

**Dr. Don Dizon:** This podcast is brought to you by Conquer Cancer, the ASCO foundation. Our mission is to accelerate breakthroughs in life-saving cancer research and empower people everywhere to conquer cancer. You can help by donating at [conquer.org/podcast](https://conquer.org/podcast).

Welcome to *Your Stories*, a podcast where we hear candid stories from people conquering cancer. I am your host, Don Dizon.

'Listen to your body', this is advice doctors and other health experts offer people every day, and it's the message Mai Achong shares after surviving a rare form of ovarian cancer nearly 15 years ago. Hi, Mai!

**Mai Achong:** Hi!

**Dr. Don Dizon:** Thank you for joining us here on our podcast. I'm really excited to talk to you about your story and the lessons you have for everyone around. But let's begin by asking how you were originally diagnosed. Take us back to that time.

**Mai Achong:** So, I was diagnosed at the age of 26. Leading up to that I was actually having a lot of pain, fatigue, abnormal bleeding, and irregular menstrual cycles. So, the pain though, was probably what really prompted me to seek medical attention.

I made an appointment with my regular primary care physician. They actually had an ultrasound machine there and were able to perform an ultrasound. There was low visibility for my left ovary. So, they actually referred me to a gynecologist who ordered a CT scan, and that's where they visualized there was actual mass.

**Dr. Don Dizon:** When you look back on it, how long do you think you were symptomatic for? As someone who also treats ovarian cancer, there's always this retrospection that happens when someone is finally told you have ovarian cancer and they look back and say, 'Gosh, you know, I've been sick for a while.'

**Mai Achong:** Yeah, I want to say that I was having symptoms, even four years prior to that diagnosis, the same type of symptoms. I did see a gynecologist at that time. They saw a small cyst on my left ovary, but we never followed up on it.

**Dr. Don Dizon:** You must have heard that 'Oh, cyst? Young woman, menstruating, totally normal, don't worry about it.'

**Mai Achong:** Exactly.

**Dr. Don Dizon:** So, what ultimately led to the diagnosis? How were you finally told it was cancer?

**Mai Achong:** So, after the CT scan was ordered, they did visualize that there was a mass, a sizable mass, my gynecologist thought at the time that it was probably a fibroid but wanted to have an actual specialized ultrasound to really take a look at it. At that ultrasound, the radiologist came in, and he was

pretty clear that it was something that was more serious. And so, he and my gynecologist were able to refer me to a gynecologic oncologist to get me ready for surgery.

I think at that time was probably the first moment that I realized that it might be something serious. When he sat me at the table and said, 'In the best case, it may be a fibroid. We cut in and we take it out, everything's good, you move on. But worst-case scenario, if it is cancer, and we get in there and it's possibly spread to the other ovary, maybe to the uterus, I may have to do a total hysterectomy.'

**Dr. Don Dizon:** For our listeners, a gynecologic oncologist is a specialist trained in OB-GYN, and cares for people who are diagnosed with ovarian cervix or uterine cancer or suspected of having it. A lot of our colleagues do the surgery as well as the medical management. Some just do the surgery alone.

Getting back to your story, though, Mai, when you heard the word cancer at the age of 26, what was that like for you, do you remember?

**Mai Achong:** It was scary just thinking that, up to that point, I wasn't ready to have a baby, but just knowing that this was going to change my life if that's what it was, that I could possibly never bear a child, and to have my grandmother crying, that's when the emotions actually really hit me.

**Dr. Don Dizon:** I think that's so interesting and perhaps you can speak on it if it was something you experienced. When I meet someone young, the tendency is to treat them almost like my child and say, 'We're going to get you through this. You're going to live.' Outline a plan, like, this is the surgery, then this is the chemo and this is that really not even veer off of this. 'This is what we're going to take to cure you.' But we now know that people need to see a life beyond just cancer. So, I think it's really striking that you mentioned, 'Boy, what is this going to do to my prospects of having a baby someday?' Was that something that stayed with you at the original diagnosis?

