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The IAL News is published four times a year by the International Association of Laryngectomees

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Contact Allison Reber Wurz, theialoffice@gmail.com, for all updates to the IAL website, club postings, changes to club contacts and professionals, in addition to resources you may need from the IAL office.

Thank You!
I BECAME A LARYNGECTOMEE AT 33

My name is Corey Sullivan. In 2007, at the age of 29 I was diagnosed with squamous cell carcinoma on the left true vocal chord. I noticed my voice getting hoarse and I was always clearing my throat. I had a few people ask why my voice was low. So, I went to the doctor where a biopsy was done and I was given a referral to Ellis Fischer Cancer Center in Columbia, Mo. I went through 35 radiation treatments after which I was declared cancer free.

I continued to see my doctor on all of my follow-up appointments after the radiation treatments but four years later, July 2011, I’m now 33. Once again I noticed I was getting hoarse and I struggled to voice. My voice was very very low I would say lower than a whisper. I went back to my doctor, he did a biopsy and ran other tests only to determine that the cancer had returned. At this time my doctor told me that I would need a laryngectomy. The doctor suggested doing a partial laryngectomy but wanted me to agree to a total if he had to do it. I did agree with him because I respected him for always being direct and forward with me.

I expressed my concern about having a laryngectomy, my mental state really wasn’t good, being young I feared my life wouldn’t be nearly the same. I was scared! For 13 years I made my very enjoyable career as a 911 operator. I was also an Emergency Medical Technician (EMT) for 10 years. I wasn’t sure if I could continue to do the things I so badly wanted to continue after having a laryngectomy.

September 21, 2011 was the date of my surgery. I did meet another laryngectomee prior to my surgery and that kind of eased some thoughts and being so scared. While in the hospital I learned how to use esophageal speech.

Once out of the hospital I was learning to use the hands free valve with my TEP and about 10 months after I noticed I was having a sore throat. After seeing my doctor and a few tests later, it was discovered I had a reoccurrence of cancer on the esophageal wall. My doctor explained the need for more surgery and a forearm flap to rebuild the esophagus.

I was very discouraged because I was just learning to use the TEP hands free now I wouldn’t be able to and likely would have to start over. The free flap surgery was a success but healing took a little time and it would be more time before I could use the TEP. I was able to return to work, still on my same career path.

September 2021, my doctor told me there isn’t a need for me to make another appointment unless something comes up.

Ten years after my laryngectomy surgery, I am still active in my career as an EMT with an Ambulance service. 911, my primary job is mapping and addressing but I still do 911 dispatching.

I currently live a very normal life in Tipton, Missouri. I am divorced and have five children, Taylor 26, Heidi 23, Ashley 20, Matthew 16, and Aydan 9. Aydan was born 3 months after my laryngectomy. I also have three grandchildren Rayna 4, Cohen, 1 and will have another little grandson in February 2022

*********************************************************************************

WORDS OF WISDOM

The man who asks a question is a fool for a minute, the man who does not ask is a fool for life.  
CONFUCIUS

It is not because things are difficult that we do not dare; it is because we do not dare that things are difficult.  
SENECA

The only true wisdom is in knowing you know nothing.  
SOCRATES

The greatest wealth is to live content with little.  
PLATO

Waste no more time arguing about what a good man should be. Be one.  
MARCUS AURELIUS

In the midst of chaos, there is always opportunity.  
SUN TZU

Know how to listen and you will profit even from those who talk badly.  
PLUTARCH
The 3 Ways My SLP Changed Everything

By: Drew Ross

After being diagnosed with squamous cell carcinoma of the larynx, I’ve undergone radiation treatments, four surgeries, and more procedures and therapy visits than I can count. During this ordeal, I’ve benefited from some of the finest health care support across Houston, Atlanta, Cincinnati, and beyond. But one speech-language pathologist in particular, Jodi Knott, went above sharing her wealth of expertise. She motivated me time and again to raise my fists and fight on, even when all hope seemed lost.

During my many visits with Jodi, she smiled, she listened, and she fought for me. These three things she did for me would benefit any patient working with an SLP, I think.

Laughter really is the best medicine

One day, as Jodi and I were finishing a visit, I shared a funny story about my daughter. A student was shadowing Jodi, and the three of us began laughing like we were out on the town. As Jodi handed me my new supplies and opened the door to the hallway, two doctors stood wide-eyed. Apparently, we were being too loud.

In all the countless hours I’ve spent with health care professionals, I’ve certainly never laughed like that with a doctor or surgeon. But Jodi always found a way to bring joy into the midst of even the most horrific ordeals, and to this day I still can’t think about her without smiling.

Listening makes a big difference

Many medical professionals care about their patients, but few will put their own neck on the line to advocate for them. While I was still recovering from major surgery, I shared with Jodi that I felt “off.” I didn’t know how to explain it. I just knew something was wrong. I expressed this to numerous nurses and doctors, but because I had no fever, they’d all dismissed my concerns. Jodi, on the other hand, didn’t hesitate to take my side in the fight. Though my words hadn’t moved the health care team, hers did.

When they removed my trach, at Jodi’s recommendation, they found the ruptured balloon covered with “pus and gunk.” Thanks to her, I had someone on my team who would not only listen and believe me but take action on my behalf. Jodi never hesitated to make sure my voice was heard by the doctors and nurses, an invaluable gift to someone who has been made to feel “voiceless” at every turn.

Motivation takes many forms

At times, cancer has clouded my judgment, and I’ve held onto ridiculous vows. For one, I never wanted to use an electrolarynx (EL) because of the stigma associated with it. But Jodi knew that for me, as a teacher, talking was a major part of my identity.

