SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.

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President's Message

By Lois Dickerman PhD

As I ponder the course of my husband's treatment and recovery from Stage IVB esophageal adenocarcinoma the past 40 months, I remember each milestone as if it were etched in my brain…the first PET/CT scan that showed reduction of liver tumors, the decision of his physician team to halt the chemotherapy and try a new approach

that was very successful, and finally overcoming massive dehydration and extreme weight loss after multiple rounds of radiation therapy are just a few that leap out at me. But some of the most poignant memories are those associated with small acts of kindness and thoughtfulness.

One February day, Dick was undergoing chemotherapy and the weather was very cold

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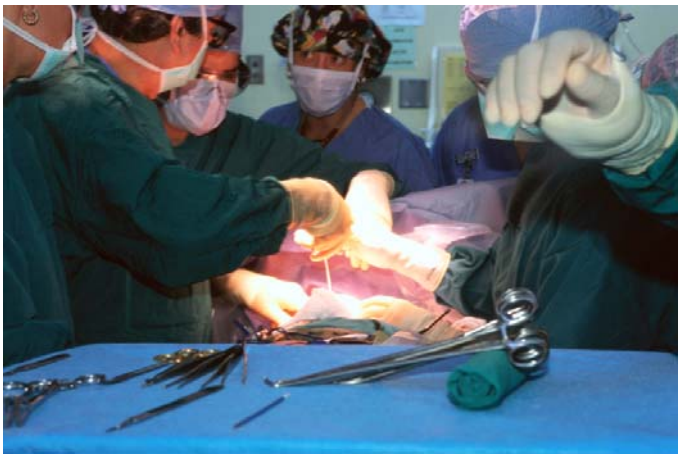
Post-Operative Esophagectomy Care

By Dick Steinmier M.D.

This article discusses topics that patients and caregivers may need to know about post-esophagectomy care and problems. They are most appropriate for those who have had a resection of the mid or lower part of the esophagus, with the possible removal of some of the stomach, and the connection of the remaining stomach to the upper esophagus by making part of the stomach into a tube. Some major topics are often discussed elsewhere in great detail and do not receive further coverage here. Instead I cover topics that are sometimes thought to be too trivial for attention, yet still important.



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outside. The wall of the infusion therapy suite, despite being thermal glass, seemed to be absorbing all of the heat in the room. One of the marvelous volunteers, a tiny little woman in her 80's who literally bustled with energy, came by and saw my husband huddled beneath a small lightweight lap cover. She said "Oh, my goodness, you're cold, aren't you? " She turned quickly and disappeared for a few minutes, and then came back with a cotton thermal blanket that she had pulled from a warming oven. As I sat near him, I even appreciated the heat it radiated. In a few minutes, he dozed off like a baby in a snuggle suit and captured some much needed rest. I wanted to hug her in gratitude, but she quickly disappeared to help someone else.

She was the epitome of the countless angels who helped us along the treacherous road of all his cancer therapies. There were too many other acts of kindness from friends, neighbors and even acquaintances of only casual contact in our 19 months of fighting cancer to list in appreciation. Yet they made an enormous difference. All of us probably have memories of similar gestures that helped so much. I just want to remind all of you how rewarding it is to "pay it forward" to others in very small ways.

The big gestures like running in a marathon to raise money for cancer research; spending time and energy to raise money in a local cancer event, or donating to local cancer hospitals and centers for special fundraising projects are all incredibly important. But there are so many other ways to help one on one and these are the acts that warm the heart.

Think of things like picking up some special food items for a friend at the grocery store on a regular trip or the pharmacy to pick up a prescription, picking up a book at the library, offering to accompany the patient in a brief walk in the park on a sunny day, taking over a bouquet of the first spring flowers that appear, etc. Our joy in life is rarely measured in large, extravagant gestures and events, but most importantly in small thoughts and deeds that touch the heart and soul. These acts are double blessings, both for the giver and the recipient. I believe that it is particularly important for those of us who have been lucky to fight "the beast" and to enjoy a new beginning to remember this. –*E*–

Turning a Corner

By Roger Tunsley

It's Sunday evening, around nine o'clock. My wife Kathy and I are watching TV. I turn to her and ask if she would like anything – a snack or a drink. Then I suddenly remember; I have a scan in the morning and I'm not supposed to have anything after around eight o'clock. I mention this to Kathy, and then we both realize what's happened and we grin at each other. I've turned a corner.

