

# Talking About Head and Neck Cancer and Mental Health

A DISCUSSION TOOL FOR PATIENTS AND CAREGIVERS



Head and Neck Cancer (HNC) and its treatment can present with side effects and other challenges for patients and caregivers. Receiving a head and neck cancer diagnosis may feel overwhelming and may cause you to have a lot of questions. You may meet several different members of your care team and will likely be provided a lot of information.

This guide has been created to help you and your loved one take control of your HNC care. It will give an overview of HNC and HNC treatment, address side effects and mental health concerns, and discuss support for HNC patients and caregivers. This guide will also provide you with questions to ask your care team, as well as resources that provide guidance and information.

## WHAT IS HEAD AND NECK CANCER?

HNC includes a wide range of cancer diagnoses based on where they originate in the head and neck area. These cancers are separate from those in the brain. HNC accounts for nearly 4% of all cancers in the United States. HNC includes cancers of the voice box (larynx), throat (pharynx), lips, mouth, tongue, nose and nasal cavity, thyroid, and salivary glands.

There are common risk factors associated with HNC and they include Human Papillomavirus (HPV), use of alcohol and tobacco, and Epstein Barr Virus (EBV). However, you may still receive a HNC diagnosis without having these risk factors.

- **Tobacco and Alcohol use** - Tobacco use, either previous or current, is considered a risk factor for HNC. Continued use of tobacco products after diagnosis can reduce the effectiveness of treatment. It is never too late to quit. For guidance and tips on the importance of tobacco cessation, refer to [BeTobaccoFree.gov](https://www.betobaccofree.gov). You can also speak to your care team about local tobacco cessation programs available to you.
- **Human Papillomavirus (HPV)** - A HNC diagnosis is considered HPV-positive when HPV has been detected and the tumor has certain biomarkers. HPV is a common infection transmitted through sexual contact. Speak to your care team about the specific options that are available for you.
- **Epstein Barr Virus (EBV)** - EBV is a virus spread through saliva and other body fluids. It has been more closely tied to cancers of the throat, nose, and mouth (oral cavity). Let your care team know if EBV was previously detected in your body.

Contact your care team about any concerns you may have regarding your health history. You may refer to Cancer Support Community's webpage on Head and Neck Cancer for more information and resources: [www.CancerSupportCommunity.org/Head-Neck-Cancer](https://www.CancerSupportCommunity.org/Head-Neck-Cancer).



## DENTAL CARE

Make sure to speak to your Dentist about your diagnosis and treatment. Your Radiation Oncologist will likely ask you to see a dentist or oral surgeon before radiation to make sure that your teeth are healthy.

## HEAD AND NECK CANCER TREATMENT

Treatment for HNC will vary based on specific diagnosis, stage, and other tumor characteristics. The type of HNC will impact the available treatment options. HPV-positive and HPV-negative HNCs may differ in treatment options. Speak to your care team about what options you have. Do not be afraid to pursue a second opinion to find what will be best for you and your personal goals. Below are the most common treatments for HNC. Your treatment plan may consist of one or several of these options.

Surgery	Surgery may be a treatment option for HNC, especially for HNCs diagnosed in earlier stages. The goal is to remove as much of the tumor as possible. The specific procedure will vary based on the cancer stage and its location and size. Surgeons will preserve as much of the appearance and function (for example, swallowing) of the area as possible.
Radiation	This involves a machine that sends high-energy beams to the cancerous area to kill the cancer cells. Radiation can be given at different points throughout treatment based on your HNC type, stage, and other factors. It is important to start radiation within the time recommended by your care team.
Chemotherapy	Chemotherapy, or chemo, uses drugs to damage fast-growing cells such as cancer cells. These drugs shrink tumors, slow the cancer's growth, relieve symptoms, and can help increase overall quality of life. In HNC, chemo is most often given through an IV, before or alongside radiation. It may be recommended to receive both chemotherapy and radiation at the same time.
Immunotherapy	Immunotherapy uses drugs to strengthen the body's own immune system. This allows for the various cells of your immune system to further attack the cancer cells. Immunotherapy is typically given through an IV.
Targeted Therapy	These treatments target specific aspects of the cancer cell to kill the cancer cells. This results in less harm to the healthy cells.

## CLINICAL TRIALS

Be sure to ask your care team about any available clinical trials that you may be eligible for. Ask about the potential benefits and risks. It is important to make sure you are aware of all your treatment options. Clinical trials give access to the latest therapies that are only available through enrollment in these studies. For more information on clinical trials or how to find one, visit [www.CancerSupportCommunity.org/Clinical-Trials](http://www.CancerSupportCommunity.org/Clinical-Trials).



