

The Heartful Parent Nancy Balin mixdown

Nancy Balin shares stepson Jameson's battle with testicular cancer on Heartful Parent Podcast, urging early detection and proactive health measures. Listeners are encouraged to prioritize health and advocate for transparent healthcare communication.

[0:00] Music.

[0:30] Back to the Heartful Parent Podcast. I have an incredibly important interview for you this week. And one that when you hear the subject of, you may think, oh, I'm not sure that I want to think about that or listen to that right now.

And I'm going to ask you, just set those feelings aside and listen anyway.

Anyway, the story that today's guest is going to tell you is riveting, heartbreaking, and so important.

[1:04] Today's guest is my friend, my former colleague, Nancy Balin.

Nancy and I were prosecutors together for a number of years.

We also saw each other socially.

Nancy and her then wife attended my wedding.

To my husband, and we've just been in one another's orbits for a really long time.

And the story that she's about to share with you is the story of her stepson, Jameson,

Heartbreaking Diagnosis and Missed Opportunities

[1:40] who received a really scary diagnosis and who did not ultimately survive that diagnosis. diagnosis.

I'm not telling you anything that you're not going to hear. I'm not spilling the end of the story. I think it's important to know at the outset that this does not have a happy ending.

[2:00] And yet it's such an important story. If you yourself have testicles or love somebody who does, your partner, your father, your brother, whoever it might be, this interview is so incredibly critical. Because not only is the story, like I said, the story is heartbreaking and the purpose of this isn't to make you feel sad. And full confession, I cried during this interview.

The purpose of this interview is so that your son, your nephew, your husband, your brother doesn't, like Jameson Jones, die from embarrassment.

And Nancy's going to explain what that means in the course of this interview, but suffice it to say that Jameson didn't have to die.

And so we all need to know how we can prevent this from happening to our loved ones.

Nancy attended Tufts University. She has a law degree from the University of Puget Sound, which is now known as Seattle University Law School.

Like I said, she was a prosecutor with me for many years and what she's about to share will, I wager, be a story that you won't soon forget. it.

Without further ado, Nancy Bailyn.

[3:27] Nancy, welcome to the Heartful Parent Podcast. I love that you are here.

Thank you. I'm so happy to be here. So obviously, I let everybody know as I introduced this episode that you and I know each other from way back.

We were colleagues together in the prosecutor's office, but clearly that's not what we're here to talk about today.

Nancy's Emotional Journey Begins

[3:48] So I want to jump right in and ask you to share your story. And I know it's a difficult one, but it's such an important one.

[3:57] Okay, let's see. Give a very little bit of background.

I became a stepmother when my stepson was 11.

And so I like to say I missed all the fun stuff because I love newborns.

And I have sisters and really didn't know what to do with a boy.

So I remember the first time he and I ever sat down to dinner and it was just the two of us. I remember panicking. What am I going to talk about?

What am I going to do with him for a half hour?

And I think it went fine. I don't remember. But I remember worrying about it.

He was six foot 135, which meant that at the sport he chose, which made sense, was cross-country.

Perfectly built for cross-country. And he started running in junior high.

And like a good step-parent, I went to his meets, all of his meets.

And it was a blended family. So we had a main group of, I'll call it, a main group of five parents, one dad and four moms and step-moms.

And all of us went to his meets. We were all good parents. And we all saw him double over at finish lines.

[4:59] And this is, let's see, grade eight, grade starting.

He started running probably age 12 or 13.

So that's about where we are in time in his life. And so we saw him double over and I knew a very limited amount of something called torsion, which is what can happen to testicles if a runner or active person, I guess, basketball player, lets them bounce.

They can twist like a dog with bloat or a horse with colic they can twist get necrotic and die and it's very painful and so I kept telling his father will you tell your son he needs to wear better training shorts or whatever he's wearing under there because it's too old for me to ask he needs to wear better training clothes because that's what I figured was happening.

[5:47] And I, we all saw it happen at least once. And he was a very circumspect child and stoic as well.

Then one Saturday morning, when he was supposed to be getting ready for the ski bus to go up and have lessons, instead of being ready in the living room, his mother found him writhing around on the living room floor.

And she asked him what was the matter. And he somehow made it clear that his testicles hurt.

And she said, let me see. And he said, no. and she said, let me see.

I was sick in bed upstairs.

And apparently it was about the size of a tennis ball or a softball. It was huge.

And so she came up to tell me that they were on their way to the emergency room.

And so I climbed out of my sick bed, got dressed, followed in my own car.

And by the time I got to the emergency room, he was being diagnosed with testicular cancer. The ultrasound was ending.

And he was 14. 14 years old in ninth grade on a Saturday morning.

[6:47] Testicular cancer. He was diagnosed by the urologist on call at the hospital.

He had the only treatment for testicular cancer is surgically removing that testicle.

And you don't do a biopsy because it's one of those cancers where if you do a biopsy, you can explode the cancer all over. And it was very clear what it was.

