

# LGSOC Patient Impact Quotes

The following quotes are from qualitative interviews conducted as part of the LGSOC Patient Impact Survey and illustrate the unique challenges faced by people with LGSOC regarding diagnosis, disease management and mental, physical, and emotional well-being.



“ I went to about five different gastroenterologists, bounced around over those probably for another two years, trying different diets, trying different medication. They thought it was IBS, and so, it was a lot of ‘people have this and you’re too young for it to be anything serious and blood work looks good.’ And I went to my gynecologist and they said, ‘seems like a gastro issue.’ And the gastro said, ‘seems like a gynecological issue.’ And I kind of got passed back and forth. [until I was diagnosed with LGSOC]. ”

Ellie H.

“ Along the journey of getting my diagnosis, my obstetrician gynecologist continued to tell me, ‘Oh...you don’t have cancer. You’re too young.’ ”

Connie B.

“ I think that as a whole, we don’t know enough about the disease... Low-grade serous ovarian cancer is...completely understudied...medical oncologists and researchers have a lot more work to do...there’s just so much more to learn about what causes it, what treatments could be effective, and how to support people who live with it. ”

Ellie H.

“ The medicine I’m taking...it’s not even for ovarian cancer. It’s actually specifically for metastatic breast cancer, but they found that it helps with metastatic ovarian cancer as well. It’s like we don’t even have our own treatment. We’re using other diseases’, other cancers’, medicine to help us. Why don’t we have a treatment for low-grade [serous] ovarian cancer? ”

Tiffany R.



“ The emotion that I feel from the physical impacts that this condition has had on me is devastation. I never thought I would be so tired and slow. I was always the one coming up with things to do and encouraging people to get out, and now it’s me saying, ‘Well, if I feel okay, I’ll join you, but most likely I’m going to have to take it easy.’ And to have that as my future and potentially as long as I’m on this maintenance medication is horrible. ”

Connie B.

“ [My] main wish going forward...is getting women out there to literally shout it from the rooftops. Hey, if you’ve got these symptoms for more than two weeks bloating, more frequent urination, pelvic pain, menstrual irregularities, let’s spread the word. We need to let women know to really be observant of their bodies and make sure that you’re talking either to your primary care physician or your obstetrician gynecologist. And if you don’t get the answer you want, if you want follow-up, if you want a second opinion, go seek it out. ”

Connie B.