## PHYSICAL SIDE EFFECTS OF HEAD AND NECK CANCER TREATMENT

It is beneficial to learn about the potential side effects you may experience before you begin treatment, so you know what to expect. Managing symptoms and side effects can help you feel better physically as well as emotionally. Different treatments for HNC can cause different side effects. Side effects of HNC treatment can present during, immediately after, or much longer after treatment. All side effects can vary from person-to-person. Side effects from HNC treatment may include:

- Difficulty with eating or drinking
- Difficulty with speaking
- Difficulty with hearing
- Physical disfigurement because of surgery
- Loss of voice box
- Lymphedema (swelling due to a blockage in the lymphatic system) in head or neck
- Difficulty with or discomfort while sleeping
- Mouth, throat, or general pain
- Jaw stiffness
- Dental issues and/or loss of teeth
- Fatigue
- Nausea/vomiting
- Diarrhea/constipation
- Peripheral neuropathy (numbness and tingling in fingertips or toes)

It is important to notice when the side effects occur and how often they last. Make sure your care team is aware of what you are experiencing. **Any physical side effects may also impact your mental health and emotional well-being. This will be discussed later on in this resource.** Your care team may provide additional ways to reduce the side effects and their impact on your quality of life.



There are some additional physical side effects that are considered **delayed** because they may not occur until long after treatment. Some of these are:

- Dry mouth
- Taste or appetite changes
- Speech impairment
- Tightening of jaw, neck or shoulders
- Hypothyroidism
- Osteoradionecrosis (indicated by pain, speech difficulties, bad breath)
- Dental caries (tooth breakdown)
- Impact on carotid artery
- Burning mouth syndrome (indicated by mouth burning/dryness, loss of taste, increased thirst)



## MENTAL HEALTH AND HEAD AND NECK CANCER

Decisions about treatment for HNC may need to be made quickly. You may feel that you need time to process everything or feel hesitant about what side effects you may experience. You may also feel or experience stigma from others. Due to the different surgeries and other therapies, your activities of daily living may be impacted. You may experience feelings of self-consciousness or grief if your body functions differently when eating or speaking. This may make it difficult and cause you anxiety when considering attending social gatherings.

Feelings of anxiety may also occur when anticipating upcoming appointments or scans. This type of anxiety is commonly called “scanxiety.” This emotion is a common feeling among cancer patients. You may also feel anxious about the financial impact of your diagnosis. Financial toxicity is the financial burden that cancer patients and caregivers face because of their care. Speaking to a financial navigator about the cost of your care may help you feel better prepared.

Regardless of what causes these changes in emotions, all of these feelings are completely normal. **Remember, just because the feelings are normal, doesn’t mean that you need to experience them alone.** Your emotional health is just as important as your physical health. Reaching out to your care team can be the first step in helping you to cope with the feelings you are experiencing.



### COPING WITH THE STIGMA OF HEAD AND NECK CANCER

Anyone can be diagnosed with HNC. No one should be judged, nor should they feel responsible for their HNC diagnosis. Stigma can happen when something is judged or spoken about unfairly. Stigma can affect how you feel about yourself or how you think others feel about you. It may discourage people from seeking medical care or lead to emotions such as anxiety or distress. People with HNC may feel shame and stigma because of HNC’s association with HPV and alcohol and tobacco use. Changes in body appearance and/or function may also lead to feelings of shame or stigma.

You deserve good care regardless of your medical condition or possible physical and social history. Speak to your care team if you are experiencing stigma from others. It is important to find people on your care team that you trust. Social workers, therapists, and community leaders may provide the support you need to navigate these emotions or experiences.



## WHAT IS MENTAL HEALTH?

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Mental health refers to your overall emotional, psychological, and social well-being. A HNC diagnosis is a major event for everyone involved. This news can have an impact on your emotions, thoughts, and quality of life. After a HNC diagnosis, you and/or your caregiver may experience distress, anxiety, depression, or stigma.

- **Distress** is an unpleasant state that can affect how you think, feel, and act.
- **Anxiety** is a feeling of uneasiness, worry, or fear that usually occurs because of stress.
- **Depression** is a diagnosed condition that causes a persistent feeling of sadness or loss of interest.

