



# Patient Power

## Life-Changing CLL Diagnosis: Finding Balance With a Chronic Cancer

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**Michele Nadeem-Baker:**

Thank you for joining us. I'm Michele Nadeem-Baker, CLL patient and advocate, and this is Patient Power's Partners program. Thank you all for joining me today here on my panel. I have our expert today, who is Maryellen Collamore. She's in Massachusetts. Her specialties have been oncology and cancer care, and she is hailing from just north of Boston, and she has worked at both UCSF and Dana Farber Cancer Institute, and now she is practicing as an independent social worker and certified music therapist. Did I get that right?

**Maryellen Collamore:**

You did. Thanks so much for having me.

**Michele Nadeem-Baker:**

We also have people from all over globally, which I'm very excited about. We have Jay Blatt, not so far away, in East Hampton, New York. Hi, Jay.

**Jay Blatt:**

Hi, Michele. Nice to finally meet you—I can't say "in the flesh," but in digital land.

**Michele Nadeem-Baker:**

Exactly. That's what I was thinking, too. Many of you may know Jay. He's very vocal online, and he is a great patient advocate. You probably know him from Facebook—a great CLL support group that he is the administrator for. So, I know I'm so excited to finally kind of meet you, at least cyberly.

**Jay Blatt:**

Same here.

**Michele Nadeem-Baker:**

We have Adrian Warnock from across the pond in the U.K.

**Adrian Warnock:**

Yeah, hi.

**Michele Nadeem-Baker:**

Thank you for joining us, Adrian. It's great to have you.

**Adrian Warnock:**

It's great to be here. If I fall asleep during the call, you can forgive me, I'm sure.

**Michele Nadeem-Baker:**

You can forgive us. Hopefully, we'll be so exciting with our topics that you won't fall asleep.

**Adrian Warnock:**

Yeah, but you know what I'm saying. It is late for me, so I've got an excuse. It's not that you're boring if I do fall asleep.

**Michele Nadeem-Baker:**

We won't take it personally. And, we also have in Florida—and, we're all very envious—we have Edward Spuzello, and he is here with us today as well, a CLL patient. Hi, Edward. Thanks for joining us.

**Edward Spuzello:**

Hi.

**Michele Nadeem-Baker:**

So, today, we're going to be talking about our main topic, which is basically how we all cope day to day with having CLL, and what it's been like on our journey, and how we continue on. I know many of you are very vocal in the CLL communities. So, I would love to start by asking Maryellen what happens when patients come to her, and they're CLL patients—I know that you meet with them and a lot of other hematology types of patients.

What happens when someone like one of us comes to you and they are either recently diagnosed, or suddenly, they've relapsed, or they're just finding it hard to deal with—they have CLL. Maybe it's affecting their lives. Maybe it didn't, and it is now. What would you say to all of us?

**Maryellen Collamore:**

That's a great question and thing to bring up. I hesitate to call myself an expert, because I think all patients are really experts in their care, but when patients come to me, it's often with this idea that they need to know everything at once—certainly, at the time of diagnosis, but also, along the journey, there's a desire to have all the answers and have a plan. And so, I usually will sit with someone—whether it's meeting them initially or it's someone I've met over time—and really check in with them, and talk about what it's like to live with some uncertainty, and learn to balance that. That's really the key in managing a lot of different illnesses, but particularly CLL, being a more chronic and longstanding disease.

**Michele Nadeem-Baker:**

Thank you. So, I'd love to hear from my fellow patients that we have today and how—to just get a little basics for our viewers. Jay, what happened—at what point in your life did you learn you had CLL?

**Jay Blatt:**

Well, I suspected that something was wrong in 2008, actually, when I had swollen lymph nodes in my groin area, and I kept going to doctors, and they kept saying, "Oh, you're healthy as a horse, and you probably must have just pulled something, and you have what we call a sports hernia. Don't worry about it." And then, a couple of years later, a doctor looked at me and said, "Did anyone ever tell you that your platelets are all over the place and your white blood cells bounce up and down, but your platelets are 130? That really shouldn't be. We want to look at it."

