

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
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Coronavirus and COVID-19: What People With Cancer Need to Know

Merry Jennifer Markham, MD, FACP, FASCO

The American Society of Clinical Oncology (ASCO) is aware that people with cancer and cancer survivors, particularly those with compromised immune systems, are likely worried about the potential impact of COVID-19 on their health. Patients should talk with their oncologists and health care teams to discuss their options to protect themselves from infection.

What is COVID-19?

COVID-19, or coronavirus disease 2019, is an illness caused by a novel (or new) coronavirus that was first identified in an outbreak in Wuhan, China, in December 2019.

Coronaviruses are a large family of viruses that can cause mild illnesses, such as the common cold, to more severe diseases, such as Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome (MERS). Because the novel coronavirus is related to the SARS-associated coronavirus (SARS-CoV), the virus has been named SARS-CoV-2. The exact source of SARS-CoV-2, which causes COVID-19, is not certain but likely originated in bats.



The virus can spread from person to person, through small droplets from the nose or mouth that are produced when a person coughs or sneezes. Another person may catch COVID-19 by breathing in these droplets or by touching a surface that the droplets have landed on and then touching their eyes, nose, or mouth.

Symptoms from COVID-19 can be mild to severe and may appear between 2 and 14 days after exposure to the virus. The symptoms may include fever, cough, shortness of breath, chills, headaches, sore throat, and new loss of taste or smell. Other symptoms may include aches and pains, fatigue, nasal congestion or runny nose, or diarrhea. In some people, the illness may cause severe pneumonia and heart problems, and it may lead to death. Other people who are infected may not develop any symptoms.

COVID-19 can occur in both children and adults. However, most of the known cases of the disease have occurred in adults. Symptoms in children seem to be milder than symptoms in adults. There have been recent reports of a multisystem inflammatory syndrome in children associated with COVID-19, with symptoms such as rash, fever, abdominal pain, vomiting, and diarrhea.

An analysis of 928 people with cancer and COVID-19 presented during the ASCO20 Virtual Scientific Program revealed that having active, progressing cancer was associated with a 5 times higher risk of dying within 30 days compared with patients who were in remission from cancer.

What can I do to avoid getting COVID-19?

There is not currently a vaccine to prevent COVID-19, although several clinical studies are being performed to develop an effective and safe vaccine.

The most important way to protect yourself is to avoid being exposed to COVID-19. Stay at home as much as possible and avoid areas where people gather. Avoid unnecessary travel, and follow guidance on travel restrictions issued by the U.S. Centers for Disease Control and Prevention (CDC) or the World Health Organization (WHO).

Another critical way to protect yourself is to wash your hands often with soap and water for at least 20 seconds, about the amount of time it would take to hum the Happy Birthday song from beginning to end twice. If soap and water is not available, use hand sanitizer that contains at least 60% alcohol. The best way to clean your hands, though, is through soap and water.

In addition to washing your hands frequently, it's important to:

- Avoid touching your eyes, nose, and mouth.
- If you must cough or sneeze, use a tissue. Then throw the tissue away. Or, cough or sneeze into your elbow rather than your hand.
- Avoid close contact with people who are sick.
- Clean frequently touched objects and surfaces with household cleaning spray or wipes. These surfaces and objects include doorknobs, counters, toilets, keyboards, tablets, phones, light switches, and more.

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Founder
In memoriam

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Some people with COVID-19 have no symptoms and don't know they have the virus, or they may not have yet developed symptoms. Because of this, the CDC recommends wearing cloth face coverings when you are out in public. Cloth face coverings won't necessarily protect you from developing COVID-19, but they can help prevent the spread of the virus in the community. The face covering should cover the nose and mouth. Surgical face masks and N95 masks should be reserved for health care workers because these masks are in limited supply. Remember that wearing a cloth face mask or face covering should not replace social or physical distancing. There is no evidence that taking vitamin C, even at high doses, can help to prevent COVID-19.

Are there special precautions that people with cancer should take?

People with cancer, people who are in active cancer treatment, older patients, and people with other serious chronic medical conditions, such as lung disease, diabetes, or heart disease, are at higher risk for the more severe form of COVID-19 that could lead to death. Recent data have shown that people with active or progressing cancer may be at higher risk than those whose cancer is in remission. The same rules apply for people with cancer as for those without cancer: Be sure to wash your hands well, and wash them frequently. Avoid touching your face, and avoid close contact with people who are sick.

People who are at higher risk of getting very sick from COVID-19 should avoid any non-essential travel during this time of COVID-19 outbreak. In most parts of the United States, a "shelter in place" or "stay at home" order has recently been in effect or may still be in effect. For people with cancer who live in these areas, avoid leaving your home unless it is necessary. For people who live in areas where a "shelter in place" restriction issued by the government has been lifted or is in the process of being lifted, it is best to live as if there is such an order still in effect. Stay at home to reduce exposure to other people. Avoid any social gatherings. If you must leave your home, keep a distance of at least 6 feet between yourself and other people. Only leave your home for essential reasons, such as buying groceries, going to the doctor, or picking up medication from the pharmacy. Wear a cloth face covering or mask, and make your trip out as brief as possible. Another alternative is to have your food and medications delivered, so you do not have to leave the home.

