

DR LOVE: Welcome to the Heart of Oncology. This is medical oncologist Dr Neil Love. There is something about a cancer diagnosis that cuts to the core of any individual's being, but in many cases, patients find a strength they never knew they possessed. You're about to hear a whimsical 39-year-old former drummer in a rock band whose life — like all people with this disease — was turned upside down with the cancer diagnosis of chronic lymphocytic leukemia.

MR H: Freaked out. A lot of crying. Didn't want anyone to know. You think you're going to die. I remember being in the hospital and thinking I wouldn't wake up. So I would never go to sleep. I was always up. They had to shoot me with Ativan, which really calmed me down and I could go to sleep, or I could stay up. It was a real mellow — whatever it was — anxiety reducer. I kept wondering, it just didn't seem right to me that I was going to die. I had all these things I wanted to do, so I just suddenly became — either you keep living in this misery of death around the corner every day or you get real positive and go and do things that you've always wanted to do, that you were always scared to do before. So, in the hospital, I made that decision, that I was going to be positive and proactive about it and not dwindle in the scary part. Since then, I've done a lot of things I've always wanted to do. I have my own TV show now — I always wanted to do that, but, for some reason, never had the balls to do it. I do a lot of things like that — I'm a lot more aggressive in business and life and I do a lot more fun things. When you think you might die, your whole life changes. All those little problems and things you were scared of before are all out the door. So it's a real kind of freeing experience in the same way as it's a very scary experience.

DR LOVE: Who were you sort of sharing this with? Who were you talking to at that time?

MR H: My friends and my family. I had a bunch of people who were always coming to see me every day. It was a little room full of people. It was good that everyone was always positive and up. My mom was with me every day, and my ex-girlfriend. And all these people who flew in were staying with me and my brother. If any of them would have showed emotion, it would affect me greatly. But everybody was really good and not sobbing and crying. It kept me that way, too. You're an emotional wreck the first stages of realization. But the quicker you get to the positive part, the better you can help yourself. I really felt like that was a big deciding factor in me getting better, was me deciding that I was going to get better.

DR LOVE: Had you ever faced a serious health or safety problem before?

MR H: No.

DR LOVE: So this was all new?

MR H: Yes. It was completely new. I never really get sick, either. It was a very new experience for me.

DR LOVE: How long a period of time was it that you were in limbo, or before you were able to find the sort of strength you're describing?

MR H: I would say a few days into it I decided that if I was going to die, I was going to go out being happy. That's a very hard thing to decide upon, for some reason, because you think you're going to die every day.

I had another friend that went through it, too, and she was real positive. And she's through it. I'm not saying that's a cure by any means, but it's definitely a cure to a good ending of a life. You

can be scared and freaked out or you can just be happy and go do things you want to do while you can do them. I don't know. I just really had a feeling like there was something else meant for me, that I needed to do. And that kept coming back to me. Then I just realized I had to just go with that and see what happened, be positive and get through it as best you can.

DR LOVE: As you were sort of thinking this through and sort of coming to terms with it, again, I'm just kind of curious, was it more an internal process going on or was there somebody or some people that you were discussing this with?

MR H: It was more internal because that's the one thing about it. You're the guy sitting in the bed in the hospital room, surrounded by all your friends, looking out at them instead of looking at your friend in the bed.

And you go on the internet and then it starts showing you the fatality rate and the odds, which freaks you out. So you have to just take that kind of with a grain of salt also, and decide your own path. But it was a lot of me, by myself, figuring through it.

DR LOVE: Again, during that initial period, what was explained to you, specifically, in terms of the kind of therapy that you'd get and sort of what to expect in the future?

MR H: It was explained to me that there's no cure, and it was a slow-moving disease, and I was a younger person to be getting an older man's disease. They said if I wasn't responding to treatments, I could always do a bone marrow transplant, which is like a last-ditch effort. And the odds of that still aren't that strong, of it taking.

So I always knew there were some desperate roads I could take, but I also knew there were a lot of things I could do right away with treatment, that my doctor's taking me through now. I'm lucky that I respond to these things really well. And I seem to be healthy enough to handle them.

