Survivor Perspective- Head and Neck Cancer

Guest Expert: Dell Yarbrough, MD
Professor of Surgery in Otolaryngology and of Pathology and Section Chief of Otolaryngology, Yale School of Medicine

Michael Mayes
Head and Neck Cancer Survivor

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

Listen live online at

OR

Listen to archived podcasts at
Welcome to Yale Cancer Center Answers with your hosts doctors Francine Foss and Anees Chagpar. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at Yale Cancer Center and is an internationally recognized clinician and clinical researcher. Dr. Chagpar is Associate Professor of Surgical Oncology and she is Director of the Breast Center at Smilow Cancer Hospital at Yale-New Haven. Yale Cancer Center Answers features weekly conversations about the most recent advances in the research diagnosis and treatment of cancer and if you would like to join the conversation, you can submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about head and neck cancer with Dr. Wendell Yarbrough and Michael Mayes. Dr. Yarbrough is Professor of Surgery in Otolaryngology and of Pathology and Section Chief of Otolaryngology at the Yale School of Medicine and Michael Mayes is a head and neck cancers survivor. Here is Dr. Anees Chagpar.

Chagpar Michael, why don’t you start with telling us a little bit about your story. How all of this started and how your journey progressed?

Mayes I am definitely a good example of why you need to do screening, early detection is key. I sat on a little lump that I felt on the side of my neck for, I am embarrassed to say, I was a fool for about a year, and it started growing and growing and growing until one day one of my best friends noticed it and she said to go and see a doctor. And I knew there was something wrong, but I was doing the guy thing, burying my head in the sand, but she finally grabbed me and said, I will club you over the head and drag you to a doctor, go see one. So I did, and I went to the emergency room, which kind of fast tracked me to Dr. Yarbrough at Smilow and we started doing tests and finding things out. By the time I was diagnosed I was about stage IV I think.

Yarbrough Yes, that is right. And these things, as Michael just attested to, can progress fairly rapidly by the time it is noticeable. So that is why it is important to have the diagnosis as early as possible.

Mayes It was terrifying from my side as I was feeling it growing. One day it was the size of a pea and the next day it was longer and longer and longer and by the time I got to you, it was 3 or 4 cm long. I knew there was something wrong. I was terrified. Once I got there and we finally had a name for what it was and a treatment plan, it is amazing how relaxed I felt about everything. I knew I was in the right place at that moment and I knew that everything was going to be okay.

Chagpar Let’s talk a little bit about how you actually got to Dr. Yarbrough and then Dell maybe you can tell us what happened from there, but Michael you said that you went to the emergency room?

Mayes I did, because it was either get clubbed over the head by my friend and dragged to a doctor or just do something, so I said I will go to the emergency room, they will tell me it is a cyst, and we will all have a good laugh about it. Once I got into a room where they were doing an ultrasound, everything changed, the girl that was working the equipment was fun and we were kind of laughing and having a nice time and then her face got real serious and she walked out of the room and she called the doctor and then I went downstairs and I sat in the room and then the doctor...
came and that is when he said to me, this could be cancer and at that moment I remember grabbing
my chair. The room literally was spinning and I thought I was going to fall off the chair and I had
to accept that this could be what it is, and he called my primary physician, and he called Smilow to
see if we could get me in more quickly and it really was fast tracked, I mean I was there within
days.

Chagpar Wow, that is great. So Dell, Michael shows up in your office, what happens? I mean that must
have been terrifying for Michael. What happens once they reach you?

Yarbrough The first thing is even before Micheal comes, we have a lot of data we are gathering from previous
appointments, his emergency room visits, what was known about the ultrasound and some patients
already have biopsies, imaging studies and those types of things. So it is a big process to get all
the information and Michael is exactly right, we try to get patients in within one week of when
they call and the reason is that people are worried and some people already know their diagnosis
but they do not know what the next step is and that is a tough time for patients. So, we try to get
patients in as quickly as we can with as much information as possible, so that we can take the next
step and I just want to say, this is really a team effort because head and neck cancers in general
affect areas that have to do with voice, communication, swallowing, and appearance and because
of all of that and because of the complications of the treatment as well as the disease, it takes a
large team. We try to get patients to not only to see one doctor, but sometimes multiple doctors
within several days so that their treatment plan can be arranged very quickly and that is the case
with Michael. Michael came in, we got him in to see multiple doctors very quickly so that we
could have a treatment plan. Then we talk about our patients at a tumor conference, it is called a
multidisciplinary tumor conference where there are multiple physicians as well as other care
providers that have to do with preservation of voice, swallowing, physical therapy, dentists,
because treatments can sometimes effect the teeth and we discuss the best treatment plan and then
we take that back to the patient and give our recommendations and then start planning treatment.

