

Lung Cancer CHESS:

Owen-

Nancy was originally diagnosed with stage 4 lung cancer as a result of a physical exam which was done as a pre-op for gallbladder removal. They happen to take an x-ray on the spot, and that was the genesis of our lung cancer adventure. Nancy quit smoking 15 years prior and we were not expecting cancer. We were in disbelief, denial, I'm sure just like everyone is shocked, and you regroup.

Toby Campbell-

When I first meet someone with lung cancer, they are really desperate for a lot of different kinds of information. They need to know what the treatment entails. There are a lot of questions about what is going to happen to them in general. "Is this cancer going to go away?" "How sick am I going to be?" "How long do I have to live?" They really need a lot of detailed information as well as, sort of, a broad overview of information.

Jen Verhoeven-

And they need a lot of support, you know, why is this happening to me and how could this have happened to me, and not just me but my family? So, there is a lot of emotions that people go through when they are first diagnosed with lung cancer and there are a lot of needs that come with that diagnosis.

Dave Gustafson-

CHESS is a computer program that helps people deal with various serious diseases by providing information, emotional support, and tools to help them cope more effectively. We decided to build a CHESS program for patients dealing with lung cancer, but in addition to the patients, we wanted the program to provide support for the family caregiver.

Lori DuBenske-

So CHESS may provide a unique resource for them and that it can meet a lot of different types of needs in one spot, and it also is a consistent resource for them across the continuum, so that it stays with them from diagnosis, through survivorship or through end of life, and for the caregiver, it still is with them for bereavement support as well.

Owen-

I read several of the personal stories, the informational articles, I read a number of those. Interestingly, I probably checked the discussion groups almost daily, but I never participated or responded, but it was always interesting and maybe supportive for me to see what other people were going through. I think, I think after Nancy died, I think it was good, and very very helpful

to have people that have lost their spouses to be available for conversation and information, because there are just so many things that come up, “how do you handle this, how should I handle that?” I don’t really want to talk to my kids about this, I don’t even want to talk to my friends about. So I think it’s, it’s good to have someone that is distant that you can visit with.

Lori DuBenske-

We did find that those people that received the website after six months did have less anxiety, less depression, and less caregiver burden, than those who had used the internet alone.

Dave Gustafson-

We were also surprised to find that patients who received CHESS, actually lived longer than patients who didn’t. As a matter of fact, about 40% longer.

Lori DuBenske-

So the new lung cancer study is a follow up study to see if we can test specifically whether or not CHESS indeed does have a survival benefit, and if so, what might be the mechanism that is causing that benefit?

Toby Campbell-

When patients are meeting with me and we’re there to talk about chemotherapy and other, you know, details of taking care of their cancer, sometimes it’s easy to lose in that fog, the person, the human, who is seeing grandkids this weekend, who is wanting to go to the fair. CHESS helps us to not lose completely that focus. It both provides them with the, I think, the language and the knowledge that they need to say to me, “is it ok if we delay chemotherapy by a week, because,” as a case in one of my patients from last week, “it’s very important for me to the State Fair with my kids next week and I don’t want to be feeling sick.” And I think, without the information that they learned on CHESS that it’s OK to delay chemotherapy by a week from time to time, they probably wouldn’t have said anything, and maybe wouldn’t have gone to the fair and had a great time.

Owen-

I think, having the information on knowing what the situation is and then having faith that whatever would be would be. It’s really simplistic, but I don’t think we were afraid of death. That was the farthest thing and we accepted the disease and we fought it the best we could.