“Don’t be silly, Drew. You’ll get used to it,” she said. “Trust me.”

I chose to trust her.

A few weeks later I dropped my EL device and had to wait four days for a replacement. I almost lost my mind waiting for the tool Jodi had told me I would eventually cherish. Despite my initial reluctance, she had dared to fearlessly confront me in a way that challenged me to get out of my own way. I look back now and can’t imagine I could have sustained any quality of life for long without that EL. I owe that freedom of communication to Jodi. She never let me quit.

After my last surgery, it was time to find out whether or not my rebuilt (for the second time) throat was going to be able to produce sound with a tracheoesophageal prosthesis. A portion of my leg had been used to rebuild my esophagus, and I’d been warned that the tissue might be too rigid to create viable sound. I will never forget the look of relief and jubilation on Jodi’s face when the transplanted tissue began vibrating to form my new “Batman voice.”
From day one, Jodi had helped me believe I would speak again. And fueled by her belief in me, I did just that. Through all the defeats and disappointments, Jodi smiled, listened, and pushed me. She changed my life because she helped me see I wasn’t alone in the fight.

Special thanks to Julie Cantrell, a certified SLP who currently works fulltime as an author, editor, ghostwriter, and story coach. She helped me tell my story.

Drew Ross grew up as the typical lost and wandering latchkey kid. Along with his siblings, he shuffled from his mother to his grandparents, to his father, and back again. In the midst of a chaotic, ever-changing universe, he remained determined to find love and belonging, eventually doing his best to build his own happy family.

But even though he was a teacher and preacher, Drew lost his marriage, career, and voice in the space of one horrible year. All the lessons he’d learned and taught others were powerless to help him hold it all together.

While recovering in a hospital bed shortly after his voice box has been removed, a powerful encounter with a fellow cancer patient forces Drew to look at the pain of his past in a new light. Choosing to fight rather than to run and hide, he begins tracing the threads that are coming together to form the fabric of his future.

How to Survive a Throat Punch: A Memoir of Love, Learning, and the Fight for What Matters Most

by Drew Ross (Goodreads Author)

By sharing a tapestry of heartbreaking, gut-wrenching, and often hilarious lessons involving family, romance, and identity, How to Survive a Throat Punch is a call to everyone enduring hardship to share their victories and failures, and, in doing so, begin to fight for what matters most.
**The Benefits to Laryngectomees of Getting COVID-19 Vaccine**

Laryngectomees are more susceptible to respiratory infections because the air they inhale is not filtered by passing through their nose. Consequently, they are at an increased risk of inhaling respiratory pathogens (viruses, bacteria, and fungi) directly into their lungs. There is mounting evidence that patients with cancer are at increased risk of severe illness and death if they are infected with COVID-19 virus. Furthermore, certain survivors of cancer have a higher probability of infection and COVID-19-related death compared to the general population.

Laryngectomees are also at high risk for poor outcomes when contracting COVID-19 because of their propensity to suffer from collapse of the lower lobes of their lungs (atelectasis). This is due to loss of upper airway resistance and impaired mucociliary functions, and mucosal irritation from cold, or dry inspired air. Further comorbidities such as advanced age, chronic disease (pulmonary, peripheral vascular, cardiac, cerebrovascular), diabetes, and past smoking, increase this risk.

Therefore, laryngectomees have to be vigilant and protect themselves from becoming infected with COVID-19. This can be done by wearing heat and moisture exchanger (HME) with greater filtering properties (i.e., Provox Micron TM); using 2 surgical masks (preferably N95), one over the stoma and the other over the mouth and nose; staying at least 6 feet away from others; washing hands often with soap and water for at least 20 seconds; and not touching their stoma, HME, eyes, nose, and mouth with unwashed hands.

Laryngectomees can protect themselves by receiving vaccination against COVID-19. All COVID-19 vaccines currently available in the United States have been shown to be highly effective at preventing COVID-19. It is also important to receive the booster vaccine as recommended by the Center of Disease Control (CDC). Getting a COVID-19 vaccine may also help keep one from getting seriously ill or dying if one becomes infected with COVID-19. Being vaccinated may also protect people around the vaccinated person, particularly those at increased risk for severe illness from COVID-19. This also contributes to curbing the national and world pandemic.

Among the benefits of being vaccinated is the emotional relief of gaining protection from the virus, and the ability to feel safer in face to face social interactions and when seeking medical and dental care. Clinical trials demonstrated that the known and potential benefits of these vaccine outweigh the their side effects, and the known and potential harms of becoming infected with COVID-19.

Many individuals are delaying their medical appointments that could lead to early diagnosis of new or recurrent cancer as well as deterioration in their health.

Vaccination is not expected to relax the CDC recommendations for continued use of masks and social distancing. This is because vaccines are not 100% effective, their protective effect is not maximized for at least six weeks, and vaccines may keep a person from getting sick but not from transmitting the virus. Masks and HMEs reduce the spread of any mutated strain of coronavirus such as the Delta strain. It is prudent to following the guidance and instruction issued by the CDC and the local government health authorities.

It is advisable to contact one’s physicians for guidance about vaccination or if one gets ill with the Corona virus. There are currently treatments available that can be administered early in the course of the infection to mitigate the illness and prevent complications.

Itzhak Brook MD, MSc.Dr. Brook is a physician and a laryngectomee. He is an Infectious Diseases Specialist, and a Professor of Pediatrics and Medicine at Georgetown University School of Medicine. He is the author of “My Voice: A Physician’s Personal Experience with Throat Cancer”, Laryngectomee Guide Expanded Edition"
Life After Laryngectomy: One Survivor’s Story
By: Stacey Brill M.S.CCC-SLP

As readers of this journal well know, being diagnosed with head/neck cancer is devastating and to undergo a total laryngectomy is life changing. It is important to know that, as incomprehensible as it might seem at diagnosis, life does not end after a laryngectomy … it can be as or more rich and fulfilling. In this article, Steve Cooper shares his laryngectomy journey, including returning to work.