So, that's when I suspected something was a little weird. I ignored it for—until 2016, and then, actually, in December of 2015, I was on a rock, fishing in the middle of the Atlantic Ocean—surfcasting—I bent down, and I had a blood clot the size of Texas in my thigh. And then, I said to myself, “Uh-oh, this is not good.” And then, I really took action, and that's when they did the test, and they determined I had CLL.

**Michele Nadeem-Baker:**

And, did you, at that point, how did—what did you do about that? You seemed very active, and I know right now, you're incredibly active physically. Were you midstream in a career? Did things have to take a back seat?

**Jay Blatt:**

It's almost like it was fate that I would get this disease. What happened was I had a—we still have a very successful advertising agency and publishing company, and—but, once I got the disease, once it was 2016, I had no energy at all, and what I did was I said, “Well, if I'm going to survive this, this is not a good way to live, because I just don't feel well.” So, I began to study healthy ways to at least minimize the impact of the disease, and I began to exercise. I dropped 55 pounds within six months.

I got into learning about a macrobiotic diet. I'll soon be a macrobiotic healer. As of February, I'll have a certificate, so it's been four years. It changes your life. Totally changed my life, and I realized I didn't—I was making—we had a very good business, and I enjoyed making the money, but it isn't what my true calling was. So, I think that there are positives and negatives to everything—there's a yin and a yang—and in this case, some good things have happened, where I've realized what my priorities are.

**Michele Nadeem-Baker:**

Jay, I'm going to circle back to you in a few minutes for a little more in depth about that. I do know for myself, what's been very helpful has been advocating for other CLL patients, and also reporting what's been happening in my own journey and what's been happening in CLL news for treatment, and I know that that was not how I started out in life, but that's where I am today, and it does make me feel a lot better. But, I want to ask—Adrian, in your life, where were you in life? I believe you were recently diagnosed compared to the rest of us, correct?

**Adrian Warnock:**

I guess. It was two-and-a-half years ago now.

**Michele Nadeem-Baker:**

Oh, you're a newbie.

**Adrian Warnock:**

That's the weird thing, actually, because it still feels that way, even though an awful lot's happened in that time. It was a strange thing for me, because it was really quite sudden for me, actually. It was quite unusual, I know. I guess things were creeping up on me, but I just didn't really realize.

I got a new—I'd spent about a year-and-a-half or so working out of the home, in London, so I just thought I was maybe a bit more tired, because I was commuting, and it was only minor, and I was still working really long hours in a high-pressure job, and still able to hike and walk around, but one day, I just collapsed with pneumonia and was admitted to hospital, and they couldn't quite work out why my immune system didn't seem to be doing very much, and yeah, I was quite unwell.

That went on for a few weeks, and they realized that that was when I had CLL. And, of course, they then told me, “Oh, it's very early CLL. It'll be years before you'll be treated.” I was feeling really rough, even after the pneumonia had officially resolved. They said, “That's just all the pneumonia. Don't worry, you'll pick up and get back to your normal life.” But, I never did, and in fact, maybe there was a slight improvement for a few weeks, but then it just got worse and worse.

I ended up having two lots of surgery, believe it or not, which is quite unusual with our condition. I had my tonsils removed, and then my lingual tonsils removed, and the first ones were actually as an emergency because they started to choke me to death. And then, about six months after that, I needed to have treatment, and I ended up being perhaps one of the last

cohorts of FCR; I don't know, maybe not, because I think there's still some debate on that as to whether FCR should continue.

But, I had it, and at least, in terms of my numbers, it worked for me. Again, all the way through that, I was thinking, "Oh, great, once this is over, I'll be fine. I heard about some GP who's retired, and when he was about four cycles through FCR, he was then riding a bike on Dartmoor and really feeling fine." And, that really hasn't been my story. I ended up in hospital for a month needing full mercy care just soon after I started the chemo. I have gotten better, but it's been very slow, and I'm still not able to work, and I still have lots of infections, and quite frankly, I'm here to learn as much as to contribute today.

**Michele Nadeem-Baker:**

Thank you very much. As you've learned—and, for some people who have joined us today—for CLL patients, two and a half years in CLL-speak in general terms is kind of a newbie, but it looks like you were thrown right into things, and perhaps you had had these symptoms and ignored them with your hectic lifestyle.

