The Season of Spirituality

Reverend Sue Wintz

Did you know that several major religions and cultures celebrate during the month of December? While we may think of only the Christian holiday of Christmas and the Jewish celebration of Hanukkah, there are also observances being celebrated by those from Buddhist (Bodhi Day), Hindu (Pancha Ganapati), African-American (Kwanzaa), Native American (Soyal), and Chinese (Yalda) traditions just to name a few. While the traditions may be different, each of these celebrations focuses on common themes: feasts, gift-giving, families, giving thanks for the past year and looking forward to the new one.

In all communities, families, and lives there are things that are important at this time of year. Maybe it is gathering around a meal or taking part in an event such as a religious service, or going to a play or concert. Alternatively, perhaps we find joy or comfort in reading familiar words or listening to music quietly by ourselves. Sometimes it’s formal events and at other times it is simple rituals that we have come to identify with the holidays.

An example from our own family:

When our children were young, and throughout their elementary school years, my husband and I were co-pastors of a church congregation. Being a semi-large church, there were always two services on Christmas Eve. Because we lived across the country from our extended families and were unable to be with them on the holidays, our children would be with us throughout the Christmas Eve extravaganza, coming to the first service and then playing in our office during the second.

Between the services, one of us would run down the street to buy dinner for them from McDonalds, which was a special treat for them since they didn’t get it very often. While our children loved all the holiday traditions including the church service, it is not surprising that for them, McDonalds was one of the highlights of Christmas Eve. They associated it with the magic of Christmas and being together as a family. To this day, our son, who now has a family of his own, insists that the Christmas Eve tradition of McDonalds continue at our home to bring that touch of magic to his own children.

Whether you identify with a religious or cultural group or you find your sense of spirituality and meaning in other ways, the holiday season invites you to take the time to reflect on the things that mean the most to you. While some of your traditions may be more formal than others, the key is discovering what it is that brings us that sense of magic, connectedness, or peace. Whatever it is, like our McDonalds Christmas Eve dinner, it is not so much the event itself (or the hamburgers) but rather the feelings and memories the tradition evokes.

The other key thing to remember is that not all the events or traditions of the holidays need to be big. While all of us enjoy times spent with loved ones or participating in large events or services, sometimes it is the smaller observances that bring us joy.

I grew up in the Midwest and I remember one of the traditions of my German-speaking grandparents was to place a candle in the window of their farmhouse despite the fact that their nearest neighbors were over a mile away. When I asked why they did that, my grandmother told me that it was a symbol of inviting Mary and Joseph into their home on that long ago night when they were looking for shelter. It also, she explained, was a way of demonstrating that they were waiting to welcome family and friends. To this day, we keep an electric candle in one of our front windows that we turn on each evening and during the holiday season we have one in every window of our home.

I also learned from my grandmother to write down the story behind every ornament and decoration we have. So often, we have special items that we bring out during the holidays that have a story behind them, but the stories aren’t always passed on. When I got married, my grandmother gave me a journal to keep track of the items and memories that she said would become important as we started our own family. Every decoration our children made and each item we bought all of which remind us of an important event or feeling has been written down in that same journal for the past 33 years. It is a legacy and a gift that will be passed on to our own grandchildren.

Maybe you find yourself at the low end of the energy scale this year, but that does not mean that you cannot find a sense of joy in the holidays. Even when we cannot be part of big events, there are things we can do to embrace our sense of spirituality, religious, or cultural beliefs.
SPIRITUALITY continued from page 1

- Intentionally look for the small, often overlooked parts of the season. This in itself is a spiritual practice. You may find yourself noticing things that you were not aware of before.

- Take part in the observances that you can and do not worry about the rest. This is just as true for our religious and spiritual observances as well as the other celebrations that we take part in. Do only what your energy allows you to do.

- Create your own religious or spiritual rituals and observances. This can be as simple as listening to music or lighting a candle to reading some of the religious, spiritual, or cultural texts, alone or with others, that are appropriate to the holiday.

- Instead of worrying about how you are going to buy gifts for others, think about a gift that you can give that won’t take an enormous amount of energy. One example is the sharing of traditions, like the way my grandmother taught me to write them down. You will be surprised how meaningful it is to the recipient when you share with them even one.

