?

May Sappers I think were the engineers.

Gore Gotcha.

May He spent over 300 days wandering Europe disabling bombs and landmines. He actually told me the story where the bomb sometimes landed inverted where the fuses were down. He had to get into the field to disarm it.

Gore Wow.

May He would dig a hole under the bomb, he would sand his fingertips, he would then feel for the serial number to determine that the 6-digit was a 4 and if it was, then the bomb was booby trapped, so I am looking at him and I am like, that sounds very dangerous.

Gore No joke right.

May He looks at me and says, we lost a lot of men.

Gore Yeah, I've heard about that.

May I mean these World War II veterans, Korean War veterans, these people have paid the ultimate sacrifice for our country and we are just so proud to be out and honoring them and their surviving spouses. The 9/11, post 9/11 veterans, have a tough road to climb here getting back and integrating back into society, a lot of them are plagued with PTSD, so we have helped a number of veterans get their house, restore their house to safety, and an accessible condition and help them deal, and take the load off their mind to help them heal in a quicker manner.

Gore And how do you become aware of the veterans in need or their spouses, do they apply for help or is it through word of mouth?

May A lot of our references come from veterans' organizations, VFWs, American Legions, DAVs. We have a small percentage now being referred to us via the VA Healthcare System, so as we are expanding in the state, we are getting more well known for our work and people are actually stepping up to refer veterans which is great because veterans can be standoffish regarding help; they think they

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can do it on their own and the fact of the matter as in my case, we are all going to need a leg up somewhere down the road and so it is really great to be involved with that. It energizes me. It gives me the strength to carry on and really not just survive when I am going through cancer but to thrive.

Gore You mentioned that some of the help has been national and not in Connecticut. Is your organization one that was started in Connecticut and it spread, or are you a branch of a National Organization?

May The National Organization was started outside the gates of Fort Benning, Georgia, in Columbus, Georgia in the year 2000. It started out small. The original intent of the Congressional Delegation of Georgia was to have a chapter in each congressional district in the United States, so we have 5 Chapters and 400 more to go, but I am also the National Chairman of the organization and my goal is really to now build an easy button for veteran service, so I am envisioning an online system that could enable people to honor veterans in any community across the country, any time by simply coming on to our website, following our processes and procedures and hopefully we can be helping 1000s of veterans across the country in the next couple of years.

Gore I am sure that many of our listeners would be interested in learning how to hopefully donate, if you accept donations on the web or by paper and they may know of veterans who could need some help, so how do people get ahold of your organization?

May Our website is the place where we can accept the recommendations for veterans, you can sponsor a veteran there, you can donate and you can volunteer. Our website is hohct.org.

Gore Hoh is for House of Heroes and CT for Connecticut, hohct.org.

May Yes.

Gore That is great, hopefully we have something on our website where they may be able to be connected as well, but hohct.org, so you were involved with this before your diagnosis it sounds like, is that right with the House of Heroes, you were doing this work before you developed cancer?

May Yes, I started this with my partner, Steve Cavanaugh, in the year 2012 here in the State, so we have been active for 4-1/2 years at this point.

Gore And it sounds like somehow your diagnosis has energized your focus on the work.

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May Yes, actually I decided to give up my branding career and to come full time with House of Heroes in an effort really to drive it to a larger organization and a nationwide organization and to help as many people as we can, so it is my mission in life at this point.

Gore Why do you think, if you have insight into this, how did the impact or how did the diagnosis of cancer impact on these life choices, was this kind of an existential moment for you about really understanding that regardless of the outcome of therapy, all of us have limited time and how you want to spend your time or what was the process like for you or did it just make sense somehow?

May To me it just made sense if I had limited time to really figure out how I could help as many people as I can along the way. I get inspired by many things, many people, I have been lucky to be mentored by some Generals and Officers, Vietnam veterans in my life that really have grounded me in the meaning of selfless service. I drew some inspiration just last week from a former Navy Seal commander, his name is Jocko Willink and he had a podcast called GOOD and he has an interesting philosophy in life and he says that when he was a seal commander people used to bring him their problems, both personal and professional and when they would tell him the problems, he would look at them and say, 'Good' and that was really the basis of my leadership style in the Army as well where you have a problem in your life, you just say the word 'Good' and why is it good, I did not get promoted, well, good you have the opportunity to get better, so the whole idea of having a mindset that no matter what problems you have in your life you just say the word good, even if you can only mutter it, it means you still have some breath left and if you have breath left, you have some fight left in you and you get up every day, you dust yourself off, you reload, you recalculate, you recalibrate, you reengage and you go on the attack and in my case get strength to go out and help as many people as I can.

