



## Young Adult Oncology

Hosted by: Steven Gore, MD

Guest: Asher Marks, MD, Assistant Professor of Pediatrics

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Welcome to Yale Cancer Answers with doctors Anees Chapgar and Steven Gore. I am Bruce Barber. Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer. This week, it is a conversation about young adult oncology with Dr. Asher Marks and Amanda Garbatini. Dr. Marks is an Assistant Professor of Pediatrics in Hematology and Oncology at the Yale School of Medicine and Ms. Garbatini is the Adolescent Young Adult Program Coordinator at Yale New Haven Hospitals. Dr. Gore is a Professor of Internal Medicine and Hematology at Yale and Director of Hematologic Malignancies at Smilow Cancer Hospital.

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Gore You know, I have to say that none of us like to think of young adults as having cancer. I mean, right, I mean I guess that's all, you know, obviously, you are in job, so maybe it is good for you guys, but right? I mean, sure, no, we do not like to think of it either, but it is our job and it is the population that we take care of and that we focus on, and it is interesting that you say that people do not like to think about it because some of the issues that we come across and some of the struggles we have is, is that they are an underserved population. And I guess we should state for the outset I hope that adolescent cancers are uncommon, right?

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Marks Not common, no.

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Gore Are there any numbers. You know, people are going to start worrying like "oh my God, my kid has cancer."

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Marks So, what I can tell you about the numbers is that we see on the pediatrics, I would see about 100 patients a year.

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Gore Total?

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Marks Total. In terms of oncology diagnosis you know, here at Yale. In terms of the population that falls within adolescent, young adult which we define as about 13-30. You know, if you look at the NCI, they say 15-39, it is a moving target.

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Gore What about 61 year olds who act like adolescents? Don't know I count.

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Marks No couple of them, yeah. But from that population, about two-thirds. So, you know...

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Gore Two-thirds of the kids?

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Marks Of the kids fall within this adolescent kind of young adult population. So, we think about pediatric cancer and a good number actually run into these issues of being a bit older and have their own kind cancers and psychosocial concerns. So, yes it is unusual in general, but the population we see, we definitely see a good number.

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Gore And am I correct in saying that Yale New Haven Hospital has about half of the pediatric cancers in the state or something like that?

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Marks Something like that, yeah.

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Gore So, maybe about 200 across the state.

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Marks I think that's fair, yeah.

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Gore And what kind of cancers are prevalent in this population?

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Marks Yeah. So, the cancer prevalent in this population, you really get a mix of the adult cancers and the pediatric cancers, and that is another thing that makes this so difficult. We are very much siloed. You know, I am a pediatrician, we have our adult counterparts. So, on the adult side, they are seeing things like melanomas, thyroid cancers, breast cancers in younger populations, they can see testicular cancers. Whereas, on our side, we are seeing pediatric cancer in this age group. So, we are seeing leukemias, we are seeing lymphomas, brain tumors, certain solid tumors. So, it runs the gambit and the thing that AYAs, you call them AYA - Adolescents and Young Adults, the things that they have in common are not necessary their disease process so much as the other psychosocial needs that are very unique to the population.

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Gore So, Amanda, it is great to have you here as a social worker. I can imagine that your involvement is really important from the get-go with a teenager, let us say teenager, because I think they are 20- to 30-year-olds in my mind anyway, we kind of think of them as potentially more developed in terms of their ability to process, maybe not?

04:19.800 --> 06:01.400

Garbatini You know, that is a great question because we actually will at least see a few 20, 21, 22-year-olds on the pediatric side for sure and they are the ones that actually really need the most help because they are the ones, they are supposed to be, we think of them as the most resilient population. They have got their whole lives ahead of them, they are you know graduating high school, graduating college, finding a job, but that is why they need the extra help because they have all these really milestones up ahead of them, whether it is again graduating, getting a job, dating, marrying, having kids, you know there is no handbook on how to date when you have cancer. There is no handbook on how do you tell like on a dating app that you have cancer. There is no like protocol for that. So, that is where

like the psychosocial usually come in because as a 13-year-olds you know maybe you are not looking at that kind of stuff just yet, but as a 21-year-old, you are. And even as a 30-year-old, you might be worrying about getting married, having kids, can I have kids, and what all I need to do to make sure that I can have kids, and those are all things that we kind of take care of within the AYA program, but they have a really unique set of psychosocial needs. They are going through all of these changes, both physiologically, physically, mentally, emotionally. I mean, being a teenager is awful on its own and then you throw in cancer and it makes everything that much harder, and teenagers, you know they are naturally kind of self-isolate and cancer just makes you that much more isolated. So, our goal is to just kind of get them together and see what we can do.