Initial Diagnosis
Steve made an appointment with an ENT to see why his voice was hoarse. It had been hoarse for some time but he figured it would just get better. When it hadn’t, in December of 2018, Steve went to an ENT, who performed
a laryngoscope. On reviewing the results, the doctor thought there was some kind of “paralysis” of one of the vocal chords. He then referred Steve to another specialist more familiar with that type of issue, but never sent the laryngoscope video. Thus, the new ENT asked to do another scope. She had an associate in the exam room. According to Steve, when the scope was fully inserted, she turned to the other doctor saying: "Do you see that?” and the mood in the room immediately changed. She retracted the scope, looked at the video again and said "I see something that concerns me and I want to refer you to another doctor for a better look". Sensing the somber mood, Steve asked if it was cancer. He was told this was indeed a concern but that's why she felt the need to take a better look. Two days later, Steve was back in the office. This time he was seen by an head and neck cancer surgeon who took a small tissue sample which confirmed that Steve had Stage 4 Squamous cell carcinoma of the vocal cords. After a PET Scan was done, the doctor informed Steve that he would need a Total Laryngectomy, followed up with several weeks of radiation treatments.

**Initial Reaction**
Steve’s says his initial reaction to being told he had cancer was shock. He was devastated. He reports the few weeks after his diagnosis were a bit of a blur. Initially he told the doctor he wasn’t going to have the surgery and would rather let the cancer run its course. Steve had a home-based business as a Wholesale Food Broker. Although email is an important form of communication in his business, his primary role was in purchasing and sales. Often the best way to “close a deal” was by simply picking up the phone. Steve feared that he would lose the ability to effectively communicate. For that reason, he thought his career was over. He reports it was a very depressing time, which led him to his initial thoughts about refusing surgery. The doctor proceeded to explain that if he chose that route, he “would suffer and die a very painful and gruesome death.” It was the thought of putting his family through that, of his wife losing her lifelong partner and his kids losing their father that was the primary reason Steve decided to agree to the surgery.

**Preparation**
When asked how prepared Steve felt for surgery he stated “we are really NEVER fully prepared for surgery. The fears and emotions consume our thoughts every day and night”. With that said, Steve did the single greatest thing a person facing a TL could do. Before surgery, he connected with laryngectomees and, specifically, a local laryngectomee. It is commonly agreed that meeting with, and talking to, other laryngectomees prior to surgery is extremely helpful in gaining some insight into the process and outcome. It helps pre-surgical patients see that they can lead full and productive lives post-surgery.

**Surgery**
During Steve’s surgery, in addition to his larynx, over 30 lymph nodes were removed. Fortunately, the general margins were clear and every lymph node tested 100% negative for cancer. It was strictly confined to his larynx. Chemotherapy and radiation were not needed. The surgery was a success and the results were good. Steve would have CT scans every 3 months for the first 2 years, then every 6 - 12 months for the next 3 years. At the 5-year mark, if scans remained clear, he would be considered “cured”! (NOTE: this is Steve’s experience and is not necessarily representative of what individual patients may face).

**Post Surgery**
Steve was a Wholesale Food Broker for over 40 years. As noted above, he feared that after the surgery, his career would be over. However, Steve was answering emails on day 5 from his hospital bed. He could only work one or 2 hours before getting very tired. He reports he did notice that it was a bit difficult to concentrate and that he had to re-read emails 2 or 3 times before hitting send. For the first few months, communication was difficult and extremely frustrating and depressing at times. He was using an Electrolarynx but, due to swelling, lymphedema and being a novice EL user, it was a bit difficult to be understood. During those few months, he relied on others in his company to make calls for him and did as much as possible via email. However, as soon as Steve was starting to be understandable with an EL, he forced himself to make phone calls when it was necessary. He found this was helpful in getting more proficient with using an EL and to get over his feeling of
the stigma of what his voice might sound like. To his surprise, although there were several weeks of downtime, he has fully returned to the same business with the same abilities as before. In fact, he reports that many customers and vendors actually seem kinder now. As it turned out, Steve says the most difficult part post surgery was not work related. It was trying to deal with the insurance company and get the supplies he needed. Having someone else calling the insurance company was frustrating. Steve knew best what supplies were needed and what the obstacles were. It actually took fighting with his health insurance company for 7 months and only when he threatened to file a complaint with the insurance commissioner in his state did they finally agree to purchase directly from the vendors that sold the supplies. Even once they agreed, it still took almost 3 additional months for the insurance company to get the paperwork finalized.

What would it have been helpful to know?
When Steve was asked what did he wish his medical team had shared with him prior to surgery he replied “I wish my medical team was more informative about what’s ahead”. Their primary concern was getting rid of the cancer. In hindsight, there wasn’t enough attention given to the “whole patient” and tips and techniques to combat the emotional issues. Also, he expressed a desire for a better mechanism to get pre-approval with the insurance carriers for required supplies. “Once you’ve had the surgery and can’t communicate at first, it’s impossible to argue your case with the insurance companies.” This only compounded the frustration of trying to get badly needed supplies. When he speaks now to pre surgery patients, he makes these aspects part of his focus.

