HEAD & NECK
CANCER ALLIANCE

THE FIRST YEAR OF HEAD & NECK CANCER:
Guidance, Support, and What Lies Ahead

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THE FIRST YEAR OF HEAD AND NECK CANCER: GUIDANCE, SUPPORT, AND WHAT LIES AHEAD

MODERATOR

Mark S. Chambers, DMD, MS | The Susan and Christopher Damico Chair in Viral Associated Malignancies | Deputy Chair, Department of Head & Neck Surgery | Chief and Medical Director, Section of Oral Oncology | Professor, Department of Radiation Oncology | University of Texas MD Anderson Cancer Center

MEDICAL PRESENTERS

Matthew Spector, MD | Chief, Division of Head and Neck Surgical Oncology and Microvascular Reconstruction | Director, Head and Neck Surgical Oncology and Microvascular Reconstruction Fellowship | Professor of Otolaryngology, University of Pittsburgh School of Medicine

Taylor Wilde, M.S., CCC-SLP, BCS-S | Speech-Language Pathology Supervisor, Rehabilitation Services, City of Hope

ALLIANCE AMBASSADORS

Todd Landaburu - Survivor of Mouth Cancer

Charlotte Bayala - Caregiver to Husband, Survivor of Thyroid Cancer

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Todd Landaburu
Alliance Ambassador
Survivor of Mouth Cancer

Overcoming & Forging Forward

- Before my diagnosis, I was managing depression and low self worth.
- Offered my dream job in June 2022
- In the middle of July, began experiencing shooting pains from my neck to my ear that would last for months while waiting for an opening with an ENT
- Eating and drinking became difficult. Knew it was more than a sore throat.

Managing and Maintaining

- In the middle of July, began experiencing shooting pains from my neck to my ear that would last for months while I awaited an opening with an ENT
- Maintained nutrients by having a feeding tube before treatment began
- Bonding with my care team, Nurse Audrey had a plan and was going to hold me to it
- Spent 10 days in inpatient

Coming Home

- Made it home to enjoy Thanksgiving with family but wasn't allowed to have food or liquid orally
- Concurrent radiation and chemo treatments began at Christmas time
- After roughly 3 weeks of treatments, the physical toll began - started a severe mental downward spiral. Maintaining faith and belief that I was meant to be able to overcome kept me alive
- Meditated, believed and accepted what was happening - even in the darkest times

Keeping a Sacred Family Tradition

- After first “clean” PET scan post-treatment, was able to continue a 23-year family tradition of attending the San Francisco Giants Home Opener
- First dinner out since early January at the House of Prime Rib

Getting Stronger

- At 3 months post-treatment, was able to eat small portions of solid food. Still 80% reliant on feeding tube
- April 25, 2023 - Day 1 of three consecutive years of exercising at least 50 minutes daily (streak continues!)
- Began home physical training and workouts to build strength back Slowly started to increase calorie intake
- Began to live again

Back To Full Strength

- Today, healthier than I have ever been
- Full calendar year of exercising 50 minutes daily
- Back to golfing, snowboarding, and playing soccer with friends
- Family and personal relationships are stronger than ever

During my darkest days, I needed a sense of belonging. A sense that I wasn’t alone. Vowed to live a life being of service to others who are in isolation.

