

FOOD, COMMUNICATION, AND CONFIDENCE

# Throughout Your Treatment



During treatment, you may want extra support. Changes in your body may lead to changes in how you eat, talk, and feel about yourself. Take a look at the suggestions in this guide for ideas that may help.



[Managing Meals During Treatment](#) ▶



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## CAREGIVER CORNER

Pay attention to this section on the following pages. It offers tips for you as a caregiver.

# Managing Meals During Treatment

You may have noticed some changes in the way foods taste, feel, smell, or even how they appeal to you. During treatment, it's important to keep up your strength with proper nutrition, even though it can feel challenging. You can always ask your health care team if you need to talk to a dietitian or nutritionist if you feel you're not able to eat enough.

Here are some ideas to help manage mealtimes:



Choose soft foods that are easy to chew and swallow



Cook foods until soft and tender to make eating easier



Drink with a straw to help push liquids past painful points



Marinate and add extra flavor to help foods be more appetizing to you



Cut food into small pieces or puree it for ease of eating



Try adding moisture with gravies and sauces to help prevent scraping



Find foods that look and smell good so you are excited about eating



Eat small meals frequently instead of a few large meals

## FOOD FOR THOUGHT

There are organizations dedicated to helping VHL patients and their families. The organizations listed below have more information about nutrition and VHL treatment.

- [The VHL Alliance](#)
- [The National Organization for Rare Diseases \(NORD\)](#)
- [The Genetic and Rare Diseases \(GARD\) Information Center](#)
- [Disease InfoSearch](#)

## CAREGIVER CORNER

Your loved one's food preferences might change from day to day, so try not to be upset or surprised if you aren't able to predict what or when they want to eat.

# Finding a Connection

Food can represent a connection to memories, culture, and social interaction. How you eat may be changing, possibly leaving you feeling left out. Identifying the connection between your emotions and certain foods can help you cope with the feeling of loss.

**IMAGINE YOUR FAVORITE FOOD OR MEAL IN YOUR MIND...**

## ...NOW, CONSIDER



**Why did you choose this specific food or meal?**

*Example: Because it's my favorite food and I miss it the most.*

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**What do you remember when you think about it?**

*Example: We always made this on Thanksgiving and I think of my family.*

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**What feelings come up around those memories?**

*Example: It makes me think about being happy with all the people I love.*

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**How can you recreate those feelings without it?**

*Example: I can have a party with different foods—or even without food—and make new memories.*

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## CAREGIVER CORNER

You can try this activity if you feel like you are missing some of your favorite foods while you adjust to your loved one's dietary needs.

# Taking a Minute for Yourself

When treatment leads to changes in your body and to how you eat, it can affect your confidence and create stress. Taking a minute to focus your attention on the present moment may help reduce stress. You can do these activities anywhere at any time. All it takes is 1 minute.



## BREATHE

Count down from 10, breathing in on 10, out on 9, in 8, out 7, in 6, out 5.

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## GROUND

From a standing or seated position, place your feet flat on the ground and notice how you feel.

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## GAZE

Look out a window and focus your gaze on a tree, flower, or other natural object. Notice all you can about it—the color, the texture, and any other details.

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## FOCUS

Bring your attention to your body and scan each part of your body, giving each part a moment of attention before moving on to the next part, head to toes.

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## QUIET

In a comfortable place, close your eyes. Turn your attention to your breath to help clear your mind for some quiet time from your thoughts.

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## NOTICE

In turns, focus on each 1 of your 5 senses, taking a moment to notice what you smell, taste, feel, hear, and see.

## CAREGIVER CORNER

You may experience a lack of confidence and stress as well. All it takes is 1 minute. Any of these 1-minute activities may help you cope with these feelings, too.

# Spending Time With Loved Ones

You may notice how your life changes are affecting your social and family life, especially around events that involve food. It's important to talk to your loved ones about this so they understand when and why you are feeling left out. Try thinking about the conversation you're going to have before you start.

## 1. WHO

Choose who you want to talk to.

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*Example: My best friend*

## 2. WHAT

Pick 1 thing that you would like to talk about.

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*Example: I want him to know I can't go out to eat.*

## 6. HOW

Try the activity on the next page for more ideas about how to start the conversation.

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*Example: DEAR loved one,...*

## SET UP THE CONVERSATION

## 3. WHERE

Find a relaxed and comfortable space.

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*Example: I will invite him over and we can talk.*

## 5. WHY

Decide what your goal is.

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*Example: I want to spend more time with my friend.*

## 4. WHEN

Find a time when you have the most energy.

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*Example: I don't like mornings, but I have energy around 4 PM.*

## CAREGIVER CORNER

Try this activity if you're having a hard time talking about what your loved one is going through during treatment. Remember, you're going through a lot too. It's important to express yourself, even if it feels difficult.

# Finding the Confidence to Have Conversations

Because food is such an important part of life, you may feel like you are missing out on daily events with loved ones when you aren't able to join in the eating experience. How can you start a conversation about this? Start with "DEAR."

**D** **DESCRIBE** the topic in a simple way, stating only facts.  
*Example: It is hard for me to say no every time you ask me to dinner.*

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**E** **EXPRESS** how you are feeling using "I" statements.  
*Example: I feel left out when I can't go to our favorite restaurants together.*

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**A** **ASSERT** what you want in a clear, firm way.  
*Example: I want to be able to do something else with you besides going out to eat.*

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**R** **REINFORCE** how this will benefit both of you.  
*Example: We can spend more time together, which I really enjoy.*

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## CAREGIVER CORNER

You may also feel a sense of loss about food. It may seem like you can't enjoy foods that your loved one can't eat. This activity can help you talk with them about how you're feeling and what you need.

◀ [Spending Time With Loved Ones](#)