Mayes Could I just jump in to say that going into this, I make my living with my voice. I am a voice over
actor, I do commercials, cartoons, radio and have 25 years into this business and so I was terrified.
My tumor was on my neck and as I was learning that we were going to do radiation and
chemotherapy and everything to take care of this big tumor, I said, what is going to happen to my
voice, that is my life, what am I going to do? And they took real extra caution and they were very
careful to put together this amazing treatment plan and I managed to work pretty much through
everything. I think there was a period of about 4 days that I had to not talk as much, which was
four long days because I talk a lot. But other than that they sat down and they just put a lot of time
and effort into giving me the best treatment program.

Chagpar That is awesome.

6:53 into mp3 file http://yalecancercenter.org/podcasts/2014_0420_YCC_Answers - Dr Yarbrough.mp3
Yarbrough And that is what we try to do, I mean each patient is different and each patient's disease is different. So personalizing treatment with innovative treatments is one thing, but personalizing treatment with standard treatments is another and all of that comes into play when we consider the best treatment for a patient.

Chagpar I think that is amazing. I want to get back to Michael’s story because here he is with a lump on his neck, and it could have been a cyst, it could have been anything, and then you get whisked into Dell Yarbrough's office. Dell, how do you make the diagnosis and how is that conveyed to the patient? You talk about personalized medicine and how there are multiple different kinds of tumors that this could be, how exactly is that done and then I want to get from Michael, how did that feel?

Yarbrough There are multiple ways to make the diagnosis, but I would say that typically we do some office based procedures and some procedures that may need to be done in the operating room to make the diagnosis. For some patients we can do a fine needle aspirations of the lumps in the neck and that can be done in the office, it’s like getting a shot except rather than putting in medicine we are trying to draw a few cells out of the tumor and then we look at those cells under the microscope and sometimes that can make the diagnosis. Some patients also require a trip to the operating room to biopsy the tumor that is inside the mouth and throat because the lymph nodes in the neck or the lumps in the neck are not where the tumor starts, it is where the tumor spread to and we want to know where the tumors starts and where the tumor spreads to because that can effect where the treatment is aimed and what kind of treatment the patient may need to receive. So for each patient, even making the diagnosis is a different process.

Chagpar How was that process for you, Michael, did they just stick a needle into your neck, what did they do?

Mayes We started with the needle in the neck with biopsy and some blood tests and different tests like that and it kept coming back strange, where we could not quite figure out what was going on and then I remember you saying, well we will test cat scratch fever, and I thought, I did a pet event and I held cats in New York City, that is it, I have cat scratch fever. But it was not and then we did surgery, we did a biopsy and I do not remember, I was asleep, but I know you checked my stomach, and my throat I think and looked around for something and then finally came to determine what it was and that is when I got the news, which again was another surreal moment for me, another room spinning moment, hang on to my seat sort of thing, and I remember at that moment when I found out what it was, the first thing I did was I called one of my closest friends.

Chagpar The same one who was going to club you over the head?

Mayes No, a different one and when I called my friend Sarah and I told her she was real supportive and she said, Oh my god, what did your mom, what did your sister or Chaz, my friend that was going
to club me over the head, what did they have to say? And I said that I have not called them yet and I said I called you first and she said, why, and I said, I needed the practice. I had to be able to say cancer out loud. It was the first time I said, I had heard it at that point, but the first time I actually said, Hey I have cancer and we are going to treat it. So, once I accepted and I felt myself saying it and then called a few other people, then I called the friend that was going to club me over the head and then I called my mom and I was scared to tell my mother. My mom lives in upstate, New York, far away from here, and I was worried. I did not want her to suffer, I did not want her to be scared, and she said, do you want to come home and we can look into hospitals here, and I said, Mom, I am right down the street from Smilow, I do not live far away, and I think I am at a pretty good place. So she was at ease and doctors Yarbrough and Deshpande too were great about talking with my family, my mom placed a few phone calls and got information. She is a nurse, so she wanted to hear particulars I am sure from doctors. It was once I started saying those things and then started thinking about, I am a dad, my daughter was 14 at that time, we have an amazingly close bond, and I remember being in the shower and it hit me, and I burst into tears and said, I am not going to let this take me away from a high school graduation, picking colleges, walking her down the aisle and many years from now, being a grandfather. I refused to let this do it, so at that point it became not so much about my voice but more about this amazing little person that I have to be there to see, maybe I needed her more than she needs me, but whatever, I am not going to let cancer beat me. So that was the attitude that I started forming as I went towards my treatment and I think that is a good attitude to have, I am not going to give into this disease, no matter what it brings, I am going to get through and go on to the next thing.

