SWALLOW TALES

The Newsletter of the Esophageal Cancer Awareness Association, Inc.

PO Box 25792, Tamarac , FL 33320
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July 1, 2008
Volume 2, Issue 3

President's Message

By Lois Dickerman PhD

As I pondered what to write for this edition of Swallow Tales, I realized that this was the sixth issue and we are into our second year of publication. It really is a milestone of sorts for those of us on the Board of ECAA. When we thought about a quarterly newsletter over a year ago, it seemed a somewhat foolish idea. Our goal, as always, was to increase awareness and spread information about esophageal cancer, but with a few exceptions, we were ill prepared to do so. Most of us on the Board had no real experience in writing articles for a specialized audience, just experience with esophageal cancer.

Our prime mover is our editor, Roger Tunsley, who has the background and experience that

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Minimizing the Side-Effects of Treatment

By Cary Johnson

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

Side effects from radiation therapy, chemotherapy, and surgery vary widely from person to person and depend upon a range of factors.
One of the most important things you can do to minimize side effects is to address them immediately after they have begun to develop. Tell your doctor or nurse the instant you begin to experience any symptom such as pain, nausea, mouth sores, and so on.

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the rest of us lack to write, format, edit, design, collate, and badger us for articles. Without Roger, the first issue would never have been designed and published, and a second year would never have been possible. Also I want to pay tribute to everyone else on the board as we start a new quarter of a new year. All the members of the board stepped up to the plate, or should I say keyboard, as we began the newsletter and wrote informative, helpful, historical, and even whimsical articles. I was so amazed at my compatriots on the board by the quality and variety of their ideas. To all the board members, I say thank you as well for your creativity and dedication to our cause of awareness.

We now begin our second year, and I would like to issue a new challenge. This one is for all of you; readers, lurkers, bystanders, and curiosity seekers about EC. Please help us grow, develop and expand. We want you to submit articles, write letters to the editor, suggest topics you would like to see in *Swallow Tales*, ask questions, and be a part of this publication, as well as a reader. We want to know how we can improve the content for all of you. It is hard to determine when a publication exists only online, what the readership volume really is, whom we are reaching, and whether we are making a difference at all. We have some idea of how many have looked us up casually to read what we have written, but we really need to know more about you. We want you to feel that *Swallow Tales* exists to express your thoughts, concerns, questions, stories and tributes as well as ours. We need you to tell us how to make year two of *Swallow Tales* even more informative, thoughtful, helpful, fun, and useful than year one. Please email us.

Many thanks for your support and interest. –ℰ–

Changes on the Board

This month, we say goodbye to our secretary, Pat Caldwell. Pat has served the board well in various capacities and, as a nurse, had a valuable insight into caregiving. Thanks Pat, we'll miss you.

We also welcome Amy Schoener as our newest board member. Amy is a marketing director and brings a new drive and expertise to the board. Here is a short bio from Amy herself:

Amy Schoener

My father, Edward N. Johnson, 64, was diagnosed with Stage IVB Esophageal Cancer with mets to the liver on January 29th - or better known to us as the day that flipped our world upside (and my husband's birthday). A short few weeks later, my uncle, Richard Johnson, some ten years younger than my father, found himself in a similar place, when he was diagnosed with Stage 1 EC.

I, an only daughter, along with my wonderful husband, have found quickly that cancer is rather like a club that you never want to become a part of, but from the very second that you join, there is no turning back. From the first glance of the oncologist's office to the first run of chemo, I just know that nothing will ever quite be the same again.

As a child and a caregiver, the feeling of helplessness can be overwhelming and lonely. Additionally, while the resources that are available for cancer patients are wonderful, we have come to find a lack of resources regarding EC. It is my greatest hope, to help change that. These patients need support and I believe that the ECAA's mission to meet this need will be successful.

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Surgery

Many patients fear that they will experience a great deal of pain following surgery. This is not typically the case. Potent pain medications almost always keep your discomfort in check.