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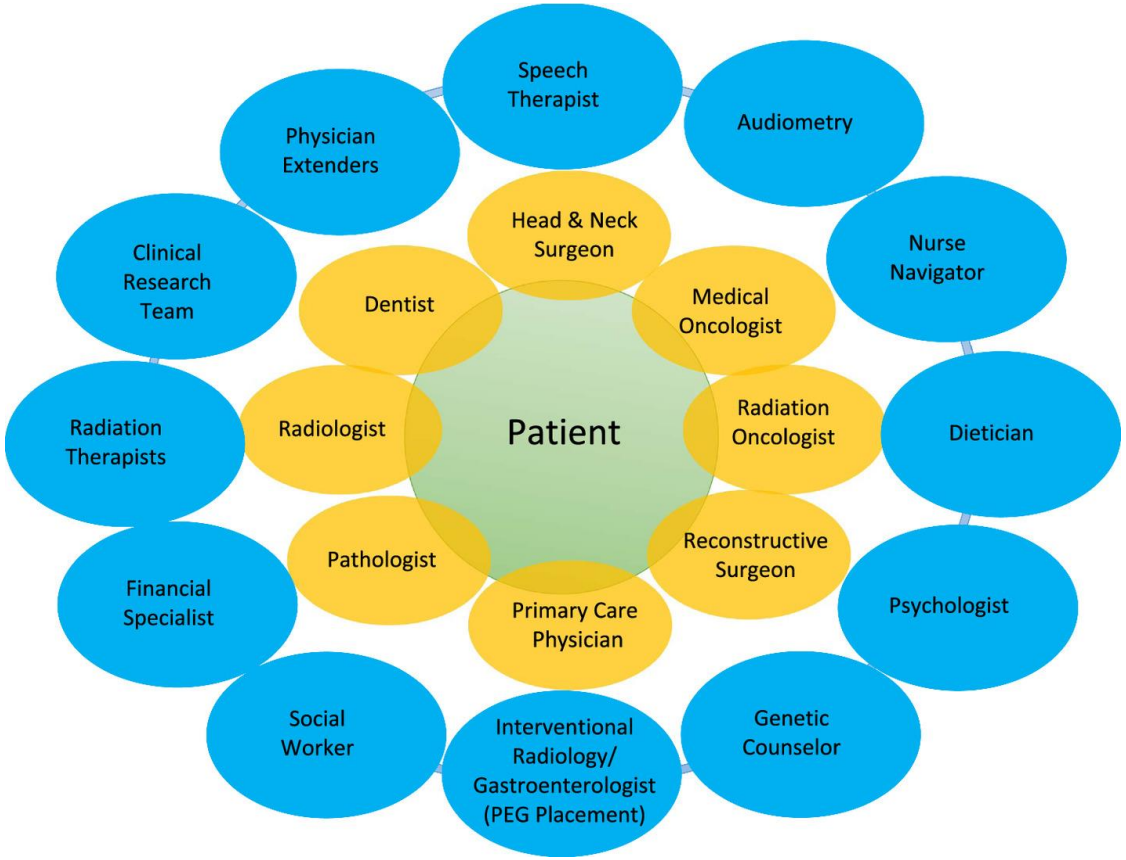
The Emotional Impact of Diagnosis

- The first many visits and diagnosis can feel overwhelming and frightening
- Patients often experience anxiety, uncertainty, and information overload
- Fear of treatment side effects and impact on speech, swallowing, and appearance is common
- Family members and caregivers are also deeply affected
- Early support and clear communication are essential

Understanding Your Treatment Team

- Head and neck cancer treatment is complex and highly individualized
- Care is best delivered in a multidisciplinary setting
- Teams may include surgeons, radiation oncologists, medical oncologists, speech pathologists, dietitians, dentists, social workers, and nursing navigators
- Collaborative care improves coordination and patient outcomes



