

James Hiter:

I think each one of us has to find that thing that allows you to feel in control when you're really along for the ride in a lot of ways.

Diane Mulligan:

None of us likes to feel out of control. It's a terrible feeling, whether you're in a car veering out of control or facing a very serious health diagnosis. Right, Sarah?

Sarah Beatty:

That is so true. And I think finding a sense of control over a really scary situation is the first step to confronting a big challenge with determination and resolve. Jordan, that's what you found with a group of guys you had the privilege to talk to recently?

Jordan Sherman:

Absolutely right. These guys are all living with lung cancer and they shared some of the ways they're managing their diagnosis with the support of their wives, and families, and a shared sense of purpose.

Diane Mulligan:

Advances in lung cancer treatments over the last few years have made it possible to live with lung cancer for years after diagnosis. So many people are doing things they love and that give them fulfillment as they're living with lung cancer. And for some, one of those things is advocacy. I'm Diane Mulligan.

Sarah Beatty:

And I'm Sarah Beatty. It's the guys' turn again today, dropping their guard to help other guys living with lung cancer learn how to adjust to their new reality as men, and as husbands. That's today on the Living With Lung Cancer, Hope With Answers podcast.

Diane Mulligan:

Lung cancer is a tough topic. It's a disease that affects patients, families, friends, coworkers. But first, it's a disease that affects people. The Hope With Answers: Living With Lung Cancer podcast brings you stories about people living, truly living, with lung cancer, the researchers dedicated to finding new breakthrough treatments, and others who are working to bring hope into the lung cancer experience.

Sarah Beatty:

Okay. We're all experienced in the art of marriage, what it takes to make a relationship work through thick and thin. But what happens when that for better or worse marriage vow that we all have made is really tested?

Diane Mulligan:

That's the question in front of three of the greatest guys we know, A.J. Patel, James Hiter, and Frank McKenna. They're sharing the joys and challenges of learning to live with lung cancer. Jordan, you really had an intimate conversation with these guys.

Jordan Sherman:

So true. These guys have been living with lung cancer for a number of years, and thanks to research they have the experience and commitment to help others facing the same shocking diagnosis. But they'll be the first to admit learning how to live with lung cancer can be a challenge for guys.

A.J. Patel:

This is a fantastic topic and podcast, because part of the problem that I experienced is, being a guy, you know, I don't like to ask for directions when I'm lost. I don't like to go and deal with the doctor when I've got some probably wrong with me I'm not sure what to do. I just live with it and say, "Oh, it'll go away." You just chalk it up to, "Hey, we're macho we can handle this." So, that's part of the problem is that we are vulnerable. And women seem to be better voices. And so, men need to talk about this and address these things because it can make a difference in the treatment plan.

James Hiter:

Everybody came together in such a way that really allowed me to make that shift from the, "Why me, why not me?" fairly early on. And I know that's a struggle because if you don't have that support network then it is hard. It's hard to make that shift. It's hard to get there quickly. But from a mental standpoint, the sooner you can get there, the sooner you can start to feel in control through a time when there's very little, that you feel so out of control. And so, for me running was also that thing that I wanted something that I controlled. And so, I wanted to be able to run every day. So, I think each one of us has to find that thing that allows you to feel in control when you're really along for the ride in a lot of ways.

Frank McKenna:

I don't want to be the role model or the poster boy, but if I can get it, anybody can get it. But if I lend my knowledge of fitness and staying in shape, maybe that will help other people to stay in shape and battle this. I'm not going to let cancer beat me. I'm going to do everything I can to stay as strong and as fit as I can and fight and beat cancer.

Diane Mulligan:

Frank is such an inspirational guy and he's a certified cancer exercise specialist who helps people living with lung cancer learn how to continue making exercise a part of their lives.

Sarah Beatty:

Frank, and all the guys you talked to, Jordan, they're all married and they shared how their relationships changed and actually deepened as they learned how to navigate living with lung cancer. Right?

Jordan Sherman:

Yeah. And as a newly married guy myself, I really listened as they talked about how they had to lean into a new experience as they leaned on their wives for support and looked for ways to continue contributing as equal partners.

Frank McKenna:

But I think during that time my wife took charge and said, "We're going to fight this and you're not going anywhere." And we always had a good, strong relationship and it strengthened even more. Our relationship now is better than it's ever been. And I think she took that attitude, "You're not going anywhere. And regardless of how you feel, or what you think, or what you say, I'm not letting you go anywhere." And it was that fight and that determination that told me, "Okay, she's got me. And I'm going to fight this myself." And if I need that help she's definitely right there.

James Hiter:

My wife knew it was important for me to eat. And so, she would start naming off foods. She would say, "How about some peanut butter toast?" And I'd be like, "I am seriously going to vomit right on you if you name..." "How about soup?" And, "Oh, I'm not kidding I'm going to throw up on you if you keep naming..." "How about..." And then, finally she would hit the thing that was the thing. And I would eat it and I would be so happy. But I was so about to wring her neck for naming off all these foods until she finally hit the one. And she did that every single chemo session and was such a trooper about trying to have the right foods in the house to make sure that there was something here that I might like to eat.

A.J. Patel:

Once I understood that my gift really left on this planet is to gift others with love and happiness. And so, I do that... I bring the very best version of me in the moment that I'm living. There are some moments where I'm not feeling that great, but that's okay. I'll bring the best version. I'll still muster a smile. And that's helped to nurture a much deeper relationship and an appreciation of really what a partner brings when they say, "I do." And they will work through sickness and health. You realize just how fragile life is, but at the same moment just how beautiful it is, because you can see the love from a person.

