

SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.



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President's Message

By Lois Dickerman PhD

The Board of Directors of ECAA came away from our first "in person" Board meeting in Maine last month with a clear recognition that we need to find a way to reach more people facing esophageal cancer and to provide more support than ever, as the rate of this ugly cancer increases. Yet, we have so few members, such



restricted revenues, and so little support from national cancer organizations. What can we do and how can we succeed?

I have no other answer than "people power". If we are going to reach esophageal cancer patients throughout the country, we have only ourselves to rely upon. We are the EC patients and survivors, the spouses, the sons and daughters and other relatives linked

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What to Expect After Treatment

By Cary Johnson

This article is excerpted and adapted with permission from Cary's web site www.esophagealcancer.org.

This article describes some of the things you might experience during the first year or so after treatment. There are so many variables involved in each person's circumstance that it is impossible to predict with certainty how any individual's recovery will go. How quickly and completely you recover depends upon numerous factors including your age, general health, extent of your cancer, the particular type of surgery employed, the specific chemotherapy drugs and dosages used, whether chemotherapy and radiation treatments were administered before or after surgery, your own unique physiology, etc.



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President's Message – from page 1

together by our common struggle against EC. Sadly, many individuals struggling with EC and the families of those who have lost their battles with EC, do not have the strength or the energy to continue to support our efforts to educate and reach out. We all know too well the physical and mental struggles dealing with EC can bring. For those who have lost a loved one to EC, we recognize with emotional clarity the depth of the sorrow that remains and the time that it takes to heal the wounds of loss. For those of us who do have the ability and energy to help, we have a critical mission.

So as president of ECAA, I am asking all of you to consider becoming a member of our association. Lifetime membership dues of \$25.00 (\$30.00 per couple) are a very important way to help us continue with our efforts. We also want you to consider becoming an ECAA associate. We want to identify members in every state to be contacts for other EC patients and families in that state. We would like for our "associates" to help distribute our ECAA brochures, to communicate one on one with newly diagnosed EC patients in their area, to act as a "focal point" to set up at least one annual "get together" in their area, and to form "mini" associations. The Atlanta, Chicago, and Boston luncheons, where energetic and gregarious EC families have set the precedent, are examples that ECAA would like to see in every state. Our personal experience at our recent Board meeting in Maine made us realize that all of the support in the world through newsletters, information, discussions, and so on, can never replace the power of bonding and friendship that a handshake, a hug, and real understanding, shared face to face can bring.

Please let us know if you would be willing to act as an associate. We want to work with you and we want you to work with us, with the goal that no one should ever be told he or she has esophageal cancer without someone to reach out to them in person. We assume that if you are reading this president's message in Swallow Tales, you have some personal experience with esophageal cancer. We need your support through membership dues and your enthusiasm to help us reach all esophageal cancer patients and families. We know that not all members of ECAA will be able to volunteer in this way, but your membership dues will help greatly toward building a coalition of support within ECAA. Please help us grow in numbers. –E–

Changes on the Board

We welcome Ann Novogradec as our newest board member. Ann brings a new drive and expertise to the board. Here is a short bio:



Ann Novogradec

Just as for many of you visiting this site and reading this newsletter, my interest in esophageal cancer is a personal one. My father was diagnosed with esophageal squamous cell carcinoma at the age of 49 in 1998. At that time I was pursuing an undergraduate degree, but also spending much of my time going to specialist appointments with my parents and pouring over the literature in search of answers about causation, treatment, survival – anything or anyone I could reach out to for help and education on this disease.

My father passed away in 2000, shortly before my graduation. With a Business degree in tow and a heavy heart, I made the decision to follow my instincts and to pursue esophageal cancer academically. In 2003 I completed my Masters of Environmental Studies at York University where I studied the environmental causes of esophageal cancer – but it didn't end there. Upon graduation, I was accepted into the Ph.D. program where I have been researching the living and working environments of esophageal cancer patients.

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I came across Cathy's EC Café shortly after my father passed away and read the posts from the EC-Group for years. As I watched the Esophageal Cancer Awareness Association grow, I recognized that I was amongst many others whose lives were touched by esophageal cancer. I also came to the realization that as a Canadian, there should be a point of contact for other Canadians.

