



## Information for Head and Neck Cancer Survivors During the COVID-19 Pandemic

### **To our patients and survivors**

*Steven Cannady, Andrew Coughlin, Patrick Ha.*

*The current Covid-19 pandemic has undoubtedly created added concerns for head and neck cancer patients and survivors struggling to understand what the changes in medicine will mean for their care. Recognizing the burdens of this undue stress, your head and neck providers want to reassure you that we are also wrestling with these issues at the forefront of knowledge, thought, and action in response to the viral outbreak we are all facing.*

*The American Head and Neck Society is working to determine how to best deliver care and make sure that you, your medical team, and others remain healthy and at low risk for contracting the virus. We are committed to providing the high standards you have come to expect while facing your head and neck cancer diagnosis. Fortunately, health care centers have rapidly evolved to allow for alternatives to help meet with your care provider and still proceed with a face to face evaluation if that might become necessary in the short term. Your health care team recognizes that you are a partner in your care and should be part of the decision-making process.*

*What you will see below is guidance based on the best judgment of head and neck oncologists with the current state of knowledge. Thus, should you notice changes that you feel should be brought to the attention of your provider, rest comfortably in knowing that we are still working for you to answer your concerns and make action plans in response. We will maintain the highest possible level of cancer care during these uncertain times, and we remain committed to your care. As always, don't hesitate to reach out to your physicians with any questions.*

### **The constraints placed on the health care system and the needs to change aspects of follow-up care**

*Vlad Sandulache, Mauricio Moreno*

Cancer surveillance is a critical component of caring for head and neck cancer survivors who have completed extensive therapy. Surveillance and survivorship care is time intensive for both patients and providers, and may include utilization of multiple health care tools such as endoscopic equipment, laboratory testing and advanced imaging tools (for example, ultrasound, CT and MRI machines). Under the current conditions, most of these normal components of surveillance and survivorship care, must be redirected in order to assist in the care of patients who are acutely and severely ill. For cancer survivors, re-orientation of these resources will provide a brief, temporary interruption in a life-long process designed to maximize the duration and quality of your life. However, it is critical to understand that reducing routine interactions with the healthcare system will allow health care systems to – for a brief period of time – redirect their attention and efforts to individuals suffering the effects of the current pandemic.



## **Your Surveillance Follow-Up Visits During the Pandemic**

*Neerav Goyal, Andrew Coughlin*

After treatment, head and neck cancer survivors are followed closely by their head and neck oncology team (surgeons, radiation oncologists, medical oncologists, and/or advanced practitioners). In usual circumstances, routine follow up for head and neck cancer survivors is recommended every 1-3 months during the first year, every 2-6 months during the second year, every 4-8 months during the third through fifth year after treatment, and annually thereafter. The goal of these clinical visits is to identify cancer recurrences, cancer-related issues and to improve quality of life. While survivors and physicians appreciate these follow up visits for cancer surveillance and side effect management, in the current crisis, these visits are elective and may increase risk of exposure to COVID-19 to both survivors and physicians.

With the recent COVID-19 outbreak, it is important to limit transmission to survivors, their families and clinical teams. Many hospitals will be postponing non-urgent surgeries and routine follow up visits to minimize the spread of COVID-19 to you or your care team and importantly to maintain protective resources that are in short supply. This may result in postponing follow up visits that are normally part of your post-cancer treatment. Your currently scheduled scans (PET/CT, CT, MRI or Ultrasound), swallow studies, thyroid function labs and/or other testing may also be delayed. If your physician has deemed you at low risk for recurrence and delayed your follow-up visit, this should not have a serious impact on you.

If you are having new signs or symptoms you should reach out to your doctor and cancer care team. Signs and symptoms can include worsening mouth or throat pain, pain or difficulty swallowing, changes to your voice, otherwise unexplained ear pain, or a new mass or lump in the neck. If you are having symptoms such as a new sore throat, fever, cough, shortness of breath or muscle aches or have an exposure to someone with confirmed COVID-19, your team may request that you be evaluated outside of the clinic.