**Mai Achong:** That did stay with me at the original diagnosis. It was after surgery when he told me that he was able to spare fertility, that was like a breath of fresh air, just knowing that I had that choice.

**Dr. Don Dizon:** Did you guys talk about fertility preservation options, even before when you were planning the next steps?

**Mai Achong:** Not initially. That consultation happened pretty quickly following that CT scan, and we went into surgery very soon after. So, there wasn't really a time that he brought up that 'Maybe you might want to preserve or save eggs', or anything like that. It didn't even cross my mind.

**Dr. Don Dizon:** Yeah, I think that is the challenge. We do know for folks diagnosed with breast cancer at a young age or diagnosed with colon cancer, for example, providing that window where we're the ones, the oncologists are the ones that say, 'Have you thought about this?' Almost you need that thing to pull you back into perspective, don't you think?

**Mai Achong:** I agree 100%. Because fast forward to my recurrence...

**Dr. Don Dizon:** How long was it until you recurred?

**Mai Achong:** So, I recurred just shy of 5 years, but again, I did have symptoms leading up to that. So, I want to say probably in that 3rd to 4th year, is when it was actually back. But leading up to that surgery, that's when my doctor, a different gynecologic oncologist at this time, brought up fertility sparing.

I did go to a fertility clinic. I did speak with the specialist there, but with her and my gynecologic oncologist, they decided that the hormone treatment would not be in my best interest. It was still my decision, but they strongly were against it.

**Dr. Don Dizon:** How did that make you feel?

**Mai Achong:** Mixed feelings, I would say. I think that at the time of my recurrence, I already had my daughter, and had I not I think I would have been different. I think I would have done anything at that time to spare my fertility or to save eggs and do what it might take for the future. But knowing that I had my daughter and my gynecologic oncologist told me, 'You are my concern, and I want you to be here so you can be there for your daughter.' I mean, that was it.

**Dr. Don Dizon:** I congratulate you...

**Mai Achong:** Thank you.

**Dr. Don Dizon:** For having your child. Do you want to tell us a little bit about how that happened? Like, where did your daughter come in between these two cancer diagnoses?

**Mai Achong:** Very soon after my first surgery when I was diagnosed, I became pregnant with my daughter, because I had abnormal menstruations for years and because I was missing an ovary, I don't know if it was just false thoughts, but I thought I was 50% less likely to conceive a child.

I was pregnant very soon after my first diagnosis. I was monitored very closely during my whole pregnancy. I had ultrasounds every single month to make sure that cancer wasn't growing back while I was growing a child.

**Dr. Don Dizon:** Because we know that these tumors, and I can understand the concern your gynecological oncologist had, we believe these granulosa cell tumors, which is the type of cancer you had, can be hormonally driven.

So, yes, anything that might simulate makes us a bit nervous. I recall, a completely separate - someone came to see me after a diagnosis of breast cancer because they got pregnant on Tamoxifen and they were advised to abort.

**Mai Achong:** Really?

**Dr. Don Dizon:** This child, which they really want, and were sort of coming to see me with that. And I think it again speaks to that paternalism that sometimes oncologists have when it comes to the people that we care for because we care for them very, very much. How was the news that you were pregnant so soon after your first pregnancy, how was that received?

**Mai Achong:** Honestly, I was shocked. I wasn't ready. I'm like, 'Okay, so I'm 26. I have cancer. I overcame that and now I'm pregnant. How does this happen in the blink of an eye?' I wasn't ready. But at the same time, I was so grateful that just months before, I thought I would possibly never have a child to having that blessing, basically, of being pregnant and knowing that I was going to be a mom.

**Dr. Don Dizon:** That's so fantastic! Congratulations, again. So, you mentioned that with the relapse, was your experience getting diagnosed with the recurrence different from when you were first diagnosed in terms of how you perceived it? How ready were we to diagnose this?