The key to managing pain and discomfort is to address it before it becomes acute. First and foremost, don't try to be a hero by "toughing it out" as long as you can. Apart from being pointless and unpleasant, the "tough guy" approach makes it harder to bring the pain under control once you decide you need some relief. A far superior approach is to constantly monitor your level of discomfort and ask for medication just as you notice the discomfort beginning to increase. By actively keeping "on top" of your discomfort, you'll be able to maintain it at a consistent, low level.

Weakness is an almost universal complaint following major surgery. You can get your strength back more quickly by exercising appropriately, eating a balanced diet, and getting plenty of rest (though these things are tough, if not impossible, to do in the early days following surgery).

You will also experience fatigue in the weeks (and probably months) after surgery. To minimize fatigue, limit your activity and use your free time in a restful way. Save your energy for doing the things which you feel are most important. Do not feel that you have to do everything you normally do. If possible, ask family members or friends to help you with daily chores, housework, childcare, etc. Try to get more sleep at night and plan your day so that you have time to rest if you need it. Several short naps or breaks may be more helpful than a long rest period. Sometimes light exercise such as walking may combat fatigue. Ask your doctor about how much exercise you may do during your recovery. Also, limit your consumption of caffeine and alcohol. Eat as well as you can and drink plenty of fluids.

Major surgeries – particularly those affecting digestive function – can suppress appetite. Loss of appetite, physical discomfort, "dumping syndrome" (see below), and increased metabolic activity occurring during the healing process can all contribute to substantial weight loss following esophagectomy. In order to minimize weight loss following surgery, you may need to take steps to increase your appetite to ensure an adequate intake of calories. Here are some suggestions:

- Try frequent small meals with snacks in between, especially if you feel full after eating only a small amount. Often it is helpful to eat on a regular schedule.
- Take advantage of the times when you feel good. Eat a hearty meal when you are hungry. Many people have their best appetite in the morning when they are rested.
- Limit fluids with meals since liquids create a feeling of fullness. Drink liquids 30-60 minutes before or after meals.
- Vary the color and texture of foods to make the meal more appealing.
- Keep snacks readily available. Bedtime may be a good time to snack because your appetite for the next meal will not be affected. However, if you do eat at bedtime, remain upright for 30-60 minutes after eating.
- You may find that cold or room temperature foods are more appealing right now.
- Experiment with foods. Favorite foods may no longer appeal to you, but foods that you have not been fond of in the past may become more appetizing.
- Regular exercise may stimulate your appetite.

You can increase your calorie intake in numerous ways: Use butter or margarine generously; spread peanut butter on toast, bread, apple or banana slices, crackers or celery; add powdered creamer or dry milk powder to hot chocolate, milk shakes,

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Side Effects – from page 3

hot cereal, gravy, sauces, meat loaf, cream soups, or puddings; eat breaded meat, fish or poultry rather than baked or broiled; add brown sugar, honey, dried fruit or cream to hot cereals; serve desserts topped with ice cream, whipped cream, or cream; use fruit canned in heavy syrup; drink beverages that contain calories like fruit juice, lemonade, malts, floats, and soda, etc. You should also consider trying commercial meal replacements such as "instant breakfast" drinks or "shakes" like Ensure. (Note: Esophagectomy patients often have difficulty digesting rich, greasy, or sugary foods. You will need to experiment a bit to determine which of these foods your digestive system can handle.)

Talk to your doctor or the hospital's registered dietician for advice on how to increase your appetite and maintain your weight following surgery.

