



Information Gathering As a Care Partner

Alice Sperling
Care Partner

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Andrew Schorr:

Andrew Schorr sitting with my new best friend, Alice Sperling, whose husband was diagnosed with chronic lymphocytic leukemia in 2002.

Alice Sperling:

Correct.

Andrew Schorr:

You've been married 47 years.

Alice Sperling:

Right.

Andrew Schorr:

And you read everything you can. You go over the internet. You taught in college for a number of years, so you're a researcher.

Alice Sperling:

Right.

Andrew Schorr:

Okay. Why do you keep researching? And I understand you look up stuff like every day.

Alice Sperling:

I do. I read—I get e-mails from two or three different listeners. Of course, I get the Patient Power emails. I get CLL Society emails, so I'm actively engaged all the time.

Andrew Schorr:

Okay. But isn't it too much sometimes, Alice?

Alice Sperling:

Well, I think at one point it might have been, but I think I took it slowly. I mean, I only discovered the websites kind of one at a time, and I'm not adding very many more, although there are a couple in the folder that I might go look up, so I don't think I overwhelmed myself with the information so much as I was hungry for it.

Andrew Schorr:

Okay. Now, how do you determine whether something is reliable? Do you triangulate between these different, credible sources? Are the same things coming up? Is that how you do it?

Alice Sperling:

Yeah, absolutely. So I'm on the Facebook group. Now, I normally wouldn't consider Facebook a reliable source of information, but because I do all the other research I know—I mean, I've been doing it for since 2002, so that's 17 years I've been reading about this disease. So I recognize now the names of the doctors and the institutions that they're under and where the information is coming from, so I think I'm pretty good at sorting through.

And I read a lot from other patients, and I'm pretty good at sorting through how knowledgeable they are. You know, Chris Dwyer, who recently.../

Andrew Schorr:

...passed away.

Alice Sperling:

Passed away, but I would—so I would look for certain names and knew who to trust.

Andrew Schorr:

So, Alice, you're the advocate in particular for your husband, Jay.

Alice Sperling:

Right.

Andrew Schorr:

And you're looking at all this information and try to simulate it and be discriminating. How much do you tell Jay, right?

Alice Sperling:

Right.

Andrew Schorr:

Because, you know, you be obviously have developed the aptitude not to get worried...

Alice Sperling:

Right.

Andrew Schorr:

...but to be knowledgeable, but you don't want to worry him.

Alice Sperling:

Correct.

Andrew Schorr:

So talk about the relationship between the wife who's garnering all this information, husband who may not be nearly engaged, what do you tell him and when?

Alice Sperling:

So if I see some new development that I think is really interesting, a new drug in development, I send that email right on to him, and so I forward information to him on a pretty regular basis. I don't think he's uninformed in any way, it's just that I'm after the sort of nitty-gritty details that he's just not that interested in.

Andrew Schorr:

Okay. And do you screen some stuff out? Let's say if there was—let's say on a ListServe or Facebook, let's say somebody passed away, and you were sad about it, of course, do you like keep things from him?

Alice Sperling:

I don't keep that kind of thing from him. And he's sitting right there, so I'm a little nervous about telling him what I keep from him. But I think there are times when I'm reading about rare side effects of a drug that he's on or a treatment that he's had that I just—I don't want him to worry about it, because there's no evidence that he's suffering from the same thing. So that might be a time when I might just say he doesn't need to know this.

Andrew Schorr:

You go to doctor appointments with Jay.

Alice Sperling:

Absolutely.

Andrew Schorr:

Okay. And you have questions.

Alice Sperling:

Yes.

Andrew Schorr:

But are you cognizant of letting him be the patient?

Alice Sperling:

I try. I try. We see Dr. Sherman, and we have a wonderful relationship with him, and sometimes because I've read the research Dr. Sherman and I will get to talking, and Jay will be sort of sitting there, okay, hello, hello, I'm the patient. How about talking to me? So, yeah, I try to—there is a line, and I do cross it sometimes.

Andrew Schorr:

All right. Lastly, what do you want to say to other spouses, care partners of someone with CLL on what is a healthy way to help?

Alice Sperling:

Yeah. You have to do what you're comfortable with. I think it's real important to have somebody else in the room with you when you have your appointments, and it doesn't matter particularly whether it's your spouse or a good friend who can go with you or—but some continuity of having somebody with you at the doctors' appointments. It makes such a difference to have two pairs of ears. We don't always hear things the same way, and we talk about it afterwards, and what did he mean by that, and how do you feel about this? So that I think is real important.

I think it's important for somebody to be doing the research, and you suit yourself on the depth that you're interested in. I mean, most people I know are not reading about this every single day the way I do. I don't spend hours at it, but I get in bed at night with my iPad and I'm looking through my emails, and, oh, there's three CLL things, and so I read them.

Andrew Schorr:

And lastly, how do you have this not dominate your life but for both of you, you and your husband, go on with your life.

Alice Sperling:

Yeah.

Andrew Schorr:

You have children, you just go on with your life.

Alice Sperling:

Yeah. Jay's the best example of that that I know. He refuses to let it govern his life. He just always has—since diagnosis, he's just said this is—we're going to be okay, we're going to deal with this as it comes up, and I'm not going to worry about it, and I'm not going to think about it.

His sort of slogan is watch and live as opposed to watch and worry. He was seven years before he needed treatment, and I was doing a lot of research during that time. He was trying not to think about it, and I think he did a real good job.

Andrew Schorr:

Well, Alice, thank you for being the information-gathering partner for Jay. You're a wonderful couple, and I wish you another 47 years.

Alice Sperling:

Another 40—oh, God, no.

Andrew Schorr:

That would be something. Okay. Andrew Schorr with Alice Sperling from Oregon being the real information gatherer for her husband, Jay, but then living well together.

Remember, knowledge can be the best medicine of all.

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