**Biggest Impact**
Steve feels strongly that the biggest impact in becoming a laryngectomee is emotional. Physically, he healed fairly quickly but believes emotional aspects can last a lifetime. As he states, “Our voices are our personality. When we lose our voice, we lose a part of ourselves. Until we regain a way of communication, it takes a toll. We can be angry and resentful, especially to those closest to us.” There were a few times that Steve says he just fell apart, crying uncontrollably and completely debilitated. It was a very dark period in his recovery. Steve stresses the importance of post laryngectomy patients to seek help from a psychologist, psychiatrist, a pastor or anyone trained in dealing with depression. Also, diet, exercise and developing hobbies or staying active is very important as well. Steve says on the positive side, it did change his perspective of what’s important in life. He feels he learned to “not sweat the small stuff” and to focus on what’s truly important; health, family and friends. Also that we only have so many days on this earth… Spend each one wisely!

Steve’s advice for someone facing a laryngectomy is never just assume that you won’t be able to work again. Make a plan! Tell others that you may be out of commission for a short period of time. Assign tasks to others. Let them run with them, don’t try to micro manage. And keep in mind that many laryngectomees actually find a new and different career after surgery, so there are many possible scenarios that lay ahead.

**The Path Forward**
Prior to surgery, Steve was only occasionally involved in community volunteering activities. After surgery, he became committed to helping others that are faced with having a laryngectomy. As a result, he is a past board member of the International Association of Laryngectomees, a board member of the Laryngectomee Club of Montgomery County (MD), a board member of the Governor’s Advisory Board for Telecommunications Relay in Maryland and a past board member of WebWhispers, Inc. He is also a peer-to-peer mentor for laryngeal cancer patients with Imerman’s Angels, George Washington University Hospital, as well as several other Washington, DC Metro area hospitals and other mentoring opportunities. Steve regards his biggest “achievement” has been meeting other pre and post laryngectomy patients, holding himself as an example and leaving them with the comfort in knowing that they will be OK, we can lead full and productive lives after a Total Laryngectomy, and they too can “do this”.
IAL ANNUAL MEETING AND VOICE INSTITUTE HAS BEEN RESCHEDULED

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SAVE THE DATES

JUNE 13 - 18, 2022

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Please note:
In 2020 we had to cancel our AM/VI due to the Covid-19 pandemic.
In 2021 we again cancelled due to Covid-19 and the fact that the hotel was not fully operational as far as guests amenities.
In 2022 we have rescheduled. I want you to know that as time goes forward I will let you know exactly what amenities the hotel is offering it’s guests. I am going to promise you that this AM/VI will not be cancelled or postponed.
We need to renew our old friendships while making many new friends. I look forward to seeing as many of you as possible. I am really excited about planning this event and hope it will be one of the very best.
Sometimes people with cancer worry about, joke about, or become frustrated by what they describe as mental cloudiness or changes they might notice before, during, and after cancer treatment. This cloudiness or mental change is commonly referred to as chemo brain. Doctors and researchers may call chemo brain many things, such as cancer treatment-related cognitive impairment, cancer-related cognitive change, or post-chemotherapy cognitive impairment. The word "cognitive" refers to the way your brain works to help you communicate, think, learn, solve problems, and remember.

**What is chemo brain?**
Most define it as a decrease in mental “sharpness” and describe it as being unable to remember certain things and having trouble finishing tasks, concentrating on something, or learning new skills. Even though its exact cause isn’t known, it can happen at any time when you have cancer.

These mental changes can make people unable to perform usual activities like school, work, or social activities. Or it can seem like it takes a lot of mental effort to do them. Many people don’t tell their cancer care team about their problems until it affects their everyday life. It’s important to get help and support, so be sure to let your cancer care team know if you notice any mental changes, no matter how small.

Here are some examples of what patients with chemo brain may experience:
- Forgetting things that they usually have no trouble remembering (memory lapses)
- Trouble concentrating (they can’t focus on what they’re doing, have a short attention span, may easily “space out”)
- Trouble remembering details like names, dates, and sometimes larger events
- Trouble multi-tasking, like answering the phone while cooking, without losing track of one task (they’re less able to do more than one thing at a time)
- Trouble learning new things
- Taking longer to finish things (disorganized, slower thinking and processing)
- Trouble remembering common words (unable to find the right words to finish a sentence)

For most people, these mental changes only last a short time. Others can have long-term or delayed mental changes. How long chemo brain lasts is a major factor in how much it affects a person’s life. When it starts, how long it lasts, and how much trouble it causes may be different for every patient. Usually the changes that patients notice are subtle, and others around them might not even notice any changes at all. Still, the people who are having problems are aware of the differences in their thinking.

**What causes chemo brain?**
Chemo brain is most commonly connected with chemotherapy, but other treatments, such as hormone therapy, radiation, and surgery may be associated with it also. These treatments can cause short-term, long-term, or delayed mental changes or cognitive problems. Beyond the chemo brain symptoms that start during and just after treatment, there are some cases where chemo brain symptoms start and continue after treatment is over. Some people with cancer have very real brain problems even though they haven’t had chemo.

Certain things can increase the risk of developing chemo brain or worsening brain function problems. These include:
- The cancer itself, for example brain tumors
- Other drugs used as part of treatment, such as steroids, anti-nausea, or pain medicines
- Other conditions or illnesses, such as diabetes or high blood pressure
- Having other symptoms like tiredness, pain, or sleep problems
- Emotional distress such as depression or anxiety
- Older age
- Being weak or frail
- Surgery and the drugs used during surgery (anesthesia)
- Infection
• Hormone changes or hormone treatments
• Being postmenopausal
• Nutritional deficiencies
• Using alcohol or other substances that can change your mental state

Most of these cause short-term problems, and get better as the underlying problem is treated or goes away. Others can lead to long-lasting brain problems unless the cause is treated.