Esophagectomy affects the shape and function of the stomach. Because of this, food may enter the small intestine more rapidly and in larger amounts than normal. As a result, "dumping syndrome" may occur. Symptoms of dumping syndrome can include diarrhea, nausea, vomiting, abdominal cramps or fullness. Some people may also experience weakness, sweating, light-headedness or rapid heartbeats. The good news is that these symptoms are largely controllable by making dietary changes. The following suggestions may help:

- Eat a balanced diet that includes a variety of foods.
- Eat small, frequent meals or snacks (six or more per day).
- Limit your intake of foods that have high sugar content.
- Dairy products are generally tolerated in small amounts (e.g., 1/2 cup of milk at a time).
- Eat an adequate amount of protein-rich foods such as meat, fish, poultry, peanut butter, eggs, cheese, and so on.
- Eat only moderate amounts of foods that contain fat such as butter, margarine, cream, cream cheese, mayonnaise, salad dressing, gravy, and so on.
- In the first weeks after surgery, limit fluids to 1/2 cup servings at a time.
- Try to consume most of your fluids between meals. Don't drink for 30 to 60 minutes before or after each meal. (You may drink a small amount with your meal.)
- Chew your food well and eat slowly in a relaxed setting. For some people, resting in an upright position for 15 to 30 minutes after meals may help slow the rate that food enters the small intestine.
- Check with your physician about the need for taking vitamin and/or mineral supplements.

As your body adapts to its new plumbing arrangement, you will find that the symptoms of dumping syndrome will diminish. Over time, you will be able to eat a larger quantity and richer diversity of foods.

Your doctors and nurses can explain the possible side effects of treatment as well as suggest ways to help relieve any symptoms that may occur during and after treatment. Also, helpful pamphlets on managing the side effects of cancer treatment are available from the National Cancer Institute (1-800-4-CANCER) and the American Cancer Society (1-800-ACS-2345). (These free pamphlets will probably also be available at the hospital where you receive treatment.) Much of the advice set forth in this section is taken from these materials and from other reputable cancer-support resources. –ℰ–

Firefighters and Cancer

By Steve Preston

Firefighting has been known to be a hazardous job all by itself. Fire is the usual "enemy" to firefighters. In fact fire has a nickname called "the red devil" to many firefighters. However, in recent years fire hasn't been the only enemy. Firefighters are being diagnosed w/cancer of one form or another at an alarming [no pun intended] rate. I personally know of four firefighters, two within my own dept., that have passed away because of EC alone. And I can't even begin to count how many other firefighters that I've actually known who've been diagnosed with some other form of cancer. Several, like you, are fighting that battle currently.

Many, like me, have been a firefighter for a long time prior to diagnosis. I was a firefighter for about 25 years prior to my diagnosis. During that time considerable change in our industry has taken place. What used to be unusual to have plastics burning is now the rule. There are hundreds, if not thousands, more chemicals being used today versus decades ago. When they burn they produce harmful carcinogenic byproducts. It doesn't have to be a raging house fire either. It can be something as routine as that Teflon-coated pan that burned dinner on the stove. Or that small fire in the couch from an accidentally discarded cigarette.

Some of the causes may be of our own doing. Exhaust from diesel engines of our fire trucks has, up until recently, been ignored and looked at as "part of the job"! We can't do much at the scene of an incident but we can in our own firehouses. Products like the "Plymo-vent" system eliminate the exhaust from the truck and out of the building before it gets into our lungs.

Breathing apparatus has improved considerably since its inception some 40 years ago. The problem is that we don't always wear them when we should. Some of the stuff that has been considered routine for years is slowly being changed to require wearing an air pack.

I can't tell how many firefighters have been diagnosed with EC in this country. But I can tell you that I miss the ones who I've known personally who are no longer with us. And I encourage any of you out there who might be a firefighter, a spouse, or a friend of a firefighter to talk about cancer risks amongst your brother firefighters or family members. A good place to go for support is www.firefightercancersupport.org for much more information on a variety of cancers.

One final and positive note, one of the few with EC, the diagnosis of certain forms of cancer, including EC or stomach cancer, doesn't mean financial disaster for the firefighter's family. Many states have passed "Presumption" laws which make it a job-related disease. In some states like California, firefighters like Steve Gregory, a Ventura County firefighter, have successfully gone one step further and made diagnosis a workman's comp event. Unfortunately, Steve lost his personal battle with EC in 2007 but the law that he helped pass is still on the books today. This will help firefighters with EC for generations to come in paying for those very expensive medical bills so the family doesn't have to declare bankruptcy in doing so.