My hope is that one day people will be as aware of esophageal cancer as they are of breast cancer. I believe that education, research, and social organization are the key – with the increasing rates of esophageal adenocarcinomas in North America we simply cannot afford to turn a blind eye. I look forward to fulfilling my role as the newest board member and I am confident that we can beat this horrible disease one family at a time.

Other Changes

Our treasurer, Bob Ginsberg, who is still gamely battling the disease, has passed his duties on to Dick Dickerman. Bob is such a dedicated and enthusiastic supporter and one we can always rely upon. He continues on as a board member.

Connie Corrigan has taken on the role of Secretary of the association.

We are always on the lookout for people who would be interested in joining us and contributing their time and energy to esophageal cancer awareness. If you are interested in fund-raising, membership administration, promotion and marketing, writing, or any other ways you can think of to help, please email Lois Dickerman at ixd4@att.net. –E–

What to Expect – from page 1

Regardless of your particular situation, you will certainly experience some lingering side effects during your recovery. The side effects you experience may be few or many, negligible or significant. But know this; they will diminish over time and you will continue to improve. In fact, if you put some effort to it, you may eventually find that you feel as good, and possibly better, than you did before your cancer diagnosis.

Here are some of the treatment side effects that may persist for at least some of the time during the recovery period:

Fatigue

Although individual experiences vary markedly, you will likely experience some level of fatigue for a number of months, and probably longer, following surgery. While fatigue can hang on for a long time, it usually either disappears altogether or at least

devolves into a livable condition. Persons who do experience lasting fatigue often describe the experience as having "less energy" than they did before treatment. You may also find that, as the fatigue diminishes, these feelings become episodic rather than continuous. In my case, even many months after surgery, I would sometimes feel exhausted after playing with my toddler for only a few minutes, but I'd be able to run three miles later the same day. It is also possible that you will have as much energy – and even more – than you did before your cancer diagnosis. This is even more likely if you were overweight at the time of your diagnosis. In my case, I lost more than 50 pounds during cancer treatment, and I have maintained most of that weight loss. By not having to walk around all day carrying the equivalent of a third grader on my back, I have substantially offset any lasting effects of fatigue arising from cancer treatment.

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Flu-like Feelings

Depending on a variety of factors, you may experience certain "flu-like" symptoms for some number of weeks following cancer treatment. These symptoms might include nausea, light-headedness, and a general.

Acid Reflux

The esophagectomy procedure usually involves removal of the lower or distal portion of the esophagus. This is the part of the esophagus that contains the esophageal sphincter, a mechanism that (when functioning properly) closes to prevent the contents of the stomach from moving back up the esophagus. When the sphincter is removed, the patient is left with no mechanism to prevent stomach acid from washing back into the esophagus. In addition to rendering headstands inadvisable, this circumstance can cause significant acid reflux discomfort. Fortunately, reflux is largely controllable by taking a few simple steps: avoid certain acid-producing foods like tomatoes, chocolate, peppermint, and so on.; remain in a more or less upright position for 15 to 30 minutes after meals; elevate the head of your bed by at least six to eight inches; and, if recommended by your doctor, take an anti-reflux medication such as Nexium or Prilosec.

Reduced eating capacity

Esophagectomy changes the mechanics of the digestive process, and these changes are amplified if a portion of the stomach is also removed during the procedure. One of the side effects of the procedure is reduced eating capacity. Immediately after surgery, you will only be able to eat small quantities of food. As the weeks and months pass, you will be able to eat substantially more food, but it is quite possible that you will never regain the full stomach capacity you once had. Many of us can consider that a good thing.

Dumping Syndrome

As noted, esophagectomy changes the function of the stomach. As your body adjusts to its new digestive configuration, you will almost certainly experience dumping syndrome – a condition frequently occasioned by diarrhea and/or nausea and vomiting. The frequency and severity of dumping syndrome will diminish over time, but dumping syndrome may visit you on any occasion you disregard the unmistakable new rules established by your digestive system. For example, my system rebels if I eat too much or if I eat too fast. It also acts up if I eat foods that are too greasy, sugary, or rich.