I also want to just use a disclaimer here that I am not a doctor, and I don't try to be, so anything that I say are my own opinions and not those of the medical community, but as a patient and advocate. But, I also want to ask Edward—now, Edward, you are the veteran of all of us, the longest-term veteran here, as juxtaposed to Adrian and Jay and myself, and you have had CLL—you were first diagnosed quite a while ago, from what I understand.

**Edward Spuzello:**

1988, 31 years ago.

**Maryellen Collamore:**

Wow.

**Michele Nadeem-Baker:**

So, Edward, you must have all this sage knowledge for us that we would love to learn, and as Adrian said, he would love to learn more—always learning out there in this journey that we have with CLL and its ups and downs. So, I believe you were in Iowa before Florida. Is that correct?

**Edward Spuzello:**

Well, I'm in both. I'm a snowbird here in Florida. My home is actually in Iowa.

**Michele Nadeem-Baker:**

So, what were you doing when you found out you had CLL? I would imagine that it would have been a bit different back 31 years ago.

**Edward Spuzello:**

Yeah. Well, I had started with swelling in my neck, and I thought that something was wrong, so I went to see my primary care doctor. He looked at it. He didn't know—he suspected that it was something that should be biopsied. So, he sent me to a surgeon and got a biopsy. So then, I was—initially, they said SLL, which, in later years, became CLL/SLL. I think it's all pretty much the same thing.

But, in those days, about the only treatment that was available was chemotherapy, so I had 10 monthly treatments of chemotherapy, and was in remission, and stayed there for 16 to 17 years, and it didn't really affect me during all those years. It's affected me a lot more since. I've had several relapses now, several different kinds of treatments, and so on, but nowadays, there are a lot more treatments available than when I started.

**Michele Nadeem-Baker:**

Thank you for sharing that. I would love to delve more deeply into that as we go through the program, and to find out what we can all learn from you, and that you had a remarkable, long, deep remission, it sounds like. And, look at you—you're still looking great. How is your energy level?

**Edward Spuzello:**

Well, it's pretty good right now. I've had several relapses—several different treatments—and right now, I'm on venetoclax (Venclexta), if you're familiar with that. I'm on a two-year treatment with Venclexta at the Mayo Clinic in Rochester. Venclexta does take some toll on your energy levels, and it also—makes me—tire easily. But, I'm also 77 years old, so it's kind of hard to tell what's going on. But, I'm active. I do a lot of exercise, I ride my bike, I swim, I go to the gym, and I think this helps. I feel okay.

**Michele Nadeem-Baker:**

I'm very happy to hear that. I want to switch us a little now so we can tap into Maryellen's expertise for us. So, I've heard from all of you the point about when you've been diagnosed, where you were in life, how you've handled things, and I've heard a lot about physical activity, diet, but I'd like to do a deep dive a little more into how did you handle things emotionally?

And, I know we all put on a great game face—"This is who I am, I have CLL"—and everybody's looking good here, but I'd like to know—I really hesitate to use the word "normal" because I really detest the saying "the new normal" because I feel it's rather insulting to us, but that's my own opinion. But, how did it feel that now, life was changed, or did your life—it sounds like everyone changed their life a bit around this. I don't know if Edward did in the beginning, and also, he gets to retire now at this stage of the game in his life, but emotionally, how did you handle this, Adrian, just a couple of years ago—two-and-a-half years ago, as you said?

**Adrian Warnock:**

I don't mind admitting that it was like a tsunami hitting my whole life, my whole family, and my whole career. Really, everything was left in tatters. There's no other way of putting it. And, it happened so suddenly. To me, my life now exists in two halves—the half before April the 28th, 2017, and the half after it, even though it's far from half. I was obviously 46 when I was unwell, and it's only been two-and-a-half years, but I feel like a different person.

I look back on the old me—I talk often about the old me, and the old me was a very different person, really. The thing is, everything gets robbed from you, or it can do. For me, I did try and get back to work for a while, but it was not really working. I don't know how it is in the U.S., but in the U.K., we have this thing called reasonable adaptations that your companies are supposed to make for you, so they're supposed to be adapting to a reasonable level given the disability that you have. And, my company did far more than that. They allowed me to work from home 90 percent of the time. I had a colleague who ended up covering all of my travel that they should have done—this wasn't immediate, but over time.