Chagpar Right, I am going to beat cancer, cancer is not going to beat me.

Mayes Exactly.

Chagpar Dell, tell us about how exactly you figured out where Michael’s cancer was, I mean you had this lump in the neck, which is where cancer goes to, is there anything that gives you a clue as to where to look or do you kind of look everywhere? Then tell us about what the experience is like as a doctor to give that news to a patient?

Yarbrough First of all, let me just say, our patients, many are like Michael, what they go through is amazing, but I have got to say the grace and the character that most people bring to this process never ceases to amaze me, because the strength that it takes when you have young children and you are thinking about those life events and then to have this diagnosis thrust upon you, you are not asking for it, it is amazing. I am always amazed by what our patients go through and how they handle it. When we are looking for these tumors sometimes it is simple and sometimes it is hard, and in many cases now younger patients are getting head and neck cancer. There are two big categories of head and neck cancer, one is related to carcinogens, typical carcinogens that cause head and neck cancer and one related to a virus called human papillomavirus and we are seeing younger patients and patients who have smaller primary tumors, but tend to have larger neck nodes. Sometimes those primary tumors
tumors can be very hard to find and imaging studies can help with that and sometimes we get PET scans, CT scans, MRI scans, the other thing though we can do is, as I mentioned before, take the patient to the operating room and use magnification and microscopes while we are examining the airway, the throat, the voice box, the base of their tongue and their tonsils and do biopsies of those if we see any particular lesions and that is usually sufficient to make the diagnosis.

Chagpar That is great. We are going to pickup with what it is like to give a patient a diagnosis of head and neck cancer right after we take a short break for a medical minute. Please stay tuned to learn more information about head and neck cancer with our guest Dr. Wendell Yarbrough and Michael Mayes.

Medical Minute In 2014, 200,000 Americans will be diagnosed with lung cancer and in Connecticut alone there will be over 2500 new cases. 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. New treatment options and surgical techniques are giving lung cancer survivors more hope then they have ever had before. Clinical trials are currently underway at federally designated comprehensive cancer centers such as Yale Cancer Center and 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 combination of drugs based on personal biomarkers can help to control non-small cell lung cancer. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale New Haven. More information is available at YaleCancerCenter.org. You are listening to the WNPR, Connecticut's public media source for news and ideas.

Chagpar Welcome back to Yale Cancer Center Answers. This is Dr. Anees Chagpar and I am joined today by my guests Dr. Wendell Yarbrough and Michael Mayes. We are talking about Michael's story of survivorship with head and neck cancer and right before the break, Dell, you were telling us about how when Michael initially presented with this lump in his neck and you did a fine needle aspiration it told you that there are malignant cells, but you had to take him to the operating room to look around with magnification to make the diagnosis. What is it like as a doctor to tell a patient that they have got cancer? Michael was telling us about all of these life events that he had going on, and cancer did not seem to put an appointment on his calendar, what it is like for you as a doctor to tell patients about cancer every day?

Yarbrough It is never easy, I guess the more you do it you kind of get used to it, but what I do is try to lay out the different possibilities that it could be and one of the possibilities is cancer. I am always hoping it is not going to be the answer, but I am pretty upfront initially that this could be one thing that we are looking for and so that seed is planted in the patient’s mind, because I think there is a coming to grips with it at a different level for the patients and then when the diagnosis is known the tact

17:20 into mp3 file http://yalecancercenter.org/podcasts/2014_0420_YCC_Answers_-Dr_Yarbrough.mp3
that I take is just try to be as upfront and honest as I can and at the same time make it clear that there is plan. We have capabilities to treat this and this is not a diagnosis that means this is the end, so I think what really comforts patients as much as anything else is once they know the diagnosis, they also know that there is a next step, here is what I need to do next and whether it is coming for the next appointment, getting another scan, have something that is the next step that leads to treatment, and in these cases these tumors are very treatable, even sometimes at advanced stages they are still very treatable and very curable, so it is important that I think patients realize that and they also need to realize that it is not going to be an easy thing to go through and I am sure Michael probably has something to say about that.

Chagpar

Michael, how easy or not easy is it once you hear the "C" word, do you hear the rest of it that says we are here for you, we have a plan, or is this just like a deer in headlights?