Some institutions will be offering virtual follow up (see telemedicine below) or will discuss any imaging or testing results with you on the phone to reduce your potential exposures to COVID-19 and that of the health care staff.

If you are going to a clinic visit, know that some aspects of a typical exam will not be performed (such as mirror exam or endoscopy) unless absolutely indicated to limit the risk of COVID-19 infection. Please know that your healthcare team may be wearing personal protective equipment including masks, gowns, gloves, and face shields to reduce exposures.

Please understand that these changes to your cancer follow up are anticipated to be temporary and are for your safety and the safety of your healthcare team. If there are clinical concerns reach out to your care team.



## **What is Telemedicine?**

*David Cognetti, Neerav Goyal*

Telemedicine is a substitute for a face to face clinic visit which you are used to. It may take the form of a telephone call with a member of your cancer treatment team which may or may not include the use of video. If you have concerning symptoms, the team will help arrange for further testing or an in-person examination while keeping you, your family, other patients, and the healthcare team safe. Telemedicine is particularly valuable for head and neck cancer survivors, as it reduces individual patient exposure to crowded healthcare delivery areas, such as clinics and hospitals, and minimizes the risk to other cancer patients, whose immune systems may have been weakened by their treatment. Head and neck survivors should be reassured that virtual interactions are a sound approach to cancer surveillance, when in person visits are less feasible. Telemedicine consultations allow providers to identify patients who may need to be seen in person for further evaluation and testing.

## **Will My Physical Examination Change if I have an In-Person Clinical Visit?**

*Neerav Goyal, MD, MPH, FACS, Scharukh Jalisi, MD, MA, FACS*

In light of the current pandemic, your healthcare team may change their approach to your clinical exam to maintain safety for you, your family, and the healthcare team. Specifically, the use of flexible laryngoscopy, rigid nasal endoscopy (“scopes”), or mirror examination may increase the risk of exposure or transmission of the virus. As such, while these tests may typically be a routine part of your cancer care, the healthcare team may not perform these evaluations at this time unless there is a specific urgent or emergent need for using these tools to evaluate your health.

Additionally, your healthcare team may have used nasal sprays to help numb and decongest your nose in preparation for these procedures. These sprays also may increase the risk of exposure to COVID-19 to others in the room. Instead, if these procedures are necessary, the team may choose to use medication-coated cotton strips or nothing to minimize this risk while maintaining your comfort.

## **Why Does My Provider Need To Wear Protective Gear?**

*Scharukh Jalisi, MD, MA, FACS*

COVID 19 is a contagious disease and hence it spreads through respiratory droplets. This means if you are infected without being aware of it, coughing or sneezing during exam or clinic visit may result in the provider and staff in the room getting infected. Personal Protective Equipment (PPE) is a set of materials that may include a mask, eye shields, gloves, gown, and hat. The goal of this gear is not to make you uncomfortable, but to protect your provider. It is possible during the check-in process for your clinic visit or procedure you may be provided a mask to put on as well for your own protection and for those around you.



## **Why is my procedure being postponed and/or rescheduled?**

*Scharukh Jalisi, MD, MA, FACS*

COVID-19 is a virus that spreads rapidly from one person to another through respiratory droplets, and even touching surfaces. It may result in a serious infection of the lungs which could lead to life-threatening breathing problems. The breathing problems can be severe enough to warrant the placement of a breathing tube and ventilator in an intensive care unit. Your safety is our primary goal. The reason for postponing any surgeries that are not emergent, is to protect you from catching the coronavirus during your hospitalization and hence preventing a possibly catastrophic outcome including death.