[06:01.400 --> 06:21.600](#)

Gore I just have to imagine that across the family spectrum, from the younger siblings if there are any to the parents and others I suppose, the diagnosis of cancer in a young person has just got to be just rock people's worlds right? I mean, everything is up in arms, all your assumptions right?

06:21.600 --> 06:45.000

Garbatini I mean, when we think of teens as these, you know, invincible kids, and they are still kids which is also difficult because yeah parents, you know, they might their oldest child all of a sudden has these huge medical needs and you know maybe the younger kids, I do not want to say neglected, but they certainly are not getting the attention that they used to have.

06:45.000 --> 06:45.500

Gore Feel neglected perhaps.

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Garbatini They feel neglected. So, we do try to work our best with the whole family unit. You know, parents and siblings as a whole just to make sure everyone is getting their needs met because, you know, behind every seriously ill child is a family in crisis.

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Gore So, what kind of interventions or support systems are in place for them or do you put in place for them?

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Garbatini So, we have a really great care team. Asher runs the AYA Clinic every Thursday at Yale New Haven Children's Hospital. We have a dietician, we have a fertility specialist, we have a psychiatrist and a psychologist. We have 3 social works, I guess now including myself, and we all really work together to make sure that they are getting the best possible care both from the physical illness perspective and the psychosocial perspective.

07:33.900 --> 07:46.300

Gore So, does every family meet with a mental health worker regularly once assessed, are there groups available, support groups?

07:46.300 --> 07:56.600

Garbatini Every child gets assessed by a social worker who is newly diagnosed and then from there they can make referrals to either the psychiatrist or the psychologist depending on what their needs are.

07:56.600 --> 08:16.800

Marks It is actually our goal to have Kathi Croce who is our psychologist. She has a big belief in this resistance model of teaching resistance. So, every person I think diagnosed with cancer quite frankly and especially in this age group I think would benefit, does benefit from psychosocial intervention.

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Gore I agree.

08:18.600 --> 08:37.000

Marks I mean, it is a tremendous thing to take on. And she actually has a series of kind of four sessions, she likes to have with almost all of our patients. You know, if possible, if they are open to it, no matter what their needs, and what these four sessions do is that they actually teach a model of resistance to help them through this difficult process.

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Gore Resistance?

[08:38.400 --> 09:11.700](#)

Marks Resistance, resilience. That's the word that we use. And you know, within those sessions, you know, they are also used to evaluate for other needs that they may have, whether it be psychiatric further cognitive-based therapies and things like that. So, it is an ongoing process. You know, there is an initial screen, but then we do, always try to delve a bit further. It is one thing to kind of get through with the cancer, it is another to actually thrive through it, which some of our patients actually have and it is quite remarkable.

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Gore And what about for the parents?

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Marks Parents have their own special needs. They really do.

09:22.100 --> 09:27.300

Gore Parents are not just big little...

09:27.300 --> 10:35.700

Marks It is so true. It is remarkable... I am in pediatrics, I love working with kids, I love working with young people because they bounce, you know, they often find that resilience, they find that strength to get through. And sometimes the parents are left behind. You know, sometimes they are trying to find their own way through this most times. And so, that support system that we have, you know as Amanda was saying it is not just for the patient, it is for the entire family. Support groups is a great question. It is something that we have been struggling with to be quite honest. It was one of my goals when this program started about 4-5 years ago, one of the first things I wanted was support groups, and so Dr. Croce and I, we started trying working - whose appropriate, when can we get them in, how we are going to do this. Maybe, you a physician and not natural patient thought it was a great idea that oh, while we would run their chemo, they can sit around and talk because that is there time. And you know, lot of virals, what an idiot. So, they do not want to sit around while they are getting that nausea-inducing meds looking their worst, feeling their worst, that was a terrible idea, nobody went for it.