But while I was getting treatment, sitting in the room in your La-Z-Boy chair, I see one of my buddies across the room, an older guy, who's a lawyer in Fort Myers, and he has the same type of disease. And he's had it for 25 years. So, talking to him, I was like, "How do you deal with it? Do you ever think you're going to die or something?"

He said, "I'll go into remission; I'll come out. I'll be good for a month; I'll be good for six months. I'll come back out. I'll get some other things," he said, "There's always been a silver bullet treatment that comes up that I can take."

He's had it for 25 years, which I thought was really impressive. I feel like there's going to be something like that for me also. If it comes down to a bad situation where I'm not responding anymore, I have a bone marrow match, which is my brother, and hopefully, by then, there'll be a little better odds of it taking.

DR LOVE: Have you gotten to know other cancer patients?

MR H: Yes.

DR LOVE: What's that been like?

MR H: Really interesting. I like it. I'm a little younger, compared to all these people in the room. Sometimes, there's younger than me, but there are mostly old people who sleep through their

treatments. There's some really interesting people that you meet. I have a lot of really good friends now through it. And just really cool people. A lot of them don't talk. You kind of sit in your chair and they've got their own little thing going. But a lot of them want to find out about your story, too, because everyone wants to kind of relate their condition and get through it together. I've really met some special people. I really have. And I've really enjoyed that part.

DR LOVE: Anything you've observed in terms of the kinds of people or situations where people tend to be able to adapt to this kind of situation whereas people who are not able to adapt?

MR H: Yes. I think I've definitely noticed. I don't know a lot with these older people that are so quiet — and there's so many of those — that you see every other day or whenever. But, for people that I talk to, a lot of people ignore it and kind of just live another life besides it and don't like it. But the people that really want to get through it seem to get through it. I've just noticed that attitude is better than chemo. I believe that if someone doesn't fight it and kind of works with it, if they have a good attitude and a positive outlook, their condition is much better. There's a lot of them that complain about their doctors or the needles or whatever and kind of bitch at why they got it or whatever. I keep seeing that, but you really can't be that way. You have to be positive and get through it in a positive manner, or you're hurting yourself more than you know. And I've noticed that with friends that I've met. The ones that are real carefree and kind of open and want to talk and stuff seem to do better. Of course, there's a lot of times where everyone's in pain and feeling real horrible. But we have to get through it with a good light. And it seems to be a lot better condition for you.

DR LOVE: Where do you think that comes from, being able to find that strength?

MR H: I think it's just being a strong person to start with. I think a lot of it is that, or you kind of learn to do it. I've seen that, too. I see these introverted people that read a lot and don't really do things, and suddenly they're in these rooms full of people. And either they talk to you or they don't. The ones that kind of reach out and just kind of experiment with their condition and try to meet people and do new things as best they can have a lot better condition of life. I mean, some people will just go through the treatment and be their same kind of self. But the ones that kind of want to meet you and talk to you a little bit always seem to be a little better and a little up and normal.

DR LOVE: Is there anything positive that came out of this experience?

MR H: Yes. Just the fact that it drops all these social barriers for me was a really cool thing, a lot cooler than I thought. You realize the fear of dying really limited you before. Then suddenly you know you're going to die, you don't have that fear anymore and you kind of look at things that you want to try and do. And I remember making a list of things, like my top ten things I wanted to do. And I just got out and done them. I rode a bull for my TV show. That was just the craziest thing I've ever done in my life.

DR LOVE: You rode a bull?

MR H: Yes. I entered a rodeo in the Professional Bull Riders, the PBA. And I had a buddy who was a rider, and so he got me in. And I didn't do any training. I just did it, walked up to the rodeo, signed up and did it. I mean, by far it was by far the scariest thing I've ever done, but the coolest thing. You don't expect it to be fun. You expect it to be horrifying and you might die — and that was definitely there — but suddenly I'm sitting on a bull. There's this crowd screaming. The cameras are around me. And it was just a really cool experience. And I rode it for a few

seconds and it threw me. But riding it for those few seconds was a cool moment that I would never have ever done that. And I was still on chemo at the time. But that was incredible.

And the TV show is incredible. That's something that — I always wanted to do my whole life, but never approached it because I was doing something else or I think I was just a little scared to start the process. And I decided I was going to do it. As soon as I did, people just came to me. I had investors. "Here's a program. We can buy this show," and I had a half-hour show I was doing every other week.