- Write. Whether you choose to write down memories of holiday celebrations, reflections on your current celebration, illness journey, or messages to loved ones, it can be amazing what putting those thoughts down into words can do for our spirits and for others if we choose to share them.

The other thing that needs to be acknowledged and not overlooked is that it might be one of those years when one feels that there is nothing to celebrate. Not only is energy at the low ebb, but also so are our spirits. If this is happening, the most important truth to realize is that it’s okay. If you find that our “dark night of the soul” is taking too great a toll on you and your loved ones, then it is time to reach out for help to a religious leader or spiritual counselor. One free resource if you do not have someone to turn to is HealthCare Chaplaincy’s Chat with a Chaplain, which can be found at http://www.chatwithachaplain.org. It is staffed by professional chaplains who do not impose a particular belief system on you or tell you what you should believe but rather help you identify the beliefs and values that are important to you and walk beside you as you seek to find meaning.

The holidays are a wonderful and magical season filled with family, loved ones, celebrations, events, and times of joy. This year, find ways in which you can focus on bringing that celebration to the spirit: your own and those around you. Look for ways to name the things you are thankful for no matter how small. Best Wishes for Happy Holidays.

Editors Note: Rev. Sue Wintz is a board certified health care chaplain with over 30 years of clinical, administrative, educational design, development, and teaching experience. She is a Director, Professional and Community Education at HealthCare Chaplaincy Network in New York, a non-profit health care organization that helps people faced with the distress of illness and suffering to find comfort and meaning.
“Nurse Ratchet Tips”
compiled by Amy and Lewis Beilman - Facilitators,
SPOHNC Palm Coast Northeast Chapter Support Group

The following is a list of tips for caregivers, compiled by the members of our SPOHNC support group. Being a “Nurse Ratchet” for an oral/head/neck patient brings its own special challenges. Hopefully these will help out the new patients’ caregivers.

• **BECOME THE PATIENT’S ADVOCATE** (Everyone agreed that this one role was the **MOST important**).

• Learn about products that are helpful in soothing radiation burns, such as Eucerine and Radioderm and Miaderm...and other products like the Wedge pillow to help a patient sleep better after treatment stops.

• Try to communicate to all the other family members/friends who need to know "what's happening". Try to do it in one swoop, such as an email to everyone, or ask others to call others to help save your energy.

• Just being a caring loving partner is sometimes enough.

• Write everything down....including reactions to certain drugs, etc.

• Remember that one more treatment is one less treatment "to go".

• Be a cheerleader whenever you're able to.

• Use soft cotton t shirts during treatment period.

• Don't be afraid to "kick the patient's butt" (when and if they need it).

• Keep a journal of how you're feeling - try to do it daily/nightly. It helps you see the progress.

• If patient is on a lot of meds, draw up a clock, and mark off around the dial what needs to be given at what time. Tape the clock where you can see it.

• Stay occupied with normal life activities whenever possible. It's helpful emotionally and it distracts you from “cancer” 24/7.

• Don’t be afraid to seek a second opinion.

• Always try to have the Doctor's appointment together. Two sets of ears are better than one.

• You don't get special training to become a "Nurse Ratchet". It just happens and somehow, if you keep positive, and you keep taking care of yourself, and live one day at a time, you will march through this journey.

~ Amy & Lewis Beilman
atwil001@msn.com

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If you have tips, tricks, recipes or ideas to share with your fellow survivors, patients, caregivers or family members, please feel free to send them to SPOHNC at info@spohnc.org.

We’ll be happy to share them with our readers in an upcoming issue of the newsletter.

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**“Thanks so much for all the information. Thank goodness organizations like yours are available for those who need the help & a big “dose of uplifting.”**

~ Jan C.
From the Executive Director... Honoring the Spirit of Survivorship

In the spirit of the season you will find snapshots of SPOHNC’s “Family of Faces,” here in our December issue. We asked you to send in your selfies and we were so grateful to receive an overwhelming response from people throughout the country.

SPOHNC’s “Family of Faces” represents our community of Oral, Head and Neck cancer survivors who are a part of our Chapters and National Survivor Volunteer Network, as well as members celebrating their survivorship and resilience.

It is the time of year when everyone hopes to celebrate the joy and promise that survivorship brings to one diagnosed with cancer. Our strengths come from being able to support one another. We know and understand that anyone diagnosed with this disease endures a battle unlike any other.

You have experienced the challenges and successes of many who were diagnosed, and you’ve also celebrated the survivor in everyone.