I tried to get back to work after that pneumonia, and it was an absolute, real, utter disaster because it was truncated by me not being able to cope, and basically lying in bed, answering a couple of emails, and doing a few phone calls, and not a lot else. I would occasionally haul myself out of the house and into the office, but it wasn't easy.

And so, of course, you then feel all that sense of achievement, all that sense of self-worth just ebbing away. You feel really guilty. I did my best to hand over to a colleague and try and finish a few projects during those months, and actually, there are some things I look back on that I did manage to achieve during those months, but as a high achiever—I was actually the medical director of a pharmaceutical company working in researching drugs, helping to get drugs onto the market, and helping to explain the results of clinical trials, and all of that, and then, to suddenly be unable to do any of that, and, at my worst, literally need full nursing care.

So, you can imagine there's no real easy way of saying it, but to say it's been like a tsunami in my life, and emotionally, that's been very much the case at times. Obviously, you do learn certain ways of coping with that and dealing with that. I'm not ashamed to admit I've had counseling and done various things like that. And yeah, I cope with it better now, but there are times when it's bad, and there are times when it's not so bad, but I wouldn't say that I've recovered anything like the quality of life at this point.

**Michele Nadeem-Baker:**

Maryellen, when you have a patient come to you—and, I am happy to divulge I have been one of Maryellen's patients in a very similar situation to you, Adrian, in that I'm a very high achiever, although very different set of circumstances with my CLL. One of the hardest things has been for me to understand that my professional career as it was, which was a fantastic

career, is totally changed. “Tsunami” is a pretty wonderful word for that, but mine was more—would be a different kind of front, moving a little more slowly, because I wasn’t thrown into everything. I had to watch and wait for some time.

But, one of my biggest challenges—after we hear from Maryellen, I would love to hear from Jay and Edward to find out—and, Jay already told us a little bit—if they had totally change parts of their lives like they were. You can all take yourselves back to that moment back then, but I know for me, it has been one of the most difficult, difficult things.

Maryellen, when someone like Adrian, myself, or any others here have this happen, and it’s really—I know this doesn’t happen to all CLL patients, but to many, their lives have just really changed. Not necessarily—other things come with that, such as not being able to earn money. Adrian, I know you have children. Maryellen, what do you suggest to all of us out there?

**Maryellen Collamore:**

Adrian and Michele, I appreciate you sharing this side of things. I think there is this culture—it’s starting to change—this idea that you should bounce back to the normal you or the “you” you were before your diagnosis, and that just isn’t the case. I think number one, the step of acknowledging that this was a tsunami, this was a huge shift over time that causes really significant loss—number one, loss of identity—but then, certainly, it trickles down to loss of finances, loss of maybe relationships in your life that people don’t understand what you’re dealing with.

Physical health can change—fatigue, as Edward mentioned—and things that change for your physical self—it all impacts, then, our emotional health, which Michele is bringing up. Again, step No. 1 is the awareness of that, and also, normalizing that. So, when I meet with patients, it’s really taking a step back and saying, “This is really difficult,” and it sounds so simple to reflect on that, but instead of diving forward with what treatment is next, where can I go, how can I make my life what it was, we really have to say what is my life now, where am I, and what are my new priorities? And, that can look different day to day, depending on where you are in that journey. But, acknowledgement is a really big piece.

**Adrian Warnock:**

I think one of the challenges for me personally—I’m sure it must be the case for a lot of others as well—is the way in which the situation changes so dramatically. I was really ill with pneumonia, I come out of hospital, I’m starting to feel a little bit better, and the doctors all think that I’m going to recover.

So then, you start to think, “Oh yeah, this is about recovery, I’ll be able to get back,” and then you suddenly realize, “Hang on, I’m trying to cling on here with my fingernails, and this isn’t working,” and then, suddenly, something really more serious happens again, and maybe—even right now, I still don’t know—it’s still six, seven months after FCR now, and I’m told that people do recover over time, so I guess it’s possible. I don’t know that I might get back to my work. Not sure. So, you’re in that huge uncertainty, and I think that’s almost worse.