People throughout the United States are testing positive for COVID-19 and many are requiring ventilators in intensive care units. There is a dire need to preserve these ventilators (many of which are in operating rooms) for patients who would otherwise die of COVID-19 complications. Other important reasons are that the health care workforce is suffering from quarantines and COVID-19 related illnesses, which means your health care team is not at full capacity. In addition, much of the equipment used to protect patients and health staff from infection (such as gowns, masks, gloves, and face shields) are in limited supply and there is a need to preserve these resources to the care of the most acutely ill patients. Lastly, you may have COVID-19 and could spread the virus to others (patients and health care workers) in the hospital or develop a life-threatening lung infection due to COVID-19. For these reasons, government officials have recommended postponing elective surgery when possible.

We understand that surgery for cancer does not feel elective, but rather feels like an emergency. We hope that you will be patient with your providers as we continuously reassess the impact of this pandemic.

## **Potential Changes in Treatment**

*Andrew Day, MD*

In the current pandemic, multidisciplinary teams are rethinking the urgency of your care, alternatives for your care that are equivalent and the potential risk of COVID-related complications or your hospitalization in the midst of COVID-19 pandemic when hospitals are strained. Your doctors may need to change your cancer treatment plan first and foremost for your own safety and secondarily for the safety of the doctors and health care staff. Sometimes radiation with or without chemotherapy gives you the same likelihood of cure as surgery. In these cases, your doctor may recommend avoiding surgery. On occasions when surgery is delayed and your doctor has concerns, drugs may be recommended to partially treat your cancer. Delay in surgery for a few weeks to allow enhanced preparation to do your surgery more safely, provide you safer care in the hospital and ultimately be in your best interest. Your doctors will watch your cancer closely if surgery is delayed.

Your doctors will discuss your case with all the other head and neck cancer doctors and then discuss your case with you. You and your doctor will then make a decision about treatment.



## How to Prepare Better

Aru Panwar, MD

- 1) Follow and share information from only the trusted sources for guidance
  - a. CDC: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
  - b. WHO: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>
  - c. Follow local and state guidance
- 2) Exercise trusted health care interventions, such as:
  - a. Stay at home, and avoid venturing out if it is not essential
  - b. Avoid congregating in groups and maintain social distancing
  - c. Wash your hands with soap and water frequently. See instructions on proper hand washing here: <https://youtu.be/d914EnpU4Fo>
  - d. If unable to wash hands, use hand sanitizer
  - e. Disinfect commonly used surfaces such as table tops, door knobs, phones etc.
  - f. Cover your cough and sneezes
- 3) Monitor your health as a head and neck cancer survivor
  - a. Learn about symptoms of COVID-19:  
<https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
  - b. Monitor your general health, COVID-19 related symptoms, and symptoms related to underlying disease conditions including head and neck cancer
- 4) Have a communication plan with your loved ones and your healthcare team
- 5) If you're concerned, reach out to your healthcare team by phone or messaging (email/ patient portal), in advance of in-person visits
- 6) Ensure you have a sufficient supply (at least a 2 week supply) of:
  - a. Food items that are easy to preserve, dry goods, canned goods, and others
  - b. Fever reducers (such as acetaminophen, commonly known as Tylenol) and other regularly used non-prescription medications.
  - c. Daily essentials
- 7) Contact your physician to ensure:
  - a. Availability of medication refills
  - b. If you're in the midst of treatment, discuss how it may or may not be affected
  - c. If you need medical supplies (tube feed formula, suction equipment, wound care supplies), please evaluate your needs and ask your healthcare team for additional supply, proactively
- 8) Avoid in-person visits for non-emergency care to avoid your risk for exposure and to prevent overwhelming health care systems. Use video or telephone-based consultation, if available, through your healthcare providers
- 9) *For individuals with unique needs* and barriers (for example, patients with laryngectomy): In some cases, if you need emergent care, you may interact with healthcare workers who may not be well versed with your unique anatomy, health condition or needs. Keep relevant alert mechanisms on your person at all times. These include:



- a. Medical alert bracelets for compulsory neck breathers
- b. Medical alert notice on front door
- c. Carry a medical alert card with you, detailing your health conditions, and the contact number for your cancer doctor