Gore We are going to want to pick this up after the break, but right now we are going to take a short break for a medical minute.

*Medical
Minute*

This year over 200,000 Americans will be diagnosed with lung cancer. More than 85% of lung cancer diagnoses are related to smoking and quitting even after decades of use can significantly reduce your risk of developing lung cancer. Clinical trials are currently underway at federally designated comprehensive cancer center such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for lung cancer. Advances are being made by utilizing targeted therapies and immunotherapies. The BATTLE-2 trial at Yale aims to learn if a drug or a combination of drugs based on personal biomarkers can help to control non-small cell lung

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- Gore Welcome back to Yale Cancer Center Answers. This is Dr. Steven Gore and I am talking tonight with my guest, Bill May, about his experience with cancer and about his important work in the House of Heroes of Connecticut charitable organization which provides help in rehabilitating housing problems for veterans and spousal survivors of veterans. Bill, you were telling me before the break about this inspirational mentor or person whom you have met recently or who was your mentor who told you about this 'Good' approach.
- May It was just a little podcast.
- Gore It was a podcast. Gotcha, so this was recently, this was not something you could do just going back to when you were diagnosed with cancer, do you think now with your new approach would you have been able to bring out that 'Good' right away?
- May My whole life has been about the idea of positive thinking and really influencing things for the better, so ever since the diagnosis, I truly have been keeping positive in just my style of life and it has worked for me so far, so we will continue to see what happens.
- Gore How long did it take you from the time when you learned you had cancer to get yourself into let's take care of this one step at a time forward moving motion?
- May A microsecond.
- Gore Really.
- May Yeah, I do not let things get me down. I view everything as an opportunity to excel, to have growth, to learn so I think I can beat this. I remain positive that I can beat this.
- Gore Aree one of those stoic veterans you were telling us about?
- May I am not sure it has to do with being a veteran but I think it does have to do with the warrior mentality of we will not be defeated, we will continue to drive on.

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- Gore I remember about 20 years or so ago, one of the actresses, I do not remember whom, had breast cancer and wrote a book or movie that was called *First You Cry*, I do not remember who that was, that was not your experience, you didn't have a moment of why me?
- May No I have not, through the 14 months of chemo, there have been ups and downs, the revelations that it is being reduced and then the revelation that it has grown and then the revelation that it is mixed, so while I was told at the beginning that there would be a different drug that can be used to help me and we have a lot of opportunity and the research is right down the road and in retrospect, 14 months later, I am down to one drug that has been able to help me and statistically, I have been told that 1 in 10 will survive past the 5-year point, and I hope to be one of those numbers, I hope to drive on and I am really encouraged by the research that is coming down the road. I have been encouraged by the medical marijuana program and the attributes of and the benefits of that here in the State of Connecticut and the research that has been done internationally and so I hope that we can get on with that in the United States and get medical cannabis reduced from a schedule one drug down to schedule two so we can get on with research to see that there has been centuries of work and benefits of medical marijuana, support of the American Medical Association, and it is time to get on with this research.
- Gore Have you been using medical marijuana?
- May Yes, I have participated in the medical marijuana program here in Connecticut and it is about 8600 participants so far.
- Gore And how do you feel that it helps you?
- May For me, it comes in many forms and once you get over the stigma of medical marijuana that has been developed in the United States since it has been moved to the schedule I in 1942, you understand that it can be of great help in pain relief, sedation, reducing anxiety, increasing appetite, all those are just some of the many benefits of what I have learned, I am big proponent and I hope to assist wherever I can in getting as many veterans involved in this program, especially in the use for PTSD in our young veterans.
- Gore Did you get support from your medical practitioners and oncologists in your use of medical marijuana, was there a push back? You can be honest.