Treatment of chemo brain

Treatments for chemo brain may include:

• **Cognitive rehabilitation**: This might be part of a cancer rehabilitation (rehab) program. It includes activities to improve brain function such as learning how the brain works and ways to take in new information and performing new tasks; doing some activities over and over that become harder with time; and using tools to help stay organized such as planners or diaries.

• **Exercise**: Exercise can improve your thinking and ability to focus. Activities such as gardening, caring for pets, or walking, can help improve your attention and concentration levels.

• **Meditation**: Meditation can help improve brain function by increasing your focus and awareness.

Talk to your cancer care team about these treatment suggestions and other options they may recommend to help you cope with any cognitive problems.

Day-to-day coping with chemo brain

There are some things that you can do to help you sharpen your mental abilities and manage chemo brain. Some examples are:

• **Use a detailed daily planner, notebooks, reminder notes, or your smart phone**. Keeping everything in one place makes it easier to find the reminders you may need. You might want to keep track of appointments and schedules, “to do” lists, important dates, websites, phone numbers and addresses, meeting notes, and even movies you’d like to see or books you’d like to read.

• **Do the most demanding tasks** at the time of they day when you feel your energy levels are the highest.

• **Exercise your brain**. Take a class, do word puzzles, or learn a new language.

• **Get enough rest and sleep**.

• **Keep moving**. Regular physical activity is not only good for your body, but also improves your mood, makes you feel more alert, and decreases tiredness (fatigue).

• **Avoid alcohol and other agents** that might change your mental state and sleeping patterns

• **Ask for help when you need it**. Friends and loved ones can help with daily tasks to cut down on distractions and help you save mental energy.

• **Track your memory problems**. Keep a diary of when you notice problems and what’s going on at the time. Medicines taken, time of day, and the situation you’re in might help you figure out what affects your memory. Keeping track of when the problems are most noticeable can also help you prepare. You’ll know to avoid planning important conversations or appointments during those times. This record will also be useful when you talk with your doctor about these problems.

• **Try not to focus on how much these symptoms bother you**. Accepting the problem will help you deal with it. As many patients have noted, being able to laugh about things you can’t control can help you cope. And remember, you probably notice your problems much more than others do.

Tell others what is happening

Another thing you can do to better manage chemo brain is tell family, friends, and your cancer care team about it. Finding and getting support is important. Let them know what you’re going through. You may feel relieved once you tell people about the problems you sometimes have with your memory or thinking.

Chemo brain is a side effect you can learn to manage. Even though this might be a change that’s not easy to see, like other changes such as hair loss or skin changes, your family and friends might have
noticed some things and may even have some helpful suggestions. For instance, your partner might notice that when you’re rushed, you have more trouble finding things. Tell your friends and family members what they can do to help. Their support and understanding can help you relax and make it easier for you to focus and process information.

**Talk with your doctor or cancer care team**

If brain problems cause trouble at work or school, or interfere with your usual activities, talk with your doctor to try and pinpoint what’s causing your brain fog and what can be done about it. This is especially important for people with chemo brain that lasts longer than the treatment period and keeps causing trouble in their daily lives.

It helps a lot if you have a diary or log of the situations you have trouble with. It also helps to let your doctor know some of the things that make the problem worse or better. For instance, are they worse in the morning or evening? Do you have more trouble when you are hungry or tired? Does it help to nap, walk, or have a snack? Your doctor will want to know when the problems started and how they affect your daily life.

- Write down questions about the problems you have. Take them to your appointment along with your memory tracking log to talk over with your doctor. Ask what may be causing the problems, and find out if there’s anything the doctor can offer to help you.
- Bring a list of all the medicines you take, including herbs, vitamins, supplements, and those you take on an “as needed” basis.
- Take a friend or family member with you to help you keep track of what’s said during the visit. They can also describe the changes they see if the doctor wants a different viewpoint of how your brain problems are affecting you.
- If your memory and thinking problems keep causing trouble in your daily life, ask your doctor if you might be helped by a specialist such as a neuropsychologist, speech language pathologist, occupation therapist, or vocational therapist. These professionals can test you and may recommend ways to help you better handle the cognitive problems or changes that you are experiencing. (You may hear this called **cognitive rehabilitation**.)

You may need to visit a larger hospital or cancer care center to find experts on testing brain function, including chemo brain. Ask if you can get a referral to one of these specialists who can help you learn the scope of your problem and work with you on ways to manage it. You’ll want to find out what your insurance will cover before you start.

**Questions to ask about chemo brain**

These are just some of the questions you may want to ask your doctor:

- Based on my treatment, am I at increased risk for brain changes?
- When might these changes happen and how long will they last?
- Are there other medical problems that could be causing my symptoms?
- Is there treatment for my symptoms?
- What can I do to manage chemo brain?
- Is there anything I can do to help prevent or decrease chemo brain symptoms?
- Should I see a specialist? Can you recommend one?

**Can chemo brain be prevented?**

So far, there is no known way to prevent the cognitive changes that cause chemo brain. This is because the causes are still being studied. For some people, treating their cancer will mean they might have trouble with thinking, memory, planning, and finding the right words. Chemo brain seems to happen more often in people who get high doses of chemo, and is more likely to happen if the brain is also treated with radiation therapy.

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Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

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Radiation Therapy Side Effects

It's very important to remember that every person reacts differently to treatment. Any side effect you might have depends on the type and location of cancer, the dose of radiation being given, and your general health. Some people have few or no side effects, while others have quite a few.

How long do side effects last?