10:35.700 --> 10:43.200

Gore It was not a terrible idea. I thought of the idea.

[10:43.200 --> 11:31.700](#)

Marks And so, then the idea was, well maybe afterhours. But these were young people. They are trying to live their lives, they have jobs, some of them, they have families, they have school, they do not want to be in the hospital any more than they have to. So, we have been struggling with support groups. Trying to move forward a concept to do these support groups in kind of a virtual space using technology, using virtual reality, have teamed up with a great consult from the New York to help us with the software, contracts which are signed, just trying to get it through, some kind of safety parameters, but it is one way that we are trying to kind of innovate and get these patients together to get them to socialize, we know that they feel lonely and we want to get them to talking to each other as much as you want support groups, somebody to guide them, ultimately we want them to talking to each other and this is what we are going to try.

11:31.700 --> 12:14.600

Gore You know, it is interesting that that may be the model that works the best logistically and yet it seems to reinforce the whole, you know, transition of our society from downwards, people who do not know how to talk on the phone, people who do not know to have a conversation, text messaging, you know, I mean maybe it is better if you are skyping or whatever you are doing or virtual realizing, you know, it is more like a real interaction but it is still not face to face right. There is so much that is lost and from my opinion that is an old guy.

12:14.600 --> 12:35.800

Garbatini You know, we do have the new teen center, the Lauren Telesz Smilow Teen Center, which just opened up in November and what we found is that once you get the teens into that space, into the room, whether it is you know doing a group or a virtual reality group, the conversations happen organically, like they just, they create their social connection even if they do not realize that they do and

12:35.800 --> 12:36.600

Gore And would never admit it if they ever did.

12:36.600 --> 13:02.800

Garbatini They would never admit it if they did, but you know, all of sudden it becomes, oh you know what meds are you on, is that your port scar, this is my port scar kind of thing, and it just snowballs and it happens and they make these connections in person in the teen center which is great, but that right now, it is kind of it is inpatient only. So, we want to have it open to all of our teens and AYAs, especially ones who are only treated outpatient.

[13:02.800 --> 13:52.500](#)

Gore Now, that's fascinating. I mean, I would like to come back to what you said about the really needy 20 and 22-year-olds, you know there is a rubric, then I think we may need to move this to the second half of the show that with young male patients, particularly with curable diseases like Hodgkin's, there is a large failure to follow through because of anger, and you know, disbelief or denial, but I am told that we need to take a break. So, we in fact, we are going to take a short break for a medical minute. I hope that everybody has got on tenterhooks now about those curable diseases, please stay tuned to learn more about young adult oncology.

13:52.500 --> 14:08.700

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14:08.700 --> 14:52.000

This is a medical minute about melanoma. While melanoma accounts for only about 4% of skin cancer cases, it causes the most skin cancer deaths. When detected early, however, melanoma is easily treated and highly curable. Clinical trials are currently under way to test innovative new treatments for melanoma. The goal of the specialized programs of research excellence in skin cancer or SPORE Grant is to better understand the biology of skin cancer with a focus on discovering targets that will lead to improved diagnosis and treatment. More information is available at [YaleCancerCenter.org](http://YaleCancerCenter.org). You are listening to Connecticut Public Radio.

14:52.000 --> 15:30.400

Gore Welcome back to Yale Cancer Answers. This is Dr. Steven Gore, and I am joined tonight by my guests, Dr. Asher Marks and Amanda Garbatini. We are discussing the field of young adult oncology. Amanda, before I so rudely cut myself off before the break, I had asked you a question about this kind of, I do not know if it is an urban legend or not, about young particularly men in their 20s, not being compliant with therapy for Hodgkin's lymphoma or leukemia, curable diseases, just not showing up, lot of anger, is that just a myth?