Walking or exercising outdoors is fine as long as the area is not crowded and you are able to keep a distance of at least 6 feet from other people.

Be sure to keep enough essential medications, both prescription and over-the-counter, to last for at least 1 month. Create or update an emergency contact list that includes family, friends, neighbors, and community or neighborhood resources who may be able to provide information or assistance to you if you need it.

In order to stay connected to your support system, connect with your family and friends virtually, through video chats or phone calls. Some examples of technology that can be used for video or other live chats are FaceTime, Zoom, Google Hangouts, and social media platforms, such as Instagram and Facebook.

If you are scheduled for cancer treatments, have a discussion with your oncologist about the benefits and risks of continuing or delaying treatment. If you are not scheduled for cancer treatment

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but are scheduled for an appointment with your oncologist, it may be possible for the doctor to conduct the visit using videoconferencing or telemedicine. Be sure to check with your cancer care team to see if this is recommended for you.

Finally, it is always important to have your health care wishes in writing, in case you are too sick to make decisions for yourself. This way, your family and your medical team will know what is important to you and what your wishes are. If you have not yet done this, now is a good time. Cancer.Net has valuable information on this topic. Because some hospitals and clinics are limiting visitors, and some are allowing no visitors, having your health care wishes in writing is more important than ever. Here are some examples of important questions to ask yourself, to discuss with your loved ones, and to write down:

- What level of quality of life would be unacceptable to me?
- What are my most important goals if my health situation worsens?
- If I am unable to speak for myself, who is the person in my life who I would want to speak for me?
- Who should **not** be involved in making decisions for me?
- If my heart stops, do I want to have CPR (cardiopulmonary resuscitation) done?

Will anything change with my cancer-related medical visits?

Due to the COVID-19 pandemic and the increased risk of exposure to the virus by going out in public, most hospitals and clinics have changed their visitation policies. Some may allow 1 visitor per patient, and others may allow no visitors. Before heading to your medical appointment, check with the clinic or hospital for their current visitor policy.

Your cancer care team may switch some of your appointments to telemedicine. During a telemedicine appointment, you are able to stay at home and visit with your doctor or other health care team member through video conferencing using your phone or computer. Your doctor's office will let you know what system they are using

for telemedicine appointments, and they will give you instructions on how to have your visit this way. If you are interested in having a visit by telemedicine rather than in person, ask your doctor's office staff if this is possible.

Your doctor may recommend delaying some treatments for supportive care, such as bone-strengthening treatments, for example, denosumab (Xgeva) or zoledronic acid (Zometa), or intravenous iron supplementation. They will only recommend delaying treatments if they feel it is in your best interest to do so. Cancer screening tests, such as mammograms or colonoscopies, and other tests, such as bone density tests, may also be delayed to reduce your risk of exposure to the virus.

Oncologists may recommend stretching out the length of time between cancer treatments using medications, such as chemotherapy or immunotherapy. Or they may recommend delaying starting these treatments, based on your cancer diagnosis and the treatment goals. It's important to remember that your oncologist will only do this after weighing the risks and benefits for your situation.

For people who don't have a cancer diagnosis but are at high risk of cancer, such as those with a hereditary cancer syndrome like Lynch Syndrome or a *BRCA* mutation, your doctor may recommend delaying some screening tests or cancer risk-reducing procedures. In general, it is safe to have these delayed for some amount of time. If you have concerns about your particular risk, have a discussion with your doctor about the risks and benefits of delaying procedures.

What should I do if

I think I may have COVID-19?

Call ahead before visiting your health care professional or the emergency department if you have a fever and other symptoms of a respiratory illness, such as cough and shortness of breath. Let them know if you think you may have COVID-19. They will ask you questions about your symptoms, travel history, exposure, and medical risk factors to find out if you should be tested for COVID-19. They will then give you instructions on how to get tested in your community.

A common question I hear from patients is about which doctor to call. I

recommend calling the doctor who you have the most contact with. If you have been off cancer treatment for more than a year and are seeing your primary care provider regularly, you may call your primary care provider. However, if you are seeing your oncologist more regularly or are on active cancer treatment, call your oncologist.

If you are receiving cancer treatment that suppresses the immune system and you develop a fever and respiratory symptoms, call your oncologist as you usually would if you develop a fever while on treatment. Be sure to follow their guidance on when to come into the office or hospital and when it's safer to stay home.

Severe symptoms could be a medical emergency, and you may need to call 911. If you or your loved one has symptoms, such as trouble breathing, persistent pain or pressure in your chest, new confusion, or bluish lips, you should seek medical attention immediately.