Remember that the type of radiation side effects you might have depends on the prescribed dose and schedule. Most side effects go away within a few months of ending treatment. Some side effects may continue after treatment ends because it takes time for the healthy cells to recover from radiation. Side effects might limit your ability to do some things. What you can do will depend on how you feel. Some patients are able to go to work or enjoy leisure activities while they get radiation therapy. Others find they need more rest than usual and can't do as much. If you have side effects that are bothersome and affecting your daily activities or health, the doctor may stop your treatments for a while, change the schedule, or change the type of treatment you’re getting. Tell your cancer care team about any side affects you notice so they can help you with them.

Early and late effects of radiation therapy

- **Early side effects** happen during or shortly after treatment. These side effects tend to be short-term, mild, and treatable. They're usually gone within a few weeks after treatment ends. The most common early side effects are fatigue (feeling tired) and skin changes. Other early side effects usually are related to the area being treated, such as hair loss and mouth problems when radiation treatment is given to this area.

- **Late side effects** can take months or even years to develop. They can occur in any normal tissue in the body that has received radiation. The risk of late side effects depends on the area treated as well as the radiation dose that was used. Careful treatment planning can help avoid serious long-term side effects. It’s always best to talk to your radiation oncologist about the risk of long-term side effects.

Radioprotective drugs for reducing side effects

One way to reduce side effects is by using radioprotective drugs, but these are only used for certain types of radiation given to certain parts of the body. These drugs are given before radiation treatment to protect certain normal tissues in the treatment area. The one most commonly used today is amifostine. This drug may be used in people with head and neck cancer to reduce the mouth problems caused by radiation therapy.

Not all doctors agree on how these drugs should be used in radiation therapy. These drugs have their own side effects, too, so be sure you understand what to look for.

Common general side effects of radiation therapy

**Fatigue** is feeling tired physically, mentally, and emotionally. It’s very common for people with cancer and often happens with radiation therapy. Most people start to feel tired after a few weeks of radiation therapy. This happens because radiation treatments destroy some healthy cells as well as the cancer cells. Fatigue usually gets worse as treatment goes on. Stress from being sick and daily trips for treatment can make fatigue worse. Managing fatigue is an important part of care.

Fatigue felt during radiation treatment is different from the fatigue of everyday life, and it might not get better with rest. It can last a long time and can get in the way of your usual activities. But it will usually go away over time after treatment ends.

Only you know if you have fatigue and how bad it is. No lab tests or x-rays can diagnose or describe your level of fatigue. The best measure of fatigue comes from your own report to your cancer care team. You can describe your level of fatigue as none, mild, moderate, or severe. Or you can use a scale of 0 to 10, where a 0 means no fatigue, and a 10 is the worst fatigue you could imagine.

Either way you choose, it’s important to describe your fatigue to your cancer care team. Be sure to talk with them if:

- Your fatigue doesn’t get better, keeps coming back, or gets worse.
- You’re more tired than usual during or after an activity.
- You’re feeling tired, and it’s not related to something you’ve done.
- You become confused or can’t focus your thoughts.
You can’t get out of bed for more than 24 hours.
You fatigue disrupts your social life or daily routine.
If you need to take time off from work, talk to your employer.

Skin problems
Your skin in the radiation treatment area might look **red, irritated, swollen, blistered, sunburned, or tanned**. After a few weeks, your skin might become dry, flaky, or itchy, or it may peel. This is sometimes called radiation dermatitis. It’s important to let your cancer care team know about any skin changes. They can suggest ways to ease the discomfort, lessen further irritation, and prevent infection.

These problems usually go away gradually after treatment ends. In some cases, though, the treated skin will stay darker and might be more sensitive than it was before.

You need to be gentle with your skin. Here are some ways to do this:

- **Do not wear tight, rough-textured, or stiff clothes over the treatment area.** This includes anything tight or elastic that squeezes the area. Instead, wear loose clothing made from soft, smooth fabrics. Do not starch your clothes.
- **Do not rub, scrub, scratch, or use adhesive tape on treated skin.** If your skin must be covered or bandaged, use paper tape or other tape for sensitive skin. Try to put the tape outside the treatment area, and don’t put the tape in the same place each time.
- **Do not put heat or cold (such as a heating pad, heat lamp, or ice pack) on the treatment area** without talking to your cancer care team first. Even hot water may hurt your skin, so use only lukewarm water for washing the treated area.
- **Protect the treated area from the sun.** Your skin may be extra sensitive to sunlight. If possible, cover the treated skin with dark-colored or UV-protective clothing before going outside. Ask your cancer care team if you should use sunscreen. If so, use a broad spectrum sunscreen with a sun protection factor (SPF) of at least 30. Reapply the sunscreen often. Continue to give your skin extra protection from sunlight, even after radiation therapy ends.
- **Use only lukewarm water and mild soap.** Just let water run over the treated area. Do not rub. Also be careful not to rub away the ink marks needed for your radiation therapy until it’s done.
- **Check with your cancer care team before shaving the treated area.** They might recommend that you use an electric shaver.
- **Ask your cancer care team before using anything on the skin in the treatment area.** This includes powders, creams, perfumes, deodorants, body oils, ointments, lotions, hair-removal products, or home remedies while you’re being treated and for several weeks afterward. Many skin products can leave a coating on the skin that can cause irritation, and some may even affect the dose of radiation that enters the body.

Hair loss
Radiation therapy can cause **hair to be thinned or lost** in the area being treated. For instance, radiation to your head may cause you to lose some or all the hair on your head (even eyebrows and lashes), but if you get treatment to your hip, you won’t lose the hair on your head.

Most people find that their hair grows back after treatment ends, but it can be hard to deal with hair loss. When it does grow back, your hair may be thinner or a different texture than it was before. Ask your cancer care team if you have any questions or concerns about hair loss.

