Cancer and Quality of Life: How to Stand Up for Yourself

March 1, 2020 By Jennifer L. Cook

People with cancer, and survivors, face a series of quality-of-life challenges, from debilitating side effects to financial burdens. Fully addressing these will require major changes in how we fund research, develop treatments, provide support for survivors, address financial burdens and much more. But that doesn't mean you need to wait to make things better for yourself or someone you love who has cancer.

Here are suggestions from patients, researchers, doctors and advocates to help you get the care you need without sacrificing your quality of life.

- Choose the best care you can find. Dan Engel, a 20-year melanoma survivor who was treated at the Angeles Clinic and Research Institute in Los Angeles, one of the top 10 melanoma centers in the country, went through 10 surgeries, radiation, gamma knife surgery for a brain tumor and six clinical trials and is now cured. "All along the way, I had a plan and followed it religiously, and I believe everyone should. I think it makes a huge difference," he says. Comprehensive cancer centers, a designation awarded by the National Cancer Institute, offer high-quality care, clinical trials and extra resources. (For more tips, see Newly Diagnosed? Start Here.)
- Request a meeting with a palliative care team. It's like an extra layer of support, says Anna Berman, a nurse and metastatic breast cancer survivor who works at the John A. Hartford Foundation. If your course of treatment is likely to be grueling, the palliative care team's job is to focus on you as a person and help you manage your pain and other symptoms. In addition, if your cancer is terminal, the team will help you with spiritual support and advanced care planning and help you focus on your goals for your remaining days. Whatever your stage or cancer type, ask about mental health resources as well.
- Get help with the cost of care. Speak up about the issue with your health-care providers.

“Patients will often hesitate to say that cost is a concern because they don’t want it to be perceived that they’re not taking their health seriously or that they’re rationing in some way,” says Mary Politi, PhD, associate professor of surgery at Washington University in St. Louis. “But it’s the reality of the system. Sometimes we can better help people find something that works, without compromising care, within their insurance plan.” You can also ask about a cancer center’s resources, which might help offset costs; some have expert financial navigators who can help you find resources. Ask pharmaceutical companies about drug rebates for which you might be eligible. Here is a list of organizations that can provide financial assistance.

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- Sign up for a clinical trial. These are often the best way to get new treatments for specific cancers. Clinical trials have historically excluded certain patient groups, including older people, those with other illnesses and women who could become pregnant. But efforts to be more inclusive are increasing, especially since positive trial results often aren’t matched in the real world, where patients may not be as young or healthy as those who were enrolled in studies.

- Join an advocacy group and raise your voice. Thanks to the internet and social media, it’s easier than ever to join groups, get support and stay on top of treatment advances. Plus, there is power in numbers. Patient groups that represent different types of cancer can help communicate specific needs and wishes—which may differ among cancers—to researchers, doctors and government agencies. Patient groups need to and are becoming savvier partners in regulatory science, Pitts says, “moving away from simply collectors of patient anecdotes to collectors of validated data and helping theFDA [Food and Drug Administration] direct actual guidance—being part of the solution.”

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- Ask for a care plan when your treatment is done. Patients are increasingly surviving their cancer—more than 15.5 million in 2016, according to the American Cancer Society. Advocate for yourself as you finish treatment by making sure you receive a plan that spells out what follow-up tests and other care you may need in the coming months and years. In 2006, the National Academies of Sciences, Engineering, and Medicine addressed this issue in a report

titled From Cancer Patient to Cancer Survivor: Lost in Transition. In the years since, survivors' needs, care and concerns are receiving more attention. One direct result of that report was the establishment of Journeyforward.org, a nonprofit resource that provides patient tools, including a self-care plan for patients and one for survivors who have finished treatments.

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In the end, quality of life comes down to getting what you need as a patient, and that's why Mailet Lopez, a breast cancer survivor and founder of IHadCancer.com, says, "We are big believers in making sure that you advocate for yourself. If you don't feel your questions have been answered or a doctor is ignoring some of your side effects, continue to ask and push until you get what you are looking for, even if it means switching to a new doctor. Our community insists on making sure they are being heard. That's part of the empowerment that people are starting to feel as patients."

Read the whole special report...

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How to Stand Up for Yourself

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