Testing for COVID-19 involves inserting a 6-inch-long swab, similar to a Q-tip, deep into the nasal cavity for at least 15 seconds. The swab is inserted into a special container and send to a laboratory for testing. There is 1 U.S. Food and Drug Administration (FDA)-approved at-home self-collection kit for this virus, approved under an emergency-use authorization. This self-collection kit is currently only available to health care workers and first responders who have been exposed to the virus or who have symptoms of COVID-19.

If it is possible that you have COVID-19, you should stay at home and isolate yourself while you are tested and waiting for your test results. Staying home when you are sick is the best way to prevent transmitting the novel coronavirus and other respiratory viruses, such as the flu, to other people. If you live with someone, you should quarantine yourself in one part of the home, if possible, to lower the risk of spreading the virus to the rest of the people who live with you. And again, be sure to wash your hands often.

If you are concerned that you've been exposed to someone with COVID-19, closely watch for developing symptoms. Check your temperature regularly for fevers. If you have active cancer or are currently in cancer treatment, let your medical team

know about your possible exposure. On June

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3, 2020, a study was published in the *New England Journal of Medicine* that included 821 people with no symptoms of COVID-19 who had a household or work exposure to COVID-19. This study showed that treatment with hydroxychloroquine after an exposure to someone with COVID-19 did not provide any benefit.

Is there a way to find out if I have already had COVID-19?

Antibody tests, also known as serologic tests, are being developed. These may be able to find out if you have already had a COVID-19 infection. These tests look for antibodies in the blood. Antibodies are specific proteins made by the body in response to an infection.

Antibody tests will not necessarily tell you if you are immune to COVID-19 or if you might be immune to a second COVID-19 infection. Some people who get COVID-19 may not make antibodies. Or they may make very low levels of antibodies. Some people may have a “false positive” antibody test, meaning the test finds antibodies, but the antibodies are related to a different coronavirus and not COVID-19. Antibody tests are not widely available yet, and you can’t yet do these tests at home.

If I have had COVID-19, will I be able to continue cancer treatment?

If you have tested positive for COVID-19, you should have a discussion with your oncologist about the impact of this on your cancer treatment. At many centers, a negative COVID-19 test is recommended before chemotherapy or other cancer treatment starts again. However, some patients with COVID-19 continue to test positive even after recovering from their symptoms. In this situation, your health care team will consider the risks and benefits of restarting cancer treatment despite the positive test.

When your cancer treatment resumes, it is important to wear a mask when coming to the infusion clinic or cancer treatment center

and to practice good hand hygiene by using hand sanitizer or handwashing before and after visits.

Are there any treatments available for COVID-19?

Scientists are working hard to develop and test treatments for COVID-19. Clinical trials are research studies that involve people. Working very quickly, researchers and physicians have developed clinical trials to find effective treatments for this disease. Clinical trials for potential COVID-19 treatments are now open in many locations in the United States and in other countries. If you have been diagnosed with the coronavirus disease and you join a clinical trial for patients with COVID-19, you may be able to receive these medications. Also, by joining a clinical trial, your participation will help scientists find the most effective and safe treatment for the illness. The Beat19 study, the NCI COVID-19 in Cancer Patients Study (NCCAPS), and a study at Stanford, for example, are designed to collect symptoms from people who may have COVID-19 to help researchers learn the course of the disease and help find a treatment.

Remdesivir, an antiviral medication, may be potentially helpful in treating COVID-19 infections. This is just one of many medications that is being studied in clinical trials as a possible treatment for infections from this virus. Remdesivir received an Emergency Use Authorization from the FDA on May 1. This authorization allows this intravenous medication to be given to hospitalized patients with severe COVID-19 infections.

Convalescent plasma is the liquid portion of blood that can be collected from people who have recovered from COVID-19. This plasma may have antibodies to SARS-CoV-2.

Convalescent plasma is not yet an approved treatment for COVID-19, but it is being studied in clinical trials as a possible treatment. If you have fully recovered from

a COVID-19 infection, you may be able to donate your plasma at a blood bank in your area in order to potentially help others. Learn more about donating convalescent plasma at the websites of the Red Cross and AABB (formerly known as the American Association of Blood Banks).

Hydroxychloroquine (Plaquenil) and chloroquine (Aralen) are also being studied as a treatment for or as a way of preventing COVID-19 after a small French study involving 20 patients showed possible activity of these medications in treating people with COVID-19. Other studies have shown increases in deaths related to these drugs. On April 24, the FDA issued a warning that these drugs should not be used outside of a clinical trial or hospital because of potentially fatal heart rhythms that can occur as a side effect of this combination of medications. On May 25, 2020, the WHO temporarily stopped clinical trials using hydroxychloroquine after a study was published in the *Lancet* journal that found an increased rate of death in patients with COVID-19 who took hydroxychloroquine compared with those who did not take the drug. However, the study authors were unable to perform an independent audit of the data and retracted it from the journal. As a result, the WHO resumed study of hydroxychloroquine on June 3. A study presented at the ASCO20 Virtual Scientific Program found that patients with cancer who used a combination of hydroxychloroquine and azithromycin, an antibiotic, as treatment for COVID-19 had a nearly 3 times greater risk of dying within 30 days compared with patients who didn’t receive either drug. On June 15, the FDA revoked its emergency use authorization for hydroxychloroquine and chloroquine due to their findings that these drugs are not helpful in treating COVID-19 and that the risks outweigh the potential benefits of taking these drugs.