DR LOVE: What kind of show?

MR H: We called it Lounge Television. I used to do a live show and write a column in my town in Ft. Myers called "Ask Andy," and it was kind of a sex column. So, I had lounge girls in the TV show, and it was just a variety show. I'd go out and ride a bull. I'd have a band every show. I had dancers, a DJ. It was a really cool, kind of fun variety show. That show was a good example of something you can achieve once you get this release of worrying about dying. I still don't like the fact that I have a death sentence hanging over me or whatever, but it's really given me the power to not be afraid to do things, because — as relaxed as I've always been, and confident that I've always been in myself — and I've done a lot of crazy things — there's always been barriers that stop me from going over to talk to that person or to ride a bull or to start a TV show or start my own column or whatever. And after you get through the initial shock value, you realize you've been given a freed-up kind of feeling about yourself now, which is something new to me.

DR LOVE: Any fears or concerns about the future?

MR H: Yes, definitely. I could die. I could get the flu out here today and, me being on CamPath, be real complicated. But it doesn't bother me. I could also walk out and get hit by a piano coming out of the building or a car that runs off the road. We all have that in our lives. And it's funny. I see more people dying from stuff like that than people like me with cancer. I'm concerned that I might run out of silver bullets, but I'm not too concerned about that. Why worry about something that's so far off and iffy anyways? So I'm pretty positive about the future, and I've really, in a weird way, enjoyed the whole cancer process. I don't know if you've ever heard that before, but it's been kind of fun. It's been a bunch of new experiences for me. It's opened doors. I throw these huge benefits now in my town for other cancer charities. I wrote a column for my newspaper and it was edited because I was too cheerful about my condition. They cut out some of my jokes because they thought I was being too lighthearted about getting cancer. But I've kind of liked it in a weird way. You're kind of like, "Whew. Okay. Now I know I've got it, so let's just live with it and move on, instead of worrying about it, am I going to get it."

DR LOVE: Has humor helped?

MR H: Yes. I'm a pretty weird person and I do a lot of funny stuff. I've never changed that. Dealing with cancer in a funny way can be really fun because people don't do that. So, when you say jokes, people don't know whether to laugh or whatever. It's always funny to freak people out about that. And I remember in the hospital — the column I wrote was a true story, that I kept seeing this hot girl and one of the nurses said, "Oh, this girl has leukemia, too." And besides the fact of me wanting to meet her, she was this hot little 19-year-old girl. And every time she'd walk by my room, with all her little pump and bags hanging — and I have to get mobile with mine — I could never catch her. So it was like I'm in my dress, walking around, trying to find this girl. And it was like this search to find this hot leukemia chick. And I imagined

we'd meet in the library and our chemo bags would entangle and I'd have some funny line to say to her. I never got to do that, but I'm on my deathbed and I'm wondering when the hot nurse is going to come in to check on me. So there's a lot of funny situations like that, where I'm checking out nurses, wondering if I could meet them or go out with them, and I'm bald, about to die. You meet really interesting people and you're put in some pretty funny situations sometimes.

DR LOVE: Has your reaction to this whole thing sort of surprised yourself?

MR H: Yes, I think so. But it is true to my person, the way I've gone through this. I don't think I really changed greatly. I think I have become more positive. But I was a pretty positive person before and pretty optimistic. I didn't let things bog me down, or I didn't stress out about stuff, but it surprised me a little bit that I've done so well through it, because you think, "You get cancer; you're going to die." That's not the case. It really isn't. You can beat things and get through them. And fortunately, I have a disease that's treatable. So, in that sense, I feel lucky that it's not some rare disorder that we've only seen one in a million times. There's no treatment, but we can try this. I've been lucky to get the type of cancer that I have, so I'm fortunate for that.

DR LOVE: Do you see things differently now, than before?

MR H: Yes, you definitely do. Your first night out of the hospital, it's just an incredible feeling to smell the air and see trees and plants. And my first night I went to the beach and saw a sunset. And it was just like seeing it for the first time. And being out in the world — because you're kind of stuck in this bubble, no bacteria, neutropenic environment, and you kind of get out of that alien floor that you're stuck on and it's so nice and freeing and you can just sit in a park and just be the happiest dork there because you're just happy to be alive. You don't sweat the small stuff as much anymore. That's for sure.