So he had the orchiectomy that day. He was in the hospital, I don't know, for a couple of days. And then we brought him home.

[7:16] Now, what had happened the week before, and I tell this second story because it was missed not too long before that.

He had an episode a week or two before that of shortness of breath when he was lying down.

He was feeling short of breath and had some chest pain. Again, a 14-year-old.

Not just a 14-year-old, but a 14-year-old who is not even moving.

Right. Extremely healthy. Yeah. Extremely healthy. And lying down, and that's when the shortness of breath. Yeah, lying down. Yeah.
Which I now understand is a sign.
So we took him to a cardiologist and he was diagnosed with what I understand to be, we don't know what it is.
It's a diagnosis that just went out of my mind.
Oh, it's an inflammation of the lining of the heart. Right now I've forgotten the diagnosis.
And so antibiotics, it's an infection.

[8:08] Antibiotics, go home. So that happened about a week before, maybe two weeks before the cancer diagnosis, which was on a Saturday.
As it happened, he had a follow-up with the cardiologist. I believe it was the following Wednesday, like four days later.
So we go in, wonderful guy at Evergreen.
We go in and he asked that question they always ask, which is, have you had any changes in your health since you were here last?
And so his mother and I laugh and say, we had this one little new diagnosis of testicular cancer.
And the doctor's face went gray and very still, which I didn't understand or really see till later.
And he said, we're going to have a CT scan with contrast and I'm going to set it up and you're going to go downstairs.
You're going to go to radiology, CT scan.
And I'm calling a friend of mine about his cancer waiting.
And I see the cardiologist walking above me on the sky bridge at 515 on a Friday.
And I remember thinking, wow, what a great guy.
He's waiting for us. This This is after the CT and waiting for results.

[9:10] And then it goes by and then the results come back and the person in the office says, the radiologist will be right with you to tell you what he found.
The radiologist is not the one who comes out. It's the cardiologist.
Because what had happened is he didn't have cardio, still can't remember the name of it.
He didn't have an infection around the lining of the heart. He had metastases all the way up to here.
And he had a tumor in the back of his heart that was pushing on it.
And so that was how we found out. And that's why the doctor's face, it went like this when he heard about the cancer, because he immediately realized, oh, no.
And so it was so it wasn't just cancer in the testicle. It had metastasized all the way up his body.
In fact, it metastasized up to here.
And you're pointing to your leg right behind you. Yeah, he his this scar started from here and went all the way down.
Now, when the doctor looked at his x-ray again, he could see the shadow of one of the tumors pressing on the back of his heart.

[10:09] So that was a small amount of time that was missed.
The larger amount of time that was missed was, this was January 15th of 2005.
He had to have a sports physical every summer because he was an athlete.
And we had a family physician whom I won't name.
And so he had been back there, he would have been 13 then, and she did not do a testicle exam.
She had done them before, and he had a previous issue with his scrotum, just a cyst.
But we later found out that she hadn't done it.
Wow. And we don't know what happened in that room. We don't know if she wanted to do it and he refused it, or she didn't even offer it. We don't know which of those two it was.
But her face also turned gray when she found out what type of cancer he had.
That was seven months of diagnosis time that we missed.
And the reason that's really important is because Jameson had three types of testicular cancer.

One of them doubles in size every three weeks.

So you do the math about how many stages we probably missed.

Yeah. Over the course of seven months. Yeah. Right. So that's what happened on January 15th of 2005 and the two things that happened just before that, way before that.

And I personally believe that the lack of the testicle exam the prior June was.

[11:34] May have been the tipping point in his not surviving his cancer.

I can't know that. I don't know that. I would never name that doctor.

That doctor has to live with her own omission.

Since then, when I taught health classes at Garfield for several years, after I met a bunch of health teachers down at the school district office in Seattle, that's when I started telling, youth, not only people with testicles, but their partners, that if there is ever Oh, if I would have a raise of hands, how many of you are athletes and the hands go up?

And how many of you have a sports physical every year and the hands go up?

And then those of you with testicles, I was very careful to make sure to include all different gender identities of people, which was pointed out to me by one of the students when I first started teaching. teaching.

Then I'd ask a third question. Those of you with testicles, how many of you either refused a testicle exam during your sports physical when the doctor offered it or the doctor didn't offer it? And then some of the hands would go up.

And I'd say, so you're never going to do that again, are you?

You're going to ask for one or you're not going to defer it next time, right? And all the faces would go up and down.

So I started teaching the physicals and and sports physicals, that's a time when that subject should come up and an examination should be made.

Yeah. Nancy, you obviously touched on this, but Jameson did not survive.

The Impact of Jameson's Diagnosis Unfolds

[12:57] But it wasn't obviously immediate right after his diagnosis.

Can you walk us through what the next years looked like? Yes. Right.