A version of chloroquine (chloroquine phosphate) is used as an additive to clean fish aquariums. Consuming this fish tank additive has led to at least 1 death and other overdoses. Do not consume this product—it can kill you.

Drinking bleach or injecting bleach or other household disinfectants is very dangerous and can kill you. These are not treatments for COVID-19, and they will not help prevent it.

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When will things return to normal?

Public health experts have worked with the local and federal governments to help answer this question. In many parts of the United States, shelter-in-place or stay-at-home restrictions have been lifted or may be lifted in the coming days or weeks. However, we know that the coronavirus continues to circulate in the community and in some communities more than others. As nonessential businesses reopen and as more people begin to leave their homes regularly, it is possible that we will see another surge in COVID-19 cases and deaths.

If your local community, county, or state has allowed nonessential businesses to reopen, the best way to stay safe is to continue to stay at home and avoid being in public as much as possible. Wear cloth face masks or face coverings when you must

leave your home. Continue to wash your hands thoroughly and frequently and stay at least 6 feet away from other people if you need to go to the grocery store or pharmacy or other areas where other people may be.

If you decide to eat at a restaurant that has reopened, it's safest to eat outside. The restaurant should have social distancing measures in place. Avoid buffets. Try not to handle a menu unless you've seen it cleaned first, or read the restaurant's menu online on your phone. Always wash your hands or use hand sanitizer after touching anything.

The safest approach, especially if you are considered high risk, is to continue living as if the stay-at-home restrictions are still in place. If you have questions about your personal risk due to your cancer or cancer treatment, be sure to speak with your doctor for their guidance.

Where can I get the latest information about COVID-19?

Staying up to date on the latest information on the COVID-19 outbreak is important. The CDC and your local and state health departments will have ongoing information about whether the disease has been diagnosed in your community.

Editors Note: Merry Jennifer Markham, MD, FACP, FASCO, is the Interim Chief of the University of Florida (UF) Division of Hematology & Oncology, an Associate Professor in the UF College of Medicine, and the Associate Director for Medical Affairs at the UF Health Cancer Center. Dr. Markham is the past chair of ASCO's Cancer Communications Committee. Reprinted with permission. © 2020 American Society of Clinical Oncology. All rights reserved.

Masks and Summer Heat: Expert Tips

June 17, 2020 - U.S. News & World Report (HealthDay News) - Dr. Teresa Murray Amato rode the subway into Manhattan from Queens the other day and found that summertime and face masks aren't an easy fit.

"It was a warm day. I definitely felt it was a little hot," said Amato, director of emergency medicine at Long Island Jewish Forest Hills in Queens, N.Y.

Despite her discomfort, Amato resisted the urge to remove her mask -- and she recommends that you do the same.

COVID-19 continues to spread even in the humid heat of summer, so it's important to keep wearing masks and maintaining social distancing to prevent transmission, said Dr. Waleed Javaid, director of infection prevention and control at Mount Sinai Downtown in New York City.

At least 10 states -- Alabama, Arkansas, California, Florida, Nevada, North Carolina, Oklahoma, South Carolina, Tennessee and Texas -- reached record levels of hospitalized COVID-19 patients on Sunday, the Washington Post has reported.

This was the risk of reopening, but public health officials have said it's worth it if people wear masks.

Evidence has shown that masks can reduce transmission of the new coronavirus, if everyone wears one, Amato said.

Summer heat may make your mask feel stifling, but you should keep wearing it if you're near other people or in enclosed spaces, she said.

"Even though we know it's going to be a little uncomfortable, I really think the benefits outweigh the discomfort of being a little warm while wearing your mask,"

Amato said.

Keeping both your mouth and nose covered is important. Folks struggling with their mask in the heat might try switching to a lightweight one that's more breathable.

At this point, surgical masks are in good enough supply that people who are uncomfortable with a cloth face covering might consider buying a box, Amato said. Even grocery stores are carrying them now.

"A light surgical mask probably does the trick with the least amount of discomfort," she said.

Sweat is another problem. If your mask becomes damp with sweat, its ability to screen out coronavirus is diminished, Amato and Javaid said.

"If it gets sweaty or damp for any reason, you should change the mask," Javaid said.

Consider keeping at least one mask on hand to swap out if necessary, Amato said.

"In an ideal world, you'd be able to have a few clean ones in your pocket, but I know that's not always possible," she added.

Folks who find themselves struggling to breathe should take a short break, Amato said.