The Importance of Treatment at Specialized Centers

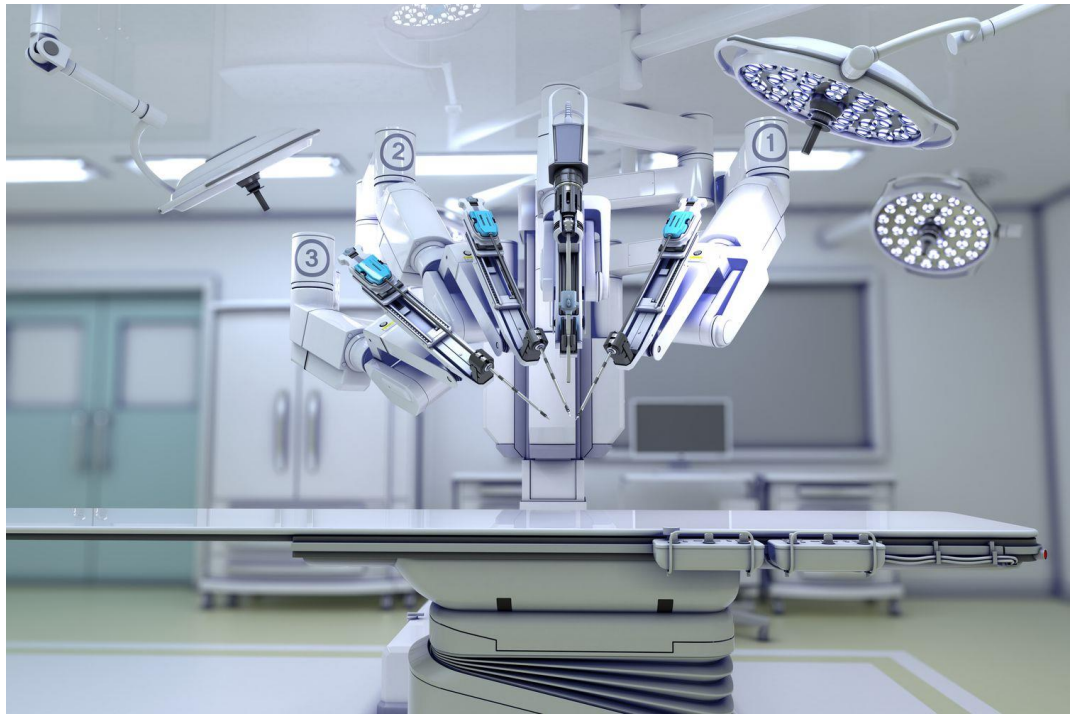
- High-volume multidisciplinary centers provide coordinated expertise
- Access to advanced technologies and clinical trials
- Comprehensive supportive services are available
- Patients benefit from streamlined communication between specialists
- Second opinions can help patients feel confident in their care plan

The Role of Nursing Navigators

- Nursing navigators help patients move through a complex healthcare system
- Assist with scheduling appointments and coordinating care
- Provide education and emotional support
- Help connect patients with financial, nutritional, and supportive resources
- Serve as a trusted point of contact during treatment

Treatment Options

- Surgery may be used to remove tumors and involved lymph nodes
- Radiation therapy is commonly used for local and regional control
- Chemotherapy may enhance radiation or treat advanced disease
- Immunotherapy is increasingly important for recurrent or metastatic disease
- Many patients receive combinations of these treatments



The Dual Role of the Head and Neck Surgeon

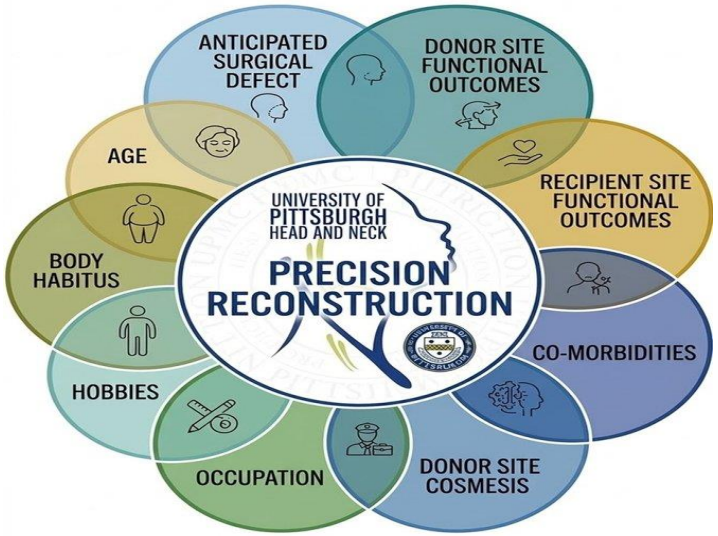
ROLE 1: CANCER REMOVAL

- **Achieve oncologic cure**
- Remove the primary tumor with clear surgical margins
- Address regional lymph nodes when indicated
- Preserve critical structures wherever oncologically safe
- Collaborate with radiation and medical oncology on combined-modality planning