15:30.400 --> 15:53.800

Garbatini Actually, I think Dr. Marks going to speak more about treatment adherence in that population. But there is that, you know, kind of urban legend, urban myth that that age group think they are invincible. So, you know, maybe with their diagnosis kind of hits them like a boulder and they

do not really know what to do and they, I imagine do get angry about, I think Asher can speak a little bit more about that.

[15:53.800 --> 18:03.400](#)

Marks Yeah. You know, it is a matter of different coping mechanisms is what we are seeing with that, you know, anything from denial to feeling they are invincible to frankly flat out rebellion. And I think it depends on the disease process. There are certain cancers where it is unavoidable. They are going to, you know, feel sick, they are going to have to be inpatient, they are going to have to be in the clinic, we are giving IV medications and in those situations, you know, for better or worse, it is tough rebel. It is tough to be noncompliant. I think what we see bigger issues are with cancers such as leukemias where a large portion, for when they are being treated for around 3 years, to a large portion of that time is dependent upon taking oral medications at home, and if you look at the literature, you will see that there are decreased survival rates in this age group in all cancers, and I am sure compliance plays a role, particularly like I was saying with leukemia, if they are not taking their oral medications at home, they are at very high risk for relapsing. And so, it does become an issue and we try to get creative in ways to get them to take the medications, everything from, you know, taking their phones for the appointments, setting alarms for them, not that the cancer on this alarms off, but it is easier to not. So, sometimes that works out; to having nurse practitioners and social workers who are really on top of them. If you look at kind of survival rates of patients in their 20s with leukemia being treated on the adult side by adult oncologists versus pediatric oncologists, you will see that when they are treated on the pediatric side, their survival numbers are a little bit better. Why is that? There is some debate. Needless to say, there is some debate amongst the physicians as to why. Some of it thought that the adult oncologists are too nice. No, seriously.

18:03.400 --> 18:09.200

Gore You guys are more bad 'tushed', right?

18:09.200 --> 18:10.000

Marks Tough love.

18:10.000 --> 18:18.200

Gore Tough love right? Even the parents are, you know, hovering over them and that we are like, yeah you want to go to Bermuda next week? Sure, why not? More delays, that has been proposed.

[18:18.200 --> 18:45.100](#)

Marks That has been proposed and I think it is probably the biggest reason. You know, I think there is that we can be a little bit more aggressive with the regimens that we get because we feel like they can handle, we have seen younger kids bounce, so we think that these kids can bounce, but a lot of it is that tough love, you know, and that we try to have the resources to make sure they are taking their meds. You know, because frankly we need it.

[18:45.100 --> 19:25.200](#)

Gore Yeah. You know, we participated when I was a Johns Hopkins and I do not know if the study was open here or not at Yale, in a study up to 40 years old with leukemia, with childhood-like leukemia, treating this AYA population according to your touch love pediatric protocols and although I am not sure it is populist, yet I hear that the really the long-term outcome is significantly better than what we usually get, obviously, but it was really hard to treat those patients with that, and I think a lot of people dropped off the study because it is really hard.

[19:25.200 --> 19:33.300](#)

Marks It is hard. It is hard, not doubt it is hard. And it takes I think a lot of resources to support that kind of treatment.

[19:33.300 --> 20:20.500](#)

Gore Yeah, really interesting. You know, people may not know, if people were fortunate not to be involved with need for cancer care, may not know that our adult hematology clinic in Smilow and the pediatric oncology clinic neighbor each other on the seventh floor, and so, I often up and down the elevator and out to the bathroom and stuff, see these kids riding around in the middle with scooty things or walking about with their parents and you can see they have lost their hair and they are like just nothing has happening and ...., those are really the little kids, I do not know about the adolescents. I mean I don't pay attention to the adolescents, I guess the little kids catch my eyes.

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Marks They are always cute.

[20:22.900 --> 20:34.100](#)

Gore Well, they are not as cute, and it would be inappropriate for me to think they were not in the #metoo era, never do that obviously, but the look is that they are super cute we have to say....