"It does help if you can take a little bit of a break, distance yourself from people and lift the mask up a little bit, cool yourself off," she said.

Be sure to stay hydrated, Amato said. Dizziness or a racing heart could be a sign of heat exhaustion. In that case, get out of the heat, remove your mask and seek medical care.

The good news is that you can take your mask off when enjoying the pool, beach or local park -- as long as you maintain social distancing.

"Getting out there and getting some fresh air just makes you mentally feel better," Amato said. "If you can social distance and you can stay quite a bit of distance away from other people and you're outdoors, we feel pretty comfortable saying you can take that mask off."

The same goes for outdoor exercise like jogging or cycling. As long as you can stay at least 6 feet away from others, you don't need to wear a mask.

~ Dennis Thompson HealthDay Reporter

HOW TO WEAR A MASK?



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Time for Sharing...My Journey

It was early December 2009. The tenth. I thought I chipped a molar, and the rough edge was irritating the side of my tongue. I mentioned it to my doctor at the Rochester, NY VA Outpatient Clinic. She looked and suggested I see the dentist, which I did on the 14th. The dentist looked and said that I may have been correct. She smoothed the tooth surface, placed a patch on it, and asked me to come back in a week to follow up.

I immediately felt some relief, but over the week I realized it still was irritating. On the 19th, the patch fell off. I returned with my report of little relief on the 22nd, and the dentist, noting a growth, called for a consult with my doctor's PA. The two poked and prodded, discussed it, and decided something was amiss, but beyond their ability to give a diagnosis. The dentist filled the tooth and got me a consult. On the 29th, the dentist found the filling OK, and the tongue improved.

So, that afternoon, it was off the VA Hospital in Buffalo, NY to see an ENT doctor. He looked, numbed the area, and took a biopsy with what I'm convinced was a pickaxe and a snow shovel. He let me know that among the possibilities were papilloma, lymphoma, and squamous cell carcinoma. My wife, Jeanne, and I were on pins and needles as we waited to hear the results of the testing, all this happening during the week between Christmas and New Year's Day. On New Year's Eve, the call came from the doctor. He said he wanted me to come in right after the holiday; that he didn't like to give labs results over the phone. I cajoled him, saying I'd rather have bad news immediately, than wait nearly a week to get back in to see him. He relented and let me know I had squamous cell cancer of the tongue. He advised me to come back to the hospital as soon as possible after the holiday to consult with the ENT Oncological surgeon. So, I called off work, and bought a hat.

On the day after the holiday, I met with my Pastor. Her kind words and prayers were a great comfort to Jeanne and me, and we went forth with attitudes as positive as the

unknown would allow.

We returned to the hospital on the fourth and spoke with the ENT doctor. He scheduled an MRI for the eighth, and a surgical pre-op appointment so they could do a more complete biopsy to determine the extent of the tumor, its stage, and possible metastasis on the 15th. The results were that they caught it early and classified it as T1N0. This meant the tumor was the smallest, and no nearby lymph nodes were affected. With the negative MRI results, they ruled metastasis out as an issue.

Throughout this period, we were ready to take immediate action, while the institutional wheels seemed to spin in slow motion. I was spitting blood at random, finding this both scary and inconvenient. The surgeon who did the biopsy recommended a semi-glossectomy, taking the left side of my tongue. What he may have said about reconstruction I've lost forever, as my mind went reeling down a dreadful path of panic. He ended with the required advice on treatment plans: surgery, radiation, or to do nothing. As doing nothing

was no option for us, I asked for a referral to a radiation oncologist for further evaluation.

In February, I saw the radiation oncologist. She advised that radiation was definitely a viable option. She described the procedure and the possible side effects and negatives of the therapy. She further let me know that I would be inpatient at the Buffalo VA five days a week for treatment lasting seven weeks, going home weekends if I wished.

A new round of panic beset me. While I had the VA to provide for my medical needs, as a contract worker, I had no insurance, and no way to afford to leave work immediately and for the time needed for treatment. We discussed this, and I was told I could receive permission to take treatment at the Wilmot Cancer Center at Strong Memorial Hospital, part of UR Medicine; a big portion of the University of Rochester. This allowed me to have my radiation in the mornings, then

work my noon to nine pm hours. That lasted all of three weeks before I was getting too run down to keep that schedule, and the 50 miles a day commute.

The radiation itself was until then my greatest trial. The mask form fitted to my head to keep me still during my Tomography treatments was constricting for this somewhat claustrophobic sissy. Having my nose covered made it worse and having the mask press on my Adam's apple sent me through the roof. They were able to open the mesh on the nose and throat, making it possible for me to continue. Next, though they had taken some of my teeth out that probably wouldn't survive radiation, they wanted to give me a mouth guard that would cover the remaining teeth. Enter a hyper-active gag reflex. The mouth guard was absolutely intolerable, and dangerous as it threatened to cause, well, regurgitation. I still have teeth, but less than before.