While some degree of distress is normal, it is important to know when it is time to ask for help. If you feel consistently distressed or are no longer finding enjoyment in your life, it is time to seek help from your care team. **No level of distress or anxiety is too small to ask for help.** Talk to your care team about how you are feeling so that they can connect you with a mental health professional. Often, simply talking about how you are feeling or what you have experienced can help to reduce distress. Sometimes there is a role for medication to help treat mental health concerns. For more information and resources on mental health, visit [www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns](http://www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns).

## MENTAL HEALTH SUPPORT TYPES

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There are many resources available to help you manage and improve your mental health. It is not a “one size fits all” model. If one does not work for you, don’t give up. There is beneficial support out there for everyone. These options may be offered within your care center or at an outside provider. Speak to your care team about what is available.

**ONE-ON-ONE THERAPY** - Meeting with a licensed therapist, psychologist, or counselor to discuss any concerns. Sessions typically last 45-60 minutes and can be done in-person or virtually.

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**PEER-TO-PEER SUPPORT** - You are matched with someone with a similar cancer diagnosis and experience to provide mentorship and support.

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**GROUP THERAPY** - Group therapy is usually led by a professional such as a therapist or psychologist. Everyone in the group has similar needs and can benefit from each other’s support.

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**SUPPORT GROUPS** - These groups offer peer support or ways to cope from others in similar situations. This can be led by a clinician or other facilitator.

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**HELPLINE/HOTLINE ASSISTANCE** - Typically associated with support organizations. Calling a helpline can give you additional resources appropriate for you and in your area.

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Refer to the end of this publication to see a listing of trusted organizations. CSC and other organizations have helplines, support groups, and other ways to seek support from others.





## TIPS FOR MANAGING YOUR MENTAL HEALTH

- Talk with your doctor and confirm that the specialists on your healthcare team have experience with assisting their cancer patients with their mental health.
- Take someone with you to appointments, for support and an extra set of eyes and ears. Ask your doctor how they can also receive mental health support while you are completing treatment.
- Talk to a therapist or psychologist who specializes in cancer about your feelings and their recommended ways to cope with the impact that cancer has on your mental health. A social worker could also direct you to appropriate resources for you and/or your caregiver.
- Focusing on your physical and nutritional health can have a beneficial impact on your mental health. Consider going for a daily walk or participating in wellness activities, such as meditation.
- Keep a journal as a way to describe and release your feelings. Join a support group or speak with a family member or friend about how you are feeling.
- Pay attention to when you experience feelings of sadness, fear, frustration, nervousness or worry.

Below are some symptoms and side effects people may experience during cancer treatment, as shared by members of our Cancer Experience Registry. Think about how often they affect you.

**Talk with your healthcare team about how to best manage them if you respond with “Sometimes” or “All the Time.”**

		Rarely	Sometimes	All the time
Physical Side Effects	Changes in taste or appetite			
	Difficulty speaking			
	Pain or discomfort in affected area			
	Difficulty chewing or swallowing			
	Dry mouth or dehydration			
	Trouble sleeping or fatigue			
	Difficulty eating or drinking			
Mental Health Concerns	Jaw stiffness or numbness			
	Fear of disease progression or upcoming appointments			
	Feeling sad or depressed			
	Feeling self-conscious about function or appearance			
	Feeling nervous, anxious or afraid			
Other:				

## YOUR HEAD AND NECK CANCER CARE TEAM

Treatment for HNC can be complex and may be difficult to navigate or understand. Your care team should be a group of healthcare professionals that you trust. Due to the challenges that HNC treatment may bring, it is important to seek care early. Your team may include the following:

**MEDICAL ONCOLOGIST:** This physician specializes in the treatment of cancer. They will offer cancer treatment options and referrals. This includes chemotherapy, immunotherapy, and targeted therapy.

**RADIATION ONCOLOGIST:** Radiation Oncologists are physicians that specialize in giving radiation treatment to patients. They will advise the best timing to have radiation therapy. They work closely with your medical oncologist and other healthcare professionals on your care team.

**SURGEON OR SURGICAL ONCOLOGIST:** This person makes any surgical recommendations to remove the cancer. They determine which type of operation will be best for your treatment and perform the surgical procedure.

**OTOLARYNGOLOGIST (ENT):** This is a physician that specializes in caring for the ears, nose, and throat. They may work closely with your cancer care team to support your needs during and after treatment. They can also perform surgeries within the ears, nose, and throat.

**DENTIST, ORAL SURGEON, and ORTHODONTIST:** Dentists, Oral Surgeons, and Orthodontists provide care to your mouth and teeth. They can help with dry mouth, pain or sores in your mouth, and dental implants or temporary inserts.