DR LOVE: Any advice you would give to somebody else in the same situation?

MR H: Yes, they're going to deal with it however they're going to do it. It's either you can cry and complain about it and cuss to God, or you can do something about it and make yourself happy and do things, and be positive. And it definitely has an effect on how you progress through your condition. And I know it's hard to do it — or to see that way — but you really need to seek out positive things and know what you like and do the things you like. And if there's something you want to do, it's time to do it. And that's real good advice coming from someone who's always had things that I've wanted to do. Now, instead of putting them off, it's time to do those things. So go do them and have fun while you still can.

DR LOVE: What about exercise?

MR H: I exercise a lot. I've kind of become a freak now. I thought it was very important. When I was on the cancer ward in the hospital, I was just doing laps all the time.

DR LOVE: Really?

MR H: Just get your little pump stand with all your bags and I would just walk around the halls. I would do that as much as I could, and just stretching. Stretches and massages were so helpful, and it kind of works oxygen through your system and kind of clears out all the junk that you're taking and they're putting in you. I remember the first few days, I was always doing laps, walking around. And the nurses were looking, "Other patients wear pants, Mr H." I noticed I was in

boxers my whole time, and everybody had nice bed pants on. But exercise, definitely important. And I've exercised through all of my treatments.

Sometimes, I take it easier, when my red blood cells are down. But even if I can't do something, I'll just stop it and move on to something else.

DR LOVE: What kinds of benefits have you seen from exercise, specifically? Does it help relax you? Does it help with that thing of positivity that you said was so important?

MR H: Yes, it does help with that. You actually start feeling good about yourself. You see results, too. You think you can't look better while you're in this bad state, but you really can. It's surprising. And you'd be surprised at how much exercise you really can do once you try it. I have noticed I'd go in to exercise, sometimes not feeling good, feeling a little tired from the treatments, and then once I've stopped working out, running or on the Stairmaster or lifting weights, after you kind of sweat it out, you feel good after that. And you get energy from it and it relaxes you in the same way. That was a huge benefit for me, and I really like it now. I keep asking the doctor, "Should I not be working out?" Because I work out as hard as I can now, and I'm right in the middle of treatments. And he's always like, "Go ahead and do it. If you feel good about it, do it, because it's going to be good for you to get your system moving like that." And it really has. I've never had any trouble, even through chemo. You don't feel good, but you can do stuff. And any type of exercise, I think, is good, and I think people should be doing it.

DR LOVE: Any other sort of lifestyle things that have been helpful? What about things like music or meditation?

MR H: I meditate. I have before, though, also. But I do notice that when you think you're going to die, everyone's telling you all this information, all these books, these web pages and videos. You're overwhelmed with stress and information. It's real important to just, at one point, sit down, relax and try not to think about anything, and just be calm and concentrate on breathing. Once you come out of that for five or 10 minutes, you'll be blown away at how focused you are and relaxed and how able you are to deal with situations now. That's really helped me.

DR LOVE: Do you think these kinds of things that you're talking about apply equally well to older people?

MR H: Yes, I do. I know a lot of older people are real fragile. And you can really see that when they're getting treatments and getting up and down. But I also think those people would be surprised at how much exercise they're able to do still. It's kind of the case where you have a sore shoulder, so you start favoring it and you don't want to do too much with it, but you realize, "Jeez, I can do this move." And once you start stretching it out and doing something with it, it gets better on its own.

DR LOVE: What about food and nutrition issues?

MR H: I think it's important to be on a good diet, but I also think it's important to chow down on a Philly cheese steak, if that's what you're craving right now. I think it's important that you go after any type of food you want to get when you feel like it.

Now, of course, once you start getting a little stronger and better, I think diet is really important. And it's probably the worst thing that I'm at right now. I work out, but then I'll go home and have

a milkshake and a cheeseburger. So it's really hard for me now, to be a good eater, but I know that would be a major compliment to getting me better would be a good diet.

DR LOVE: Where does humor fit into life with cancer? What about dreams and fantasies? There is only one path to answer such questions and that is to ask. This is Dr Neil Love for the Heart of Oncology.