Pain and Discomfort

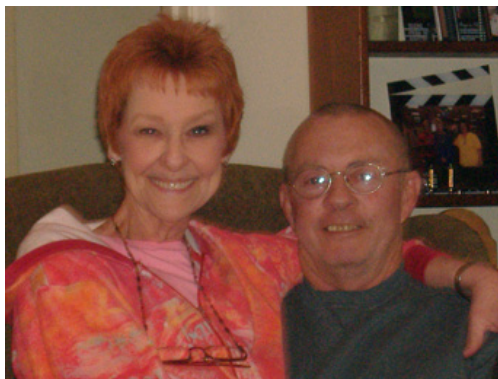
You may continue to experience some low-grade pain or discomfort for some weeks or months following surgery. Pain and discomfort may occur at the site of the incision(s), or it may arise as a result of injury done to muscle or nerves during surgery. Pain and discomfort are usually short-lived and.

In addition to physical maladies, the cancer experience can also cause certain mental side effects such as anxiety and depression. Every esophageal cancer patient lives with the fear that the cancer may return. But when this fear turns into a chronic anxious or depressive condition, it can actively undermine the patient's recovery. Fortunately, there are a great many things the cancer patient can do to manage stress and anxiety.

The recovery process involves physical and mental challenges, but the cancer experience can also produce some beneficial side effects. For those willing to embrace it, the upside to the cancer journey can include an awakened spirituality; a deepened connection to family and friends; an enhanced clarity of purpose; an ability to live more deliberately; an active and pervasive sense of gratitude for life, and so on. Indeed, thousands of patients – myself included – consider the cancer experience to be one of the best things that ever happened to them. –ℰ–

Termites?

By Ruth White



Ruth and Billy Joe White

Over twenty years ago, I had my first introduction to cancer at 44 years old. I had Hodgkin's followed up with radiation. My recovery was quick. I went back to work almost immediately after having surgery and I had reached the 5-year NED mark pretty much problem free.

One year later, I was diagnosed with breast cancer discovered through my annual mammogram. I had a right mastectomy followed by chemo. Radiation was not an option this time because of my prior exposure. The chemo was rough, but I continued to work during my treatments. My prognosis was excellent. My long term follow up consisted of a yearly mammogram, chest x-ray, blood-work and checkups with my oncologist. The very next year I was diagnosed with lung cancer discovered through my annual chest x-ray. Surgery removed the lower right lobe and no chemo or radiation was necessary. I went back to work and continued to do my annual checkups, scans, etc.

It had been 10 years since my cancer treatments and my husband and I were ecstatic that I had reached the "10 year NED mark". The very next year I started having problems, not exactly problems with swallowing but difficulty in getting the food to make it to my stomach, it kept getting stuck somewhere near my breastbone. I thought at first it was my gallbladder and had it checked out by my GP.

After numerous tests, scans and scopes I was diagnosed with esophageal cancer. I met with a team of doctors, a gastro surgeon, thoracic surgeon, radiation specialist, cardiologist and my oncologist. It was explained to me that the tumor was butted up against or attached itself (they couldn't determine which) to the aorta. Surgery would be extremely risky, so as a prelude to surgery, chemo would be necessary to try to shrink the tumor as much as possible before even attempting to do the life saving surgery. The chemo consisted of a 24/7 chemo pump (fanny pack) and trips to the hospital for the "big boys" chemo infusions. The chemo proved to be successful in shrinking the tumor but not successful at removing it from the aorta. The surgeons told me that I had a 50/50 chance at successfully removing the tumor without damaging the aorta. It was my decision as to what to do at this point. They were ready to do whatever I decided. I was scared to death!

My husband and I decided to get a second opinion from another major cancer facility in the area. After having all my records transferred to this new gastro surgeon, supposedly a cracker jack in his field, off we went to meet with him. We could not get out of his office quickly enough. He told us that surgery was definitely out of the question. He said that if surgery was attempted, I would most likely die on the operating table, that the aorta involvement was just much too risky. He said that they had drugs that would make me as comfortable as possible during my remaining 6 months or so of life. We were both in shock.

