

Made of More

Navigating your patient-caregiver relationship

After a head and neck cancer (HNC) diagnosis, it's common for romantic partners, family members or close friends to help their loved one by becoming their caregiver during the cancer journey. It's possible that some patients and caregivers may experience strain in their relationships caused by the changes in their roles and emotions that may follow a HNC diagnosis.

Every patient-caregiver relationship is unique. If you're experiencing challenges, it's important to work together to find effective ways to communicate with compassion during what can be a period of adjustment and stress. Below is a guide with tips and tools designed to help navigate some of these situations.

“ After my husband's HNC diagnosis, I was put into a position of providing intense at-home medical care on top of parenting, working and all of my other roles. The number of plates I have spinning at any given moment can be a lot. As much as I slip into the nursing role, I'm still his wife and support him in that way as well. ”

Allison, caregiver

Common causes of strain

In the patient-caregiver relationship, there are many situations that can become a source of strain and disconnection following a cancer diagnosis, including:

- **New and/or changing emotions**—for both the patient and caregiver—like feeling unappreciated, alone or a loss of control
- **Challenges during treatment and recovery**, including new routines and adjustments around eating abilities
- **Lack of communication**
- **Decision-making**—whether it be about daily tasks, or larger topics like treatment choices
- **Shifting roles and juggling new responsibilities**
- **Changes in social life, finances, career and routine**

Everyone expresses their emotions in unique ways

It's important to remind yourself that experiences, feelings, opinions and reactions may differ between patient and caregiver. Differences can, of course, be difficult to resolve and cause feelings of stress. Try to communicate openly and clearly, allow yourself time to process your own emotions, be patient, give space and time when it's requested and have empathy for the other person.



About Made of More

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

Examples of patient-caregiver relationships

Family members

Whether the person being cared for is a parent, sibling or close relative, it's important to work together as a family to maintain an environment of openness, connection and compassion. Some tips include:

- **Holding family meetings** for sharing information, like the latest update received from the care team or determining ways each person can pitch in around the house
- **Expressing thoughts and feelings** around financial concerns and balancing work with caregiving
- **Keeping an open line of communication** with children in the family and making space for them to share any feelings they may have. You may also want to share possible side effects, like hair loss or fatigue, so they won't be surprised
- **Determining which family member will be spearheading conversations** with friends and other relatives, how much you're comfortable sharing and how often

Romantic partners

According to the National Cancer Institute, nearly all couples feel more stress than usual after receiving a cancer diagnosis. There are some issues that may arise that are more specific to this relationship, like:

- **Feeling disconnected romantically**
- **Struggles with parenting and childcare**
- **Challenges keeping up with daily chores**
- **A loss of intimacy**

It's important to engage in activities together and try to find ways to remain close. You can try:

- **Going on dates or spending time together**, whether it's watching a movie at home, going out for coffee or taking your pet for a walk
- **Cooking together** to help ease challenges related to eating
- **Making plans for special occasions** like birthdays, holidays and anniversaries
- **Finding ways to increase connection**, like doing hobbies or activities you can both enjoy together

Helping children and teens cope with a loved one's cancer diagnosis

Although it may be difficult, it's necessary to be open and honest with children in your life. Talking about serious issues can be uncomfortable. It's important to try to explain that nothing they did caused this, and that it's okay to have big feelings. You'll want to use words that are appropriate for the child's age and development, too.



Talking about difficult topics and having important conversations

HNC diagnosis, treatment and recovery can bring up a lot of complex emotions for both the patient and caregiver. Knowing how to approach tough conversations can help keep an open line of communication between you and your loved one.

How to bring up hard topics

- **Practice what you'll say beforehand**
- **Find a quiet time** and ask permission to speak openly
- **Understand that the other person may need to process and wait** until they feel ready to have a hard conversation
- **Speak from the heart**
- **Be an active listener**—listen to understand, not to respond. Don't feel the need to resolve everything at once

“ Helping a loved one through their cancer diagnosis can be very hard both emotionally and physically. I struggled to communicate how I was feeling to my husband because I didn't want to burden him with my worries as he was going through his treatment and recovery. It was hard to be able to understand what he needed and how to make him feel more comfortable, but I was there. I feel that patients need somebody who is there with them, who gives that support and company in that difficult time. ”

Becky, caregiver

Try to start the conversation

Starting a conversation can be the hardest part.

The other person might be more willing to respond if you begin first. You can do this by saying things like:

- “I know this is hard to talk about but know that I'm ready to listen and talk any time.”
- “I feel it would be helpful to talk about how your treatment is going and how we're both coping. Would you be willing to talk with me about that sometime this week?”

It may be helpful to ask questions when approaching a tough conversation to help the other person feel seen and heard. Here are some examples of questions you could ask:

- “What makes you feel cared for?”
- “What are you thankful for today?”
- “What do you need more of? What do you need less of?”

If you're struggling to engage in tough conversations, it's okay to seek professional help

It's normal for patients and their caregivers to feel disconnected, and there's nothing to be ashamed of if you feel like you could use help from an unbiased third party like a therapist, counselor and/or cancer support group.

Enlisting a professional can be a good way to facilitate healthy communication, and there are many therapists who specialize in helping people and families dealing with cancer. Visit the Resources section on MadeofMore.com and click on “Find Support” to find links to various support groups and communities for HNC patients and caregivers.



Ways to improve communication

When you and your loved one are experiencing changes in your relationship following a cancer diagnosis, authentic and compassionate communication can help you understand each other's limits and needs.

Make decisions together

You and your loved one should try to approach decision-making as a team. It may help to think through:

- Which decisions should you make together?
- Which decisions should each of you make alone?
- What were some other tough times you got through together? How is this situation similar/different?
- Which tasks are easier? Which are harder?
- What do each of you need?

Be open and honest

Try these approaches to help foster positive and authentic communication:

- Use "I" statements like "I feel _____" or "I need _____" rather than focusing on the other person's actions, which can sometimes lead to feelings of defensiveness
- Focus on the present instead of bringing up past examples of hurt feelings
- Practice respect for yourself and your loved one
- Speak about your own feelings and what you can control

“ My wife was such an important person and caregiver in my recovery process with how strong she was. She was handling so many things at that time and showed me that I have a person I can trust my life with, who really loves me and takes care of me. It's important to have that type of support when you are going through recovery. ”

Ashwin, patient

Set and respect each other's boundaries

It's important for each of you to establish and maintain boundaries, like:

- How and when you will have check-ins or hard conversations
- Consistently taking "me-time" and prioritizing self-care
- Sticking to a schedule
- Finding ways for each of you to maintain your sense of independence

Remember to show appreciation for the other person

Whether you are the patient or the caregiver, it's important to express gratitude, either verbally or through small acts you know they'll appreciate. It's important to give each other grace and connect with your loved one through positive gestures and interactions.

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