Okay. So he's diagnosed January 15th, which is a Saturday. By Monday, we're talking to an oncologist at Evergreen.

And the next thing that happened, which also is important for your audience to know, is Jameson went to 14.

And as we know, what happened, the treatment for cancer is chemotherapy.

And what some of us know is that chemotherapy kills fertility or can certainly affects it and can kill it.

And so So it making him unable to have children.

And so the first place that the oncologist at Evergreen sent us was to overlay reproductive to make sure Jameson banked sperm.

And because we didn't want to start chemo until he had done that.

So as I remember, it was very quick. It was three or four appointments over maybe a week and a half or two weeks.

[13:57] And luckily, I didn't have to make the decision about, videos versus books versus magazines.

And that's where one of, I'll tell you, the moments of graveyard humor, is that what it's called?

The Importance of Early Detection

[14:10] Something like that happened as a parent of a child with cancer.

And you have to find humor where you can.

And so his mother and I are sitting in the waiting room with all these young couples, very sad looking couples, of course.

[14:27] And he comes And I think it's his last appointment.

Maybe he'd been there two or three other times. And he comes out and I'm not even thinking. I look at my wife and I'm like, dude, 15 minutes. Nice job. Big high five.

And we walk out and people must be thinking, what the heck?

[14:44] Gallows humor. Yeah, Gallo's tumor of, I have a child who has to give sperm donations because he's about to have the most horrible chemo.

And I'm congratulating him on how fast he can get that done so we can go off on our other appointments. So I've told that story a lot.

It was funny. I didn't mean to be funny, but it was funny. So that's the first thing we did. I have to tell you, as somebody who has sat in those infernality rooms, waiting rooms, I think I would have actually appreciated the lightness of that.

I don't remember seeing anybody or looking at anybody.

I just remember what I said in the high five as we walked out to our next thing.

Yeah, I'm glad it could have helped. Yeah. Yeah. So that happened first.

And then he had chemo. He had four rounds, four rounds or six rounds.

Compounds and the way he, and because thank God he was a pediatric patient because when adults have chemo, they go in, they sit in the chair and then they go home and then they have to manage their hydration, their nausea, their diet, their exhaustion, their everything.

Thank God he was pediatric because his chemo was inpatient.

And the very first time he had chemo.

[16:02] There were three or four different drugs given. And the first time he was given one of the drugs, the next thing that happened was he turned purple and stopped breathing, had an anaphylactic reaction. And thank God we were in the hospital.

I noticed he couldn't talk. I noticed his color and a lot of running around happened.

And so then we knew that he had to be premedicated before that's called bleomycin.

And that also causes hearing damage and lung damage.

So I guess it makes sense that it can cause anaphylaxis.

Yeah. He had four rounds of chemo. And then after the chemo shrunk the tumors, then he had multiple surgeries.

And here's another very important fact about cancer is you want to be treated where they treat your cancer, your type of cancer.

And Children's Hospital in Seattle is a wonderful, amazing place.

And it is a children's hospital.

[16:56] Testicular cancer is not a children's cancer. cancer. So what we did, his mother pretty much was able to keep herself alive by being on the internet around the clock and researching everything everywhere.

And of course, this is 2005, Lance Armstrong had not been that many years before when he had publicized it.

And there've been a couple of other athletes, almost all of them athletes since then.

So she did that research and we discovered who had treated Lance Armstrong.

And the person who treated Lance Armstrong is a wonderful man named Larry Einhorn, who is an oncologist in Indianapolis.

And he actually is the one who in the seventies, as like a resident or a very new doctor, he's the one who discovered the combination of chemo that caused testicular cancer to stop being a death sentence and reversed the survival statistics from 20% survival to 80% survival.

And now it's 95% curable, not just survivable but curable Dr.

Einhorn invented the cure for testicular cancer wow before the days of um.

Consulting Dr. Einhorn: A Turning Point

[18:01] That caring bridge before caring bridge i used to send emails and when i would send an email when i would refer to dr einhorn i just started referring to him as god because he was god to us yeah he would he's still alive and he's still practicing i shouldn't put him in the pastor so we consulted with him we sent jameson faxed all of his records i fedexed all the cds of all of his scans this early in my knowledge about how to advocate for a child with cancer i i got very before i started He started screening at insurance companies and other things like that.

Yeah. And so he really became Jameson's primary oncologist.

What he was, he quarterbacked the care and children's took orders from him, which they wouldn't appreciate it being told that way. But that's what happened.

And the reason that was important was because when there's a thing called neutropenia.

And so you've heard that sometimes that when people have cancer, their white counts go down because you're killing their immune system.

And when white counts go down far enough, in the case of leukemia, you hold chemo.

You don't give chemo to kids with leukemia if their white count is low enough.

So there was an afternoon where Jameson's attending told us he was not going to get chemo that day.

We shouldn't bring him in because he was neutropenic.

And I knew that testicular cancer was different.