In 2006, I was diagnosed with stage 3 esophageal cancer. The memory of that moment is as clear as this morning's breakfast, but the conversation afterwards, the drive home, in fact the whole of the rest of that day, is a mystery to me. The world stopped with the word – cancer. The word bounced around inside my skull. I saw the doctor's lips moving but I was not taking anything in at all. Luckily Kathy was with me and although deeply shocked herself, she was able to remember the important information.

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Medical Aftercare

Most surgeons expect the patient's medical oncologist and/or primary care physician to resume the ongoing long-term care. So don't expect the surgeon to become the new family doctor. Plan to get back to these other doctors as soon as all the direct complications of surgery have been taken care of. If the person has no primary care physician, an internal medicine doctor who specializes in "outpatient care only" is a good choice. Anyone who has had an esophagectomy to treat invasive EC should already have a medical oncologist. Depending on the personality and temperament of the oncologist, he or she can often perform the primary medical oversight, at least for six months or so.

Post-operative care after surgery requires periodic visits to x-ray departments, laboratories, and usually several specialists. There is, of course, no standard as to what needs to be done, but let me give you an idea of what the minimum might be. If the person with treated EC is not getting this care, at least ask "Why not?" The following comments assume a case in which all the tumor has apparently been removed, there are no metastases and no special complications have occurred; in other words a best case situation.

Radiology department CT scans should probably be done yearly, at least for the first three to five years. There is a slight but definite risk of causing a new malignancy by receiving CT scans, so excessively frequent exams are not good. The exam should definitely include both the chest and abdomen. A combined CT/PET scan may often be requested at the time of the first anniversary of the completion of treatment.

A chemistry laboratory studies test panel should be done at least yearly. A reasonably complete biochemical profile or survey is obtained that includes studies that evaluate the status of many organ systems, not just those that are most likely to be altered by the effects of EC or its treatment. The name for this panel differs from laboratory to laboratory. It should include a full set of lipid studies, considering the usual moderately advanced age of most people with EC. Also required is a hematology department complete blood count (CBC) test group. A urinalysis will almost certainly be obtained for completeness. In the rare case in which tumor markers were found to be elevated preoperatively, these should be repeated. If you know of any unusual lab abnormity that you have or had when you left the hospital, remind the person setting up the order panel of this situation as follow-up for this abnormality may well be indicated.

The primary care doctor and/or oncologist should be visited every 2 or 3 months until the expected postoperative problems have been stabilized, and then at least once a year for at least five years. If radiation treatment was received, expect to see the radiation oncologist at least yearly for five years. The surgeon will probably want to see the patient on a yearly basis for a while, and this is a good idea. A visit to the gastroenterologist at about six months to a year after the surgery was done is probably a good idea, in order that a repeat endoscopy can be done. If any cardiac, pulmonary or other major organ system complications occurred during or after surgery, visit specialists in the appropriate system at least once.

Digestive Issues

The stomach is almost always smaller than before, and meals need to be smaller and more frequent. The sense of taste is usually altered, especially if chemotherapy has been used, so finding foods to eat can be a real problem. Use a trial and error approach; there is no explaining or anticipating what will go down. Avoid excess fluids, excess bread and excess leafy vegetables at first. The patient will have to be convinced that he or she must try to eat as much as they can, but persistent nagging doesn't help. (That's just my opinion, having "Been there …").

The stomach releases food into the small intestine more rapidly and in greater quantity than before which often results in a disorder called dumping syndrome. There is much written about how to lessen the severity of this problem, so I will not go

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on about it here, but expect it and deal with it by the avoidance of eating the types of foods and the quantity of foods that cause it. Medication can occasionally be helpful.

With your newly altered and shorted internal plumbing, there are some other things you might consider. Acid production may be less than before the surgery, but treatment with anti acids, (particularly proton pump inhibitors such as Nexium), is often still needed.

The production of lactase may decrease and clinical lactose intolerance may occur. Its symptoms are almost identical to dumping syndrome. Avoid milk and milk products, or use foods prepared for those who have lactose intolerance in order to rule out or rule in this problem.

Rarely other problems could occur such as Vitamin B-12 deficiency due to loss of production of “Intrinsic factor” usually made by the mucosa of the stomach. That first shows up as anemia and is picked up in the routine periodic laboratory studies that any EC patient should be getting. There is no need for administration of digestive enzymes other than, possibly, lactase.