**Mai Achong:** Unfortunately, I want to say I wish I would have known better from the first time what to look for, and how to speak up for myself, but I kind of felt the same way from the first time, kind of ignored and had really bad follow up. We were trending my tumor markers, which for me is the inhibin B, that was trending high.

There wasn't really a lot to know or much to plan for. They thought, 'Oh, well, let's try to change your birth control, or maybe it's just birth control itself. Maybe we'll try doing the IUD instead.'

Symptoms just kind of kept going until, again, it was a lot of pain, a lot of fatigue. And then back, I was at the regular gynecologist, doing an ultrasound and finding a mass now on my liver.

**Dr. Don Dizon:** Oh my god. Okay, so it wasn't your gynecologic oncologist that helped to detect this?

**Mai Achong:** No.

**Dr. Don Dizon:** What did that do in terms of your faith in oncology?

**Mai Achong:** I was frustrated and angry.

**Dr. Don Dizon:** Well, I actually don't think that's uncommon. We rarely hear about that unless someone is diagnosed with cancer that is now deemed terminal. Or it's someone who has since died, and their family really expressing some anguish. But you have survived, you have more than survived, you've thrived. What was that like to feel so frustrated?

**Mai Achong:** I thought that since my cancer was just stage 1, that it wouldn't come back. So, I think that it wasn't under my radar, and then not being well kept or kind of ignored. It was just really frustrating.

It came to the point where I felt like I kept calling out or calling them and trying to do something on my part. And then just feeling like I'm gonna give up. Maybe it's just in my head because they don't care or they don't see that it's something big. And so, then when it was actually something, it just kind of takes your breath away, like this could have been avoided.

**Dr. Don Dizon:** Yeah. So, how did you navigate that time? So, you're in your gynecologist's office, and she's saying there's a mass in your liver.

**Mai Achong:** So, there's a mass in my liver. I asked if they could help contact my oncology department. Again, we didn't really get any answers there. And so, I went to a general surgeon.

**Dr. Don Dizon:** Wow. How did you find the general surgeon?

**Mai Achong:** They referred me and when I was with the general surgeon, I brought up that I have ovarian cancer, that it's a granulosa cell tumor, it had been a number of years, but I wanted to find out if we could do labs to see what the tumor markers were. I wanted to see if they could maybe help and find out if oncology wanted to step in. And when I came to do my pre-admission labs, they pulled my CA125, which, as you know, doesn't mean anything for me. But my tumor ruptured prior to surgery.

**Dr. Don Dizon:** Oh, my goodness! So, was the surgery relatively urgent?

**Mai Achong:** Well, they didn't know that it had ruptured until I was there in surgery. And then they realized that it was a recurrent. So, it had spread more than just my liver. It was throughout my abdominal cavity. So, they removed what they could, but they could not remove all and completed this surgery and referred me to oncology.

**Dr. Don Dizon:** So, all you have is your first experience with this, which was, not at all pleasant, but you woke up, you were told it was all... you could still have a baby. Now you're waking up for a second time, what do you remember being told, and how was that handled?

**Mai Achong:** I just remember them telling me that it was cancer and immediately me being angry, and crying, I haven't shed a lot of tears for cancer. But when the new oncologist came in and explained to me what it was and how spread it was, and that it should have been handled by oncology, I think I was ugly crying. Like, I tried.

**Dr. Don Dizon:** There was almost this point where you want to feel like the system is going to take care of you. And then when you sort of have a sense that the best that should have been done wasn't done here. I think that can be almost defeating.

**Mai Achong:** Yeah, like they failed me.

**Dr. Don Dizon:** Yeah. I think I liked the way you put that in a weird way. So many people who have come to see me, for example, have this sense that it's on them. And it's like, the only person to blame was me because I didn't advocate for myself. But in reality, so many people share your story.

'I was being followed. I was reaching out, and then this still happened.' How did you grow from that? Or do you think you did? You either have two choices, right? Either you stay in a really angry place, or you try to move on and evolve?