I muddled through the radiation therapy, and with a nasal tube installed, tried to get on with my recovery. A number of bouts of dehydration sent me back for IV infusion weekly. I suffered a lot of the usual challenges; fresh water tasting salty, saltwater tasting fresh, a lot of metallic flavor, and the like. Having cashed out my 401K to live on, I wasn't in a hurry to return to work, but in September, did land a job. So, I slowed returned to "normal"; I had to be more selective in food choices, going for softer things, and slowly regained strength.

All was well for about four years. In December 2013, the oncological ENT who was now following me determined the cancer had returned. Another round of scans, biopsy, and dental work ensued, leading to my surgery on February 12, 2014. The plan was to remove the left half of the tongue, use a free flap and vein taken from my right arm to form a "new" tongue, and grafts from my thighs to resolve the wound on the right wrist. At that time, some nearby lymph nodes were taken prophylactically. I was given a tracheotomy and a feeding tube, and commenced to try to heal, with the various wound sites and about 214 staples here, there and the other place. My planned 7-day stay grew to three weeks, and a few further emergency surgeries later as my body refused to cooperate with the plan.

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One night, my nurse rode on top of me on the bed holding his thumb on my neck until they could repair whatever it was that ruptured. To this day, I remember few of those surgeries, but Jeanne remembers vividly.

Finally returning home in early March, I got up one morning to find I was bleeding profusely from my mouth. As I was transported to the hospital, I remember the anguish as I pictured the new tongue falling apart, never to be fixed again. The ER found a bleed, fixed it, and with the doctor's OK, I went back home after the noon hour.

At about four o'clock, it all repeated. As I wrote on the bathroom counter "911" in blood, my wife got the ambulance back, and it was off to the races again. It would be another three weeks before I came home again, after having my left pectoral pulled up into my left neck and cheek to rebuild the area after removal of tissue not healthy after all the trauma. I suffered PTSD through this; thankfully I got full help to work through. One note on that flap procedure: When I shave the left side of my face, I feel it in my chest. An odd thing for sure. Another challenge: trying to convince my health insurance company that two ambulance bills in one day was not a case of double billing. That was eventually sorted out.

I was finally released for good in April. Since, I've had more "outpatient" surgeries, but insisted on staying overnight for those events, due to my particular history of healing issues. At the original surgery, I was NPO (not

even ice chips) as it became clear there was a fistula from my mouth to my neck. We tried various surgeries, dental consults, antibiotics, and a couple rounds of hyperbaric treatments to attempt resolution. To this day, I wear a bandage because of some ongoing drainage. This is preferable to another major surgery that would further disfigure my lower face, with not much likelihood of resolution.

After two years of NPO, the fistula was finally closed and taking nourishment by mouth was finally possible. But because of the logistics of moving food around to my remaining teeth with a tongue that doesn't work as well as the original, eating solids is irritating, and causes inflammation, as does speaking too much, to the relief of many.

My menu is Boost (chocolate) for breakfast and lunch. Dinner is soup run through a blender with a smoothie (Peanut butter-banana is my favorite). My weight is stable, and where it should be, my sugar is under control (yes, diabetic), and my energy level is better than before. Almost six years, no sign of cancer's return, and I'm left with a limited diet, some difficulty conversing with some people, and living a life of ease, pursuing those things I'd always hoped to find time to accomplish. Is it the life I'd planned? Of course not, but how many actually get that? Is it a life I can live? You betcha! Jeanne and I are doing just fine. Life is good.

~ Chris Wanjon
cwanjon@gmail.com

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- More information about this study, including a list of available clinical trial sites, is available for patients or physicians at <https://clinicaltrials.gov/ct2/show/NCT04084951>**

¹About SQZ-PBMC-HPV

SQZ-PBMC-HPV is an investigational autologous cell therapy product candidate engineered to target HPV+ cancers. It has not been approved for any indication by the Food and Drug Administration (FDA) or any other regulatory agency. The safety and efficacy of this therapy has not been determined.

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Safe Travel Tips for Patients with Cancer

Traveling with cancer during a pandemic requires some planning. Here's how I did it safely. ~ Martha Carlson

June 17, 2020 - Martha lives in Illinois and was diagnosed with metastatic breast cancer in January 2015. She has a husband and three children, ranging in age from 12 to 18, a dog and a lizard.

Traveling any great distance is not fun right now. Should I go? How can I get there? Is it safe? There are so many questions to ask and this is especially true if you're living with, or in treatment, for cancer.

The decisions were much simpler earlier in the pandemic. Though it was difficult to abruptly stop everything we do in person - school, work, shop, meetings, socialize - and jump to doing as much as possible from home, it also established clear guidelines to keep oneself safe and reduce the risk to others. I was grateful for all the compliance.

It's taken time to feel more comfortable with the changing rules as states and the country reopen. I just returned from a 2,000-mile round-trip drive to collect my oldest two children from the Boston area. I had been planning to do it in early April, then late April, then early May - you see the pattern. I finally hopped in the car in late May and the reality is that I feel like I've already taken my biggest risk of 2020.