It is our pledge to always see the same vision of light that was given to you when you reached out to find someone who has walked in your shoes. Your survivorship means not only surviving the disease, but also going on to live a fulfilling life. You are our celebration of hope and healing.

SPOHNC also wishes to thank all of our volunteers who participate in SPOHNC’s Outreach Program through its Chapters or National Survivor Volunteer Network. You continue to lift the hearts and souls of those who are in the midst of their struggles with this disease. You have given them the inspiration, comfort and wisdom to go forward. You have given many the ability to thrive throughout their treatments and beyond. Cancer comes and teaches us so much, including what gratitude really means. With this support a survivor can go on to know that they are not alone in their fight. Each one of you plays an important role in one’s journey with this disease.

As SPOHNC volunteers, you give the ultimate gift of your time, generosity and assistance, and we are extremely grateful for you.

From your family and friends at SPOHNC we thank you for your many talents of giving. SPOHNC honors survivorship this season and for all seasons to come.

May this coming holiday bring you, your caregiver and loved ones all of life’s beautiful blessings...good health, joy, love, promise, happiness and peace for a lifetime to come!

Fondly,

Mary Ann Caputo and your family at SPOHNC

Through the Lens

In recent issues of News from SPOHNC, we featured some of the hobbies of survivors who attend our SPOHNC Chapter Support groups. We hope you’ve enjoyed the interests we’ve shared. Through sharing those interests, we also discovered that our survivors aren’t the only ones with hobbies. Guess who else enjoys hobbies in their spare time?

SPOHNC’s Board of Directors plays an active role in the governance of our organization. Their support and the time they give to SPOHNC is invaluable. When our Board of highly respected professionals isn’t working, or supporting SPOHNC, what do they like to do? We asked them, and here’s what we found out...

Board Vice President James J. Sciubba, DMD, PhD, who was instrumental in the founding of SPOHNC and has a long and deeply committed history with the organization, has enjoyed a very fulfilling interest in photography for 20 years. Dr. Sciubba is an avid photographer – taking many photos of nature and other beautiful subjects. He shared with us that in the past 10 years, he has further developed his interest, now doing his own prints and photo enhancement, “both of which are great fun and provide a nice diversion.”

Some of Dr. Sciubba’s wonderful work graces the halls of the Milton J. Dance, Jr. Head and Neck Center at the Greater Baltimore Medical Center, where Dr. Sciubba is an active consultant, and Johns Hopkins University School of Medicine. He also has a private practice in Oral Medicine and Oral Pathology in the Baltimore area.

Dr. Sciubba recently shared some of his photos with us. Both were taken during a Winter trip to Maine about 3 years ago during a very cold spell. Dr. Sciubba said of his trip “my photo friend and I had a great time and avoided frostbite injury.” We wanted to share his gift with you – after all – “tis the season of giving!

Snowflakes are one of nature’s most fragile things, but just look what they can do when they stick together. ~ Vesta M. Kelly
A TIME FOR SHARING...An Abundance of Blessings

I wrote my last article a decade ago (April 2004). I was a 34-year-old tongue cancer survivor and am now a 47-year-old recurrent tongue cancer survivor. I thought this would be an excellent time for an update and review of what I have experienced and learned over the last decade. At the time of my original diagnosis I could not find a single reference to a 10-year survival rate. All numbers regarding survival referred to only three years or -at the most- five years. The five-year survival statistics were quite grim and difficult to read.

It is with great joy, gratitude, and abundance of blessings that I write this update. Mentally and spiritually I feel more focused and more blessed and more present in the moment than at any other point in my life.

Since my diagnosis I have been through many changes and challenges with life and career. I have moved to a new city. I have experienced a five-year faculty position in academia. I have achieved a finance MBA from a competitive business school. I have adopted two children from different countries. I helped to start a new service line in our hospital network, which is growing and thriving. I tell you this not to impress you but rather to impress upon you that there is indeed, without a doubt, life after cancer. I recently attended a SPOHNC support group meeting. It was with delight that I shared information, experiences and feelings with several newly diagnosed cancer survivors. After hearing, seeing, and feeling both the resolution and the fear of the newly diagnosed I was galvanized to share my thoughts here.