**Mai Achong:** Yeah, absolutely. You can't stay angry forever. I don't think I'll ever forget how I felt. I don't think I'll forget what happened. But it happened, and so the only thing I can do is to move forward from this.

I mean, it's taught me to advocate for myself, and thankfully, I have a care team that listens and watches and communicates but other than that, really paying attention to my body, really bringing up what I'm feeling or what I'm experiencing, asking questions, taking notes. And I've also found a way to connect kind of peer to peer to other survivors, or maybe women that are newly diagnosed, even women that have

questions that maybe it's not going to be oncology, but kind of being that cheerleader to them, and encouraging them to speak up because it's better to ask the questions and to push a little bit to find the right answers, than it is to not ask enough and to end up in a bad place.

**Dr. Don Dizon:** I think those are really wise words. You must see so many people who hear the word cancer, and it's almost like this deer in the headlights, like it sort of takes your breath away. And as an oncologist, I have learned the importance of pausing, delivering something, and just observing and watching and seeing how people respond.

But there's almost a wall that I think oncologists reach that the only person who can break through it is someone who's gone through that same experience, who can just say, 'What he just said is this and what I know about it is this.'

So, it really does point to advocacy. What is your sense of how you've evolved, not only as just a patient but in that advocacy space, almost a larger community of people who, unfortunately, continue to join not because they want to?

**Mai Achong:** Yeah, it's the club that you never want to be a part of. You know, it's funny because the women that I've met because of this unfortunate situation are some of the most kind, compassionate, and supportive women.

So, it's like finding the good and something bad is really important. A lot of us have similar stories where we felt something and for whatever reason, we didn't have the right attention, or we were misdiagnosed. A lot of younger women that I know have been diagnosed, so that was just not even under the radar. And symptoms of ovarian cancer are very common, I would say for women.

So, yeah, I think finding these women, and teaching or encouraging each other to advocate for ourselves, and for our health has really made a difference.

**Dr. Don Dizon:** So, that brings me to another question then. When you think about your life before you were diagnosed for the first time at 26, reflecting back on everything you thought your life was going to hold for you, the world is still your oyster, every door is unlocked. Now you've had two cancer experiences, one scarier than the other. How have you changed? What do you think cancer has done to you and done for you?

**Mai Achong:** So, when I was pre-diagnosed, I would say I thought I was almost invincible. When people say, 'Oh, don't eat that, or don't drink that it can cause cancer. Don't spend too much time out in the sun, you can get skin cancer.' That's like, 'What are you worried about? Those things would never happen to me. I'm healthy. I'm young. I have my whole life in front of me.' But now on the other side, and actually I've had more than just that first recurrence. I've lost count, but I've had eight surgeries.

**Dr. Don Dizon:** Oh, my goodness!

**Mai Achong:** Cancer has changed me. You can't focus on that. I would say that I've seen the physical changes initially in treatment, losing hair, losing brows, gaining weight, having poofy cheeks, and kind of

feeling really nauseous. And then, this far out of treatment - I haven't had chemo since 2017 - but still have neuropathy in my fingers and toes, and I can't have a child. I went through early menopause at 31.

So, seeing changes, hair changes, sexual changes, basically just from the effects of that at a young age, I have osteopenia. So, those are kind of the bad things that have changed and that financial burden of having cancer for more than a decade, and all the treatment and surgery that comes with it.

But at the same time cancer has changed me to appreciate life and to appreciate each day. For me, like, my first oat milk latte in the middle of the day, that's like one of my favorite moments. Waking up my daughter in the morning, even though she's an angsty preteen, and kissing her on the cheek. Driving my husband crazy because I'm always thinking about seven things at one time. But just enjoying the moments that we have together and not taking them for granted, and knowing that what I have been through and what I have learned can help someone else.