James Hiter:

One of the greatest gifts we can give to our spouse is to try and be the best patient we can be. Because, it's hard for us to ask for help, just how most guys are wired. And so, I think we owe it to them to just make a really concerted effort at trying to be the best patient you can be, and not play that typical guy card of, whatever, the guy that whines all the time, or is trying to be the tough patient. I admit that I'm not always the best patient but I do try. And when we've been in the hospital, the number of times that we've had to go to the hospital, I always say that I'm going to try and be the nurse's best patient. And I want to do the same thing for my wife when the time has come that she has to be the nurse here at home.

Sarah Beatty:

I love the idea that these guys are thinking about how they can be the best possible patient for their wives, as well as for the nursing staff.

Diane Mulligan:

And, Jordan, one of the benefits of this conversation with just, "The guys," is that they could be really open and honest about all aspects of living with lung cancer. Right?

Jordan Sherman:

Absolutely. James talks about how he got some of the best advice on some of the more intimate parts of living with lung cancer as a married guy from another guy.

James Hiter:

And we had this really great RN and it was a dude. And I think that was a gift from God to me to have a guy of this very first chemo cycle that we could just... He talked about everything with us. So, he's answering all these questions and he said, "Look, this is some nasty stuff we're putting in you, you definitely do not want to be intimate for the next seven days." Well, what he didn't share with me is that I wasn't going to really feel like being intimate for the next seven days either. And so, it all worked out fine.

Diane Mulligan:

I think this podcast will be so helpful to so many guys thanks to conversations like these.

Sarah Beatty:

So Jordan, all of these guys mentioned the challenge of feeling like they really needed to pull their weight as equal partners.

Jordan Sherman:

Yeah, Sarah, that was definitely a big theme in the conversation. And it's important that the guys were able to find ways they could contribute.

James Hiter:

I had times when I felt pretty darn good, pretty normal. And then, times when I've felt pretty awful. And I think that's probably similar to the experience of many. So, for me, what I tried to do is just... And maybe to a fault even, try to do as much as I could possibly do on those days that I felt well, so that I really did feel like I was making that contribution. Not because I felt like she expected me to do it, but more because it was what I wanted to try and do to try and pull my weight, so to speak. And then, on the times when I felt puny, just being okay with it. And she was very accepting of where I was physically in those times.

Frank McKenna:

I could never thank her enough for carrying me through that time when I couldn't do anything. And I try to just pay her back every day for getting me through those dark days. She says, "I don't like to think about those days." And I think about those days because that's strengthened our relationship so much, and just made me so thankful to just thank her each day that I'm alive because she helped me through those darkest times.

Diane Mulligan:

Frank really nails the, "For better," part of, "For better or worse," don't you think?

Jordan Sherman:

Absolutely, and all three of these guys are great examples of learning to live with lung cancer with all the complexity and the challenges that will come with it.

Sarah Beatty:

Okay. So up next, we'll hear from the guys on how they're branching out into advocacy, and find out what that means to each of them.

Diane Mulligan:

Are you enjoying the Hope With Answers: Living With Lung Cancer podcast? Consider making a donation to help LCFA produce this resource for patients or anyone seeking answers, hope and access to updated treatment information, scientific investigation and clinical trials. Just text L-C-F America to 41444 to join in this important fight.

Diane Mulligan:

Advocacy has several meanings. First, learning how to live with lung cancer means learning as much as you can about your own lung cancer in order to get the best possible treatment.

Sarah Beatty:

But thanks to research that's giving people living with lung cancer longer, healthier lives, lung cancer advocacy often changes to include lobbying for increased research funding and supporting newly diagnosed patients. All of these guys are also involved in several types of advocacy.

Jordan Sherman:

That's right. Little known fact that lung cancer kills more people than breast, colon and prostate cancer combined. And James Hiter is working to change this statistic by advocating for parity when it comes to research funding.

James Hiter:

And so, my part of what I think we should be doing, and I'm trying to do personally, is to change that is to be a voice for a more equitable distribution of one of medical research funding for lung cancer.

Bottom line is you've got a disease you didn't ask for it. And the funding should be there to be able to change outcomes for people. As far as the guy involvement thing, one of the advocacy things I do is volunteer as a phone buddy. So, I get to talk to people who are newly diagnosed.

Frank McKenna:

It's so important for guys to know that there are other guys in here. Like the three of us who work with the speaker's bureau in order to get that word out there, and do the events that we do, and appear on some of the podcasts, and on the website and some of the things we do to let people know that there are other guys out here that are willing to help, they're willing to either lead by example or give advice, or just say, "It's okay to talk to someone who knows what you're going through or has been through it." And as A.J. said, people who have been diagnosed earlier than him or recently diagnosed. We're willing to help everybody, but there is a community out here of guys who are willing to help other guys and get through this. So don't be afraid to reach out.

A.J. Patel:

There's two tracts. One is the patient advocacy tract. And the other one is a research advocacy tract. And I didn't get into the research side until I'd gotten well entrenched in the patient advocacy side. And so, why did I choose to get involved with the patient advocacy side? Simply because the only reason I am here today is because a phone buddy was matched with me eight years ago. And this person was an angel. And it was a guy. Totally living and breathing stage four lung cancer, four years prior to my diagnosis. And, for me, that was a tremendous amount of hope. Because, here I was sitting there thinking, "I won't last more than six months." And here's a guy who says, "Hold on a minute, buddy, there is a possibility."

Diane Mulligan:

Jordan, thank you for leading such a powerful discussion with these guys.

Jordan Sherman:

It was my pleasure to tap into their wisdom, their dedication, and even some good humor they work to bring to their lung cancer advocacy work.

Sarah Beatty:

Thank you, Jordan. And thank you to James Hiter, Frank McKenna and A.J. Patel for joining us today on the Hope With Answers: Living With Lung Cancer podcast.

Diane Mulligan:

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