This is going to sound really weird, but I sometimes think it would almost be better if you knew. If someone said, “Adrian, you’re never going to go to work again,” or “You’re never going to be able to walk again”—in a weird way, that would almost be easier to adapt to because you’re constantly adapting to something that’s changing all the time—at least, I have been.

**Michele Nadeem-Baker:**

Definitely. That uncertainty is the most challenging part. If you did have that concrete answer, even if it was a negative answer, psychologically, we can process that more easily. But, when it’s this uncertainty and unpredictability of what you’re dealing with, day to day, sometimes hour to hour, that is really taxing psychologically.

So, I work with patients to think about other coping skills that they’ve used in challenging situations in the past and really try to incorporate those into their day-to-day life. Something that has been really helpful and is getting more buzz now in social media is mindfulness, being present-focused, doing some really small mindfulness meditation exercises, which can help—it doesn’t take away the uncertainty, but it does take away the intensity of those thoughts that we’re having. So, things like that.

**Adrian Warnock:**

Yeah. I think the critical thing for me is actually acknowledging them. That's one of the things mindfulness allows you to do. I often talk about putting it away on the shelf, and you can do that. That is a coping mechanism—just shove it away—but the trouble –

**Michele Nadeem-Baker:**

You need to know what you're shoving away.

**Adrian Warnock:**

Yeah, you do, and the trouble is if you don't, it gets stronger and stronger, and then, when it does come back—so, I would have these scenarios where I might be fine for a while, but then, boom! It would be in your head. I've actually done a whole mindfulness course, and I find that very helpful, so I agree that mindfulness is great, just because it's trying to say, "Look, instead of trying to deny how you feel, or pretend it's not there, or indeed, actually, tell everyone"—because that's the other thing I found didn't really necessarily help, is expecting friends and family to be able to understand.

But actually, if you then—I need somehow to cope on my own, but actually, with the mindfulness, it encourages you to go, "You know what? This is rough. I do feel like this." But then, somehow, as you say, it takes the edge off it, and you're able to then recognize that there are other good things happening in your life as well, or things to be grateful for, et cetera.

**Michele Nadeem-Baker:**

I'm so glad that's worked for you. Gratefulness is a huge thing, I have found, and to be in the present about what you're grateful for. Jay, I would love to hear from you about when you were diagnosed because if I remember correctly, you're still on watch and wait, so you're still in limbo, but you're doing well, but you also said you have a company—advertising and publishing company—so, emotionally, how did this impact you?

**Jay Blatt:**

Well, it really made me realize that I enjoyed the advertising business, but it's like, no one's going to give you the Nobel Peace Prize for shaking a guy's hand, running away with his money, and making it ad. It's nice, and we need that in the world—we need people to help people promote their business—but for me, I had been doing it for a very long time.

I was officially diagnosed when I was about 62 years old, so it just changed my whole persona, and my ambition was now to do whatever I could to mess with the disease. It was bullying me, and I just got mad. I said, "You know what? I'm not going to put up with this. I'm going to change my life, I'm going to try and do something where I can first help myself, and then, I'll retire a little bit early or become semi-retired, and I'd like to try and help other people have hope."

And, the thing is you have to have hope. If you just sit around like a bump on a log and you're only putting your faith in miracle pills, it's not enough because that anxiety, that "What if?", that "When's the next shoe going to fall?" or whatever that expression is—you're just not going to be happy, you're not going to feel safe. So, for me, it just changed my whole life. I wanted to pursue something that I always was interested in, and that was diet and exercise. I began studying.

I wanted to do things—I looked at—every time I did something that would make me feel healthier and make me feel more vital and more alive, and like I was going to make it through this—every little thing I could think of to do to improve my situation, I did. So, the exercising, the suddenly realizing that what's important in life is being kind and helping people, and accepting help—these are things that sound hokey, and you can go your whole life if you're healthy and never realize just how important it is to wake up in the morning and not worry about being sick.

So, I took all that to heart, and it changed me. I don't want to sound so mushy, but I really feel this way. This has been, for me, an opportunity to grow as a human being. Yeah, I got sick, but so many other people get sick, and the idea is how do you bounce back? How do you make a comeback and never forget to love life? You do it through determination. I forget the exact phrase, but "Preparation brings opportunity," so you have to prepare and make that commitment that there's plenty of life left, and you're going to fight to hold onto it.