**Dr. Don Dizon:** Wow! We talk about something often called toxic positivity, where people will say, 'Oh, you had cancer, you look so good. Or you don't look like you have a neuropathy.' It's as if people feel like they have a mental image of what cancer looks like. And certainly, there is a mental image of what ovarian cancer looks like and you could not be farther from either. So, how do you manage all of those kinds of comments?

**Mai Achong:** Yeah, you know, that happens frequently. It's almost like within one breath, 'Well, how are you doing?' 'Well, my cancer is back. We're watching this one on my stomach and my spleen, and we're waiting for an endoscopy so I can have surgery.' 'But you look so great.'

It's like, yeah, how do I respond to that? I mean, 'Thank you?' But I think that's part of growing with positivity or growing from it, instead of letting it take you down. It's thriving when I still can. I can wake up in the morning. I can breathe lungs, without oxygen tanks. I can walk. I can go to the bathroom. I can do my normal everyday things. And so, just being as healthy as I can, staying active, and finding things that bring me joy.

I hope that I still look good because sometimes right after surgery, or during treatment, those times are awful. You don't even want your worst enemy to feel like that. So, I mean, when you know how bad bad can be, you have to take the good.

**Dr. Don Dizon:** So, your base is, like, she tells me, 'You look all this', like, 'I'll take it, it's fine. I'll take it.' So, let me ask you one other question. Parenting during cancer or with cancer or after cancer is challenging in the context of parenting in general. So, if there are - I believe there's going to be plenty of them - if there are young people with kids in your kind of situation, what is your advice to them? What have you learned that works for you?

**Mai Achong:** Yeah. As you mentioned, parenting is challenging. And every parent has a different parenting style. So, one thing that works for me may be different for somebody else, but I have always tried to keep open communication with my daughter.

When my cancer came back, she was in VPK. So, there's not much you can do to avoid the obvious changes when you're going through chemotherapy, like complete hair loss. So, I had to explain to her that

it's a medication, that I have cancer, which is a sickness, and that it is helping to heal, and that the hair loss is temporary, and it'll grow back.

I think she's always had strength, even as a young little one. The hard part for me when she was younger, is not having the energy. A lot of times I would try to put her to bed, and I'd be reading her story and I would fall asleep. So, it was almost like she was putting me to bed.

I think as she grows older, the challenge continues, but in a different way. She understands it a lot more. She knows how to even advocate for it more as a preteen like she'll kind of school people about the difference between breast cancer and ovarian cancer.

**Dr. Don Dizon:** Well, that's great. She's educating her own peers. She's becoming an advocate on her own, right?

**Mai Achong:** Exactly. But the challenges are different as she grows up because now I think she is more aware of all the effects and she is more aware of when there is a loss to someone that had cancer or just kind of like her challenges as a preteen, things that she deals with socially, emotionally, and me not wanting to overbear her with the challenges that I'm having, as to not make her feel like her challenges are less, or that my challenges I have now become her burden. It's always kind of a mental check that you have to kind of stay on top of.

**Dr. Don Dizon:** I think one of the most, if I could call it unfair things, is that life doesn't give you a break when you get cancer. I think learning how to parent as your kids develop their own sense of self is hard enough. But I think it's a really broad thing what you just said, you don't have all the answers. It starts with openness and being honest and answering the questions to the best you can and then trying to balance your needs with everything that she needs. I mean, that's what any parent is going to want to do.

One of the things that you've mentioned is that you've met so many incredible people around your time in 'cancer land', and I'm sure you've had many people that you've bonded with in the past in the offices and the infusion suites.

Well, I have recently become aware of the loss. I always think of their spouses and their kids. And I sort of think about how much I'll miss them and kind of our staff will miss them. But it came to me during a conversation with someone that I treated when she asked how so and so is doing and I had to break the news that so and so had died. And to see this person who bonded with her in an infusion unit cry for someone that they had met, as people getting treated together, it struck me that that is a source of loss that we as oncologists may be blind to, because relationships go all over the place. I wonder what you think of that as sort of the relationships within our cancer communities?