The effects of EC itself, as well as possible chemotherapy and surgery very often cause the loss of a lot of the body’s calcium, resulting in osteoporosis. I suggest you ask your physician if a study to check on the status of the calcification of bones of the skeleton might be warranted.

Other Care Aspects

Consider other aspects of care that often are not considered to be the responsibility of the medical system. Adequate exercise and rest is very important. A bed that lets you elevate your head and chest is almost always necessary. A bed that also can elevate the legs and feet makes sleeping even easier. A membership in a health club with exercise machines, swimming facilities and a hot tub is a good idea. Plan for daily walks, if at all possible.

Mental health is also something to consider. It is almost to be expected that some degree of fear, anger and depression will persist. Medication can be used if the problem becomes severe, but a lot of other things can be used to improve life. Think about travel, from short auto trips to long vacations. Make plans to have celebrations of family life such as holiday dinners and so on. This subject is also far too vast to go into further here, but must not be overlooked.

Unfortunately many recoveries are interrupted or stopped by unexpected complications. The most dreaded, of course, is recurrence of cancer. But other things can also be a severe problem. The only general advice that I can give here is to avoid a response that I hear all too often. That is, for the patient or caregiver to say “I have an appointment to see Doctor X in a - (week, or a month or in three months) – I’ll just let things go until then”. Please at least talk to the doctor’s office staff and see if an earlier appointment can be obtained. It is true that many problems that develop in the post-operative/recovery period are not made worse by waiting a little while, but the worry involved is most undesirable. Get an answer fast is my advice!

What do you do with this information? Of course the doctor involved will have records, but sometimes an emergency can occur making having a copy of the doctor’s note concerning the visit, or the report of a CT scan or an EKG, or the lab tests, an urgently needed item. It is still almost mandatory to get copies of all of these reports as soon as they are available, and keep then in a handy organized file to take to every next doctor’s visit or even an unexpected trip to the ER.

I hope this brief summary is useful. Good luck, and keep on fighting. –$\mathcal{E}$–

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My treatment was standard and successful. Chemo and radiation, followed six weeks later by an esophagectomy. Pathology results indicated no cancer in any of the slippery bits that were removed – esophagus, stomach, or lymph nodes. They killed it. A complete pathological response.

My recovery was also very positive. I did, of course, suffer from the various aftermath effects of the surgery – dumping, frequent dilations, sleeping at strange new angles, and so on.

Two months after the surgery, I return to work. Congratulations all round. Everyone is telling me I look great. Life is good. But in a month I have a check-up and a CAT scan. What if it's still there? The doctors aren't infallible. There could be a stray cancer cell in there somewhere looking for a new home; ready to settle down in a nice warm organ and raise a new brood of cute little wide-eyed cancer cells. The little grey cloud of anxiety grew over my head until by the time the day of the scan dawned it was a storm cloud. I was scared.

I had to wait three days for the results. The storm cloud stayed overhead. I was not nice to be around.

The scan was clear. The sun appeared from behind the cloud and it melted away. But never completely.

In the year after the operation I had scans every three months. The storm clouds of anxiety were present at each one. But they were all clear. After the fourth scan, the docs suggested that I move onto a six monthly routine – still having three month check-ups, but scans only every six months. I had just been pronounced NED again, so the anxiety level was low. "Sure" I said. "Whatever you say." After all, I trusted these people with my life.

But the storm cloud grew once more. I went to the check-up and, in measured tones, calmly requested a scan.

"Er, but I thought we'd agreed to six months?"

"Yes, but that was then. Now I want one."

My doctor smiled tightly. He recognized that behind my urbane outward appearance was a scared little boy, jumping up and down – "I want one, I want one." He recognized that there is more than a physical component to these scans, there is a strong psychological component as well.

I got my scan. I was NED once more. We had a further chat about the risks of continued radiation and I agreed that, from now on, it would be every six months. And so it was.

This brings me to my most recent scan. I had actually forgotten about it until the evening before. I looked up and the storm cloud wasn't there. I have moved on, into a new, much less anxious place.