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- May I think many of our hospitals are guided by conservative practices regarding medical marijuana at this point. I am in fact attempting to find an oncologist that can help me get involved in the trial of tumor regression using high THC and high CBD content oils. There has been research that shows that it has reduced cancer in-vivo, in mice, so there have been some encouraging studies in the reduction of breast cancer, so I look forward to participating in research that might shed light on whether this could help for colorectal cancer.
- Gore I am gathering from your answer that you did not find a lot of support in your practitioners particularly.
- May I have not found an oncologist that is willing to step up to do the study so far but I am just weeks into my journey at this point.
- Gore Are your oncologists aware that you use medical marijuana?
- May Yes.
- Gore And how has their approach been with that response?
- May It is really a hands-off approach at this point. There are very few doctors that I think are well acquainted with recent research and I think they are limited of course by the overall hospital and research facilities attitudes toward medical cannabis.
- Gore Right, I can tell you that at Yale-New Haven there is active engagement in having a more coherent policy or any policy because in some ways everybody was caught with their pants down a little bit, probably should not have been but there was a need for a coherent policy and they were evolving a policy that is better than the policies we have which was none but the problem is that currently, while we do not necessarily discourage appropriate use of medical marijuana, it cannot be used in the hospital, so for patients who have become really reliant upon that that is a challenge for us right now and I am sure that we are similar to many other well-meaning and excellent institutions that just have not really figured this out yet, so we really need people like you to teach us the benefits, obviously a little rough topic today but I think it is important to talk about.
- May Thank you, I am speaking with the Commissioner of Consumer Protection that runs the medical marijuana program here in our State and their view is that medical marijuana research could be the next big economic boom for the State of Connecticut.

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Gore Converting the tobacco fields.

May Not the growing of it necessarily.

Gore I am teasing.

May But the research to accomplish that.

Gore Sure.

May I think that is the next great opportunity for us all to really step up, reenergize, research here in Connecticut and perhaps become Nation and World leaders in understanding the value of this plant for medical purposes.

Gore In your work in House of Heroes, do you run into many veterans or spouses who have cancer or is that not something that really comes up?

May Everybody has their own story and I am actually absolutely amazed by the numbers that cancer is affecting people, so when I tell my story, I do not tell it to gain sympathy, I tell it to instill a sense of urgency in people to recognize that we all have limited time here, some of us have accelerated schedules, but get out there and help one another, just reach out and help your neighbor and if we go out and reach out and help the person standing next to us, you will be amazed at what you get back. In the 14 months that I have dedicated myself to doing this, I have gotten 10 times what I am trying to give. I cannot give more because people keep on giving back to me and it has just been an amazing year of my life, so I would encourage everybody to get out there and help each other.

Gore I am guessing you were kind of a giving person before your diagnosis as well. Am I incorrect there?

May You know, in retrospective, I was not really raised to give, our forefathers scrounged for everything they have and they were not necessarily the most giving people in the world but they certainly gave to me a lot of love and I am trying to use that as an example to love those outside your family and to bring in perfect strangers and to give them a hug every now and then and it has been working for me.

Gore So this has been a change for you really.

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May Yes, I believe so, but I have always been giving but now I cannot give enough.

Gore It is remarkable, I think a lot of times a big life change or an illness does help us, the positive side of us to assess where we are at, the meaning of life and quality of life and what is most important, I think it is maybe one of the messages that you eloquently gave just a minute ago, is for everybody, regardless of your health status and age to take stock of what is your life like and are you satisfied with the equation and is there enough giving?

May Right, and no matter what is happening in your life do not let it get you down, remain positive, reach out to others and life will take care of itself.

Gore How do you find balancing the sort of treatments and side effects and this very important work you are doing, is it hard to get your schedule done?

May Yes.

Gore Do you drag yourself out of bed sometimes?

May You know, the FOLFOX treatment had really kind of dragged me down for a couple of days, carrying around the pump for 46 hours after the infusion treatment is kind of mental wear and tear.

Gore Just knowing that it is there.

May Just knowing that you are attached to a machine really kind of plays with my mind every now and then and then the kind of general fatigue and nausea that might be associated with it for the following couple of days, so I am tasked with traveling around the country this year. We are executing House of Heroes projects in Illinois, Ohio, North Carolina, Texas and Louisiana. I want to do 20 projects here in Connecticut. I want to do 3 projects in Delaware, so we are going out around the country this year and trying to schedule the travel with the treatments every 2 weeks, it is a challenge but we are going to work it out. I have got a great team of people that help me, my family, my friends and we all share tasks and we just merely get it done and we get it done in an excellent manner.

Gore So it is important to have a support network as well.

May My family and friends are amazing and I cannot get enough of, he who dies with the most friends wins, so I am out there to make as many friends as I can.

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Bill May is a cancer survivor. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC and as an additional resource, archived programs are available in both audio and written form at yalecancercenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.