We wasted no time returning to my initial treatment team and I felt so much more reassured and confident in them. The doctors instructed me that this surgery would be life altering, and that it would make my previous surgeries seem like "a walk in the park" by comparison. They explained to me that during the surgery itself the thoracic surgeon would begin the surgery with one incision to

EC Events

Boston Area EC Lunch



Boston Area Survivors. From left – David Kahalas, Chris Cahill, Roger Tunsley, Paul Higgins, Jack Clarke, David Miller, David Mack, Monica Bennett (our 11-year champion!)

On a rainy September 27th, a group of EC survivors and caregivers met at the British Beer Company restaurant in Walpole, near Boston for lunch and to share our stories. Our EC experiences were varied – some had surgery as recently as May this year, while Monica Bennett, our current local champion survivor, is an eleven-year veteran. So there were plenty of experiences to talk about.

You'd think that when the time came to order lunch, the main order of the day would be – soup. No such thing. We were all heartened to see a range of foods on the table – burgers, chicken, chilli, beef sandwiches. There were even some desserts.

We shared our stories and experiences with each other, and then the conversation turned to a spirited critique of the previous evening's presidential debate.

This lunch was the second to be held in the area this year and we agreed to make it a regular six-monthly occurrence. –E–

Conversations About Cancer

Conversations about Cancer , at the University of Miami Sylvester Comprehensive Cancer Center was presented by Bach Ardanan, MD., Professor of Medicine, Miller School of Medicine, and Karen Stephenson, Department of Medicine, Division of Hematology/Oncology, Miller School of Medicine.

Dr. Ardanan detailed his work in researching the ways he is fighting this cancer. In addition to seeing patients he has his own testing laboratory.

Those in attendance were treated to a very informative discussion regarding the progress and advances that are being made in fighting digestive cancers.



Left: Mr. and Mrs. Bob Ginsberg, Karen Stephenson, Carolyn Thomas, and Dr. Bach Ardanan.

Below: Dr. Ardanan and Bob



Membership – Breaking News

As you will have seen from the president's message on page 1, the board of the Esophageal Cancer Awareness Association has decided to initiate a membership drive. We are so committed to the growth of our association that we are changing the membership structure.

Your membership dues will remain at \$25 for a single member or \$30 for a couple but your membership is now for life. Current members are automatically life members.

There are many ways in which our members can help the association. We would like to arrange more area and regional get-togethers of patients, survivors, and caregivers along the lines of the Boston area lunch on page 7. To this end we need volunteer members to arrange these events in as many areas as possible.

We would like to do more fund-raising so that we can bring our message of EC awareness to others who may be at risk. This is a tricky area, as there is little or no proven causality for our disease, but many medical professionals and researchers consider there to be a strong correlation between EC and Barrett's Esophagus with those who are frequent heartburn and GERD sufferers, those who are overweight, heavy drinkers and smokers, and possibly the close family members of EC patients.

We would like to develop public service messages regarding Barrett's and EC and these risk factors, to develop and distribute educational materials to clinics, endoscopy centers, hospitals, and so on.

All of these things take time and effort. Due to the nature of this disease, our membership is very volatile. Patients and caregivers often join when the disease is first diagnosed and, it must be said, the number of members that are able to or even wish to remain for the longer term is limited. Caregivers who lose a loved one to this disease often do not have the heart or will to stay engaged with the association due to the constant reminder of their loss.

This is still a reasonably rare disease that is aggressive and most prevalent in the older population. It is not as prevalent as, for example, breast cancer, colon cancer, and prostate cancer. It is not in the forefront of media coverage. Many of us have never heard of it ourselves until the diagnosis was made.

So, the board of the ECAA is asking for your help. We are an organization that cannot offer much in the "What's in it for me?" area other than a warm feeling that our efforts are hopefully helping others – in the best case we can help people perhaps avoid the disease altogether through early monitoring.