As I stated before, I don't have the number of firefighters diagnosed with EC or stomach cancer but I don't imagine the numbers declining in the future any more then I do for the "average" citizen.
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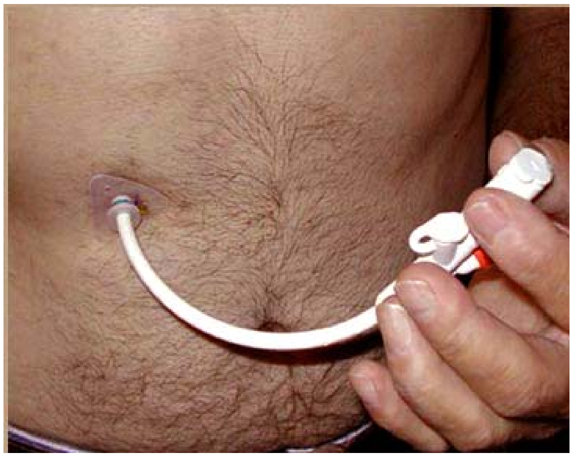
The Tube

By Roger Tunsley



Once upon a time, the tube meant only one thing to me – a nickname for the London Underground. Then along came EC and now the tube has a different meaning entirely – the hated, loathsome J-tube.

During the course of this disease, many of us have had feeding tubes installed. And for good reason – they help to keep us alive and strong enough to continue the fight to overcome our cancer. But I have never met anyone yet, even after undergoing chemotherapy, radiation therapy, and even surgery, who does not consider this stupid little tube as almost the worst thing about the whole routine. It's not that it's painful – it isn't (usually). It's just such a gosh-darned nuisance.

A J-tube is surgically implanted through a jejunostomy; a procedure that creates a small opening through the outer abdomen into the small intestine (jejunum). A thin tube is placed through this hole to allow fluids and feedings to be given directly into the small intestine.

The tube has a whole list of negatives lined up against it. It's generally secured into the skin of the abdominal wall with stitches. It seems a pretty secure solution but sometimes the stitches "walk" out of the skin over a period of about three weeks. In my case, I was terrified that the tube would come out and I had visions of a continuous flow of bodily fluid spouting from the hole in my abdomen. Little did I know that it's basically a self-sealing system and when the time comes to remove it, the doc just pulls it out.

Once installed, it needs more attention than your average puppy. It should be flushed with a syringe of water at least twice a day to ensure it doesn't clog, even when you're not using it for feeding. I spent the first week or two using boiled water to ensure sterility until I realized that what I was putting in my mouth each day, while not exactly dirty, was often not exactly sterile either. I started to relax a bit after that.

The plug came out one day, unnoticed by me until I started to feel a little damp in my nether regions. I looked down, and realized that I was giving all the appearances of having wet myself. I was standing in the staff cafeteria at work at the time. Very embarrassing. The plug was nowhere to be found – it had obviously found the escape route offered by my trouser leg and bolted for freedom. What to do? I searched around in my desk and found the perfect replacement plug – a round pencil eraser. I also put a couple more as emergency spares in my pocket. I never needed them. When the nursing staff saw the eraser plug at my next visit and how effective it was, they immediately went out and bought some from the local office supply store as they said the plastic plugs were always coming out. So why didn't they warn me?

The insertion site needs daily attention as well. Mine tended to seep a little and would need a fresh dressing applied with surgical tape. After a few weeks, I began to react to the tape adhesive and sore areas developed around the site that were quite painful.

I needed to use the tube in earnest only immediately after the operation. During that time, I was dependant on it, and very thankful for it. But for most of the time it was just a nuisance to me, flopping around uselessly, pulled on by clothing, staining shirts, and so on.

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A Party for Cancer?

By Amy Schoener

For my father the diagnosis came this January, Stage IVB with metastasis to the liver. For his brother, less than a month later, Stage I. We all know the routine. Doctors and tests come first, followed by treatments and regimens, with barely a moment to be in shock. The calendar begins to fill up quickly, and the days become as predictably read as a weather report on the weekday news…..