In my last article a decade ago I mentioned the transformatory aspect of cancer upon my life. I cannot stress those changes enough. When looking back the mental, physical, and spiritual changes have been overwhelmingly positive. I am not saying I would wish the cancer experience on anyone. I am also not saying that “everything happens for a reason” although many would conclude that. I am rather illustrating that one can make something good out of even the most horrible life event.

I live with greater focus and awareness. I use meditation and mindfulness as a way of life. I have now a palpable empathy and understanding of the plight of other humans that I did not possess prior to my cancer transformation. I am now in much better physical condition than I was a decade ago. My lab tests are excellent. I routinely complete half marathons each year, despite an absence of prior athletic activity. I have more energy, strength, and clarity of thought than I ever thought possible. I also implement choices on a daily basis that reduce my risk of another recurrence. It has been over five years since my recurrent cancer.

Some of the changes that I recommended a decade ago need to be modified. For example, I do not recommend vitamin E or vitamin A supplementation as they have been shown to cause more harm than good. On the other hand, science has shown us many avenues to modify our risk. Some of those changes that I have made have – in my opinion – allowed me to live and thrive this long. I will list them briefly here in hopes that they may encourage someone else to help themselves and feel less helpless when facing this dreadful disease.

- I drink two or three cups of hot green Japanese tea (steeped 8-10 min) every day.
- I add turmeric (with black pepper for better absorption) to my food when possible. It adds flavor to soups omelettes, vegetable dishes etc.
- I choose foods with a lower glycemic index. I substitute agave nectar for honey. I reduced my intake of white rice and refined flour products. I avoid sweets between meals, but readily enjoy the anti-cancer effects of dark chocolate after a meal.
- I take a baby aspirin every day to reduce inflammation. I started taking a fish oil (omega-3 fatty acids) capsule daily as well for the same reason. Inflammation has been found to be a significant mechanism for cancer growth.

- I avoid alcohol, which is a known carcinogen, in any quantity. For those who must continue drinking a review of the evidence would support drinking red wine with meals (especially pinot noir).
- I drink a glass of pomegranate juice daily.
- I avoid red meat and limit other meat quantities in my diet.
- Eating a wide variety of fruits and vegetables and whole grains is an enjoyable and effective means of reducing your cancer risk. There are many fruits and vegetables with proven anti-cancer benefit including, but not limited to: shiitake or maitake mushrooms, cruciferous vegetables, yams, carrots, cooked tomatoes, avocado, citrus, black raspberries, blueberries, cherries, plums, peaches, nectarines.
- Exercising regularly and managing stress well reduce the cancer threat too.
- Attend a SPOHNC support group if there is one in your area. This helps with emotional support, education and likely actual survival rates.
- I limit cell phone radiation. Choose a low SAR phone (see www.ewg.org) and communicate using speakerphone, Bluetooth, or text.
- When I eat chocolate, I try to stick to dark (less than 70% cocoa) rather than milk chocolate.
- Consider having your doctor check your 25-hydroxy vitamin D level and supplement if low.

continued on page 9
Welcome to a special feature - honoring YOU.
We invited you to Send Us Your Selfies – and you did!
In Celebration of Survivorship - SPOHNC is excited to share
our “Family of Faces!”

Visit the SPOHNC website at www.spohnc.org
Connect with SPOHNC’s “group” on Facebook
Although I am sure that some remain skeptical of the science behind these recommendations. Others feel that this program is too austere. My response is only that the evidence supports these recommendations at this time and that following them is a choice that reduces my own sense of helplessness. This is a highly individual choice.

I do not judge those who make other choices. Nevertheless, for those who are looking for ways of becoming more active in supporting their health and reducing their cancer risk, I recommend these changes.

No person could implement all of the changes at once and maintain them over time. What worked for me was learning more about the scientific evidence for each change and then implementing only one change at a time very slowly. Making one change every six months or one change every year is a very reasonable and doable option.

For those who would like more information I recommend an excellent book called Anticancer: a New Way of Life by David Servan-Schreiber, MD, PhD published by Viking Penguin in 2009. As for me, I show no signs of slowing down or succumbing to cancer. I do not take my time for granted and will live with as much quality and quantity of life as our Dear Lord will allow for me. I hope to grow, learn, love, and share for decades to come.