And I remember walking back and forth across my bedroom, pacing in my stocking feet, seat.

[19:25] Crying and begging and determining that if I had to go down there and get arrested.

[19:32] Sitting in children's and making sure he got his chemo, I was prepared to do that.

What I did do was I made her talk to Dr. Einhorn's people in Indianapolis.

And by the end of the afternoon, she had changed her mind and decided to implement

Advocating for Timely Treatment

[19:45] the chemo because you don't skip chemo with testicular cancer. You give it on time.

Okay. This is another reason why the research is really important to know something like that.

I wouldn't have known anything like that if we hadn't had our conversations with Dr. Reinhart.

So he went through his chemo. So also apropos of this subject, he had all of his surgeries in Indianapolis.

He had four separate surgeries, starting with the abdomen and just moving up the body.

The last one was to get tumors out of his neck. The one in the abdomen was life-threatening.

One of his other moms, when she was told that he could die during the surgery, surgery fainted dead away right there in the waiting room.

[20:23] So all the surgeries were there and his last surgery was in November and he was declared in remission just before Thanksgiving in that same year of 2005.

That's a hell of a journey within less than a year.

Right. Right. To go from seemingly healthy to full-on metastasized to cancer to remission.

And didn't stop going to school either. He didn't want to stop going to school.

He was in ninth grade at Skyview in Bothell.

It was the only normal thing in his life.

[21:02] And he fought. The school thought he should stay home.

We thought he should stay home. But we understood why he needed it.

So the school nurse was amazing.

He had lunch, I forget, in the nurse's office, maybe.

He did a lot of sleeping in the nurse's office, but he more than passed his classes that year. He did not fall behind.

He did not want to not go to school. Yeah. Yeah.

Jameson's Determination to Live a Normal Life

[21:26] So he finished ninth grade and went to high school the next year.

And so by that point, he's, what, 15?

In fact, in November of 2005, that was the end of his first semester of high school at Bothell High School. So, yes, he was a sophomore. Okay.

Years of Remission and Hope

[21:41] And Jameson stayed in remission for a number of years, yes?

He was in remission for four and a half years. and we did his follow-up care in Oregon because one of the Indianapolis docs left there and went to OHSU.

So we didn't have to fly to Indianapolis anymore.

After Jameson was in remission, we just had to take the train or the car down to Portland.

And after he had two years of clean appointments, meaning x-rays, CT scans, and blood work, all showing no evidence of cancer, still in remission.

[22:16] The doctor after two years the doctor said if you're not gonna if you haven't gotten it by now you're probably not going to get it probably not going to get it probably not going to get it so he's still having his appointments they stretch further more and more time in between them as time goes on and he graduated high school and got into multiple colleges decided on WSU was, snatched up by the rowing team when they saw him wearing cross-country gear because same body type very similar type of athlete he started rowing he would call us at 8 30 at night fall asleep on the phone because two workouts a day and he loved it there and they were wonderful to him there and he his mom went over for mom's weekend as they have at wsu in march and they had the obligatory mother-son picture and we had our appointment probably around then yeah in march also as it happened.

And then it took forever for the pictures to come back.

And so the pictures finally come back in May and she opens up the picture and she looks at it and she says, I find this out later that day.

She looked at the picture and says, he's sick again.

[23:24] And not being, not having been a mother at the time for long enough, I didn't see the change. Now I can see it.

There's a gray cast to his skin. And then she realized, hey, we never got the blood work results from March from Oregon. They never told us.

Either they forgot or I don't know what happened.

So she called to get them. This was a Friday. I'll never forget.

Devastating News of Relapse

[23:47] Friday afternoon, I get home from work and she tells me she called to get them.

And in fact, he was in relapse. Oh my goodness.

And so it's one of his March to May.

Right. Another six months. And only her looking at the photo. Correct.

That led to those blood work, the blood results that showed he was in relapse. That's right.

In fact, because he didn't have symptoms yet, he actually relapsed in his lungs.

And if he would have known if he was having symptoms, because you need so much of your lungs when you're doing that much hard work, rowing is so difficult.

Yes. So that was probably...

[24:23] The first week of May, second week of May. And he had a regatta that he was rowing in Sacramento at the end of the month. And he had finals coming up.

And as a group of parents, as a family, we decided not to tell him.

And to give him his freshman year and to give him his regatta and give him his piece and let him take finals in peace.

And those two weeks weren't going to make a darn bit of difference in any case.

So we didn't tell him until after he got back from Sacramento.

Decisions in the Face of Relapse

[24:52] Okay. And then he went back and he had four rounds of regular chemo, which he failed, is what you call it, failed to put him into remission.

Then he had four rounds of high-dose chemo, which involves taking stem cells out first because the high-dose chemo kills the entire immune system and then

The Harrowing Experience of High-Dose Chemo

[25:09] giving them back so he can grow a new one.