If you do lose your hair, your scalp may be tender and you may want to cover your head. Wear a hat or scarf to protect your head when you’re in the sun. If you prefer to wear a hairpiece or wig, be sure the lining doesn’t irritate your scalp. Your local American Cancer Society office may be able to help you get wigs or hats.

Low blood counts
Rarely, radiation therapy can cause **changes in your blood count levels**. These blood cells help your body fight infection and prevent bleeding. If your blood tests show low blood counts, your treatment might be stopped for a week or so to allow your blood counts to return to normal. This side effect is more likely if you’re also getting chemotherapy.

If you’re getting radiation therapy to the head or neck
People who get radiation to the head and neck might have side effects such as:

- Soreness (or even open sores) in the mouth or throat
- Dry mouth
- Trouble swallowing
- Changes in taste
- Nausea
- Earaches
- Tooth decay
- Swelling in the gums, throat, or neck
- Hair loss
- Changes in skin texture
- Jaw stiffness

How to care for your mouth during treatment

If you get radiation therapy to the head or neck, you need to take good care of your teeth, gums, mouth, and throat. Here are some tips that may help you manage mouth problems:

- Avoid spicy and rough foods, such as raw vegetables, dry crackers, and nuts.
- Don’t eat or drink very hot or very cold foods or beverages.
- Don’t smoke, chew tobacco, or drink alcohol – these can make mouth sores worse.
- Stay away from sugary snacks.
- Ask your cancer care team to recommend a good mouthwash. The alcohol in some mouthwashes can dry and irritate mouth tissues.
- Rinse your mouth with warm salt and soda water every 1 to 2 hours as needed. (Use 1 teaspoon of salt and 1 teaspoon of baking soda in 1 quart of water.)
- Sip cool drinks often throughout the day.
- Eat sugar-free candy or chew gum to help keep your mouth moist.
- Moisten food with gravies and sauces to make it easier to eat.
- Ask your cancer care team about medicines to help treat mouth sores and control pain while eating.

If these measures are not enough, ask your cancer care team for advice. Mouth dryness may be a problem even after treatment is over. If so, talk to your team about what you can do.

How to care for your teeth during treatment

Radiation treatment to your head and neck can increase your chances of getting cavities. This is especially true if you have dry mouth as a result of treatment.

Before starting radiation, talk to your cancer care team about whether you should get a complete check-up with your dentist. Ask your dentist to talk with your radiation doctor before you start treatment. If you have one or more problem teeth, your dentist may suggest removing them before you start treatment. Radiation (and dry mouth) might damage them to the point where they’ll need to be removed anyway, and this can be harder to do after treatment starts.

If you wear dentures, they may no longer fit well because of swollen gums. If your dentures cause sores, you may need to stop wearing them until your radiation therapy is done to keep sores from getting infected.

Your dentist may want to see you during your radiation therapy to check your teeth, talk to you about caring for your mouth and teeth, and help you deal with any problems. Most likely, you will be told to:

- Clean your teeth and gums with a very soft brush after meals and at least one other time each day.
- Use fluoride toothpaste that contains no abrasives.
- Rinse your mouth well with cool water or a baking soda solution after you brush. (Use 1 teaspoon of baking soda in 1 quart of water.)
- If you normally floss, ask your dentist or cancer care team if this is OK during treatment. Tell your cancer care team if this causes bleeding or other problems.
How Big is Home Plate

Twenty years ago, in Nashville, Tennessee, during the first week of January, 1996, more than 4,000 baseball coaches descended upon the Opryland Hotel for the 52nd annual ABCA's convention.

While I waited in line to register with the hotel staff, I heard other more veteran coaches rumbling about the lineup of speakers scheduled to present during the weekend. One name kept resurfacing, always with the same sentiment — “John Scolinos is here? Oh, man, worth every penny of my airfare.”

Who is John Scolinos, I wondered. No matter; I was just happy to be there.

In 1996, Coach Scolinos was 78 years old and five years retired from a college coaching career that began in 1948. He shuffled to the stage to an impressive standing ovation, wearing dark polyester pants, a light blue shirt, and a string around his neck from which home plate hung — a full-sized, stark-white home plate.

Seriously, I wondered, who is this guy?

After speaking for twenty-five minutes, not once mentioning the prop hanging around his neck, Coach Scolinos appeared to notice the snickering among some of the coaches. Even those who knew Coach Scolinos had to wonder exactly where he was going with this, or if he had simply forgotten about home plate since he’d gotten on stage. Then, finally …

“You’re probably all wondering why I’m wearing home plate around my neck,” he said, his voice growing irascible. I laughed along with the others, acknowledging the possibility. "I may be old, but I’m not crazy. The reason I stand before you today is to share with you baseball people what I’ve learned in my life, what I’ve learned about home plate in my 78 years.” Several hands went up when Scolinos asked how many Little League coaches were in the room. “Do you know how wide home plate is in Little League?”

After a pause, someone offered, “Seventeen inches?”, more of a question than answer. “RIGHT! And in the Major Leagues, how wide home plate is in the Major Leagues?

“Seventeen inches!”

“SEV-EN-TEEN INCHES!” he confirmed, his voice bellowing off the walls. “And what do they do with a Big League pitcher who can’t throw the ball over seventeen inches?” Pause. “They send him to Pocatello!” he hollered, drawing raucous laughter. “What they don’t do is this: they don’t say, ‘Ah, that’s okay, Jimmy. If you can’t hit a seventeen-inch target? We’ll make it eighteen inches or nineteen inches. We’ll make it twenty inches so you have a better chance of hitting it. If you can’t hit that, let us know so we can make it wider still, say twenty-five inches.”