I'm not naïve enough to consider myself cured. I know that the risk of recurrence is an ever-present sword of Damocles. I understand that we are all different in how we perceive and respond to risk and fear. But there was a time, not too long ago, when I did not believe that I would ever lose the storm cloud of fear. I've turned the corner - out of the shadows and into the sunshine. –$\mathcal{E}$–

From Despair to Hope

By Sandi Brown

It is my fervent desire to offer hope to Stage IV diagnosed EC patients, to let them know that the dismal statistics & prognosis can be proven wrong. It takes spirit, drive, courage and a strong will to live. Most importantly, it takes a surgeon who is willing to test his skills to the utmost limits of his expertise on a patient who truly believes in him.

My husband, Paul was diagnosed as stage IV, T1M1N1 and from the beginning was treated palliatively. At the time, Paul was 58 years old, surprised as hell at being told he had a limited time to live, to get his affairs in order and update his will. This was a man who never had anything more serious than the common cold. To say we were all in shock is but a mild expression of what he, me, our children and extended family and friends were feeling. Devastation, anger, fear of what was to come, where but a few of our outward expressions.

I joined the U.S. based digest EC-GROUP@LISTSERV.ACOR.ORG that I discovered through reading the stories of patients and caregiver's on a site called "Cathy's EC Café".

Through this site, I then joined the EC Group and the EC Caregiver's Group, where I read the daily postings. One posting reached out to me…..and this was my response.

I read your post and still have shivers going down my spine. The shivers are from the word "inoperable". Yes, it was said to us. A team of doctors in Toronto, told us that Paul could not have aggressive chemo-radiation, as it was too dangerous, he could not have a stent inserted, too dangerous, and no surgery, too dangerous, all of this because of the size of the tumour and the proximity to his heart and lymph node involvement.

Paul's esophagus was totally strangulated and he was being "sustained" by a four hour daily drip of dextrose, administered by the visiting home nurse. His pain meds were in the form of fentanyl patches. I phoned, I begged ALL the doctors and their nurses & assistants we had seen; You have to do something to help Paul, he needs nourishment. I took him to emerg. in Barrie, where he was hydrated and that dr. said.....I can admit him to palliative care, and I panicked, yes I did.....and I said....NO.....you can't keep him, I am taking him home..... You see, I had this awful feeling, that if I let THEM keep Paul in the hospital, he would never come back out & panic took over. At each appointment, I continued to ask for help, but my answer was always the same, they hung their heads, said nothing to me, or would say… we are doing what we can. I had a husband whose esophagus was strangulated by the tumour, a husband who had unsuccessfully been through aggressive chemo that had not done its purported job of shrinking that damnable tumour. A husband who could not swallow his own saliva. A husband who was being kept alive by a daily IV drip of Dextrose that was "sufficient to sustain life". And we were supposed to accept this????

During one of Paul's regular appointments, we had a "fill-in" dr. – Dr. Schaver, a GP who had an avid interest in oncology and he listened to what I had to say, and he made me a promise. He promised that he would find a way to help Paul, to nourish him…. if not in Barrie, then in Newmarket. But he would definitely

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make sure we were called and not ignored. Wellllllllllll, he came through.... There was no operating room in Barrie, so he talked to Dr. Alex Lee, the Thoracic surgeon in Newmarket, but there too, no operating room.....But, Dr. Lee came up with a plan, he told us to be at Newmarket emerg. first thing in the morning and to have him paged. We did as he said.....spent the day in emerg. with Paul being hydrated , and mostly we both slept. That night, Paul had a two hour surgery to insert a stent .....the operation was a success. Paul was in the hospital for six days. After the surgery, Dr. Lee told me that THEY wouldn't hurt Paul anymore, that he wouldn't have to go through any more appointments. etc. Yes, I heard what Dr. Lee was saying, but I didn't exactly take it all in.....I was just so happy that Paul had a stent and would be able to eat. It didn't occur to me that Dr. Lee thought this was the last procedure Paul would have. We finally went home, and Paul ate protein shakes, and puddings and soups, and we had a few incidents with food becoming lodged in his stent, which scared us both. Paul had a checkup with Dr. Lee to make sure the stent was still in place, and he was AMAZED.....he could not believe that Paul was the same man he had operated on just a few weeks earlier. He said to Paul.....you have bounced back, I can't believe it.....what if WE see about getting you into Toronto for radiation, we won't do more chemo as it was so rough on you last time.....and then we should be able to do surgery. Paul said.....Let's go for it.

