



Lori Flint, RN

Chapter 1

Why The Esophagectomy Support Group Is So Important To Me

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The support group has not only changed my nursing career, but the way I look at my personal life. I have learned so much from all of the folks who have gone through the meetings, sharing their stories, their initial struggles, and learning that having a good attitude, family/friend support, and staying busy will help you get through anything!

In the beginning

The support group came about sometime in 2002, although I really cannot remember the exact date. It started, by getting daily calls from the same patient. He was trying to get adjusted to his new way of life after surgery. The calls ranged from, 'What was he supposed to eat?', 'Why was he not hungry?', 'What was his wife supposed to do with him?'. He would periodically talk about his prior history as an alcoholic and the support he got from Alcoholics Anonymous. He kept talking about how he felt a support group would help him during his recovery from surgery. Finally, after a few weeks of daily calls (and those also calling with similar issues), I told him that - if he would help me - we could see about starting a support group. With the help and support of Dr. Orringer, and the thoracic surgery staff - including Sharon Fox, RN - the esophagectomy support group was started. I never thought it would grow the way it has, but am very proud of where it is today.

The first several meetings were small and we had a hard time finding a room that would work for all to find and feel comfortable during the discussion. As we continued to work on this, we were able to engage a very special patient, who was many years out from his

esophagectomy. (He still comes to offer his advice on living with his ‘new plumbing’.) He was on his way to Florida, when he came to that meeting. The patient who was the reason I got this support group started told me that talking with this patient helped him to turn the corner, and made a huge difference in his life and his overall wellbeing. It actually all had to do with eating strawberries. He was told if eating strawberries affected him when he ate them, then he should not eat the strawberries! This is when I knew we had to keep the support group going. Even if we helped just this one person, then it was all worth it. Little did I realize, not only would it help so many, but it also helped me be a better nurse to those going through this ordeal, from initial diagnosis to dealing with the life changes after their esophagectomy.

Through the years

We continued to try to change, improve and get the word out about the support group to help as many as we could. We started with a list of patients that others could email, and posted this on our website. As a suggestion from a family member, we were able to video one of our meetings for others to view if they could not make the support group here in Ann Arbor. This was actually funded by a patient’s family; the patient had lost his battle with esophageal cancer. It was a great gift, that allowed many a chance to see how all the patients looked following surgery, as well as listen to what their initial struggles were and what they did about them and how they are today.

We would get calls from all across the country, as there are very few esophagectomy support groups. These folks would ask about the group and ask the patients on the email list all kinds of questions. I believe the patients, as they went through the meetings and answered their emails, realized how important their input was and how much they were helping others. That is an amazing feeling.

Changing of the guard

When I was looking to change my nursing role the hardest part was trying to figure out what would happen to the support group. It was a part of me, a part of ‘my family’, and I wanted to make sure I could

continue it until it could be supported by another nurse. With knowing I could do that, I did change my nursing role. Of course, I was also able to ‘support’ the support group, until Tiffany came on board. Then I felt ‘my family’ was well cared for even though I was no longer there ☺.

Tincture of time

I wanted to make sure to point something out as you read this, whether you have just started the journey with esophageal disease or esophageal cancer, are looking at having the surgery, or have had the surgery. Know that it may not always turn out the way it was planned; remember to take it one day at a time and try to stay as positive as you can. You will be able to eat again, but this ‘New Normal’ will not be the same as now; it may be smaller food amounts, not right before bed, or not certain kinds of food.

I hope that if you are able to get to even one support group to see folks that have had the surgery and listen to how they have recovered, as well as read these stories, and see the video, it will help you make the best decision for you, and your disease process (which can be different for each person).

If surgery is set for you or done, and you are working to make it through the initial recovery period, know that you are not alone. Although each person is their own individual with different symptoms, there are many common threads and you can use all that you learn to help guide your steps to make it easier, one day at a time. Sharon Fox, one of the first thoracic surgery nurses, used to say the hardest pill to take is the ‘tincture of time’. Just remember it will take time - along with support - and a positive attitude.

My gratitude

I want to make sure I thank Dr. Mark Orringer. I feel very fortunate and am a better nurse and person having had the honor to work alongside him all those many years. It was truly a privilege and I am forever grateful to him.