**Michele Nadeem-Baker:**

Jay, I love what you said, that you got mad and you weren't going to let the disease bully you. Instead, you were bullying the disease. Maryellen, is he at graduate level for therapy, or is this?

**Maryellen Collamore:**

I love it.

**Jay Blatt:**

Maryellen, tell that to your clients, and at first, they'll think you're nuts. That's generally the—when I say to people, “Bully it back,” they look at me like, “What?”, like it's a foreign concept.

**Maryellen Collamore:**

I love that you're able to do that and allow the situation to—like you said—really change you as a person. You integrated this diagnosis into your life, and it's changed your life. I think everybody's unique and individual in how we cope, and so, for some people, that phrase “Bully it back” might be a little too much, but for other folks, that will just give them the vigor that they need to really push ahead. I think again, it's acknowledging what works for you, and that's so wonderful that you were able to really make a shift in your identity.

**Jay Blatt:**

But, some of us are blessed—those of us who have a mild aversion to CLL—I can say all these things, “You can do this and do that, and at any level of the disease process, you can still try and improve your situation, and you feel empowered. It's so important to just think that you're taking action. But, I get that there are people out there that are very sick, and they're so brave. I'm just amazed. Thirty-one years, Edward? I can't even get my head around it. What my friend Adrian has gone through in just two years—it's advanced suffering. It's incredible.

**Michele Nadeem-Baker:**

It certainly is, and as many CLL patients as there are, which you've seen, Jay, on the CLL support group, there are different stories like this, and it's amazing how people get through all of this, how each story seems to be a bit different, and there are so many different varieties of CLL that we've all been—that we all have, and what we've gone through.

Myself, for those of you here who don't know, I have been in a clinical trial for about four years at Dana Farber, and Adrian, I don't think you're the last of FCR, but I did start the trial earlier than you, but it combined six months of FCR at the same time as taking ibrutinib daily and continuing on with ibrutinib (Imbruvica) indefinitely until either it doesn't work anymore, or the side effects are so great that you no longer take it, and hope...

**Adrian Warnock:**

...just a question about that—sorry to be a bit scientific for a minute here—what if you got to MRD undetectable? Would you still take the ibrutinib then, or do you stop at that point?

**Michele Nadeem-Baker:**

It depends on when you join the trial. Sometimes, you don't have a choice, and you go off it, but there—generally, that would probably be suggested. I have gotten extremely close to MRD negativity, but I am always a bridesmaid, never a bride—although, I have been a bride, so I guess I can't say that totally, but yes, incredibly close—within 0.04 of it being detectable or not detectable.

**Adrian Warnock:**

That's really strange, isn't it? FCR plus I—there's some fantastic results with us, and almost the vast majority of people, it seems like, are getting to MRD, and you haven't quite.

**Michele Nadeem-Baker:**

I'm one of the few.

**Adrian Warnock:**

I know. I started on FCR as an unmutated IGHV person. A lot of my American CLL friends were like, “No, don't do it!” But, I had little choice in the U.K. It was that, or go into the trial. It was a FLAIR trial where FCR was the companion arm to either

ibrutinib monotherapy or ibrutinib plus venetoclax, and I was quite attracted to the idea of ibrutinib plus venetoclax because I think these combinations of the newer drugs—or indeed, maybe the newer drug with the older drug, like you're on—sounded quite good.

I actually wasn't that keen at 46 to start ibrutinib and then keep taking it for 10 years, 20 years, who knows, but I was willing to take the chance—roll the dice—because I didn't really know what the best thing to do was, and as I say, outside of a trial, it was going to be FCR anyway, but I actually got FCR in the trial, and I'm MRD-negative. I think it was 4 out of 2 million of my cells looked suspicious.

**Michele Nadeem-Baker:**

Congratulations. That's wonderful. So, you're MRD-negative?

**Adrian Warnock:**

Yeah, which no one predicted, really, with FCR for an unmutated person, but there you go.

**Michele Nadeem-Baker:**

That's cause to celebrate.

Edward, we've left you alone for a while, but we certainly need to hear from you since you have been treated a few different times in a few different ways for your CLL, one that resulted in 17 years of remission. So, if you can put yourself back to that point in time, did you think your CLL was gone? How did you feel when you heard it had relapsed again? How did you feel emotionally?

