

NEWS FROM S•P•O•H•N•C



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S•P•O•H•N•C
A PROGRAM OF SUPPORT
FOR
PEOPLE WITH
ORAL AND
HEAD AND NECK CANCER

Journaling Your Cancer Journey

Benefits of Expressive Writing for People with Cancer

Lynne Eldridge, MD

Journaling, or “expressive writing” is a creative and emotional outlet for many people with cancer. In addition to being a way to chronicle your journey and clarify your thoughts, some people have found that writing is a good way to find the silver linings, or the positive things that happen amidst the heartache and pain



of cancer. Journaling may help people cope with the emotional distress of cancer, especially expressive writing that focuses on the positive aspects of the experience. Physically, studies looking at improvement in quality of life in people with cancer who journal have found that an improvement in cognitive function may underly some of this benefit. On the

downside, expressive writing that leads to rumination could have a negative impact on well-being. We will take a look at some of the methods people use for journaling, tips on getting started, and some ideas and writing prompts to get your words flowing.

Caveat

It's important to make a quick note that even lifelong non-writers often enjoy the practice of journaling, but it's not for everyone. If the thought of writing doesn't appeal, there are many other creative outlets that some people with cancer have found helpful ranging from art therapy, to music therapy, to pet therapy.

Reasons to Write When You Have Cancer

Before beginning, it's helpful to look at some of the reasons why you may wish to journal your cancer journey. Some of these may be important to you, whereas others won't really fit. What's important is that you write for reasons that are important to you alone. Some of these include:

- To relieve stress
- To chronicle your journey. When you are in the midst of treatment it may seem that you'll always remember these moments, but that's not always the case. Having a record of what you have been through and your thoughts along the way can be priceless as you look back.
- To clarify your thoughts. People often ask those with cancer how they are really feeling, and answering can be hard when you don't really know yourself. Taking the time to put your feelings in words can sometimes help clarify those thoughts.
- To help you let go. There are many reasons to become irritated, angry, and resentful when coping with cancer. Not only are you facing a disease you don't deserve, but inevitably family or friends, especially those who have not been exposed to cancer themselves, fail us. Learning to let go to live with cancer isn't easy, but can help free you up to focus on things you do have some control over.
- To find the silver linings. You may have noticed that many people who have lived with cancer change in positive ways amidst the trauma. Studies now tell us that cancer often changes people for the better when it comes to having greater empathy and appreciation for life. Journaling can help you find those silver linings along the way.

How to Talk About Caregiver Burnout

It's common to feel overwhelmed as a caregiver—and OK to be honest about it. Try our conversation coach to practice how to share your feelings and find support.

Try It Now

- To leave a legacy. Some people journal their thoughts on topics they want to make sure they share with loved ones while they have the time. Even if you have a cancer with a very good prognosis, many people have found that when faced with the threat to life that's cancer, they are better able to share their deeper thoughts and feelings that at times when life is going smoothly.
- To write a book. You wouldn't be the first person who wrote

JOURNALING continued on page 2

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out thoughts on their cancer journey and ended up publishing them in a book. A good example includes *Cancer Journey: A Caregiver's View from the Passenger Seat* by Cynthia Zahm Siegfried.

Benefits of Journaling for People with Cancer

Studies to assess the impact of journaling on people with cancer are still in their infancy, but those that have been done clearly show some benefits. Of course, studies don't necessarily tell us whether or not you personally could benefit from writing, but your heart will probably let you know. If it makes you feel better to put words on paper, keep doing it. If you find it stressful, another use of your time might be better.

Emotional and Psychological Benefits

According to a 2015 review looking at women with breast cancer, journaling may help more with the physical than psychological symptoms of cancer, but a few small studies have found that expressive writing may help with emotional well-being as well, especially in improving the quality of life for women living with cancer.

It may be the type of writing rather than journaling itself that determines how beneficial the effect of journaling. A 2019 study looking at Chinese women with breast cancer found that journaling improved quality of life, but when broken down into groups that wrote about either the positive aspects of their cancer experience, reported cancer-related facts, or wrote about the stress and coping effects, the "positive writing" was associated with a greater improvement in quality of life.

Social Impact

Though it's hard to study the social impact of journaling, we know that communication is crucial for those living with cancer. If writing can help you clarify your thoughts so that you can better communicate your feelings and needs to loved ones and health care providers, there's a good chance it may help.