Please join our association and help us spread the word. Bring your everyday skills in marketing, writing, producing, talking, and organizing. Run a golf tournament. Get company sponsorship. Even activities as small as volunteering to distribute educational materials to related organizations is of such great benefit. We look forward to hearing from you.

There is a membership application form at the end of this newsletter.

Termites – from page 6

determine exactly how the tumor was situated near the aorta. It would then be determined that if they felt that the tumor could be removed from the aorta safely, they would remove it and that they would proceed with the rest of the stomach/esophagus resection. If the tumor could not be removed successfully, they would then sew me back up and end the surgery at that point.

This was the scariest thing my husband and I had ever been through in our entire lives, I cannot describe how scary it was. But what were my options? Either I go with the surgery and have a 50/50 chance of surviving or do nothing, and we both knew what that outcome would be. We opted to do the surgery.

Surgery was performed in February of 2007. Needless to say, the surgery was a success or I wouldn't be here to tell you the story. Recovery was and still is a very long and painful process, and is definitely life altering, as you all know, but thank God I have a life to alter. It's been over a year now, I retired from my wonderful job of 27 years and am home still adjusting to this new way of life and doing quite successfully. Every day is a new adventure in one way or another.

This past March I had my 3 month, follow up CT scan, I was NED. In April, on a Saturday night, I was craving shrimp for dinner. My husband offered to go out and pick up some from Captain D's shrimp for me, my favorite. He left the house and called me from the restaurant, he said, to ask me what kind of side orders I wanted and I couldn't understand what he was saying to me. He kept repeating himself but I had no idea of what he was saying.

He got home, as quickly as he could and found me sitting in my chair hallucinating and having a hard time breathing. He called 911 and they took me to the emergency room. They said that I had had several seizures on the way. I was admitted to the hospital and an MRI determined that I had a brain tumor.

I met with the brain surgeon and he said that I was very fortunate that the tumor was small and in a good "location" and that he could surgically remove it. It was determined that the tumor was due to mets from the esophageal cancer, a rare occurrence, lucky me.

The tumor was removed one week later and I was followed up by a radiation specialist. My head was fitted for a special mask followed by only one shot of "stereotactic radio surgery". Three months later I had another MRI and was told that the radiation had been successful and that the brain was NED.

Since then I've had more scans, colonoscopies, MRI's, and scopes, and I continue to do so on a regular basis.

Last week, before going to sleep, on the night before I was scheduled to have another scope, my husband who sensed that I was more anxious than I normally am, said to me "Don't worry honey, if something new shows up on this scan, we'll deal with it just like we always have in the past. It's sorta like having termites", he said, "every time they come back, we'll just keep treating them".

By the way, the scope was NED. -E-

ECAA STUFF

New ECAA T-Shirt now available



The new ECAA T-shirt is now available. It proudly sports the ECAA logo on the front and our name and web site on the back. Just \$12.50 each. All proceeds go to promoting awareness of esophageal cancer.



To purchase securely using Paypal, visit our website at www.ecaware.org or contact Lois Dickerman at lx44@att.net.

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



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 Connie Corrigan at ccorrigan@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.



Membership Form

Thank you for your interest in membership of the Esophageal Cancer Awareness Association (ECAA).

The ECAA depends on its active members to ensure our growth and to increase our ability to spread awareness of esophageal cancer to the general public and to the medical community.

ECAA life membership is \$25.00 for a single membership or \$30.00 for a couple (husband and wife, partnerships, patient and caregiver, and so on). This is tax-deductible and essential to our mission.

Please send your details and a check for your membership to:

Dick Dickerman (ECAA Treasurer), P.O. Box 55071 #15530, Boston MA 02205-5071

Personal Details

Name (Last, First): _____

Address:

Phone : _____ (H) _____ (M)

Email:

Interest (Optional)

- I am an esophageal cancer patient or survivor
- I am or was a caregiver to an esophageal cancer patient or survivor
- I am a medical professional
- Other (Please specify)

Volunteer Interest

- Form a local support or contact group
- Outreach to patients
- Distribute support materials at clinics and hospitals
- Membership campaigns
- Fundraising