**Edward Spuzello:**

Well, I never felt like it was gone. When I initially took chemotherapy, my oncologist at that time said, "Well, hopefully, this is going to put you in some sort of a remission," which it did. "After that, we'll just have to watch and see." I had checkups every three or four months for years, and before I had to have any more treatment, he kept warning me that my CLL was waning and waxing, as he termed it. Sometimes, it was better—my immune system was kicking in. Sometimes, it was worse. So, I was pretty much prepared for it.

So, in 2006—it wasn't until 2006 that I had my next treatment, after 17 years, and that was Rituxan. I had three months' Rituxan treatment, and it did me quite a bit of good, but three years later, I was right back where I started. I went through the Rituxan treatment again, but it didn't do a lot of good. It didn't do a lot at that time. At that time, he referred me up to the Mayo Clinic.

But, during all that time, I guess I'm not the person that we were just talking about these things—when I was first diagnosed, the oncologist said, "Well, we'll continue this treatment, and you should be okay." I said, "Fine." I didn't worry too much about it. I didn't ask too many questions. I didn't know much about it. I had a business then that I had just started two years before. I was married, I had kids, I had to make money, so I just did it, and I didn't worry too much about my condition.

In recent years, it's become more active, and in 2009, after my Rituxan treatment had basically failed again, they sent me up to the Mayo Clinic, and I got in a clinical trial up there which did me quite a bit of good, and I was in pretty good remission until 2014. In 2014, they decided to remove my spleen. It was still full of CLL, and it was eating up my platelets; my platelet count was really low, so I did—I removed my spleen and took some other chemotherapy Rituxan treatments with it.

But, when they removed my spleen and biopsied lymph nodes and stuff around there, they found that some of my SLL was morphing into large B cell lymphoma, which is much more dangerous. So, at that point, in 2014 and '15, I had a stem cell transplant, and I spent six weeks at the Mayo Clinic, living there, to do it. So, that was—I worry too much about it, but that was quite an experience. It wasn't a lot of fun.

**Michele Nadeem-Baker:**

How did you get through that, Edward?

**Edward Spuzello:**

I got through it okay. Massive amounts of chemotherapy—killing all your white blood cells—but mainly, I was just terribly fatigued. I wasn't real sick, I was just really fatigued. I slept most of the time. Anyway, I got through that, and I got better, and I was doing fine until June of '18. Unbeknownst to me, I really had a complete relapse then. I didn't see it coming, and my lymph nodes didn't swell up, I didn't have night sweats, but eventually, I had some bloodwork done, which looked terrible, and so, I had a complete relapse.

I was in the hospital for three weeks, and it took me a long time to recover from that, and I finally got on—in July, I finally got on—into August—Venclexta, which is my only hope. I could have taken ibrutinib at that time, but the Mayo Clinic felt I was better off with Venclexta, and Venclexta put me into pretty good remission, by the way, the first month. That's the way it works. So, I feel fine. I have lots of energy, and I have more fatigue than I did, but as they say, "Well, you're older now, too. You're 77 years old."

But now, I'm feeling pretty good, but I don't know what the future is. They said I should stay on Venclexta two years. Well, it could work in two, but after two years, they say, "Well, maybe we could switch to ibrutinib, actually." Also, they want to look at clinical trials, getting me into clinical trials. Things like CAR T-cell therapy are probably too far out there, and I'm a really high-risk patient right now. I have 17p deletion, I have 53g gone—I have all these things, so I'm a pretty high-risk patient, so I don't know what's going to happen, but right now –

**Michele Nadeem-Baker:**

Edward, we look at you, and it's amazing to me—you're very resilient.

**Edward Spuzello:**

I'm pretty good right now. During this whole process, I don't think it changed my life much at all, and I don't think my life would be any different than it's been. I tolerate treatments pretty well, which is in my favor.

**Michele Nadeem-Baker:**

Just to hear all that you've been through all of these years, and that you've gone these long periods of time of remission, and that you continue to fight back, and you have this wonderful attitude for people is a wonderful lesson to learn. Maryellen, do you seem to find that there are patients who seem to come in hopeless, and then realize that life doesn't have to be that way? Because it seems all of us have had different circumstances, different experiences of what we're all here to talk about and share to help others.