Physical Benefits

There have now been several studies looking at how journaling may benefit people physically while living with cancer.

Cognitive Function

Though "chemobrain" is a symptom often associated with chemotherapy, radiation therapy to the brain, and simply the stress of cancer can contribute to these symptoms of difficulty multitasking and losing car keys. A 2014 study looking at people with renal cell carcinoma (kidney cancer) found that expressive writing improved cancer-related symptoms and physical functioning primarily through short-term improvements in cognitive functioning.

Wound Healing

In one study looking at older adults (aged 64 to 97), writing expressively for 20 minutes each day was associated with better [wound healing](#).

JOURNALING continued on page 3

JOURNALING continued from page 2**Possible Drawbacks**

It's important to note that journaling may also have draw backs or lead to poorer psychological functioning in some cases. For those who find themselves ruminating about ways they've been hurt by others and hanging on to resentment, expressive writing could potentially have a negative impact on well-being.

**Types and Methods
for Expressive Writing**

Before beginning your journal ask yourself: "Who is your audience?" Are you writing for yourself alone privately, for your family, or do you wish to share with the greater cancer community? Also, ask yourself if you would prefer writing in a journal by hand or if typing at the computer or even your smartphone would work best. Some types of journals include:

- Daily thought journals
- Gratitude journals
- Online journals such as blogs, or a Caring Bridge site
- Some people prefer journaling that is not focused primarily on writing such as art journaling

Selecting a journal is an important first step, and often the biggest hurdle. Once you have your journal and a favorite writing pen, you're ready to begin whenever you wish.

Tips for Writing Your Cancer Journal

Once you're ready, a few tips may help ensure you are successful:

- As the *Nike* commercial says: Just Do It!
- Try to write every day, even if for only 5 minutes
- Make sure to date your entries
- Find a place to keep your journal(s) so they won't get into the wrong hands
- Make your area comfortable when writing, perhaps light a candle, try some aromatherapy, or play inspirational music

**Ideas for Writing About
Your Cancer Journey**

The second hardest step in journaling (after purchasing your journal) is simply to make the first entry. Instead of worrying about what the focus of your journal should be, you may want to check out some of these following questions and thoughts to stimulate your thoughts. While one of the studies noted above found that positive writing had the greatest effect on quality of life, people aren't statistics. Write about what matters the most to you.

- Who has supported you through therapy?
- I am thankful for... (fill in the blank)
- If you hear a quote or song lyrics that resonate with you, write them down and record your thoughts about how the words affect you or portray what you are feeling.
- Try "stream-of-consciousness" writing: Take 10 minutes to 20 minutes and write non-stop (without editing) about absolutely anything that comes to mind. Your ideas don't have to be connected. You may be surprised to see the thoughts and ideas you have on paper!
- Think of a particular time during your cancer treatment. What were you feeling? What were you thinking? How did that time impact you, your family, and/or your friends?
- What silver linings have you experienced?
- What would you do differently, what would you do the same?
- What are your greatest fears?
- What have you learned?
- What's the funniest thing that happened to you during cancer treatment?
- What positive experiences would you not have had if you never had cancer?
- Write a letter you won't send. If you have words that you are carrying inside

you, but can't express them to another because they won't be receptive or are no longer living, write an unsent letter.

If you are looking for further ideas, reading the blogs of others with cancer may stimulate your own thoughts and feelings.

A Word From Verywell

Journaling may have some benefits for people with cancer, but the greatest benefit may have nothing to do with your emotional or physical well-being at the time. Preserving memories, leaving a legacy, and finding the silver linings in your journey can be priceless not only for yourself, but for your loved ones as well.

Editors Note: Dr. Eldridge has undergraduate degrees from Stanford University and Bethel University where she studied chemistry and music. She earned her medical degree from the University of Minnesota Medical School and completed her residency at the University of Minnesota Hospitals and Clinics.

This article was reprinted with permission from VeryWell Health as originally published on November 18, 2019.

"Friendly people, understanding of all things we go through and its good."
~ Jack H.

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*The heart of a volunteer is not measured in size,
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to make a difference in the lives of others.*

Here is a kaleidoscope of some of the AMAZING people who are giving and receiving the many benefits that help heal and give hope to so many. Your unwavering effort is essential to oral, head and neck and cancer patients who are being challenged every day.