It involves being hospitalized in isolation. population and if you think the side effects of regular chemo are bad the side effects from high-dose chemo are horrific couldn't bathe himself his mother had to bathe him and carry him to the bathtub at children's and and remind me in a little while to talk about another of the impacts of cancer and that's economic the economic fallout economic toxicity is what i called it when i used to do workshops on it so after his high-dose chemo then he had.

[25:44] Surgery in his lung. He was 19 when he relapsed.

And so technically not a minor anymore. But fortunately, because he had treated at Children's during his first bout of cancer, they took him back as a patient.

Thank heavens, because see my earlier comments about management of chemo, especially management of high-dose chemo. So he was hospitalized for all of his chemo the second time as well. He lived in the hospital a lot during that year and a half.

[26:12] So one of his oncologists who is at Seattle Cancer Care Alliance, which is now one with Fred Hutch, again, because he was an adult, his hospitalizations were at Children's for chemo.

His surgery was at UW because he was an adult.

And we had Cancer Care Alliance docs rather than Children's docs as his attending.

So one of his attendings came in and talked with him before she talked with us. And the chemo had failed and the surgery had failed.

And we had a meeting with his oncologist, his name is Doug Hawkins at Children's. He's still there.

He also is a god. He has these huge circles under his eyes.

And it's got to be from decades of such a difficult pediatric oncology practice.

I think he's a saint. I can't even imagine. Yeah. Yeah.

I still have his direct line in my phone. I would never call it, but I, as well as Dr.

Einhorn's cell phone, and I just keep them because they're part of me now.

Yeah. So we had a meeting with him, all the parents and Dr.

Quality of Life Appointment

[27:20] Hawkins and Jameson. And what I call that meeting is the quality of life appointment.

It was New Year's Eve day of 2009.

[27:29] And Dr. Hawkins essentially said said to Jameson, you need to go do what you want to do, what you want to do in your life.

And then one of us asked Jameson if he'd like to meet with Dr.

Hawkins alone, presumably so Jameson could finally cry.

And the five of us left and he met with Dr. Hawkins privately.

And again, that was December 31st, 2009. And he was able to live to his next birthday, last birthday, which was March 14th of 2010 and died October 7th of 2010.

I know it's terrible.

Yeah it's and his last year when i had my first epiphany about fundraising because here this is something i wanted to talk about and i'll bring it up now yeah there i talked to you about the toxicity of chemo mouth sores just to to give you a sense for what he suffered with his both his chemo and his high dose chemo you probably know that chemo can cause mouth sores your mouth mouth, it's the same sort of mucosal tissue from the mouth all the way out the other end.

And he had burning sores throughout his entire intestinal system of a pain that I can't imagine.

Yeah. And I was just going to say, and I, cause I, I had to take a moment there because it's a tough story and I've heard you tell it before.

We knew each other when this happened. I had the.

[28:54] And every time I hear you say it, it gets me. Oh, I should.

I'll tell you something about that. I had back when he was still alive, but just sick.

His mother, another piece of gallows humor. His mother and I used to come home from work and say, I made three people cry today. I made five people cry today.

Because and when I started teaching this after he died and I started talking to parents, parents, they all had the same response, which was, oh, I can't even imagine.

And because I am a person with more empathy than is healthy for any one person, I would be like, oh, you shouldn't, it's terrible.

And then I realized, no, you're missing an opportunity because I want them to feel, I want them to have that moment of fear that this could have been them.

I want them to be afraid and I want them to feel sorrowful and I want them to be shocked. So they go home and they they talk to their kid.

And so I stopped saying, oh, you shouldn't. And I started saying, good, let me tell you how maybe you can prevent yourself being in my position.

[30:00] It's not quite like the gallows humor, but I don't spare people their feelings on this.

Because if I can save one boy, because his mother went, oh my God, and all of them do it, then great. Then great. Then my my life's work will be accomplished.

And I'm so glad that's the approach that you take because having known you at the time that this happened and then had you tell your story and back to you told it inside the Heartful Parent Academy a couple of years ago.

And I remember crying then as well.

When I started the podcast and it's been almost, it's been over a year now.

I remember saying as I was brainstorming who I wanted on here.

And you were right on the top of the list, Nancy, because I know.

[30:52] And that the more people who hear Jameson's story and your story, the more kids who are safe.

And I'll just mention as a side note, I am not raising sons.

Although I have talked to my husband about this. Good. Still in the demographic.

He's pretty close. Yeah.

Getting older. I'll give you the stats. Yeah, we'll talk about those.

But a dear friend of mine, her son is an athlete.

[31:19] He is a gymnast. and he was recently found like something in his testicles didn't feel right and thank goodness this child and his mother have a close enough relationship and he felt safe enough for whatever reason that he did tell her about it and and they immediately got it checked and in his case it was It was not cancer, but I remember talking with her afterwards and saying, and I talked about you, Nancy, and Jameson's story and saying how grateful she should be that she told her and that she's built that relationship with him because that very well could have been a different result. That's right.