Mayes

It is a little bit of both and I think the reason that it was easy to hear some of it, was because we had talked so many times leading up to it. Whether it was in the office during an appointment or even a quick phone call at home to say, listen I just got results back from blood work, or we just got your biopsy results, or this came in or that came in and we have ruled this and this out but there is still the possibility of cancer. When I finally got the call that it was cancer, it was at the very end of that big snowstorm that we had that shut everybody down for a week, and I was trapped in my home and I am getting the calls and I am trying to figure out what is going on with my life and I finally got a crew to come and plow my driveway because I had had the surgery for the biopsy and did not want to be lifting a shovel. So these guys came to my house to plow my driveway and I had no cash. So the first part of my driveway cleared out and I said I am driving down to the ATM, I will be back in 10 minutes with your money, keep finishing the job, so I go to the ATM, I get $40 out of the machine to pay these guys, my phone rings and I look at the phone, I do not recognize the number and I said, Why are these plow guys calling me now, they know I am down the street. So I answer and you say, Hello, it is Dr. Yarbrough, and I went, Oh no, and we talked about it, but it was the way that you said cancer, you did not say, it is cancer? There was no timid, Oh my gosh! You are doomed, kind of delivery, it was, Well, this is what we have been looking for and we found it and now we will begin treatment. It was presented to me in a way that made me say, okay, we are onto the next step. It was not terrifying and maybe because of the moment that I was in you know with the plowing and this and that and all these things going on, maybe it just did not hit me fully at the time, but again I think that the acceptance of, okay, I know what it is and know what this thing on my neck is not supposed to be there. It kind of just made me feel secure about everything.

Chagpar

And it sounds like you already had a relationship with Dr. Yarbrough and I think that confidence in part was when you were talking to your mom and you said, listen, I am in a really great place, you knew that Dr. Yarbrough could take care of this. Dell, how long have you been treating head and neck cancer? I mean, you are one of the world’s experts.

20:53 into mp3 file http://yalecancercenter.org/podcasts/2014_0420_YCC_Answers_-_Dr_Yarbrough.mp3
Mayes  I wasn’t your first one?

Yarbrough  I guess you are asking me to age myself, alright, so my fellowship finished in 1994, and since then I have been treating head and neck cancer patients pretty regularly during that time and I have got to say, I am as excited now as I have ever been about the treatment of head and neck cancer. I think there is more potential now than there ever has been in my career with new innovative therapy, therapies that allow patients to carry on with their life, to have minimal side effects and hopefully as we go forward, to give patients more effective therapies that have even fewer side effects. Our reconstructive capabilities now are greater than they have ever been, our ability to aim radiation beams to more focused areas and to avoid critical structures is better than it has ever been and now with new targeted therapies coming out, I am really excited about the next steps.

Chagpar  Clearly that made a big difference to you, Michael.

Mayes  Well it was terrifying, again it was in my neck, it was by vocal cords, this is what I do, this is my life, my living, my entire career. It was scary, but when we had that conversation also with Dr. Decker in radiation, about how they are going to pinpoint the blast of radiation, I had 38 radiation treatments, and the hardest part for me was people constantly coming up to me saying, hey where do you get your sun tan? My skin was turning red and I’d have to say, no it is cancer. After a while it was fun to do because the look on their faces was priceless.

Chagpar  Dell, talk to us a little bit about therapies in general and perhaps Michael’s therapy, was it just radiation or do people use a combination of things? A bit of surgery, a bit of chemo, a bit of radiation, and maybe some novel targeted therapies or maybe a clinical trial. Do you want to talk about that?

Yarbrough  All of those are potentials and it depends on the tumor the patient has and what areas are affected. It depends on some molecular characteristics of the tumor, and now we test the tumors for the virus and some tumors have it, some tumors do not. There are other molecular markers coming down the pipe that hopefully will help us get better therapies in the future as well, but most patients with advanced tumors like Michael get some combinatorial therapy, so they may get surgery plus radiation or radiation plus chemotherapy and in Michael’s case, he got no surgery for treatment. He got chemotherapy and radiation and that is really an advantage of being at a place where the whole team meets and talks together, because you are not just getting one point of view. You get multiple points of view and then as far as clinical trials go, we do have clinical trials that we are very excited about and some of those clinical trials are window type trials that we are starting, which basically means people will get the standard therapy, but they may get a biopsy before a short treatment and then a biopsy after a short treatment of an experimental regimen and the idea is to see if this new experimental regimen has some molecular affect, but it does not mean that the patient has to be totally treated that way. They can still get standard therapy and I think

24:47 into mp3 file  http://yalecancercenter.org/podcasts/2014_0420_YCC_Answers - Dr_Yarbrough.mp3
those innovative types of trials will help us take the next step. Once again this highlights the grace of our patients and a lot of patients are willing to do trials. It has no immediate benefit, but it may benefit somebody else down the road. Also our patients are very willing to let their tissue be used for research and so that is another area where we are trying to learn more about these tumors so that we can help the next generation of patients and by doing that the previous generation has helped this generation and this generation will probably help the next generation, so that is something that is really important to us.