SPOHNC knows and understands the value of your support and that you, as a volunteer, are the backbone of the organization. You bring light and love to many who are overwhelmed with the challenges they are enduring.

Gifts come in many different packages and SPOHNC's Chapter Facilitators, Co-Facilitators and NSVN volunteers are an everlasting gift. Your inspiration has given many the gift of life to go forward and experience beautiful days ahead.

Thank you
for making a difference...
Together WE Heal!



Our Best Wishes for
a Loving, Joyful and
Healthy Holiday
and New Year!



Chapter Holiday Wishes *from the desk of Amy Beilman, SPOHNC Palm Coast, FL Chapter Facilitator*

Everyone,

If you were NOT at our holiday meeting you missed one of the best holiday meetings in eight years. We laughed and laughed. It was almost like everyone there needed to laugh. It's been quite a year...for so many of us so being at a comedy support club was just what the Dr. ordered.

The funniest part of the meeting, besides trying to figure out how the gift exchange would work, was listening to everyone's "if you had one wish for 2020 what would it be?" The two rules were you can't wish for good health, because that was a given AND you can't wish anything for politics (to prevent any foul language or name calling). It had to be something else, big or small. Here is a sample of some of the things people wished for.....

The first wish was from Tom, who wished he could win POWER BALL We all really hope he gets his wish because he committed to giving SPOHNC 10% and also, he said he would share a lot of it with everyone that was there that night. (Let's see, \$100,000,000 minus 10 million to SPOHNC leaves plenty to go around.)

His wife Kathy has been wishing the same wish for the past twenty years, and it still hasn't come true. To lose 20 lbs. Dee wanted her son to move to Florida. Charlie wants a new healthy granddaughter next year. Although there was no politics allowed, Marti wanted world peace. That passed.

John wishes everyone could do a better job of helping their neighbors out. Sue wished that John would stop helping his neighbors out and take some time to travel. (-:

Steve wanted his adult kids to continue to do well in their workplace environment. Angela said that there are oodles of celebrations coming up in 2020 (important milestones, birthdays, etc.) and she wishes for enough energy and strength to get through it all. Scott wants to "get through" the next few months.

Joy hopes she gets some more time off. Gloria is hoping to hit it big in Vegas...her kids are taking her for Xmas. Same deal goes, she'll split with all of us. Other people wanted more time to travel, and Pam wanted Don to take more "big" trips. Heather wishes that she can continue to be generous.

Al wanted to be able to get out of the house more, and see more of the country with his wife. Pam or Don wanted good weather...(as in no bad hurricanes, probably) Lewis is wishing that the Dolphins would AT LAST have a winning season.

I can't remember each and every wish, but you get the general idea.

**MAY EVERYONE'S WISHES
COME TRUE.**

Happy Holidays, and Happy Healthy New Year. See you in February of 2020.

Lewis and I are grateful to know all of you and to know that we are all still marching is a blessing.

With Love,
Amy and Lewis



Winter

Okie Howe

On a bright winter day right after it snowed
I'm off on my skis up the Old Mountain Road
I'll rest on a log at the top of the hill
And sit still a while- all quiet and still

The woods are so lovely- the snow is so deep
The whole world around me is soundly asleep
I listen and look and there's not a sound
Just the wonder of winter- it's here all around

The sturdy old oak trees and the birches so white
The maples and beeches-the shadows and light
I'm part of it all in my own quiet way
Just looking and loving each bright winter day

My winter wings are my cross country skis
I'll fly or I'll light wherever I please
How lucky I am- I'm alive and so well
And winter's my season, I guess you can tell.

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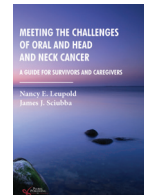
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Chapter News

It is with our sincerest thanks that we share the bittersweet news about some of our SPOHNC Chapter Support groups. Several have been in existence for a very long time... SPOHNC is grateful to each of you for the countless hours of guidance, the extra help and support, the kindness and caring and the difference you have made in the lives of those touched by oral, head and neck cancer. You have made so many cancer journeys just a little bit better...

SPOHNC wishes to acknowledge each and every one of you, and thank you, from the bottom of our hearts.