Traveling with cancer during a pandemic requires some planning. Here's how I did it safely.

Mode of transportation: Flying is so easy, but then you're trapped in a small enclosed space with people you don't know and who won't be making your safety the priority. I chose to travel by car, making the nearly-1,000-mile trip there on my own. I stopped only at state-run rest areas, where masks were required for building entry, to get gas, use the restroom, and enjoy the fresh air.

Food preparation: This trip reminded me of the days when my kids were very young and I'd pack enough food to stock a pantry.

That's because I left the house with about 30 sealed water bottles, bags of healthy and unhealthy snacks, a few sandwiches, a large bag of sliced carrots, and various other things that I would either eat or box up for my daughters and leave behind. I decided to bring as much food and drink as I could because I wasn't sure how comfortable I'd feel getting something to eat on the road. I was well into my second day of driving before I decided I needed to stop for something warm to eat.

Choosing a hotel: I've made this trip many times and I usually stay at a relative's or friend's house at the end of the first day. This time, with one friend recovering from COVID-19 and another living with her 90-something mom, I decided on a hotel. I took time to read their cleaning statements and check reviews more thoroughly than usual. I wore a mask from the time I entered the hotel until I'd wiped down room surfaces with bleach-style wipes or soap and water.

Masks are not optional: Sure, in many places they are actually optional but for someone like me (or really for anyone concerned about reducing transmission), a mask is a given. I had stocked up on disposable surgical masks, had a single N-95, and a couple of good quality cloth masks with filters. I had enough, but it was easy to see how quickly that might not be true. If you're traveling, pack masks like you pack whatever item you always seem to run out of (for me, I pack double the socks I should need and I did the same with masks).

Keep your hands clean: It's hard and expensive to get enough hand sanitizer, at least in Illinois. I brought what I had and also packed a soap and extra water so I could wash my hands in an emergency. Don't skimp on this simple step. If you wonder if your hands are clean, they're not.

Keep your distance: Most of the rest stops tried to enforce physical distancing guidelines, but it's not really a secret that too many people resent being told where to stand. If it seemed like people were crowding into any space where I was, or wanted to

be, then I left and saved that activity for the next stop.

Variety is not the spice of life when it comes to reducing your risk of exposure when traveling. Even if some special site or location is open to visitors, consider the risks. In addition, there's the problem of variety in state, local, and individual opinions about risk management. I checked the current guidelines in each of the states I'd be driving through and switched routes when I realized one way would mean I had to drive many hours through a state with lax rules and very few state-run rest stops.

Setting standards: I set out well-prepared and aware that I wanted to minimize time and contact with other people. There were times when I was the only person wearing a mask. This is somewhat uncomfortable, not only because of the disadvantage it put me at for exposure but because people can be irrationally angry at what they consider an affront to freedom. I left those places as quickly as possible.

You will have many different experiences. I am still not ready to get on a plane but maybe you are. I'd adjust the lessons above, with the addition of confirming seat spacing prior to boarding and having a properly fitted N-95 mask.

The world is opening back up and all of us long to live again. I hope we can all do it safely.

This article was reprinted with permission from CURE magazine, as published on June 17, 2020.



photo courtesy of PJ Jordan - Caregiver, NSVN Volunteer and extraordinary woman

***Eat Well Stay Nourished
A Recipe and Resource Guide
for Coping
With Eating Challenges***
compiled by
Nancy E. Leupold, Founder
in memoriam

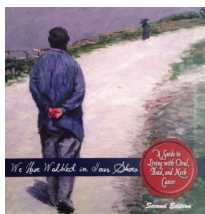


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**Splendid Summer Specialties from
“Eat Well Stay Nourished A Recipe and Resource Guide
For Coping With Eating Challenges”**

Compiled and Edited by Nancy E. Leupold, Founder, in memoriam

Berry Freeze (from Volume Two)

1/3 c. whole milk
¾ c. raspberry sherbet
6 to 8 whole fresh or frozen strawberries
¾ c. lemon sherbet

Combine and blend in blender. Serves 1.
494 calories/serving.



~ Maria V., NY

Creamy Zucchini, Carrot and Cucumber Soup (from Volume One)

2 Tbsp. butter or margarine
2 onions, chopped (2 c.)
1 Tbsp. garlic, chopped
2 zucchini, cut into half rounds
2 carrots, peeled and sliced
6 c. canned chicken broth
1 c. milk or cream
1 Tbsp. curry powder (optional)
2 cucumbers, seeds removed, sliced



Melt butter in large soup pot. Add onions and garlic. Cook until onions are transparent. Add zucchini, cucumbers, carrots and chicken broth. Bring to a boil and simmer for 20 minutes or until vegetables are soft. Put all ingredients into a blender or food processor and puree the soup. Return soup to the pot and add cream or milk. Heat briefly and serve hot or chill and serve cold. Yield 10 – 8 oz servings. 107 calories/serving.