**Maryellen Collamore:**

Yeah, I think Jay mentioned that idea of hope as well. I think it's perfectly normal and natural to have periods of hopelessness, but as I talk with my patients, I want to make sure they're not getting stuck there, and I've seen a lot of my patients come in and maybe have that initial feeling, but be able to gain hope, whether it is through changing their life, whether it's through staying true to themselves and relying on the strong support system, whether it's diving into CLL advocacy and education—Michele, you've done a bunch of that. But, there's all these different coping mechanisms that can help really re-integrate that idea of hope into our lives.

**Michele Nadeem-Baker:**

I want to thank you all, and with closing, I would love to find out one quick thing from each of you of lessons learned—something you would tell other CLL patients—for hope. Jay, I'd love to start with you.

**Jay Blatt:**

Never give up. Do everything you can. Preparation is important. Learn about your disease. Advocate for yourself. Try and build a great support team that consists of family, friends, and good doctors, and even holistic healers. Anything you can do—set a goal that anything you can do on a daily basis that lessens the impact of your CLL is a good thing. It's a good goal. Anything that makes you feel happy, pursue it, and just keep going, and just do your best. That would be—don't give up. Do your best.

**Michele Nadeem-Baker:**

Edward, what would you suggest to offer quick words of hope?

**Edward Spuzello:**

Well, I would say to newly diagnosed patients to don't overly worry about it. In today's day and age, there are many treatments available for what you need to keep your CLL in a chronic condition, not let it get out of control, and that you can expect to live a long time. I've lived a long time, and I'm still living, and I don't think they should be overly upset about it. It's a good time to get a CLL diagnosis.

**Michele Nadeem-Baker:**

Thank you. Those were great words of hope, Edward. Thank you. I appreciate that. Adrian, how about you?

**Adrian Warnock:**

I'm going to focus on that hope when you're in that recovery mode, and when it's really tough. Sometimes, you can feel like you're plateauing—I know I have—and you're like, "Am I actually making progress?" I think it's just finding things to be grateful for, finding really specific things that you can go—so, I went on holiday, for example, this last summer, and I realized although I was still not able to do as much as I wanted to be able to do, I was able to do a lot more than I could last year.

My tendency has been to compare myself now to how I was before I was ill, and that's depressing, but if I compare myself now to how I was when I was at my worst, or even how I was a month or two ago, that can be more encouraging. One of the ways I do that in a very specific way is this watch, believe it or not. It doesn't have to be an Apple Watch; it can be a Fitbit or something like that.

Just tracking my movements, because what I've noticed is that when I was at my worst, I didn't move at all, and although I have good days and I have bad days, I have good weeks and I have bad weeks of having infection, the overall trend I can see over the last few months—really, since I started chemo, more or less—has gradually gone up.

Yeah, there are times when it goes back, but if I look—there's an actual figure I look at specifically, which is the average step count per day over a month, and that's the view I look at sometimes. I go, "Oh yeah, look, it is going up, even though, Adrian, you might not feel like it. Stop comparing yourself to what you used to be. Compare yourself to your worst point rather than your best point." That has helped me a lot during my recovery, to be honest. That's some gratitude and hope, and just saying, "You know what? Forget where you're heading. At least you're moving forward."

**Michele Nadeem-Baker:**

Thank you. Maryellen, any final words for patients looking for the wisdom that you can give to them for hope, that there is hope?

**Maryellen Collamore:**

I think just reflecting on all the words that were shared already, it's really recognizing that it's a unique experience, and so, finding what works for you. As Adrian said, try not to compare to your old self, but also, try not to compare to everyone else's stories, either. Find your hope, not someone else's.

**Michele Nadeem-Baker:**

I want to thank all of you today—my fellow patients, Jay, Adrian, and Edward, and our expert, Maryellen Collamore—and I want to thank everyone for joining us today on Patient Power's Patient Partners program. I'd also like to thank our sponsor, and to note that they have no editorial control over our content. This is Michele Nadeem-Baker. And remember, knowledge can be the best medicine of all. Thank you.

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