I'll tell you the reason that Jameson's metastases went up to his neck was because he had symptoms

for upwards of a year.

Remember my earlier math about doubling every three weeks? A year.

[32:24] And as is not unusual, I'll admit this, that made me so angry that there was the reason that I, as I tell people, I'm the only female you'll ever meet who's all testicles all the time.

And that's never going to stop because the only reason he died of a 95% curable cancer is because he waited.

And in fact, years later, one of his then high school friends, he had two male best friends and one of them had a girlfriend.

[32:54] His name is Chelsea. And years later, when she was one of my sponsors for the 5K, she's a grown up, she's selling insurance.

She tells me about this conversation that I never knew about years after he died.

Jameson and his friend Trevor were having a conversation and Chelsea happened to be there.

And Jameson said, and I will never forget this quote about his testicle, it just kept getting bigger and bigger, but I was too embarrassed to tell my mom.

And when I say that to parents, they all make the same face that you just made and they cave in on themselves a little bit.

Yeah. So I, one of my, that the executive director of the Washington Urology Society suggested I have a button made.

It's very, it's, I can't think of the word. It's very provocative.

It's very provocative. And I wear it very rarely, but it has my logo on it.

And it says, ask me how my child actually did die of embarrassment.

How my boy actually died And he did die of embarrassment.

If he had been the type of kid like your friend's son, and it said, like I told you earlier, when his mother said, when he was able to admit that something, what was hurting, and she said, let me see it.

And he said, no, she said, let me see it.

What's his mother? To show her and he couldn't get up off the floor.

[34:11] Yeah. That's what kind of pain he had to be in, that he actually was not physically unable to hide it anymore.

And then I've told you about the doubling over at finish lines.

I myself, as a parent, carry guilt about that, that I will always have.

The only respite I have is that I was last in line in decision-making ability with him and his sister because of my position in the family.

It didn't occur to me to drag him to the doctor and it wasn't my place to do that.

But we all knew that he was doubling over at finish lines and that is really hard to live with.

I had never, we all knew about testicular cancer.

Lance Armstrong was famous, but it never occurred to me that it could be that, nor did I know that testicular cancer is the number one solid tumor cancer in people with testicles. between 15 and 35.

Number one, solid tumor cancer. And you're not safe if you're 40 or 45.

[35:16] It remains a risk until you switch over into prostate cancer, which is 50 or 60, somewhere around there.

I didn't know that. I had no idea.

And it's not the kind of thing that is openly talked about. It's a relatively rare cancer. Relatively rare, and yet the number one.

Yes. Age range. And here's the problem with testicular cancer.

It is the perfect storm of three bad factors because it's a young man's cancer.

And what are young men like? They're invincible. They're invincible.

[35:45] They don't want to go to the doctor. And this is embarrassing.

It's the perfect storm of bad factors. And that is why Jameson is dead.

[35:55] Yeah. And because we are so prudish in this country that we're embarrassed to talk about stuff like this. Yeah.

I stole, I have these things called nut notes, which are funny phrases about testicles, such as don't be chicken, check your nuggets.

And my favorite is carpe scrotum. I'm very proud of that one.

And I stole Don't Be Slackers, Check Your Knackers from the Brits somewhere in the British Isles because they are not embarrassed.

There were like five different testicular cancer organizations just in the British Isles. They're just not embarrassed.

I don't know what it is about Americans, but I blame our society in part as well.

I do as well. And obviously there's folks listening to this interview that are outside of the U.S., but for those of you in the U.S., where it might be more difficult to talk about, I think this story is extra important to remember.

Nancy, we could, of course, talk about this so long because Jameson's life was too short and is so worth remembering.

In the interest of time, I want to jump into, you've mentioned some of the signs.

Obviously, one of the septicles had enlarged.

He was having shortness of breath when he shouldn't be having shortness of breath.

What are some of the other signs and symptoms of this type of cancer?

Let me separate out those two families of symptoms. The shortness of breath was because of the metastasis.

[37:21] But one of the signs that are listed by American Cancer Society is back pain, unexplained back pain and constipation.

[37:30] Mostly though, as far as the testicle themselves, where it starts, which is where you want to catch it. Here's the thing about testicles.

Unlike breast tissue, they're not lumpy and bumpy. A lot of women have heard, oh, you've got lumpy breast tissue.

Testicles are not lumpy and bumpy. They should not have lumps or bumps. They should not hurt.

And they should not be radically different sizes. They should be about the same size.

And what I tell young men is, and when you forget those three factors that I just told you, walk out of here and you forget, here's what I want you to not forget.

[38:00] And this is where I decided a long time ago, I have to walk the very knife edge of being rude and funny and edgy because I'm talking to young men without offending their mom. So that's the knife edge that I walk.

And so what I tell them is, I know that you've been going down there since you were about nine months old.

And here's when the boy goes, I'm not, I don't see you. I don't hear you. I'm not even here.