~ Anne M., NY



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Head and Neck Cancer News

The role of head and neck cancer advocacy organizations during the COVID-19 pandemic

*SPOHNC was happy to participate in this very important issue of the **Journal for the Sciences and Specialties of the Head and Neck**. This special issue concentrates on the significant toll COVID-19 has on patients, survivors, caregivers and loved ones who are affected by an oral, head and neck cancer diagnosis.*

Abstract

The COVID-19 pandemic has had a significant impact on many aspects of head and neck cancer (HNC) care. The uncertainty and stress resulting from these changes has led many patients and caregivers to turn to HNC advocacy groups for guidance and support. Here we outline some of the issues being faced by patients with HNC during the current crisis and provide examples of programs being developed by advocacy groups to address them. We also highlight the increased utilization of these organizations that has been observed as well as some of the challenges being faced by these not-for-profit groups as they work to serve the head and neck community.

INTRODUCTION

The global COVID-19 pandemic has had a significant impact on all aspects of society, with a large burden falling on members of the health care community. With hospitals focusing on those ill from COVID-19, patients with cancer have the potential for delay or reduction in care as clinical resources have been compromised. Few populations have felt the effects of these changes more than those being evaluated or treated for head and neck cancer (HNC) as the multidisciplinary requirements for this population includes dental, otolaryngology—head and neck surgery, and radiation and medical oncology, among others. The mucosal nature of many of these cancers results in significant concerns about aerosolization of viral particles and the potential for delays in care. In an effort to minimize infection transmission and conserve the limited supply of personal protective equipment (PPE), health systems have instituted policies that encourage social distancing such as postponement of elective surgeries and outpatient clinic visits,

elimination of hospital visitors, and rapid adoption of alternative means of care such as telemedicine and drive-through testing.

Multiple societies and organizations involved in HNC care across different specialties, including otolaryngology—head and neck surgery, radiation oncology, dentistry, speech/swallowing pathology, and medical oncology, have promptly issued management algorithms to guide clinical care during this pandemic. The shift of focus away from nonurgent conditions has been instrumental in creating a united effort to combat infection. However, there is little precedent for navigating oncologic care during such times. These abrupt changes in management may leave patients with cancer undergoing active treatment frightened, uneasy, and isolated. Given the higher rates of emotional distress, cancer and treatment impact on daily living, and mucosal exposures seen in patients with HNC, these individuals appear to be particularly vulnerable to the fear and anxiety produced by the on-going public health emergency.

Even in normal circumstances, let alone in this current climate, HNC patients often are in need of guidance to alleviate their concerns and many advocacy organizations have been proactive in providing support through various platforms such as news articles, webinars, and financial assistance. In addition to meeting patients' needs, advocacy groups also play roles in providing patient education and raising public awareness, moderating call lines and chat forums, sustaining research through public or private funding, and representing the HNC community on legislative boards. This timely and important special communication provides an outline of the issues being faced by patients with HNC and caregivers during the COVID-19 pandemic, and some of the programs that have been developed by advocacy organizations to address them. This unprecedented collaboration among a variety of organizations and advocacy groups also provides critical information on how the current crisis has impacted the utilization of these groups and the unique challenges being faced as they work to offer needed services to their communities.

To capture up-to-date, relevant information on the impact of COVID-19 on head and neck advocacy organizations, representatives of six prominent North American HNC advocacy groups were contacted to ask for participation by providing their respective groups' experience during COVID-19. Semi-structured interviews were then conducted via phone and email communications with all responding organizations to identify: changes in volume of people in contact with their organization (including web site traffic, social media engagement, support phone line volume, and email communications), changes in observed patient concerns, changes in HNC advocacy group programs, and challenges faced by advocacy organizations during the COVID pandemic. Five out of six invited organizations participated in interviews. Information obtained from these communications is qualitatively summarized in the discussion below.

CONCLUSIONS

The COVID-19 pandemic is having a profound impact on HNC patients, creating tremendous anxiety and uncertainty for many individuals undergoing treatment or surveillance for their disease. With the current changes occurring in health care, the role of HNC advocacy organizations is becoming increasingly significant, as these groups are being turned to for information and support. Despite numerous challenges with program funding and implementation, these groups continue to find ways to offer services to their communities. Further work is necessary for these organizations to learn about the evolving needs of those they serve in order to best refine programs to support them in the future.

Editors Note: This study was co-authored by Flora Yan BA, Erika Rauscher BS, Amanda Hollinger MPA, Mary Ann Caputo BA, John Ready BS, Carole Fakhry MD, MPH, Cherie-Ann O. Nathan MD, Chris Leonardis BS, Danielle Yearout MS, Terance T. Tsue MD, Terry A. Day MD, Michael G. Moore MD.

To read the full study, go to <https://doi.org/10.1002/hed.26287>.

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~ Crystal S.



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