## Managing Stress During COVID-19

*Amy Williams, Maria Olex*

The COVID-19 (coronavirus) outbreak may be stressful for individuals. Remember, ***these are difficult times and it is normal to feel worried and scared.*** Challenging and uncertain times may cause strong emotions and worsening physical and mental health. It is important to remember that everyone reacts to stressful situations differently and there is no “right way” to handle stress. Think about ways that you have managed stress in the past and use those ways that have worked in the past. The following tips are helpful ways to manage your stress, worry, and mood during COVID-19. ***Your medical and support oncology (therapist/counselor, psychologist, psychiatrist) team are also likely available for telemedicine or virtual care check-ins as well – call them!***

**Maintain a healthy lifestyle:** Eat healthy, exercise (e.g., walk, run, yoga), and get regular sleep. Exercise is a powerful medicine for depression and anxiety. Avoid excessive amounts of caffeine and alcohol. Stay away from tobacco and other drugs.

**Stay connected with others:** Limit face-to-face interactions, but continue to talk to family and friends via phone calls, text messaging, video chat (e.g., Facetime, Skype), and social media. If you find that your social support is limited, there are plenty of online support groups.

**Minimize exposure to media:** It is important to keep up-to-date with changing news but minimize this to 1-2 times per day. Avoid news 24/7 since this increases worries, uncertainty, and fear.

**Stay busy and improve your sense of control:** Distract your mind from worrying thoughts by doing activities and keeping as much of your normal routine, as possible. Let go of those things that you cannot control and focus on what you can control.

**Ground yourself:** If you are feeling overwhelmed and find your mind wandering, use the 5-4-3-2-1 coping technique below.

Take a deep, slow breath and focus on things in your awareness.

**5:** Name five things you can **see** (e.g., chair, window, plant, etc.).

**4:** **Touch** four things (e.g., chair you are sitting on, table front of you, etc.). Notice what these feel like.

**3:** Focus on three things you can **hear**. Listen to the clock ticking or birds singing. Take a moment to hear all the noises you usually filter out.

**2:** **Smell** two things. Perhaps this is food you cooked or products on your body. Smell is a powerful sense – focus on it.

**1:** What is one thing you can **taste**? Does the inside of your mouth taste like toothpaste, coffee, or juice? If you have something in front of you, take a sip. Try to detect the subtle flavors.

Fully engaging in your five senses directs your attention to the present moment, away from stressful thoughts, and allows you to regroup and refocus your attention.



**Maintain a sense of hope:** Consider keeping a journal where you write down things you are grateful for. Each night write down 3 things that are going well and/or things that you are grateful for. Practice this with family or friends.

**Allow your emotions:** Your feelings are real and normal! Instead of pushing away your emotions, allow yourself to feel the sadness, worry, or any other emotional reaction that comes up. It is **normal** to experience fear and worry during a time of stress or uncertainty. Acknowledge what you are feeling, feel it, and then engage in a meaningful activity.

**Pace yourself:** Pace yourself between stressful activities. Do something enjoyable after a hard task.

**Set a schedule and stick to a routine:** Schedule times for work, school, chores, exercise, and sleep. Schedules promote healthy habits and less time to worry. Set alarms to wake you up at the same time daily. Get dressed – don't stay in your pajamas all day. Eat at regular times and pre-pack snacks for the day. If you find yourself worrying all day, *schedule your worry* for a specific time of the day. If you find your mind wandering outside of that time, remind yourself that you have a time set for that at a different time.

**Think about your values:** What is important to you? Family? Relationships? Health? Helping others? Think of ways you can do those things that are important to you and commit to this. Shift your priorities to focus more on what gives you meaning, purpose, or fulfillment.

**Challenge your thoughts:** Attempt to manage self-defeating statements and replace them with more helpful thoughts. Shift negative self-statement to those that allow you to function with less distress. Try changing “this is a terrible time” to “this is a terrible time that I can get through.” Words matter.