[20:34.100 --> 21:12.300](#)

Garbatini But that also comes from, you know, one of the reasons that a lot of the teens so isolated is because a lot of that attention goes to the younger kids and they are on the same floor as a 3-year-old, and for a while, there was a playroom which was very, I would like to call Fischer-Price, and did not appeal to teens and adolescents. Whereas, now we have the teen center which is really, it was designed by a former patient, by teens-14s, and it has really been a success, which has really been great, and but you are right they, you know, when you are looking at kids with cancer, cute little bald kids are the ones that you think about.

[21:12.300 --> 22:02.400](#)

Gore Well, they are also the ones that are on the St. Jude's commercials, and on the National Cancer Institute, we have cured childhood leukemia, you know, brochures and stuff which is all really fantastic, right and yet we also know that that is not always the case and that does not apply to everybody for sure. You know, Asher, I know that you are particularly interested in brain tumors and I think I just wonder since brain tumors can affect so much - the personality and cognitive function, what are the issues around dealing with that, I mean from a, you know, family first recognizing maybe there is something wrong with our kid, sure there has got to be denial about it, 'oh, his eye isn't really lazy', what is that like?

[22:02.400 --> 23:50.100](#)

Marks It is difficult. So, I wear two hats over at the Yale New Haven Hospital. So, I am the director of the Adolescent Young Adult Clinic and I am also the director of the Pediatric Brain Tumor Clinics and that pediatric brain tumor clinic includes these young adults, you know, on the brain tumor side of things, brain tumors come with a tremendous number of what we call comorbidities, which is a fancy way of saying they really suck. You have got endocrine disorders to worry about, you got your pituitary - little ball of a gland hanging on the side of the brain that can easily be affected by the brain tumor, you have the cosmetic issues that brain tumors can bring, you know, you got facial paralysis, which can become a big issue for a young adult, and you have got the teeth that often comes with some of the treatments. So, I think, you know, combining the kind of brain tumor side with the AYA side is a tremendous challenge. You know, I have got my kind of two teams that work together tremendously well. I have got my brain tumor team that encompasses our neurosurgeons, neurologists, endocrinologists, and then I have got my AYA team which is very strongly weighted on the psychosocial side. And when they come together and work with these patients, it is really a beautiful thing. And, I think that it is multi-disciplinary approach and you got to take it. You know, especially when you are dealing with complexities of complex medical situations as well as the psychosocial side.

[23:50.100 --> 23:55.400](#)

Gore And the outcomes for kids with brain tumors is getting a lot better, right? Many of them are cured.

[23:55.400 --> 24:38.100](#)

Marks Many of them are cured. So, if you look at straight numbers in brain tumors, a recent review came out kind of looking at all brain tumors. Right now, we have got 75% overall survival. And that sounds wonderful. That sounds great. That being said, I think those numbers take into account a lot of benign brain tumors and we know that there are brain tumors out there that are almost 100% mortality. So, we have got a long way to go. And what those numbers do not show are again those comorbidities. So, despite cure of the tumor, these patients have lifelong health issues and so, we are "doing well, but frankly not well enough."

24:38.100 --> 24:45.100

Gore What about cognitive function? Are they able to go back to school at the same level as they were before or are many of them cognitively impaired?

24:45.100 --> 25:08.800

Marks It depends. It depends. A lot of that comes down to the need for radiation. And it comes down to the age of diagnosis. So, the younger a patient is when they are diagnosed, the greater risk you have when you have to use radiation to cure the tumor. So, in general, we do not use radiation at all in a child under 3 years of age.

25:08.800 --> 25:10.000

Gore The brain is growing too much.

25:10.000 --> 25:32.600

Marks It is growing, just does not tolerate it. If you look at kind of trends in charts, you know, what you will see to try to simply, you see about a loss of 1 IQ point per year after treatment when you are treating a patient that young. So, that means if you start with someone with an average IQ, you know, you are dropping them fairly quickly.

25:32.600 --> 25:33.100

Gore 15 points in 15 years.