I know that you're down there. I know you're down there like every day, if not multiple times a day. and I don't care and I'm not going to ask you, but I know you're down there. Here is the takeaway.

If there's ever any sort of change, do not wait.

Whatever they're usually like, if today there's something a little different, you need to tell one of your parents or a friend's parent or somebody who will take you or tell you or get your parents to take you to the doctor and you go to your PCP, not a urologist, but your regular care doc, and you go get checked.

And you know what? It's probably not cancer, but if it is, you want to be embarrassed or do you want to be dead?

Yep. And so I tell them that. So that's all you have to remember.

No, they shouldn't hurt. They shouldn't have lumps or bumps.

They shouldn't be different sizes. But what you, all you need to know is, okay, something's different down there.

Something's different. And you'll be the one who knows if it's different.
And that's also why I talk to.

[39:20] Girlfriends and boyfriends and wives and partners, because half of the time it is the partner who drags the person to the doctor and who and more often, more to the point, who discovers the issue.

Because just like with a woman, if she's not touching her breasts and her partners, what's that? The same thing happens with testicular cancer. And so that's why I talk to partners and I talk to moms of younger kids.

And the other statistic, sorry? Oh, I was going to say, it strikes me that the other thing, and obviously moms need to know about this, and women need to know about this, and obviously men need to know about it, but their partners need to know about it so that they can chip in with their partner or their child.

[40:06] It strikes me, given the story that you just told, and this is a huge generalization, I want to own that right now, but it is often moms.

Yeah. taking their kids to the doctor.

And so whichever parent it is, moms or dads need to make sure that these primary care physicians are doing testicular checks on boys and that the boys are understanding the importance of it and not declining the exam.

Yes. And I will tell you that there's some controversy, which I'm not going to discuss us except to say this, that because self-exams and more particularly doctor examinations of testicular cancer, because it's a scary subject, there has been an opinion that's come down from a non-physician group of PhDs that doctors shouldn't do testicle exams because it's too frightening to the patients.

Those of us in the testicular cancer world.

[41:07] Have a variety of feelings about that, all of which are negative and strong and loud.

[41:12] Yeah. However, and I also, I know that they're not teaching it in medical school anymore, I've been told, and I know that some doctors refuse to do it.

If it were me, it'd be time to get a new doctor.

And the other thing is that during sports physicals, that is on the list, but the way, at least in the North Shore School District, the way sports physical forms are is there's a long list of boxes under yes, and a long list of boxes under or no.

And it could be imagined that a doctor swipes through all the yeses when he actually, or she hasn't actually done all of it.

So yes, this is where the parent needs to be an advocate for their child.

Have you done a testicle exam?

And they, depending on the age of the child, they either may or may not be in the room and they can have that discussion with their child, whether they're in there or not, and what's more likely to get the result of it getting done.

Nancy, at what age, because I think you said that this is the number one cancer or solid mass cancer for ages 15 to 35, but Jameson got this younger.

So at what age do you recommend for those folks listening that they start asking the pediatrician or whatever doctor their kid sees if they've done this exam?

That's a great question. And I'm going to answer that and I'm going to change the question a little bit. And if I don't cover the answer to that, you let me know.

I've had parents say, so I've got a son and he's little. And at what age should I start talking about this with him?

And I say, how old is he? And they'll say four. And I say today.

[42:41] I know that other work you do is about safety for children.

And so what we used to call stranger danger in the 70s when I was teaching sexual assault prevention and then known adult and all the things that we know now, you teach them in an age appropriate manner.

And so with your four-year-old, what I would suggest is so you're in the bathtub and you're washing all your things and you say, and you have a conversation such as, if you were to fall down and bang your elbow on the sidewalk, you're going to tell mama that it hurts, right? Right.

If something is happening with your whatever you call them, your private parts, whatever euphemisms or real names parents are giving them, use those names and say, if you ever feel something different in that area, you can tell me just the same way.

Now, parents, call them what they are, please. It's a safety issue.

[43:26] Yeah. Yeah. I know you're like you're totally right, Nancy. A lot of parents have euphemisms for them.

But come on, let's just call them what they are. right and that's what i tell here and that's what i tell parents i tell kids i tell everybody you know what they're just body parts yes and those body parts deserve care they deserve names they're just body parts i'm sorry that this country has made everything so embarrassing about it but it's not worth dying over in terms of the doctor and i'll tell you another story jameson's best friend has a little boy now and he was a baby and they're in their well baby exams and she's watching the doctor and the doctors examine everything, including his testicles. And she's like over his shoulder and the doctor's like, what's up with you?

And she tells the story of Jameson and especially I'm sure the doctor that didn't do the testicle exam. So one would think that a well child or a baby exam would include that, but certainly by puberty. And this is not, I don't know for a fact.

[44:29] What is the exact age that you should make sure it's happening.

But given the age range of the most likely cases, I would certainly say by or before the onset of puberty.