We went back to see him a few days later.....Toronto still wouldn't touch Paul, they said he was inoperable.....so this dr. of ours.....said..... My partner & I have gone over your x-rays, and we think we can help you. Here are the facts..... you can die on the table, you can be full of cancer and we will have to close you up, or we can have a moderate to successful operation. Your last choice Paul.....is to do nothing and you know what that means. Paul looked at him, right in the eye, and he said.....CUT THIS OUT OF ME.

Dr. Lee told Paul to go home, put on some more weight.....and he would see him in one month for the operation. That was this past September.....the operation was a success. A SUCCESS.....and a few weeks later the pathology reports came back NED.

So I say to you and your husband.....DO NOT GIVE UP.

I know that I have been beating the drum about my worries over the next checkup, and I admit, I am scared to death of what the results will show.....but we have had Paul.....me, his children, his grandchildren, his family and our friends.....for this past few months, and we have had some very good times. Life has not been easy, learning to deal with a new digestive system, withdrawal from morphine and all drugs, but Paul is quite confident now.....with what he can and can't eat, and that is because of everything I learned HERE. YES, here.....

I truly hope I have not scared you.....that has not been my intention....I just want you to know that a stage IV inoperable person.....does have HOPE, does have a CHANCE, and I shall pray that you find your miracle doctor.

You are both in my prayers and in my heart....and I shall travel this path with you.

Sandi, the quiet rebel

It has now been five months since that incredible surgery, and Paul has just finished up with x-rays and a CT scan that resulted in a NED aka No Evidence of Disease report. Dr. Lee continues to moniter Paul on a three month basis as does Paul's oncologist in Barrie. Paul is known as the Miracle Patient and we know him as husband, father, Papa Paul, son, and friend of many. A man of courage that we love deeply. –$\mathcal{E}$–

Memorial Gifts and Donations

The Esophageal Cancer Awareness Association gratefully acknowledges the following for their generous donations:

In memory of **Byron Dale Stagner**:	Debbie and Doug Walker, Madeline, and Molly
	Mr. John Muhlhausen
	Mr. and Mrs. Sammy Champion
	Byron's co-workers and friends
In memory of **Norman Ward**:	Mr. and Mrs. John Kennelly
	Lewisville Elementary School, teachers and staff
	David and Mary Helen Barnes, Trent Barnes, Laura Barnes
	Tart and Sue Lee
In memory of **Winslow (Win) Freeman**:	Smith & Loveless, Inc.
	Dennis & Lea Gerber
	Mr. and Mrs. James Loos
	Fredric Avers
In memory of **Robert (Bob) Costello**:	David Wood
	E. L. Dorchak
	Dianne and Bob Thompson
	Lois and Joe Thompson
	Mr. and Mrs. Robert Schmidt
	Mr. and Mrs. Raymond L. Graves
	Grace Grafft
In honor of **Doug Gianforte** and family:	Frank & Dale Gianforte

Help Us to Raise the Awareness of EC

The ECAA is a small non-profit organization dedicated to raising the awareness of esophageal cancer in the general public and the medical professions. If you would like to help us in that effort, please consider becoming a member of the organization. Anyone with an interest, either as a patient or a caregiver, is welcome to join. Yearly subscriptions are just $25 for an individual membership and $30 for a family membership. The ECAA is a 501C3 organization.

Contact Pat Caldwell at pcaldwell@ecaware.org

"That pill they advertise all the time on TV. I'm not sure what it is, but I want it!"

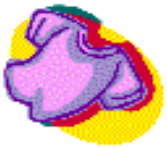
Please consider a donation to the ECAA

The ECAA is a small organization and depends upon donations and merchandise sales for all income.
We have no paid staff; we are an all-volunteer organization.
You can be sure that every penny donated will go towards helping us raise the awareness of esophageal cancer in the general public and the medical profession.

Help somebody. Donate to the ECAA.

Go to www.ecaware.org

ECAA STUFF



Spread the word about EC. We have merchandise that you can wear that will help to raise awareness of this disease. T-shirts, polo shirts and caps all display the swallow logo. Wrist bands are in the association colors of gold and blue and are impressed with "Be EC Aware".

For details, see the ECAA web site on www.ecaware.org, or contact Pat Caldwell at pcaldwell@ecaware.org

Important note: Articles published in this newsletter are from many sources and cover a wide range of topics. They are published for the benefit of our readers, but they do not necessarily represent the views of the Esophageal Cancer Awareness Association.