[25:33.100 --> 26:22.500](#)

Marks Exactly. So, you can very quickly get down into that sub-average. And so, we try to avoid it. The older patients tolerate the radiation a little bit better, but with them, we see a lot of fatigue with treatments, we see a lot of what we call brain fog or chemo brain, and so, we pull in our friends on the neuro-psych side of things where we do a lot of cognitive evaluations and figure out how can we support them through school. And so, I think that just drives home the point despite "cure," this is a lifelong illness. It is something that has lifelong consequences and we are constantly working with these patients even beyond when treatment is completed.

26:22.500 --> 26:24.900

Gore And in the younger adults, you got to their whole career issues.

26:24.900 --> 27:11.700

Marks Career issues absolutely. So, one of our colleagues, namely Nina Kadan-Lottick is an expert in long-term survival, and she does some tremendous studies looking at overall "success" in patients diagnosed with cancers who survive. And she has looked at things such as income, marriage status, job status, and all these things, these basic goals of life take a hit with a diagnosis of cancer early in life. There are foundations out there specifically dedicated to financially helping these patients through, not just during but after treatment.

27:11.700 --> 27:41.000

Gore Amanda, you had mentioned the fertility issues, which we could talk about, we have actually done some shows with our reproductive endocrinology people about some of the progress, particularly in preserving female fertility with egg harvests and ovarian harvests and things like that. But what about sex? You know, we do not like to talk about teenagers having sex, but we know that we certainly know that all teenagers seem to want to have sex, so what about that?

27:41.000 --> 27:47.000

Garbatini Yes. What about it?

27:47.000 --> 27:50.200

Gore To talk about it, is it an issue, is it kosher to talk about it in your clinic?

[27:50.200 --> 28:19.900](#)

Garbatini It is totally kosher to talk about, you know, kind of rule 1 when it comes to treating anyone from a psychosocial perspective is to meet them where they are at and if they have questions about sex, if they have questions about relationships and dating, we are more than happy to talk about it and fulfill those needs, you know, promoting safe sex and sex when appropriate. You know, we are not going to stop teenagers from having sex because it is going to happen.

28:19.900 --> 28:22.900

Gore Do you screen? I mean, because they may not feel like it is okay to talk about. Do you ask them if they are sexually active?

28:22.900 --> 28:25.700

Garbatini I do not personally.

28:25.700 --> 28:47.700

Marks I do. As a physician, I have to, you know, and I always practice it with this is part of everything that I ask everybody. You know, I am making no judgments, but I have to ask.

28:47.700 --> 28:49.200

Gore Mom and dad cover your ears.

28:49.200 --> 28:52.000

Marks Mom and dad leave the room.

28:52.000 --> 28:56.000

Gore I can tell you a story about that.

28:56.000 --> 29:00.100

Garbatini Whenever possible, if I am meeting with a patient, I ask to see them alone.

[29:00.100 --> 29:03.700](#)

Gore Gotcha. And the parents are usually okay with that?

29:03.700 --> 29:06.500

Garbatini Yeah. They understand.

29:06.500 --> 29:14.200

Gore It's different times too, right and not that they are sort of a whole variety range of what is considered okay morally and ....

29:14.200 --> 29:18.000

Garbatini Even children have their right of confidentiality.

29:18.000 --> 29:20.900

Gore No matter what their parents....

29:20.900 --> 29:30.600

Marks I will be honest. In my experience, parents are happy when I do that. When I say I need you to leave the room and I want to talk to....

29:30.600 --> 29:31.700

Gore Thank God, somebody is talking to them about that, right?.

29:31.700 --> 29:34.100

Marks Exactly. There is almost a sigh of relief those times.

29:34.100 --> 29:38.200

Garbatini They know that there are things their teens are not going to say in front of them.

[29:38.200 --> 30:12.800](#)

Amanda Garbatini is the Adolescent Young Adult Program Coordinator at Yale New Haven Hospitals and Dr. Asher Marks is an Assistant Professor of Pediatrics in Hematology and Oncology at the Yale School of Medicine. If you have questions, the address is [canceranswers@yale.edu](mailto:canceranswers@yale.edu) and past editions of the program are available in audio and written form at [YaleCancerCenter.org](http://YaleCancerCenter.org). I am Bruce Barber reminding you to tune in each week to learn more about the fight against cancer here on Connecticut Public Radio.