Valeria Targia, SPOHNC's San Diego, CA Chapter Facilitator shared with SPOHNC that after 19 years of support, she would be retiring. Valerie has been an asset to SPOHNC, and the patients we both serve. She also volunteers for our National Survivor Volunteer Network matching program.

Valerie has served on committees, attended conferences and we're sure she kept a lightness to her group, given her great sense of humor. Valerie told us that "It's been a long and rewarding journey, and I appreciate all the help I got from SPOHNC."

We will miss your group, Valerie, but we are so happy that you will continue to help others who are just beginning their cancer journey, through our matching program. We will call upon you often! We will also take you up on your offer to write an article about the experience of running a support group. You can't get away from us so easily!

Rhonda Hjelm, MSN, RN, OCN, the SPOHNC Newport Beach, CA Chapter Support Group Facilitator, has decided it is time to enjoy some leisure time, and time with family and friends. As an oncology nurse, Rhonda had a unique perspective and a wealth of professional knowledge, which undoubtedly helped her to provide hope to those in her group. Rhonda will be missed, but has left the group in capable hands, who will continue to provide support to those seeking caring hearts along their cancer journey.

Aundie Werner, SPOHNC's Santa Maria, CA Chapter Facilitator, shared the news of her retirement. Her group has been in existence since 2009. Aundie has been a steadfast supporter of so many patients, survivors and caregivers through the years. By sharing her compassion, and materials provided by SPOHNC, Aundie has been as asset to those who seek hope and healing through the camaraderie of a support group.

Gwen Paull began her journey as SPOHNC's Cleveland, OH Chapter Support Group Facilitator 12 years ago, in 2007. Gwen has spent many years providing a listening ear, a caring hand and an open heart. Gwen explained that at this time, additional demands of her position at Cleveland Clinic have necessitated the close of the Cleveland SPOHNC Chapter Support group. We are all saddened by this news, as Gwen has been a crucial part of our SPOHNC family for such a long time.

SPOHNC wishes to thank each of you from the bottom of our hearts for your years of devotion, dedication and for the blessing of your kindness toward those who have come to you seeking compassion, hope and healing. We hope that you will continue to keep in touch with SPOHNC, and perhaps we shall all meet again at a future celebration.



TOGETHER WE HEAL



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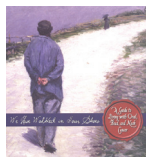
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A Recipe
and Resource Guide
for Coping
With Eating Challenges***

compiled by

*Nancy E. Leupold, Survivor,
Founder and President Emeritus*



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***Delightful December Dishes from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”***

Compiled and Edited by Nancy E. Leupold, Survivor, Founder & President Emeritus

Mushroom, Leek and Fontina Frittata (from Volume One)

2 Tbsp. olive oil, divided
2 medium leeks, whites and pale green parts
only, chopped
8 oz. cremini (baby bella) mushrooms, thinly
sliced
12 large eggs
½ c. crème fraiche or sour cream
2 Tbsp. Coarsely chopped flat leaf parsley
¾ c. shredded fontina cheese, divided
Kosher salt
Freshly ground pepper



Place rack in upper third of oven. Preheat to 350. Heat one tablespoon oil in 10 inch non-stick ovenproof skillet over medium heat. Add leeks and cook, stirring often, until softened, about 5 minutes. Add mushrooms and cook, stirring often, until softened and all liquid has evaporated. Meanwhile, whisk eggs, crème fraiche and parsley in a large bowl. Mix in ½ cup of cheese. Season with salt and pepper. Increase the heat to medium-high and add remaining tablespoon of oil to the skillet. Pour the egg mixture over the vegetables, shaking the pan to evenly distribute mixture. Cook the frittata, without stirring, until the edges begin to set – about 5 minutes. Sprinkle remaining cheese over eggs and transfer skillet to oven. Bake frittata until golden brown and set – about 25 to 30 minutes. Serves 8. 224 calories/serving.

~ Susan C., NY

Custard Bread Pudding (from Volume One)

3 c. milk, scalded
¼ c. margarine
½ c. sugar
4 slices bread, cubed
3 eggs, beaten
1 tsp. vanilla ¼ tsp. salt
¼ tsp. nutmeg or cinnamon



Mix margarine, sugar and cubed bread with milk and let set 5 minutes. Add beaten eggs, vanilla, salt and nutmeg or cinnamon. Put into a 1 ½ quart baking dish. Set dish in pan with 1 inch water in pan. Bake in a 350 degree oven for 45 to 50 minutes. Yields 6 (5 ounce) servings. 287 calories/serving.