+

ROLE 2: RECONSTRUCTION

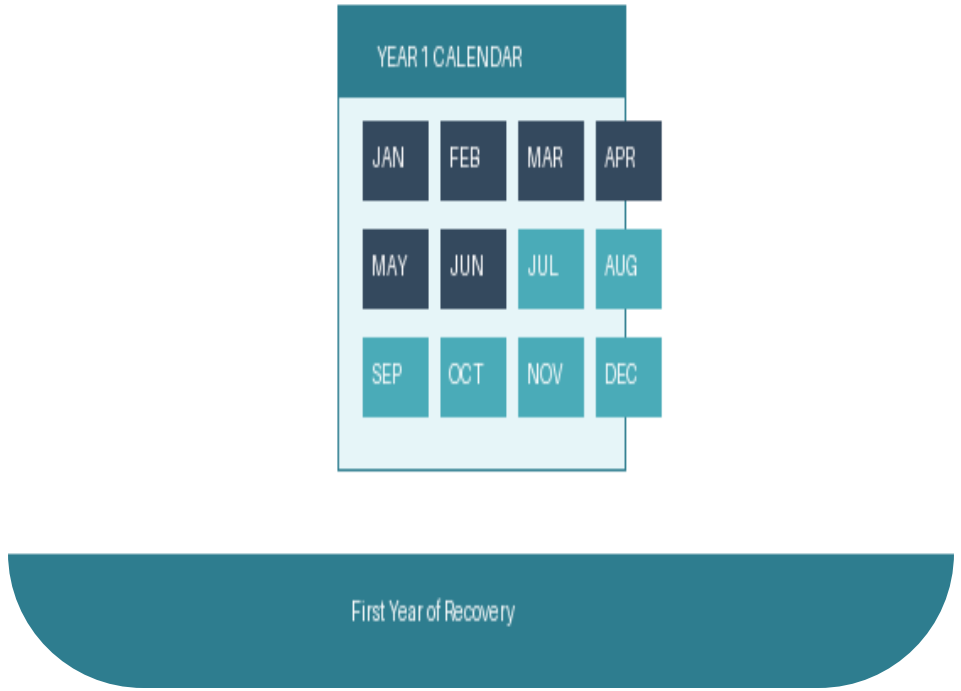
- **Restore form and function**
- Rebuild what must be removed to treat the cancer
- Tailored to each patient's anatomy, goals, and lifestyle
- May use local flaps, regional flaps, or free tissue transfer



Precision Reconstruction considers the whole patient

What Happens During the First Year?

- Frequent visits during and immediately after treatment
- Monitoring for treatment response and side effects
- Speech, swallowing, and nutritional rehabilitation may be needed
- Physical and emotional recovery can take time
- The first year often involves adjustment to a ‘new normal’



Survivorship and Long-Term Follow-Up

- Follow-up typically lasts at least 5 years
- Surveillance visits help detect recurrence early
- Long-term management of swallowing, speech, dental, thyroid, and nutritional issues is important
- Mental health and social support remain essential
- Survivorship clinics provide coordinated long-term care

Support Systems Matter

- Support groups help patients and caregivers feel less isolated
- The Head and Neck Cancer Alliance provides education and advocacy
- Family, friends, and caregivers are critical partners in recovery
- Patients should be encouraged to ask questions and seek support early

Key Takeaways

- The first year after diagnosis is challenging and support systems important
- Multidisciplinary care improves coordination and outcomes
- Treatment may involve surgery, radiation, chemotherapy, and immunotherapy
- Nursing navigators and survivorship programs are invaluable resources
- Patients are not alone — support continues well beyond treatment

