

Being a caregiver for a loved one living with head and neck cancer (HNC) isn't easy. It can be challenging to navigate conversations with those around you—both as an advocate for your loved one, and for yourself. Below is a guide on how to have discussions with healthcare providers, friends, family and colleagues.

### Conversations with the multidisciplinary team

There are various medical specialists on the HNC multidisciplinary team (MDT), and throughout the course of your loved one's treatment and rehabilitation, you'll likely be involved in many conversations with them.

**Here are some tips to help guide those discussions:**

#### Interacting with your loved one's MDT

- **Keep a notebook** where you can write down any new symptoms, treatment side effects, questions, concerns, and notes you and your loved one may have in preparation for appointments.
- **Record instructions** and discuss recommendations and options received from your provider.
- **Reach out with follow-up questions** that might arise after the appointment ends.

#### Advocating for your loved one's needs

- **Managing physical and emotional challenges:** There are various members of the MDT who may be able to help, such as a physical therapist, speech-language pathologist, or mental health professional.
- **Getting a second opinion:** Securing a second opinion can help confirm your loved one's diagnosis, provide perspectives from different specialists, and determine if there are other treatment approaches to consider.



“It truly takes a team to help someone with head and neck cancer get through treatment and rehabilitation. Caregivers deserve a lot of support and appreciation because it's very challenging. There are support groups specifically for caregivers, and I highly recommend caregivers connect with someone they can have peer support with or a mentor.”

—Ashwin, patient



#### About Made of More

Made of More is an initiative that aims to provide support and community for those affected by HNC. Scan the QR code to visit [MadeofMore.com](https://www.madeofmore.com).

# Conversations with family members

As a caregiver, you may be faced with the responsibility of answering questions and explaining details about HNC to family members. **Here are some tips for how to have successful and thoughtful conversations, particularly with teens or children:**

## Explain physical changes they might notice

Sometimes, people with HNC may undergo physical changes from treatments or surgeries that affect things like talking or eating. It's important to prepare others for these changes so it's easier for everyone involved—especially your loved one who is undergoing the changes.

## Find the balance between too much information and too little

Share any information that is relevant but try not to overwhelm them with too much information. Keep it basic and aim to stick to a short list of the most important things they need to know, like what the diagnosis is, what their treatment might involve, and what to expect in the near future.

## Let them ask questions and express their feelings

Be sure to encourage a two-way conversation and let them know it's normal to have a lot of questions and it's ok to be upset. Some kids and teens might benefit from speaking with a mental health professional.

## Check in with them regularly

Many things will change throughout your loved one's diagnosis, treatment, rehabilitation, and beyond. Make sure to have regular check-ins with your family members.

## Share resources and information designed specifically for kids navigating a parent's or loved one's cancer diagnosis

Bright Spot Network is an organization that offers access to a variety of resources and support groups for both parents and kids.

## Be honest and open

Share as many details as you can and be ready to field questions. Don't pressure yourself to have all the answers right away and remember that the things you will need to communicate will likely change over time.

## Use words they will understand

Cancer diagnoses can sometimes be complicated, with lots of specific terms that may not be immediately clear to children or people who don't have experience with cancer. Try to speak in plain, simple language that is easy to understand.



**“ You don't think cancer is ever going to happen to you or in your family or close circle. It was hard to talk with the kids about it. We would try not to get into too much detail and just focus on what the treatment is that needs to get done, what are the next steps, and then how we can surpass this. ”**

**—Becky S., Caregiver**

# Conversations with co-workers

It's possible that your responsibilities as a caregiver may sometimes conflict with work.

You're not required to share this information with colleagues, but if you would like to, here are some tips on how to talk to people in your workplace about your new role as a caregiver:

## Balancing work and caregiving

- **Learn about your legal rights.** There are state and federal laws that can be valuable for people who need to balance work and caregiving. Knowing which laws apply to you and how to approach your employer may provide some relief. Cancer and Careers and Triage Cancer are two organizations that provide information and resources about caregivers' legal rights, and *Magnolia Purpose in Planning* provides connection to legal and financial support for families affected by cancer.
- **Identify a point person** (such as your manager or someone in HR) who you can keep informed of your needs and availability in order to clearly and efficiently manage your workload.
- **Try to advocate for a flexible schedule**, whether that means asking your manager for adjustable working hours or working from home to attend appointments and manage care. Organizations like Cancer and Careers and Triage Cancer have helpful resources for those learning how to balance caregiving and work.

## Approaching conversations in the workplace

- **Decide ahead of time how many details you want to share**—both now and in the future.
- **Anticipate questions you may not want to answer**, and don't feel pressured to tell colleagues or employers everything.
- **Decide who to tell**, when, and in what setting to tell them.



“ Sometimes I want people to know about my role as a caregiver so they can be flexible or understand why I'm going to miss that meeting, and **other times I just want to be Allison**, the person who does this job, and I don't want you to ask about that part of my life right now, because I'm trying—just for a moment—not to think about it. ”

—Allison B., Caregiver

# The importance of self-care

There are many adjustments to navigate with HNC, which can impact one's vital functions like eating, swallowing, smelling, tasting, and speaking. As a caregiver, you may help your loved one process these changes in addition to helping with daily tasks such as assisting with eating, preparing meals and medications, shopping and chores, dressing, bathing, and taking them to appointments. **Whatever role you play, remember that your physical and emotional health are also important, and it's crucial to take care of yourself so you can provide the best care for your loved one.**

## How to prioritize self-care

- **Join a support group:** Being a caregiver may leave you feeling overwhelmed or alone at times. Connecting with other caregivers and people in the HNC community can help you feel a greater sense of belonging and purpose, and it can be comforting to hear from others who have been in your shoes.
- **Build a network of support:** Gather a group of friends, family members, neighbors, and other caregivers found through support groups.
- **Ask for specific help:** Sometimes you need someone to help you with your own everyday tasks, like shopping for groceries or picking your kids up from school. Ask people in your support network for help with specific tasks, so it's clear how they can help support you. Organizing and preparing meals is one way, and Meal Train is a resource that can help coordinate meal deliveries to patients and their families.
- **Take time for yourself:** Even if it's just 15 minutes a day, remember to reserve some alone time to do something relaxing and rejuvenating, whether it's reading, meditation, watching your favorite show, journaling, exercising, listening to music or unwinding on the couch. Do whatever helps you focus only on yourself and get some respite from your duties as a caregiver.

“Caregivers often feel like they shouldn't ask for help and should be able to do it all themselves, but typically people in their community want to help. I like to say that delegation is a form of self care.”

—Allison B., Caregiver



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