God Bless - To your health!
~ Brian Foley
bsfoley@gmail.com

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HEAD AND NECK CANCER NEWS
New Discovery by UCLA Researchers Could Lead to More Targeted Head and Neck Cancer Therapies

UCLA scientists have discovered for the first time that a protein usually linked to rare neurological disorders is also associated with human papilloma virus (HPV) positive head and neck cancers. The protein was also shown to help improve the effectiveness of chemotherapy treatments, laying the groundwork for the development of more specialized therapies.

Head and neck cancer is the sixth most common form of cancer worldwide, and represents five percent of all cancers diagnosed annually in the United States. Of the more than 42,000 head and neck cancer cases diagnosed each year, 12,000 will die from the disease. HPV is the most common sexually transmitted infection, and diagnoses are at epidemic proportions, with an estimate that nearly all sexually active men and women will get it at some point in their lives.

Led by Drs. Eri Srivatsan and Marilene Wang, UCLA Jonsson Comprehensive Cancer Center members and co-authors of the study, researchers found a link between the protein gigaxonin and head and neck cancer while investigating the chemotherapy drug cisplatin. The drug is successfully able to kill cancer cells by interacting with the protein p16 which is commonly produced in HPV positive cancers.

Though HPV has mostly been seen in cervical cancer, over the past several years there has been an increase in p16-positive HPV-related head and neck cancers. These cancers often affect non-smoking younger adults, who previously were not considered to be at high risk for head and neck cancer.

“We studied the interaction of p16 in the nucleus of the cancer cell after treatment with cisplatin, and observed how the protein interacted with gigaxonin,” said Dr. Wang, professor-in-residence of head and neck surgery. “We found it stops the cell cycle, allowing chemotherapy treatment to prevent the cell from growing and killing the cancer cell.”

For the study, Drs. Wang and Srivatsan as well as eight other colleagues at UCLA also analyzed 103 archival clinical samples from head and neck cancer patients to identify the relationship between p16 nuclear expression and cancer free survival. They found that patients with cancers with p16 expression had better survival rates than without p16 expression.

They hope the new findings will lead to an enhanced form of personalized targeted therapy for head and neck cancer patients, ultimately reducing the harsh side effects of chemotherapy and radiation.

“This discovery opens new possibilities in the diagnosis and treatment of HPV positive head and neck cancers,” said Dr. Srivatsan, professor of general surgery.

The study was recently published online in the Journal of Biological Chemistry.

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SURVIVOR NEWS

Jack and Temple Igleburger, Facilitators of the Northwest Arkansas SPOHNC Chapter Support group, recently shared this with us…

Exciting news!! Cynthia Dickson, 2008 Hero of Hope (HOH), and Ronnie Trentham, 2010 HOH, have been selected to represent the U.S. as 2015 Global Heroes of Hope. It’s deserved recognition for the impact both have made far beyond themselves and their own community. They join a group of 31 extraordinary survivors from around the world. Global Heroes are changing the way people talk about cancer in countries around the world. Their hopeful message is lifesaving. By talking about the disease, survivors seek treatment earlier. Associated shame is lessened. Survivors and their caregivers find hope. Lives are saved! Congratulations, Cynthia and Ronnie! Our High Plains Heroes of Hope family is proud of you! Your SPOHNC Family is proud of you also Ronnie; Congratulations from all of us!

Don’t forget to share your good news with SPOHNC. We’ll be glad to shout it from the rooftops!
Send your news to info@spohnc.org, with a photo.

Holiday Brunch Ideas... (from Eat Well Stay Nourished Volume 2)

Challah Bread French Toast

1 loaf Challah bread (day old)
2 to 3 bananas – thin sliced (optional)
5 large eggs
4 c. half & half
1 tsp. vanilla
¾ c. sugar
1 tsp. cinnamon
½ tsp. nutmeg
1 stick butter

Grease a 9 x 12 baking dish. Slice and butter bread. Layer bread in baking dish with banana. Mix eggs with the remaining ingredients. Pour over bread and let stand overnight. Bake at 350 degrees for 40 minutes. Serve with syrup or fresh fruit. Serves 12 to 14.

~ Susan C., New York

Hot Chocolate Super Soy Milk

2 c. water
2 Tbsp. Ghirardelli sweet ground chocolate powder
1 scoop WN Organic Soy Protein Smoothie Mix
1 sprinkle cinnamon and/or nutmeg


~ Sean G., Colorado

“All happiness depends on a leisurely breakfast.”

~ John Gunther

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