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Taylor Wilde, M.S., CCC-SLP, BCS-S
Speech-Language Pathology Supervisor
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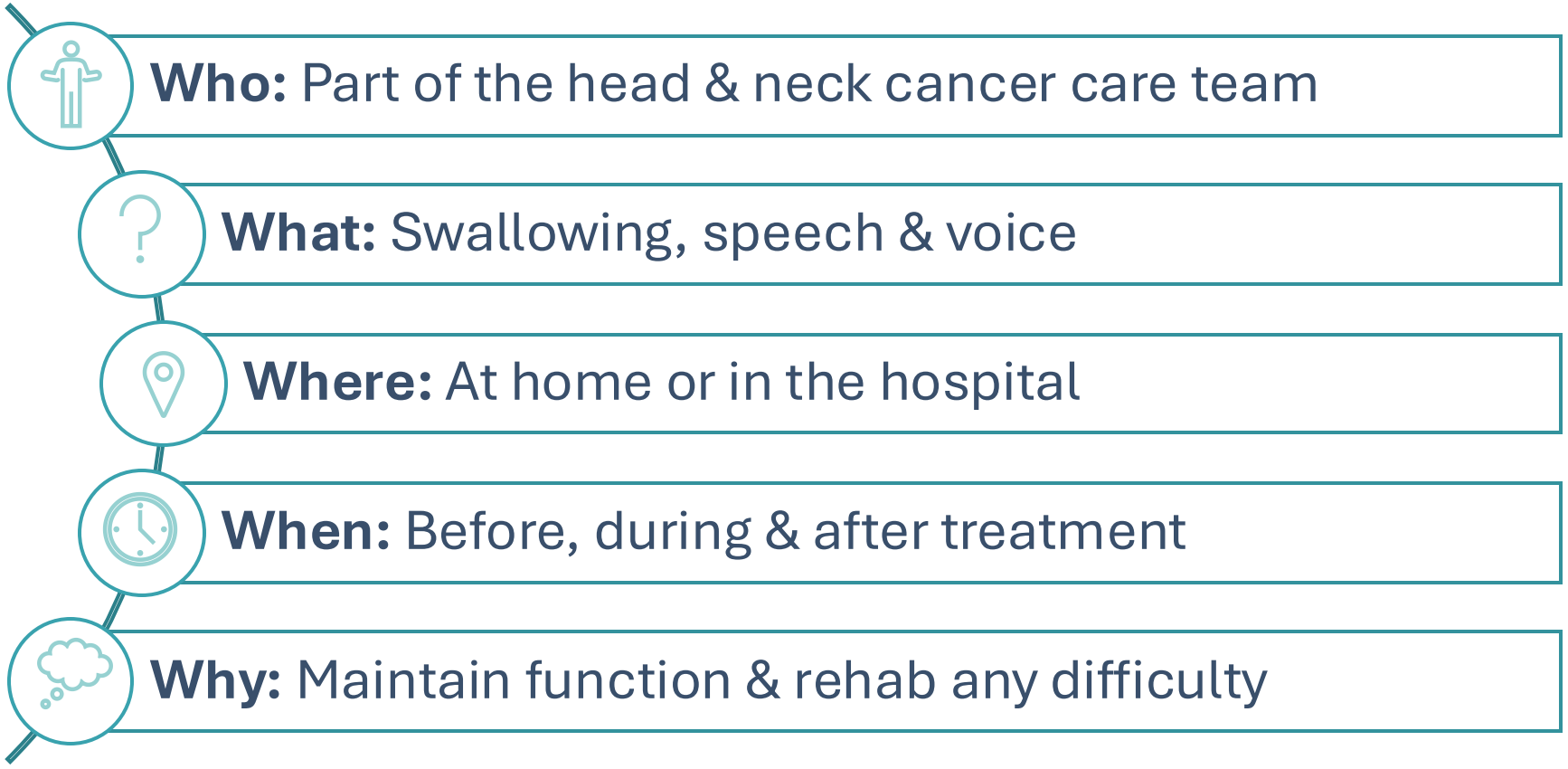
