



# Patient Power

## A Patient and Care Partner Share Lessons Learned From the Journey With Cancer

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CLL Patient

**Nelia Pacheco**  
Care Partner

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**Andrew Schorr:**

So, Mark, you decided after you were diagnosed with leukemia to get an education and become a therapist to help others, particularly cancer patients, and more recently even including a lot of work with people who are out of treatment options and are said to be terminally ill, although, quite frankly, I hate that term because I always hope medical progress will catch up.

So what have you learned? Give us a couple pearls from what you've learned in your own journey with your wife that you share with these patients or support group members who often have a close relationship with someone else to make that relationship healthier even with the diagnosis of cancer.

**Mark Silverstein:**

That's a challenging question. I think I'd go back to what I was just discussing before about communication and about expressing how you're feeling, both positive and negative. I just think in the end, sharing the language of the experience brings you closer together, but you're also sharing both the negative and the positive effects of the cancer diagnosis. I just really—the focus is usually communication.

Of course, there's—I mean, when it comes to a client in that situation, there's managing their anxiety, their death anxiety. There are other aspects to it. But we focus on trying to find meaning in everyday events. What's meaningful to you? How do you achieve those things considering your health situation? How you're feeling? How do you accomplish what you need to?

I took some training down at Princess Margaret Hospital called "Calm" and it was created by the two psychiatrists in the palliative care unit there. And the whole concept or the whole idea is how do you know your—how do you acknowledge and accept your passing away? And by the same time, carry two different thoughts at the same time, also live every day meaningfully. And how do you carry both of those things together?

And so—because otherwise, here’s your last few months and you’re rolled up in a ball in fear and anxiety, not doing anything, and then it’s done. And so how do you get something valuable out of that time? And that’s really what we like to practice and I think it’s hugely important for someone, especially in that situation, but it’s hugely important for all of us.

**Andrew Schorr:**

One time in an interview, somebody reminded me. They said, “Hey, Andrew, put cancer aside, life is a terminal condition.” And we forget that so much that we’re passing through this world. So, Nelia, so we have care partners watching. What are some things you’ve said—made some great points along the way. Is there anything particularly you want to underscore? People have different situations, different relationships, but when you talk to somebody’s wife or husband of a patient, or even kids, adult kids, what are some of the things you say to them that might be helpful?

**Nelia Pacheco:**

I think, for me, the most important thing to accept is, although we look at this as a partnership, this is Mark’s life, and it’s his decision and his choices on how he wants to move forward, whether it’s with treatment or what he wants to do with it. And although we talk about it and he’s asked me for my input, it doesn’t necessarily mean he’s gonna go with my suggestion. And I need to accept that and understand that I am there as a partner for him in this experience versus being more, “This is what I want you to do.” It’s not my diagnosis. It’s not my journey, so to speak.

So I think it’s so important just to be there and just accept their choices and to be there and support the patient’s decisions and choices, even when you may not agree with it. Because it is their life, and my role is there to support it. And, I mean, that’s really important. So to take out—it’s kind of to take out what you need in a sense and just be there and present for them.

**Andrew Schorr:**

I’ll mention, on our Patient Power website, we have a care partner section and also there are a number of groups of care partners that meet whenever Patient Power does one of our in-person town hall meetings. We get care partners together, caregivers together. So it can be a safe space sometimes to say something that you’ve been thinking that maybe you wouldn’t say to your loved one or maybe not right off the bat. So I would urge care partners to reach out to others.

But knowing, and Mark is so aware of this, knowing you two, that everybody’s clinical situation can be different. And so somebody may say to you, “You should do this, do that, tell your husband, tell your wife do this.” And it’s gonna be different. But that said, Mark, Nelia was just saying it’s your decision on your life, but I have a feeling she’s been a tremendous rock in your journey, hasn’t she?

**Mark Silverstein:**

Absolutely. I can’t even begin to honor her with everything she’s helped with and done for me and supported me with, especially it’s been seems like forever that she’s been there for me. I found especially in the last year or so, we’ve almost switched roles a little bit, too, because I haven’t been very well. She’s really taken up also the mantle of understanding the disease, recording all my blood work, challenging the doctors when I wasn’t feeling up to it.

So beyond just taking care of me, caring for me. I was so weak after transplant, I would need help just to get in and out of a shower or in and out of a bathtub and just everything. Sometimes it’s really challenging to give up control of your—to be dependent, you know? And she’s made it okay to be dependent in the sense of never making me feel bad about it or always open to helping, always open to suggesting things, always—I always feel like she’s got my best interest at heart.

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