**Mai Achong:** So, I'm a part of a support group at the hospital that I attend. I've also started a support group with two other survivors. We meet on Zoom. We have lost a number of women over the years. It is hard. I think it's hard for a number of different reasons. It's hard because we've built that relationship with them. It can happen so quickly where they seem stable and energetic, so well, and when that recurrence happens, quickly into treatment, then it's just a fast decline, it's kind of shocking. But I wouldn't take that away because there is a closeness and empathy that we share with one another because we have

experiences not exactly alike, but we have moments. And even though we see that loss, I think it's important that we're still there for one another.

The other part that's a little difficult, too, is because we all have cancer, naturally, when we see this happen to one of our 'sisters', we like to call each other, then it does give us fear for our own health, and what is to come and how that happens.

I think people that don't have cancer have this idea that someone that has cancer just looks kind of ill all the time, right? And that it just happened so quickly, like, 'She has cancer and the next day, she's gone.' But it's not like that, right?

And so, sometimes the more difficult part is, I think, knowing that the women are in such pain in the end, and just praying for comfort and peace and they've accepted it, they know, but just knowing the suffering that they have to go through, it's not fast. It doesn't seem fast for them. So, I think that also is difficult.

**Dr. Don Dizon:** Being an oncologist, I sometimes say it's like being an actor because you go into a room and you have to be there to have a very, very hard conversation. You can walk out of that room and go to someone else's room, and you have to be happy because they're in remission. It's this constant changing but what I've learned from folks like you and from training is everyone that I've treated as they change you, and you remember, and you're better for it, almost.

As a doctor, I know my approach to the people that I treat after that person is going to be different because I met that person, and it ends up being something that motivates if anything. Treating granulosa cell tumors cancer and other cell cancers, it's just not a cancer, I'm treating a person with that cancer. And that's only a lesson that I learned from being in clinic.

I have the sense that with every loss, you also have this amazing moment, maybe that this person was special to me. I think it's so important that you are there to support you because you can have your family, right? But there is this extra layer that can provide comfort, and I think people shouldn't be afraid of that.

**Mai Achong** No, they shouldn't. I think sometimes with our family and our closest friends, it's hard for them because they see what we're going through, they hear what the doctor is saying, but it's an out-of-body experience and they want to fix it. And sometimes in the support, it's not something that can be fixed. It's just something I'm going through, something I want to voice, and to have somebody to understand what you're going through, it's irreplaceable.

**Dr. Don Dizon:** Yeah. Well, I am hoping that people hear you, hear your voice and hear your experience, and hear you thrive. I think our world is really so much more complicated than being cured or dead of cancer. There are people like you, and I'm just so happy that I got this moment to chat with you. So, final question, how do you, Mai Achong, conquer cancer?

**Mai Achong:** I conquer cancer by thriving. I've been waking up using my limbs, being as healthy as I can be, eating as well as I can, moving my body, loving my family, and living and moving forward. That's how I conquer cancer.

**Dr. Don Dizon:** And I think those are words to live by.

Thank you very much for listening to this podcast brought to you by Conquer Cancer, the ASCO Foundation. For doctor-approved patient information please visit [cancer.net](http://cancer.net) which is supported in part by Conquer Cancer donors.

Conquer Cancer is creating a world where cancer is prevented or cured and every survivor is healthy. You can help by donating now at [conquer.org/podcast](http://conquer.org/podcast).

The participants of this podcast report no conflicts of interest relevant to this podcast. Full disclosures can be found on the episode page on [conquer.org](http://conquer.org).

*The purpose of this podcast is to educate and to inform. This is not a substitute for professional medical care and is not intended for use in the diagnosis or treatment of individual conditions.*

*Guests on this podcast express their own opinions, experience, and conclusions. Guest statements on the podcast do not express the opinions of ASCO. The mention of any product, service, organization, activity or therapy should not be construed as an ASCO endorsement.*