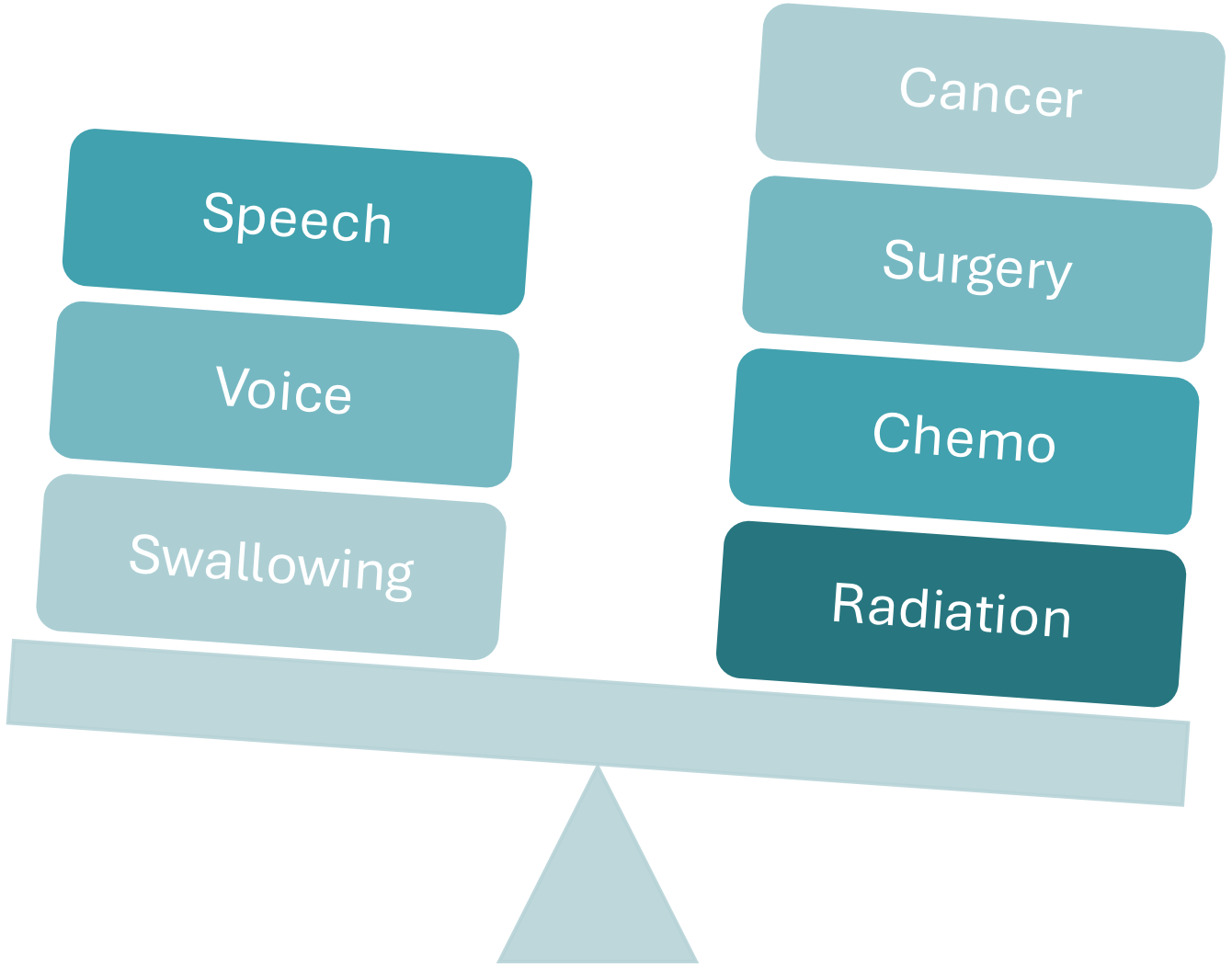
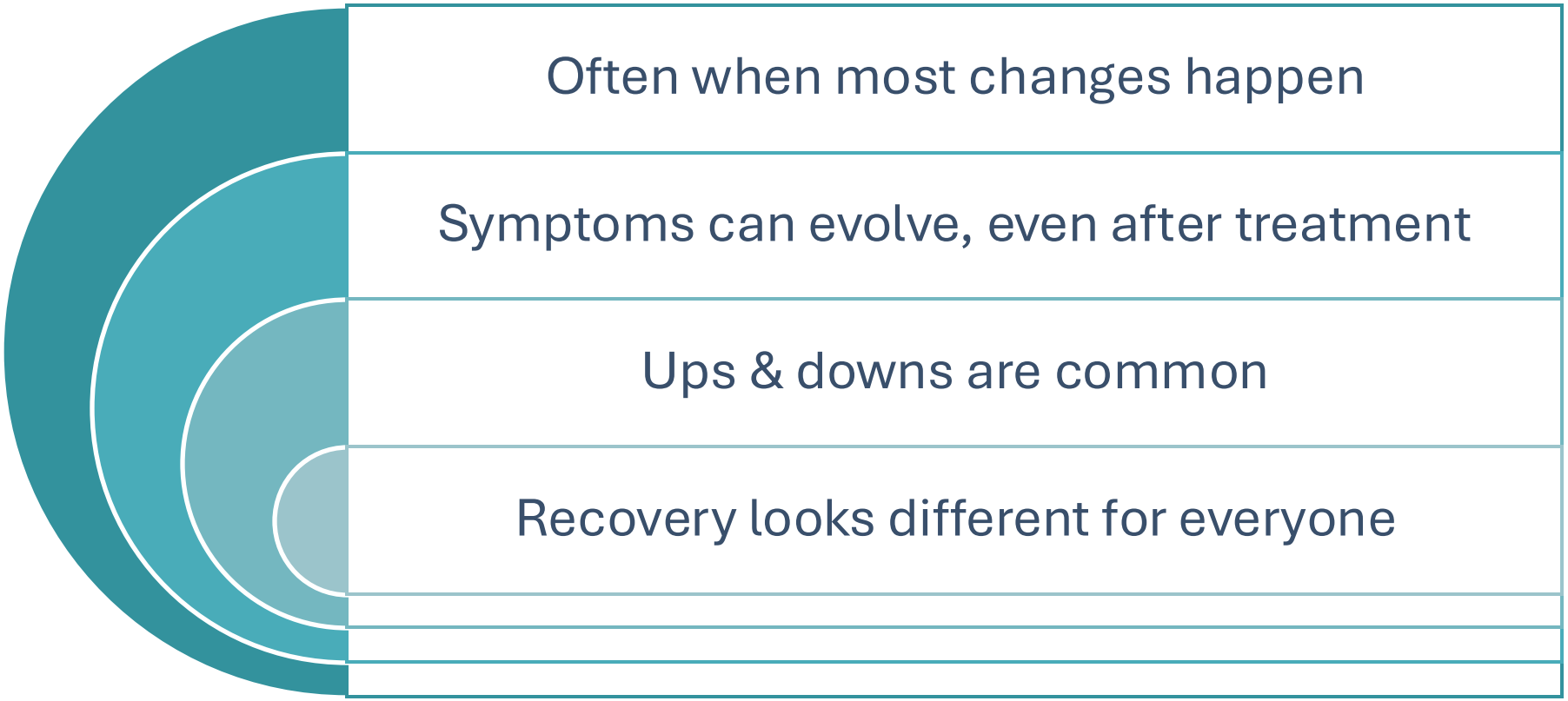
Speech-Language Pathologist (SLP)