**Engage in fun activities:** Know that this is temporary. Make time to do things at home that you usually enjoy, such as reading, watching movies or TV, listening to music, playing games, engaging in religious activities (prayer, participating in services on the internet), and completing puzzles. Be creative and engage in crafts.

**Practice relaxation:** Engage in deep breathing (e.g., breathe in for 3 seconds, hold for 1, and out for 4 seconds), guided imagery (e.g., picturing a peaceful place such as a beach, mountain, etc.), progressive muscle relaxation, and mindfulness. Schedule time to practice these at least daily. There are a variety of online videos and smartphone apps. Apps for your phone:

- Insight timer
- Breathe
- Stop, Breathe, and Think
- Calm
- Headspace
- Smiling Mind
- UCLA Mindfulness
- PTSD Coach



**Financial stress:** If you are unable to work at this time, you may experience increased stress related to your job and financial situation. Talk with your employer to reduce this stress. Provide your employer with a clear explanation of why you are away from work. Contact your utility providers, cable and internet provider, and other companies from whom you get monthly bills to explain your situation and request alternative bill payment arrangements, as needed.

Contact the U.S. Department of Labor toll-free at 1-866-4USWAGE (866-487-9243) about the Family and Medical Leave Act (FMLA) which allows U.S. employees up to 12 weeks of unpaid leave for serious medical conditions, or to care for a family member with a serious medical condition.

**Typical emotional reactions to COVID-19 include:** anxiety, worry, fear, loneliness, boredom, frustration, concern, anger, sadness, sleep issues, appetite changes, desire to use or use more alcohol, tobacco and/or drugs, frustration, irritability, and upsetting thoughts.

If you are feeling overwhelmed with emotions such as sadness, depression, anxiety, or feel like you want to harm yourself or someone else, **call 911** or the **National Suicide Prevention Lifeline at 1-800-273 TALK (8255)** or chat at [suicidepreventionlifeline.org/](https://suicidepreventionlifeline.org/)

## Caregiver Wellbeing During COVID-19

*Amy Williams, Maria Olex*

As a caregiver during the COVID-19 pandemic, we know you are working hard to deliver exceptional care, and the stresses and demands you face may impact your wellbeing. Listed below are some resources and strategies to help you get through this challenging time.

### How might COVID-19 impact caregiver well-being?

There are numerous ways that the COVID-19 pandemic could impact caregiver wellbeing. These are some common experiences caregivers might have:

- **Fear of contagion** or spreading illness and concerns about the health and wellbeing of yourself, your family, and your loved ones.
- **Uncertainty, overwhelmed, and worry** about the rapidly evolving public health data, changing policies and procedures, and 24/7 news cycle.
- **Pressure to work longer and harder**, perhaps without the usual sense of effectiveness.
- **Stigma or distrust from community, co-workers, friends, and family** as they may fear the consequences of being in contact with a caregiver during the pandemic.
- **Isolation from family, friends, co-workers, and community** support systems.
- **Significant disruption in your usual routine** and reduction in your enjoyable and recreational activities.
- **Conflicting demands** between work and family responsibilities.





- **Ethical concerns about resource availability** and access to necessary healthcare.
- **Denying your basic needs** such as need for breaks, sleep, and recovery time or feeling guilty if you take time off or attend to your personal needs.
- **Lack of typical respite time** or having others help you in caregiving due to social distancing and self-isolation.

As a caregiver of a head and neck cancer patient or survivor, as you know, you play a critical part in the treatment and recovery process. To minimize your risk of infection and the potential for passing on infection to those in your care, it is important to minimize unnecessary direct contact with others and observe rigorous hand hygiene (see “How to Better Prepare” above).

In instances where the person under your care has a tracheostomy or has had a laryngectomy, the following are helpful tips to minimize infection transmission:

1. When possible, keep the tracheostomy or laryngectomy tube covered with a Heat Moisture Exchange (HME) filter.
2. Minimize suctioning of the airway as this can result in aerosolized particles that can transmit the virus.
3. When possible, wear personal protective equipment when directly in contact with head and neck cancer patients (such as gloves, masks and eye shields).
4. If you start to develop a cough, sore throat and/or fever, contact your doctor immediately as you may be showing signs of infection and may be at risk of transmitting on to others.