Pause. “Coaches… what do we do when your best player shows up late to practice? or when our team rules forbid facial hair and a guy shows up unshaven? What if he gets caught drinking? Do we hold him accountable? Or do we change the rules to fit him? Do we widen home plate?”

The chuckles gradually faded as four thousand coaches grew quiet, the fog lifting as the old coach’s message began to unfold. He turned the plate toward himself and, using a Sharpie, began to draw something. When he turned it toward the crowd, point up, a house was revealed, complete with a freshly drawn door and two windows. “This is the problem in our homes today. With our marriages, with the way we parent our kids. With our discipline. We don’t teach accountability to our kids, and there is no consequence for failing to meet standards. We just widen the plate!”

Pause. Then, to the point at the top of the house he added a small American flag. “This is the problem in our schools today. The quality of our education is going downhill fast and teachers have been stripped of the tools they need to be successful, and to educate and discipline our young people. We are allowing others to widen home plate! Where is that getting us?”

Silence. He replaced the flag with a Cross. “And this is the problem in the Church, where powerful people in positions of authority have taken advantage of young children, only to have such an atrocity swept under the rug for years. Our church leaders are widening home plate for themselves! And we allow it.”

“And the same is true with our government. Our so-called representatives make rules for us that don’t apply to themselves. They take bribes from lobbyists and foreign countries. They no longer serve us. And we allow them to widen home plate! We see our country falling into a dark abyss while we just watch.”

I was amazed. At a baseball convention where I expected to learn something about curve balls and bunting and how to run better practices, I had learned something far more valuable. From an old man with home plate strung around his neck, I had learned something about life, about myself, about my own weaknesses and about my responsibilities as a leader. I had to hold myself and others accountable to that which I knew to be right, lest our families, our faith, and our society continue down an undesirable path.

“If I am lucky,” Coach Scolinos concluded, “you will remember one thing from this old coach today. It is this: ‘If we fail to hold ourselves to a higher standard, a standard of what we know to be right; if we fail to hold our spouses and our children to the same standards, if we are unwilling or unable to provide a consequence when they do not meet the standard; and if our schools & churches & our government fail to hold themselves accountable to those they serve, there is but one thing to look forward to …’”

With that, he held home plate in front of his chest, turned it around, and revealed its dark black backside, “…We have dark days ahead.”

Note: Coach Scolinos died in 2009 at the age of 91, but not before touching the lives of hundreds of players and coaches, including mine. Meeting him at my first ABCA convention kept me returning year after year, looking for similar wisdom and inspiration from other coaches. He is the best clinic speaker the ABCA has ever known because he was so much more than a baseball coach. His message was clear: “Coaches, keep your players—no matter how good they are—your own children, your churches, your government, and most of all, keep yourself at seventeen inches.”

And this my friends is what our country has become and what is wrong with it today, and now go out there and fix it!

"Don't widen the plate."
Welcome to The Swallows

Head and Neck Cancer Charity

The Swallows Charity supports all people affected by head and neck cancers; patients, caregivers, friends or relatives. The patient is the focus for support, help and signposting. However the role of caregivers and others is vital too, with their own support needs often overlooked. It is our intention for every person affected by head and neck cancer to have access to support at the point they need it, by the method of their choice, on a 24/7 basis. This could be by telephone, email or social media. This is the key growth area for The Swallows and we have expanded our global reach to provide resources, enabling this 24/7 support to be freely available to all people affected by head and neck cancers.

It is a proven fact that early diagnosis saves lives. Hence it is important to educate and inform people globally about a) how to avoid such cancers, and b) how to look for warning signs that allow for early diagnosis and treatment.

Our support groups

Currently we have several Support Groups in the UK and our unique virtual international monthly patient and caregiver meeting. Our aim is to increase the number of support groups over the coming years. The approach we use successfully is to provide a monthly meeting at which both patients and caregivers can attend to discuss their issues. They are given the opportunity to talk about these matters collectively or separately in a safe environment.

Our experience and feedback gathered from attendees is that they value this time spent together to talk about their own specific issues in an open and honest way and to receive support. We find that separating patients from caregivers for some of this time facilitates a more open and frank exchange which results in people in similar situations being able to offer much valued support and guidance. Feedback since 2011 has shown that this approach works very well, and this is the model that we are now seeking to use with all Swallows Support Groups in the UK and overseas.

www.theswallows.org.uk
info@theswallows.org.uk

Our main activities:

- Providing a wide range of patient & caregiver information books to patients, caregivers, relatives, GPs, professors, surgeons, clinical nurses, chemists, and dentists. We have a wide range of material covering awareness of Head and Neck cancer, early detection, signs and symptoms of what to look for, self-screening information and human papilloma virus (HPV) awareness material.

- We offer a unique & dedicated 24/7 support phone line, operated by patients & caregivers for the patient & caregiver. (This is not a call centre).

- Facilitating an annual Head and Neck Cancer Conference at which guest speakers and selected patients and caregivers from around the world can discuss key topics, key innovations in treatment methods, greater cooperation between health professionals and how to improve a patient’s cancer journey.

- We attend overseas conferences to help us raise awareness of our activities to key potential partners in major industries.

- Within the UK we are involved with health professionals at all levels to help them become more aware of the patient and caregiver journeys.

- On 27th July each year we participate in World Head and Neck Cancer Day to help generate awareness to a more global audience.

- We participate at Health and Well-Being events, often providing free oral health checks, in order to highlight the dangers of smoking, alcohol consumption and general lifestyles in the fight against head & neck cancer.

- Our website and social media platforms help to educate patients and caregivers with current and relevant information for head and neck cancers.

- The Swallows Charity shop’s primary purpose is to raise funds. This brings huge value to the local community which in turn supports local volunteers and helps boost the local high street.
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