**NURSE PRACTITIONERS, PHYSICIAN ASSISTANTS, AND NURSES:** Nurse Practitioners (NPs), Physician Assistants (PAs), and Nurses (RNs) may work with the oncologists and help answer questions about your cancer. These healthcare professionals are also a great resource to speak with about your mental health. They can connect you with social workers, counselors, psychiatrists, and others.

**SOCIAL WORKER AND THERAPIST/COUNSELOR:** A Social Worker helps you and your caregiver find resources to cope with cancer and its treatment side effects. Social Workers can help navigate costs and offer assistance with practical concerns. Social Workers and Therapists are trained mental health professionals who can help you address your emotions through individual or group therapy.

**WOUND OSTOMY NURSE:** This nurse is a healthcare professional that specializes in providing care to stomas. In HNC care, a stoma is an opening made in the skin of the neck to help with breathing. This is a surgical procedure often done for those with cancer in the neck or throat area. This nurse will educate you on the procedure and how to care for a stoma.





**REGISTERED DIETITIAN (RD) OR NUTRITIONIST:** These healthcare professionals are experts on diet and nutrition. It is important to see an oncology RD or Nutritionist early to help plan healthy meals during and after treatment. The RD and Nutritionist can recommend different food or meals that may be easier to consume while going through treatment. For specific tips and recipes, visit [www.CancerSupportCommunity.org/Eating-Well-Head-Neck-Cancer](http://www.CancerSupportCommunity.org/Eating-Well-Head-Neck-Cancer).

**SPEECH THERAPIST OR SPEECH LANGUAGE PATHOLOGIST:** These professionals help with speech and swallowing problems by providing treatment and exercises. They will make sure you are consuming enough calories with easy-to-swallow food.

**PSYCHOLOGIST AND PSYCHIATRIST:** Psychologists and Psychiatrists are trained mental health professionals. Psychiatrists can prescribe medications or other supportive care. Psychologists can help you with your emotions through therapy and teaching you other coping skills. They can provide therapy in group or one-on-one settings.

**PHYSICAL AND OCCUPATIONAL THERAPISTS** - Physical Therapists (PTs) and Occupational Therapists (OTs) provide therapy to maintain or improve your physical functioning and ability to perform activities of daily living.



## CAREGIVERS FOR HNC PATIENTS

Everyone's head and neck cancer (HNC) experience is unique. The decisions and support needed for one person may differ from someone else. This makes the role of a caregiver unique, as well. Caregiving for someone diagnosed with HNC brings its own challenges. A caregiver or care partner could be a spouse, friend, family member, or other supporter. The caregiver role can rotate between more than one person if that is what works best for everyone. As a caregiver, you will want to provide the best care for your loved one receiving HNC treatment. This may include providing emotional support, managing medications or feeding tubes, or helping with responsibilities. Some days it may feel selfish to take time and care for yourself. That is not the case! **It is essential to take care of yourself.**

The stress that comes with navigating the HNC experience can lead to a variety of emotions. At times, you may feel like you have too many responsibilities between caregiving and your everyday life. **You are not alone in feeling the emotional effects of this role.** It is natural to feel frustrated, overwhelmed, and tired at times. Identify who is in your support network and ask the care team for resources and support group options. Also, consider connecting with a therapist, social worker, or psychologist to share your experience.

Being a caregiver is an important role. It is rewarding, yet the responsibilities can often be stressful and take up a great deal of time. Throughout caregiving, it is important to take care of your own physical and emotional health. Addressing your ongoing psychosocial health is essential for you to provide long-term caregiving.

For more tips on caregiving, visit [www.CancerSupportCommunity.org/Caregivers](http://www.CancerSupportCommunity.org/Caregivers)

## QUESTIONS TO ASK YOUR CARE TEAM

Having a cancer diagnosis can be overwhelming and when you see your care team, you want to make the most out of your appointment. If you are feeling either better or worse today than at your last appointment, let your healthcare team know. Write down your questions before each doctor's visit. Below are some suggested questions and discussion points. Concentrate on the issues that are most important to you.