Chemo on Friday, tingling fingers and mouth sores for Saturday and Sunday, followed by a week of exhaustion and nausea, tests to make sure he can handle more chemo, followed by, oh, more chemo…

And we tell ourselves and we tell the “patient” that we are in the fight of our lives. That *he* has to fight to live. That it will all be worth it when the treatment works and the doctor makes the long awaited announcement of the one thing that we hold our breath for - Remission. And in the fighting for life, we seemed to forget that it is happening all around us, with us, while we are fighting.

When my father was diagnosed and the whirlwind began, we realized that this new development meant we would have to adopt a day to day living. Not sure what his response to treatments would be, or how the cancer would develop, it seemed obvious that our plans for a surprise party for his upcoming 65th birthday would have to be shelved.

But in April, after my father’s fourth round of chemo and three months of living in the proverbial cancer hamster wheel, the idea that we were going to bypass celebrating a momentous birthday, 65 great years of life, in order to fight for life began gnawing at my heart.

Does it make sense that in order to ensure a future we have to give up the present?

After a long deliberation, some rushed planning, and call to my father’s oncologist, the party was on. We did not know if he would feel well that day. We did not even know if he would want to get out of bed, but we were willing to take the chance.

On May 3rd, Dad’s 65th birthday, my father opened the door to the Slackwood Volunteer Fire Company, where our family has been involved for all of their lives, to the sound of 100 of his closest friends and family members from as far as North Carolina shouting “Surprise”. And surprised he was. The look on his face, a smile fueled by knowing that he was loved so greatly by so many, was priceless.

Even my uncle, undergoing radiation and chemo in preparation for surgery, weak from his treatments, came by to share in his big brother’s day. And though it was just for a few moments, the emotion it stirred from us all was enormous. Dad didn’t do all the things he might have if not for the cancer, he wasn’t dancing all over the room or drinking at the bar, but he was there, enjoying the moment.

Does it make sense that in order to ensure a future we have to give up the present?

I am not a doctor. I do not claim to know what is right or wrong for any other patient. What I do know is that stepping off the hamster wheel for a moment every once in a while can remind us all, patients and caregivers alike, what we are fighting for.

Make an effort every week to leave some time on the calendar unscheduled to just live. We may not be able to take that 14 day Alaskan Cruise; let’s be honest, some of us may not even be able to leave the house, so play a game of cards or Yahtzee, sit in the back yard for an hour with good friends, go out for lunch, take a drive through the country. The possibilities are endless.

Just take time to do something that reminds you what we are fighting for. Take time to live while we all fight for life. –ℰ–

Living to Eat vs. Eating to Live

By Nancy Westacott

“Just one more bite”… I think at some point in all our lives each one of us has said those words and regretted it later. I know I have, but as an esophageal cancer survivor those four little words mean more to me now than they ever did. For me, that one more bite usually lead to at least two more bites and so on because one more bite was never enough.

In 2004 I was morbidly obese tipping the scales at 379 pounds. I was 44 years old and had been overweight my whole life. Food was one of my best friends and it was not an uncommon occurrence for me to eat more in a day than a lot of people would consume in a week’s worth of meals. I lived to eat!

By October of 2004 I had lost about 70 pounds and was now surviving on “blender brew”, a far cry of the large loaded pizza that was a “snack” while watching TV on a Friday night. On October 27, 2004 I was diagnosed with esophageal cancer. In December I had my surgery, a TTE/En Bloc and for all intents and purposes was cancer free. I agreed to undergo chemo radiation therapy for insurance purposes and by June of 2005 was a svelte 143 pounds. I don’t think I had weighed that since I was 12 years old!

Instead of pure pleasure eating was now a chore of monumental proportions. For most of my life I had been told that I needed to cut down on calories and now post cancer I was told I needed to put on some weight. My body, although disease free, was a mess and in a perverse twist of fate I now had to eat to live instead of living to eat. What a quagmire! My once normal positioned stomach now resided in my chest, swallowing was almost impossible and I was being encouraged to eat!