### **How do I know if a caregiver (myself or a colleague) might need support?**

It is normal to feel increased stress as you respond to numerous challenges and demands of the pandemic. This increased stress can help us focus and attend to the very important things we need to do to remain safe at work and home, and can be overwhelming. **Caregivers and their colleagues might need more support, if they are experiencing any of the following reactions or are not seeming like themselves:**

- **Physical reactions:** fast heart rate, chest pressure, muscle tension, headaches, stomach or gut issues (such as nausea, diarrhea), insomnia, changes in appetite and weight
- **Emotional reactions:** fear or terror, anger, irritability, easily emotionally reactive, hopelessness, depression, anxiety/worry, numbness, detachment, despair, not caring about things
- **Thought reactions:** disorientation/confusion, difficulty with problem solving or decision making, imagining or focusing only the worst-case scenarios, flashbacks/nightmares
- **Behavioral reactions:** risk taking, hostility, blaming, difficulties cooperating with others, conflicts with family or friends, withdrawal or keeping to themselves



## Strategies for managing stress and restoring and maintaining wellbeing

Caregivers often focus on the needs of others before prioritizing their own needs. However, the ability to care for someone else depends on taking care of yourself, which allows you to sustain your own health, energy, and efforts in the long-term. None of these strategies alone will undo the worry and stress about COVID-19, but with regular, consistent practice you develop a strong routine of self-care, which in turn can help maintain your wellbeing during this challenging time.

<p style="text-align: center;"><b>Pace yourself</b></p> <p>Caring for others is a marathon, not a sprint. Stress might make you feel like you need to go faster and work harder. Take mini-breaks and be cautious of the tendency to over-work, push yourself, or neglect your basic needs.</p>	<p style="text-align: center;"><b>Check-in with yourself</b></p> <p>We all experience stress differently. Take a moment before and after each shift to check-in with yourself to assess your feelings and thoughts. Acknowledging and accepting how you are doing will help you meet your needs and responsibilities.</p>
<p style="text-align: center;"><b>Schedule worry time</b></p> <p>If you are finding it hard to focus while taking care of others, schedule a short time (3-5 mins) to write down all your worries on a post-it, journal, or note on your phone. It can help the worries seem more manageable and get the temporarily out of your mind, allowing you to focus on and complete other tasks.</p>	<p style="text-align: center;"><b>Be present and breathe</b></p> <p>Future concerns and “what if” questions can take you out of the present moment. Practice deep breathing or mindfulness while doing daily things like washing your hands, brushing your teeth, during your commute, or before starting the day to stay present, focused, and centered.</p>
<p style="text-align: center;"><b>Put your oxygen mask on first</b></p> <p>Attend to your basic needs! Exercise is a way to combat stress and help promote good sleep at night. Taking breaks, especially to find a nutritious meal, is worth the time and energy it takes to step away from work or other tasks. Stick to your routine as much as possible, which will help you feel good.</p>	<p style="text-align: center;"><b>Stay connected</b></p> <p>Reach out to family, friends, and colleagues for support or connection. Call or use video chat with individuals or groups to meet your social needs. Connect over your shared interests, jokes, entertainment, or other healthy distractions to avoid discussing only the news.</p>
<p style="text-align: center;"><b>Focus on success and strengths</b></p> <p>Amidst all the challenges, remind yourself of what is going well and what you are grateful for. Write these down! You have strengths that have helped you overcome challenges in the past. Bring these strengths to mind and know these will help you get through challenges you face today and in the future.</p>	<p style="text-align: center;"><b>Focus on what is in your control</b></p> <p>Defining what you can control and cannot control helps you make plans and have direction when feeling overwhelmed. Write down a list of things you can and can't control to focus your efforts and actions on the things you can, while acknowledging the things you cannot control.</p>