~ Bernice A., IL



Make a Difference. Give a Gift Today.

Time for Sharing... My Gift in Disguise

Beyond my cure, the greatest gift has been the opportunity to experience a new side of life and to be able to share it with others.

~ Robert H. Miller

I am young until I am not. One day I look in the mirror and realize I am growing older--my body and face no longer emanate grace and youthfulness. As my life evolves, I am learning the importance of hope. I am hoping that my wife, Colleen, and I will continue to enjoy good health and our family, our Lake Michigan house, and a glass of wine

together as we grow older. Life is definitely not standing still, and memories surround us everywhere we look. Silence reigns in our home where our children once were. Yet we fully

understand how lucky we are to have raised five successful kids who, in turn, have presented us with five precious grandchildren.

But life takes an entirely new turn in 2016 when two devastating almost back-to-back medical issues knock me to my knees. For the first time fragility and mortality appear in my field of vision.

My travels to faraway places for my photo-journalism career have given me priceless insights into human lives different from my own.

Seeing others through my camera lens has been like receiving a personal gift from a stranger.

Traveling to the remotest parts of the world has taught me that fragility and mortality are intermingled. Extreme poverty coupled with illness is sad and hard to see. One person is diagnosed with leprosy roughly every four minutes in India. If you are suffering from leprosy in India all you can look forward to is insolation, loneliness, and, eventually, death.

While on assignment in the tiny village of Sefhare, South Africa, I saw evidence of how AIDS has affected this village of 5,300 people. In 2014, in one week the

local cemetery dug fifty gravesites. Entire families in Sefhare were destroyed, their children orphaned.

My awareness of the problems of those in the wider world mentally prepared me for what was to come, helping me move beyond self-pity. It also gave me the strength and mental willingness to stop asking over and over again: "Why has this happened to me?" Today I ask myself: "Why not me?" I now realize I am as susceptible to all the same diseases and issues as everyone else. I now understand it is how I choose to look at problems and, most importantly, how I accept the difficulties that are placed before me.

Mortality often confronts us when we least expect it. For me, it began in 2016 while traveling in India with my youngest son, Patrick. I developed a severe intestinal infection brought on by a waterborne bacteria. I thought it would resolve itself with the proper medication as most intestinal infections do.

A month later, safely back home in Michigan and under expert medical care, my condition was not improving. My disease was now resistant to antibiotics. I was fighting a real enemy, and each day was worse than the day before. My fight would last two and a half years until, with the help of a specialized medical team, using every medical treatment available to them, I finally won my battle. It had taken three major surgeries, five additional procedures, and some of the most potent antibiotics in existence to rid me once and for all of this menacing infection.

This health challenge resulted in a new attitude forged from my past global experiences. It is incredibly hard to stay positive when faced with a major illness, but I focused on my goal of a complete cure.

Keeping a daily journal helped me as did my photography skills. They put me on the road to a positive space, providing the clarity and knowledge to help me see how I was improving. I was able to define and cope with a situation that had an end result I could not see. Out of journaling came the words and feelings to craft my personal statement below. It now serves as a cornerstone for me

in facing other life-challenging situations. "What does it take to win a challenge? If you run your kite before the wind, you can't take off. You have to turn into it. Face it. The challenge you push against is the very force that lifts you."

Then, as often happens in life, when one crisis ends another begins. Sooner than I could possibly have expected, I was once again forced into thinking about my mortality. It had only been a four-month break.

On October 26, 2018, at 9:36 a.m., I received an entirely unexpected and highly personal gift.

Slightly larger than an American dime, this gift's most interesting aspects included an irregular shape, an uneven texture, and a random color pattern. The gift was accidentally discovered by my dentist and then confirmed by numerous doctors after they analyzed multiple imaging tests and two neck biopsies. The process of locating the site where my stage four squamous cell head and neck cancer* originated reminded me of a childhood fortune hunt. Only now the hunt focused on me and my misfortune.