Chagpar  Michael, tell us a little bit about what that was like, you talked a little bit about radiation, what was chemotherapy like?

Mayes  Going in I was told to expect certain things, you sort of get a check list, your hair may fall out and your taste is going to get weird, you are going to get tired, you are going to get this, you are going to get that, and the first two weeks or first three weeks I thought, none of these things were happening.

Chagpar  Did you say, are you giving me the right stuff?

Mayes  I did, I was like, what is going on in that little black bag that you are sticking me with once a week, because Cisplatin is supposed to be this mega chemo and I am not feeling it, but then the next week I said, Okay I got you now. That is when things started happening, but I had a very close friend who was a five-year cancer survivor at that point that brought me to every cancer appointment, my friend Cindy, who made me laugh from the minute we left my house for the first treatment all the way to Smilow. We pulled into Smilow and I said, I did not realize we were even here yet, and she said, that is my job. That is what I am going to keep doing for you. So we went in with an attitude of we would laugh through it, but it would be scary sometimes. I was extremely tired. I think the scariest moment as far as chemo was, I usually have a scruffy look on my face, and I went to itch my chin and I had a handful of whiskers and I said, it is starting. I had promised my daughter that if my hair started to fall I would let her shave my head and we went to a salon, a friend of mine owned a hair salon, they took me in the back room and she had the little clippers and they gave me a Mohawk and other things. So it was tough, there were days that were hard. It was tough to eat, nothing tasted right, ice-cream still, unfortunately, does not taste good, but I am thinner, so that is cool and I said going in, isn’t this a great way to lose weight, but the doctors do not tend to like that question too much.

Yarbrough  We do not want our patients to lose weight, so we do not recommend it as a diet.

Mayes  I looked at it as some people do cardio, I did chemo, and I took a couple pounds off.

Chagpar  I mean certainly you took a great attitude towards cancer. Were you ever scared about dying?
Mayes  Yeah, I have never said that out loud, yeah that moment when everything hit me, in the shower when I burst into tears, I did. It is very strange, there was a tremendous fear and then kind of an acceptance and I just told myself I had plenty of things left to do. I am not done here.

Chagpar  Right.

Mayes  My job is not complete. So, it is not an option. It is not going to take me right now, but yeah the fear of death I think really hit me the first time when I went to visit the people in radiation and you go down to the lower level of Smilow, and that is where reality really hit me because I saw sick people. I saw people who were fighting. I saw a lot of brave soldiers and warriors down there who were tough. Little kids, old people, people of my age, pretty girls, tough looking guys, there was everybody. There was not one particular brand of person down there.

Chagpar  Yeah.

Mayes  So that was kind of scary too and then I started making jokes about that. Going into radiation I would say to my friend Cindy, I am going to go tanning, I will be back in ten minutes, so I try to put that fear of something bad behind me the whole time.

Chagpar  Dell, when patients ask you, am I going to die from this, what do you say? What is the prognosis for head and neck cancer?

Yarbrough  We do give some general idea about what the prognosis is because clearly the patients need to know and they want to know, but for each individual patient you really cannot predict how an individual patient is going to do. We can give ranges, with this type of tumor, this stage of tumor, you know, x-percent of patients will do well or not do well, and so we give those types of ranges, but I do not really like to get down to the detail of one particular percentage point, and so I like to keep the positive attitude, and I think that really helps with the treatment and to be honest we keep fighting just as much as our patients keep fighting and we let them know we are going to be in this with them and we are going to be there the whole way.

Dr. Wendell Yarbrough is Professor of Surgery in Otolaryngology and of Pathology and Section Chief of Otolaryngology at the Yale School of Medicine. Michael Mayes is a head and neck cancer survivor. We invite you to share your questions and comments with Dr. Foss and Dr. Chagpar, you can send them to canceranswers@yale.edu or you can leave a voice mail message at 888-234-4YCC. As an additional resource archived programs from 2006 through the present are available both in audio and written versions 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.