What is the type, subtype, and stage of HNC that I have?
Is my cancer related to HPV infection, and if so, how does that affect my treatment plan or overall outlook?
What treatment options do you recommend and why? What are the goals of each treatment?
What are the possible side effects and how will they be managed? Will my ability to speak or eat be affected?
Am I eligible for any clinical trials?
Do I need to see a dentist and how often?
Should I see a Nutritionist or Registered Dietician? Do I need to take any nutritional supplements for extra nutrition?
What should I expect or watch for regarding difficulties with emotions or mental health? What resources are available to me?
Who do I speak to when I am experiencing concerns regarding my emotions or mental health? How do I get in contact with them?
What should my caregiver expect or watch for regarding difficulties with their emotional wellness? What resources are available to them?
Who do I turn to if I have financial concerns?
How do I know if my insurance covers mental health services?
Do you have a list of support groups for HNC patients and/or caregivers?
What follow up will I have after treatment has ended?

The care team can support your needs and also find resources to help you. Open communication is important for both you and your caregiver. Even though a HNC diagnosis may be overwhelming, there are many resources and support networks available to help you. Addressing you and your caregiver's physical and mental wellness will help you navigate the challenges ahead.



## HEAD AND NECK CANCER INFORMATION & SUPPORT

**American Cancer Society**  
800-227-2345 · [www.Cancer.org](http://www.Cancer.org)

**American Institute for Cancer Research**  
800-843-8114 · [www.AICR.org](http://www.AICR.org)

**CancerCare**  
800-813-4673 · [www.CancerCare.org](http://www.CancerCare.org)

**Cook for Your Life**  
[www.CookForYourLife.org](http://www.CookForYourLife.org)

**Head and Neck Cancer Alliance**  
866-792-4622 · [www.HeadAndNeck.org](http://www.HeadAndNeck.org)

**Support for People with Oral and Head and Neck Cancer (SPOHNC)**  
800-377-0928 · [www.SPOHNC.org](http://www.SPOHNC.org)

**Savor Health**  
888-721-1041 · [www.SavorHealth.com](http://www.SavorHealth.com)

**Thyroid and Head and Neck Cancer (THANC) Foundation**  
[www.THANCfoundation.org](http://www.THANCfoundation.org)

**BeTobaccoFree.gov**

**Center for Disease Control (CDC)**  
[www.CDC.gov/Tobacco/Campaign/Tips](http://www.CDC.gov/Tobacco/Campaign/Tips)

**HPV and Me**  
[HPVandMe.org](http://HPVandMe.org)

**Detect EBV**  
[DetectEBV.org](http://DetectEBV.org)

## MENTAL HEALTH INFORMATION & SUPPORT

**Cancer Support Helpline®**  
Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

**Cancer Support Community**  
1-888-793-9355  
[www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**Substance Abuse and Mental Health Services Administration (SAMHSA)- Mental Health Resources**  
[www.SAMHSA.gov/Mental-Health](http://www.SAMHSA.gov/Mental-Health)

**National Alliance on Mental Illness**  
1-800-950-NAMI (6264)  
[NAMI.org/Help](http://NAMI.org/Help)

**National Alliance for Caregiving**  
[www.Caregiving.org](http://www.Caregiving.org)

**National Cancer Institute**  
[www.Cancer.gov/About-Cancer/Coping](http://www.Cancer.gov/About-Cancer/Coping)

**National Suicide Prevention Hotline (U.S.)**  
800-273-8255 or 988 (text or call)

**Substance Abuse and Mental Health Services Administration (SAMHSA)- Helpline**  
1-800-662-HELP (4357)  
[www.SAMHSA.gov](http://www.SAMHSA.gov)

## CANADIAN MENTAL HEALTH RESOURCES

**Hope for Wellness Helpline - Canada**  
1-855-242-3310 · [www.HopeforWellness.ca](http://www.HopeforWellness.ca)

**Suicide Prevention Service (Canada)**  
833-456-4566 or text 45645

**Wellness Together Canada**  
text WELLNESS to 741741 for immediate crisis support · [www.WellnessTogether.ca](http://www.WellnessTogether.ca)



## Cancer Support Community Resources

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**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793- 9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 190 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more: [www.CancerSupportCommunity.org/Find-Location-Near-You](http://www.CancerSupportCommunity.org/Find-Location-Near-You)

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at [www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org).

**MyLifeLine®** — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at [www.MyLifeLine.org](http://www.MyLifeLine.org).

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/Become-Advocate](http://www.CancerSupportCommunity.org/Become-Advocate).

This publication is available to download and print yourself at [www.CancerSupportCommunity.org/Head-Neck-Cancer](http://www.CancerSupportCommunity.org/Head-Neck-Cancer).

For print copies of this publication or other information about coping with cancer, visit [Orders.CancerSupportCommunity.org](http://Orders.CancerSupportCommunity.org)

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