Once the tumor was precisely located, I knew it was big trouble, and I was scared. But I chose to remain positive and move forward. As I sought to better understand my cancer, I began to perceive some interesting benefits it might offer, and soon I developed a new perspective. I began to realize that my gift might have good, if hidden, aspects. Either way, cancer was about to unquestionably change my life forever. It was time to focus on the positives.

And so it began. I rejected the bad, the scary, and the unknown, focusing my efforts on one positive thing after the next. Yes, the negatives were all there staring me in the face day after day, but I refused to allow them to control my life. I began to sense a new level of love and appreciation from my family and friends. Slowly my feelings recalibrated, and now I understood with a new intensity how precious life is and that each moment truly counts. I also discovered a new level of compassion, understanding, and acceptance toward others and, most important, toward myself. It also changed the ways in which I view life's challenges. My faith has been enhanced, and this gift has

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given me a keen, focused approach to my days. I only wish I had attained this level of personal introspection long ago.

I even learned things I never knew before. My vocabulary grew, with many new words, most of them complex and scientific. I am now confident participating in conversations about science, technology, and medicine. My friends are astounded.

I also gained exclusive access to a special place that was so visually stimulating to me and high-tech that I marveled at the design each time I entered that room. The gracious and highly trained hosts tasked to guide me through my radiation treatments led me to my special place, where they encouraged me to relax and put myself in a restorative position similar to a yoga pose. I was encouraged thirty-seven times to lie down for that special savasana session. This luxury occurred five days every week over seven weeks.

I also qualified for free therapeutic massages from an expert, when I needed them most, and I had access to an excellent nutritionist. I learned how to make nutrient-packed 2,000-calorie smoothies and was encouraged to drink them as often as possible. I became a bit of a snob, imbibing in San Pellegrino nonstop.

Best of all, I was encouraged to take naps every day and relax as much as possible. How quickly I understood the focus was all on me! I couldn't go wrong with a highly trained and motivated support team whose only concern was for me and my well-being. After years of traveling the world for my work, I can say the attention I was now counting on was superior to any hotel concierge service.

This gift kept right on giving. Every day challenged, inspired, motivated, and humbled me. Able to express my emotions, I learned that crying privately was not a bad thing. I was blessed to have the love and support of Colleen and our children and grandchildren. Everyone rallied around me. My life took on new meaning and purpose...unexpected and positive.

Naturally I had challenging days. Truthfully, my treatment was beyond brutal—almost tortuous—but it was worth the pain. But the backstory of being a cancer patient has allowed me to grow personally, altering my life in ways

Chemotherapy and its side effects became the true life test, shaking me to my core. Thankfully, steroids and anti-nausea drugs lessened the effects. Chemo pushed me into a world of confusion and fog. My sense of time seemed out of sync. I developed a love-hate

relationship with my chemotherapy. I define the love part as being able to fall sleep at a moment's notice, knowing that conserving my energy would help fight off disease. The hate side of chemo was the way in which it made my body feel electrified and jumpy, causing frequent waves of nausea to wash over me like a tide during a storm. I also lost all taste for food—it was horrible, now something to avoid.

It was humbling to lose my sense of taste but interesting as well. I am thankful for the experience because it has taught me to appreciate the simple pleasure of eating and tasting food. It also pulled me closer to the many people living in extreme poverty I have photographed around the world. Often they are faced with eating whatever they can find in order to continue to exist. I have food and plenty of it, but to me it is tasteless, repulsive, and sticky, with no purpose in my mouth. In contrast, poor people either have nothing to eat or have no choice but to ingest bugs or worse.

My doctors explained that this problem will improve over time, perhaps taking a year or more. So far I have recovered 30 percent of my ability to taste. Swallowing was a totally different animal. Six weeks into my radiation, with seven more treatments to go, I hit the wall. My pain level rose to a ten, and I could not swallow anything. Dealing with this much pain was impossible. I crouched on the floor, my body rocking back and forth, while desperately trying to sip water and Ensure. Each breath and swallow felt like a thousand shards of glass were being pushed further into my throat. I spent three days under palliative care with IVs for hydration. Gone was the morphine that had ceased to work. I now had a fentanyl transdermal patch to get my pain under control. This was supplemented with dilaudid transmitted through my IVs every four hours. I came home with the fentanyl patch, the dilaudid, and Tylenol and Motrin around the clock.