Unable to stomach Ensure, Boost or anything remotely similar left me with few choices on high calorie intake. Instead of margarine I now “feasted” on real butter. Skim milk was replaced with real cream – low fat/no fat was now a thing of the past. What a boon to someone who loved to eat. But wait a minute – I couldn’t eat!!! I had been given a license to “pig-out” and was totally unable to pull it off.

In addition to losing all that weight chemo and radiation had taken its toll in other areas. I had finished my treatments a week before a major heat wave hit. Already feeling like death warmed over was only made worse by the weather. I remember spending upwards of 18 hours a day lying on the couch unable to do anything other than hopefully make it to the washroom on time and then try and garner enough strength to make it back to the couch. Food was the furthest thing from my mind but I knew that if I was going to survive I needed to start eating. I was still receiving medical care – I had deadly low magnesium levels and my hemoglobin was getting to the point where any lower and I would require blood transfusions. At that point in time death would have been welcomed.

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Eating – from page 8

I can hear the collective "oh my's" – and those of you who have been there done that know exactly what I mean. Life sucked – and I was beginning to believe that surviving wasn't all it was cracked up to be. Every day was a challenge. I no longer hoped to wake up in the morning. I didn't want to die – I just didn't care if I lived. This wasn't living, this was existing.

But I trudged on, eating what I could, when I could. Montreal Smoked Meat sandwiches became my mainstay, even if it did take a whole day to eat. Milkshakes started out thick and by the time I got to the bottom of the glass they were warm soupy "goop" but I still finished them. No matter what it was I tried my best to get it down. Bagels and cream cheese, Cheez Whiz on toast, calorie-laden foods that any cardiologist would have a heart attack just thinking about. When I was able, I worshipped cake with gobs of icing. I still laugh thinking about it. For someone who was so used to having food this was cruel and unusual punishment.

Fast-forward to today, 2008. Last week I had my annual endoscopy. Gastro Guy (my pet name for this particular doctor) said to me "You have gained some weight". When I started to complain that it was too much he told me that I looked great and not to worry about it. So I won't. Summer is here and it's time for salads and all the fresh veggies and fruits that this season brings. With any luck I will sneak a couple of pounds off and when I see the Rad Onc in July he will tell me that I look great and Med Onc will tell me the same thing in August.

So eating to live instead of living to eat isn't such a bad thing after all. I just wish for once though that I could sit at dinner and eat a small baked potato, a heap of Caesar Salad and a piece of BBQ'd steak, wash it down with a glass of red wine and be finished before breakfast the next day. -ℰ-

Tube – from page 6

Imagine my pleasure to find out about a new invention recently – the Peg Belt. The idea of the belt was conceived by a Florida man who had esophageal cancer and sported a tube for six months, with just as much pleasure as me! He drew a sketch of his idea for a belt on a napkin and asked his daughter to make one on her sewing machine. He used the belt extensively once it was developed.

The belt secures around the waist with Velcro, under clothing, and holds the tube secure without needing to tape it to the body. It uses replaceable pads to absorb any moisture from the site, and is machine washable. The only downside seems to be its high cost at $99 each ($89 each for more than ten belts).

If you're interested in the idea of the belt, go to www.thepegbelt.com and take a look. -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 lxd4@att.net.

ECAA Annual Meeting

To all members of the Esophageal Cancer Awareness Association

The 2008 Annual Meeting of the ECAA will be held on July 19, 2008 from 2-4 p.m. EST (1-3 CST, 1-2 MST, 11-1 PST) in person and by telephonic conference call.

To join the conference call, dial 1-877-915-1267 (toll-free) or +1-210-301-3779 (toll number).

The participant pass code to enter into the conference call is 5617143.

For those of you who may wish to participate in person, the meeting will be held in a conference room of the Eastland Park Hotel, 157 High Street, Portland, Maine, 04106. The hotel information number is 207-775-5411, or go to info@EastlandParkHotel.com

We hope that all ECAA members will join us.