But I can also tell you that there have been babies born with testicular cancer.

There have been infants who have died of testicular cancer just because 15 to 35 or 42, depending if it's global versus US, is the most likely doesn't mean it's not going to happen.

It is a rare cancer or every time it happens.

[45:00] And it can happen to a baby. It can happen to a newborn.

Just add it to the list of things to make sure your child doesn't have, is what I would say. Yeah.

Nancy, I know there's so many more statistics and things around this, but I think you've, like, just that this is not worth dying over.

Don't, reminding our son that's not worth actually dying of embarrassment.

And I think if people walk away with that, I think you and I can consider consider this a win.

So ever since I learned about Jameson's story, I think about you so frequently, Nancy, and I tell friends and colleagues and clients who are raising sons or have men and boys in their lives that they care about.

So I would like to issue an invitation that I know Nancy will not begrudge me, which is to everyone listening right now, tell somebody about Jamison's story.

Great. Find one person to tell about Jamison's story. And if that's your own child, great. If that's your partner, great.

If that is your neighbor or your nephew or your daughter's boyfriend, great.

Tell somebody when you walk away from listening to this episode.

Family Jules Foundation

[46:17] Nancy, you started a foundation to honor Jameson's memory.

And what it really does, if I understand correctly, is it supports the siblings of children who are dealing with cancer because they get left behind.

Where can people find that organization and contribute to this cause?

[46:38] It is called the Family Jules Foundation. As we sat down one afternoon, there are at least 25 euphemisms for testicles. I can tell you, having researched it, that was the least offensive, plus the

alliteration of Family Jewels Foundation just really pleased me.
 So we are at family-jewels.org.
 And I will tell you, and the reason that we, what we do with the money that we raise, my education is just something I do as my life's work that I wasn't looking for and got.
 Where the money goes is to college scholarships, not for kids with cancer, but for their siblings.
 Because siblings of kids with cancer are actually known as shadow survivors.
 Because when you think of a child with cancer, or God forbid, a child who's died of cancer, first people you think about are the parents and then the grandparents.
 What happens to the siblings is that necessarily the attention goes to the sick child.
 And so here's what Jameson's sister's day was like when she got home.
 Come in the house. If you're sick, don't come in here. Use a Purell.
 Don't cough anywhere. where go do your homework. I'll get you dinner later.
 I got to go take care of your brother.
 Yeah. And then when this cancer sibling dies, those kids lose not only their sibling, but their parents.
 Because when you lose a child, those people are gone.

[47:53] And the loss to the siblings is so enormous.
 Plus, as I mentioned earlier, their financial toxicity, all the money that people have goes towards trying to save their kid.
 You're not saving for college when you have a kid with cancer.
 So we decided, because there's a lot of things, make a wish, God bless them, Jameson had a wish.
 There's a lot of things for kids with cancer. The siblings, shadow survivor. driver.
 So our scholarships go to students who've had a sibling with cancer.
 We currently have our seventh scholar who is in her third year at UW on her way to medical school.
 And our first scholar, whom we got, I believe in 2012, is now a PhD candidate in sports medicine and married and a grown up.
 It's so phenomenal. It is amazing.
 I know, as you said, that this life's work is not something that you asked for

Amazing Legacy

[48:51] and that you would not wish on anybody.
 But my goodness, what an amazing legacy that you have made out of honoring Jamison, honoring his sister.

[49:02] And it's just, I'm so grateful that you are able to share his story.
 To share his story. Yeah.
 And, but able to do it in such a beautiful way because I clearly struggled with listening without crying, but I know that's okay.
 Nancy, thank you for being here. I'll reiterate the, the invitation, the challenge, the request that everybody share Jamison's story at the least once.
 Good. Thank you. All right, everyone take a big, deep breath with me.
 I know that was a a difficult story.
 And if you are anything like me, you probably shed a tear or two during the course of it.
 And as Nancy said, that's okay. She wants people to know that this is sad.
 She wants people to be sad when they hear this so that they feel motivated and empowered to make sure that it doesn't happen to someone they love.
 I would like you to take my invitation, my challenge to heart.
 Tell someone about Jamison's story. Tell someone what they can do.

[50:08] Remind them that testicles should not be lumpy and bumpy.
 That they shouldn't hurt. And that they should be roughly the same size.
 Or if nothing else, that they're the change.
 That's something that needs to be checked out.

Build the relationship with your own son, with your nephew, with whoever you need to, so that they know they can talk to you about this.

And if you are someone taking a child with testicles to the doctor's office, make sure that doctor is aware of this.

Tell them the story. Tell them Jamison's story. And make sure they're doing those exams.

Preventable Cancer

[50:53] This is a preventable.

Kim, take that back. This is a curable cancer, 95% cure rate.

Don't let someone you love die from embarrassment. All right, everyone, I'm going to leave it there for the week. I'll see you next week. Cheers.