Four days after being discharged by palliative care I slipped and fell on ice, lacerating my kidney. Soon I was back at the hospital for a CT scan and further tests. I was hospitalized for another three

days while my kidney stabilized.

Thankfully I was soon back home. This mishap offered another insight into how fragile life feels when your health is precarious.

I hope you now understand the positives and negatives of receiving the gift of stage four squamous cell HPV head and neck cancer. The treatment from my amazing medical team worked, and today—cancer free—my prospects are bright.

Cancer is now a permanent part of my legacy and knowing this I plan to remain in control of my cancer—I am determined that it will never control me.

Beyond my cure, the greatest gift has been the opportunity to experience a new side of life and to be able to share it with others.

As for fragility and mortality, I know they are always going to be there, but I am moving away from both, at least for now. It's not my time. But I'm grateful to have been forced to confront what is inevitable in life.

What I hope to impart is that the next time you are surprised by an unexpected and challenging event consider that it may be a gift in disguise.

~ Robert Miller
robert.h.miller@me.com



***Snowflakes
are one of nature's
most fragile things,
but just look
what they can do
when they stick together.***

~ Vesta M. Kelly

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Chapter Facilitator Highlights

SPOHNC Salutes Polly Ubben, Lincoln, Nebraska SPOHNC Chapter

Recently, SPOHNC was contacted by Scott Weiskamp, who is an attendee of the SPOHNC Lincoln, Nebraska Chapter support group meeting. You may remember Scott for his unique Animal Run fundraiser last year, which benefitted SPOHNC. SPOHNC loves to hear news from our Chapters, so we wanted to share it with you, our readers. This is such a wonderful way to express gratitude! SPOHNC appreciates ALL of our Chapter Facilitators and Co-Facilitators. Thank you for all that you do!



Here's the e-mail that got the "snowball" rolling...from Scott.

FYI. A possible article in one of your newsletters might be about Polly Ubben, our SPOHNC Facilitator, and Speech Therapist. She is truly an amazing person, that shows by how much she cares for each of us. Not just as a client/patient, but as an individual. She is constantly bringing in speakers to educate, encourage and provide information for pre, current and post treatment patients. I've always considered her as one of my "angels" that got me through oral cancer. ~ Scott W.

Scott asked the other attendees of the group to share their thoughts about Polly – and this is what happened! We're certain more will roll in after the publication of this issue, so here is a sampling!

I'm sure many of those who have had their lives touched by Polly would agree she is a true angel. It is hard to define her mission and my suggestion would be: come see her, listen to her, watch her with patients, and the short time with our group and I am sure you will understand how caring for others defines her being.

~ Ken F.

Polly Ubben is a great therapist, leader of our SPOHNC group and a good friend. She is always there for us whenever we need help or answers about something. You can email or call and she always gets back to you

in a timely manner. She will even return emails outside of her working hours. I have learned a lot from the guest speakers and other attendees at our monthly meetings. She stays informed about all the things that are new in her field and tries to help everyone that she can. I would just like to say a big thank you from me and everyone else that she has helped. She is definitely one of a kind and after going to numerous therapists, I know that I am with the best one

out there.

~ James H.

I had/have Polly Ubben help me recover from cancer in the base of my tongue. She helped me swallow better and befriended me as well as inviting me to join a growing group that meets monthly to help each other recover and even thrive after cancer. She is one of my heroes. Her commitment to her patients is not a job it's a calling. She's all in, and we're all in with her.

~ Brad B.

Polly Ubben organized our SPOHNC chapter two years ago, and she is the reason for the success of our group. She has done a terrific job of lining up informative speakers to address our group, in addition to her time spent researching the latest developments in oral, head and neck cancer treatments and procedures. Her warm smile and positive attitude are very uplifting! I know we don't say this often enough - Thank you Polly for all that you do!

~ Les L.

I've known Polly even before I had my laryngectomy in 2009. She has always been available when I had a need. She recently went out of her way to be present when I had to have a swallow study and has helped me through many other trying times. Life would be much more difficult without her help. Thank you Polly.

~ Angie

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Merry Christmas and Happy Hannukah from SPOHNC!



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*"Thank you all for being
there for me for the past 5
years with love and support."*

~ Denise L.



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