Say More



The First Year



Swallowing

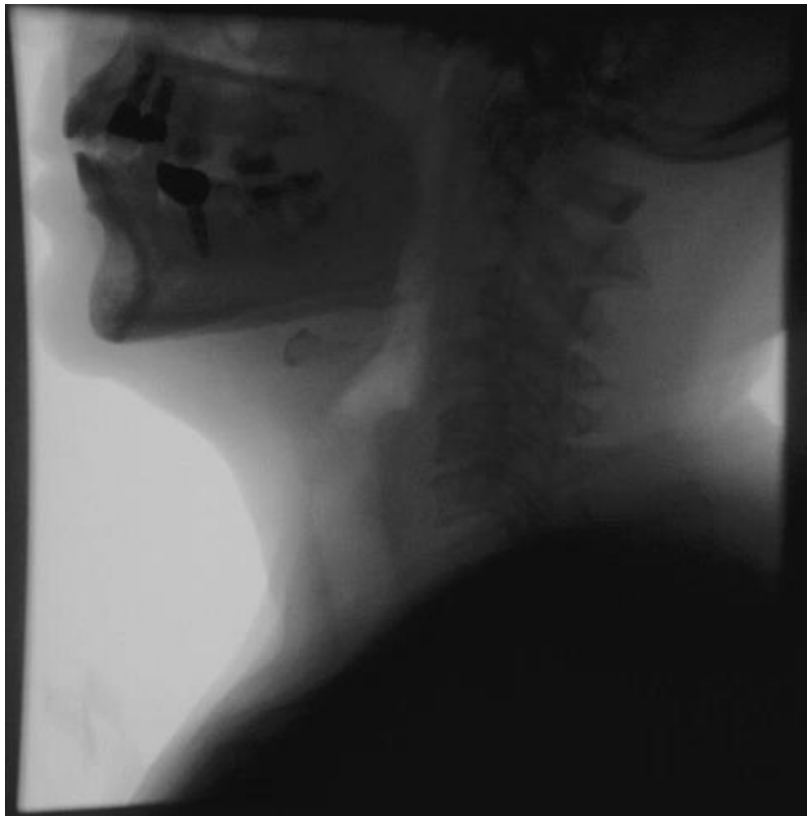
Changes depend on your specific cancer and treatment

- Dry mouth
- Taste changes
- Mouth or throat pain
- Jaw tightness
- Coughing when eating
- Food sticking
- Longer mealtime
- Weight loss

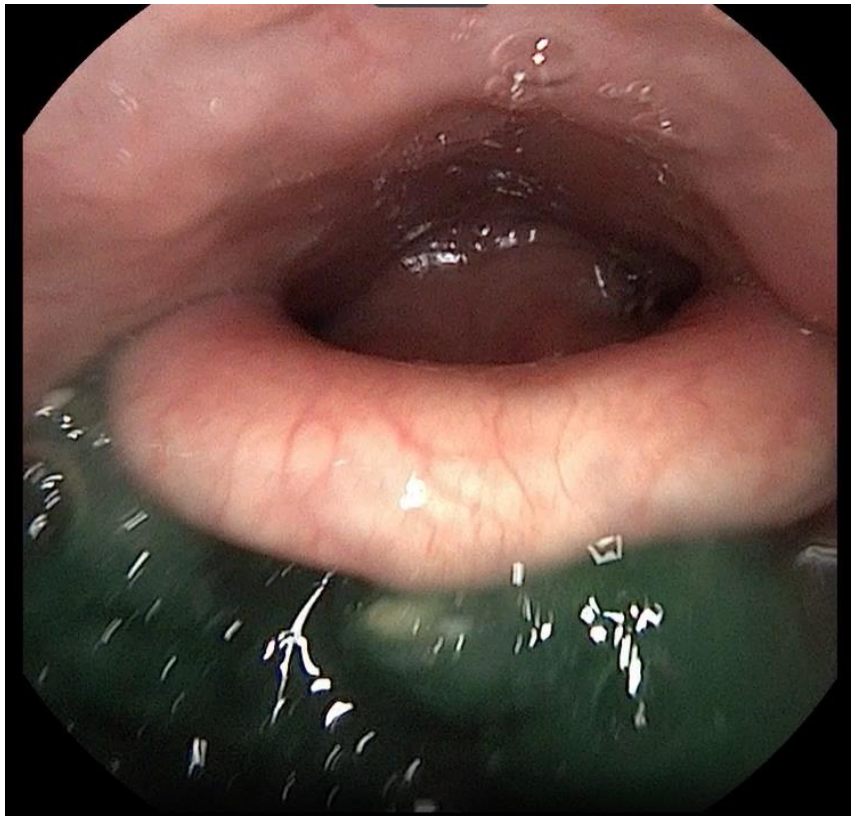
What Can We Do?

- [x] Ask your doctor for an SLP referral
- [x] Undergo a swallow test with your SLP
- [x] Follow strategies to make it easier
- [x] Complete exercises to strengthen muscles
- [x] Manage symptoms as best you can
- [x] Keep eating & drinking

Swallowing Tests



Modified Barium Swallow Study (MBSS)



Fiberoptic Endoscopic Evaluation of Swallowing (FEES)

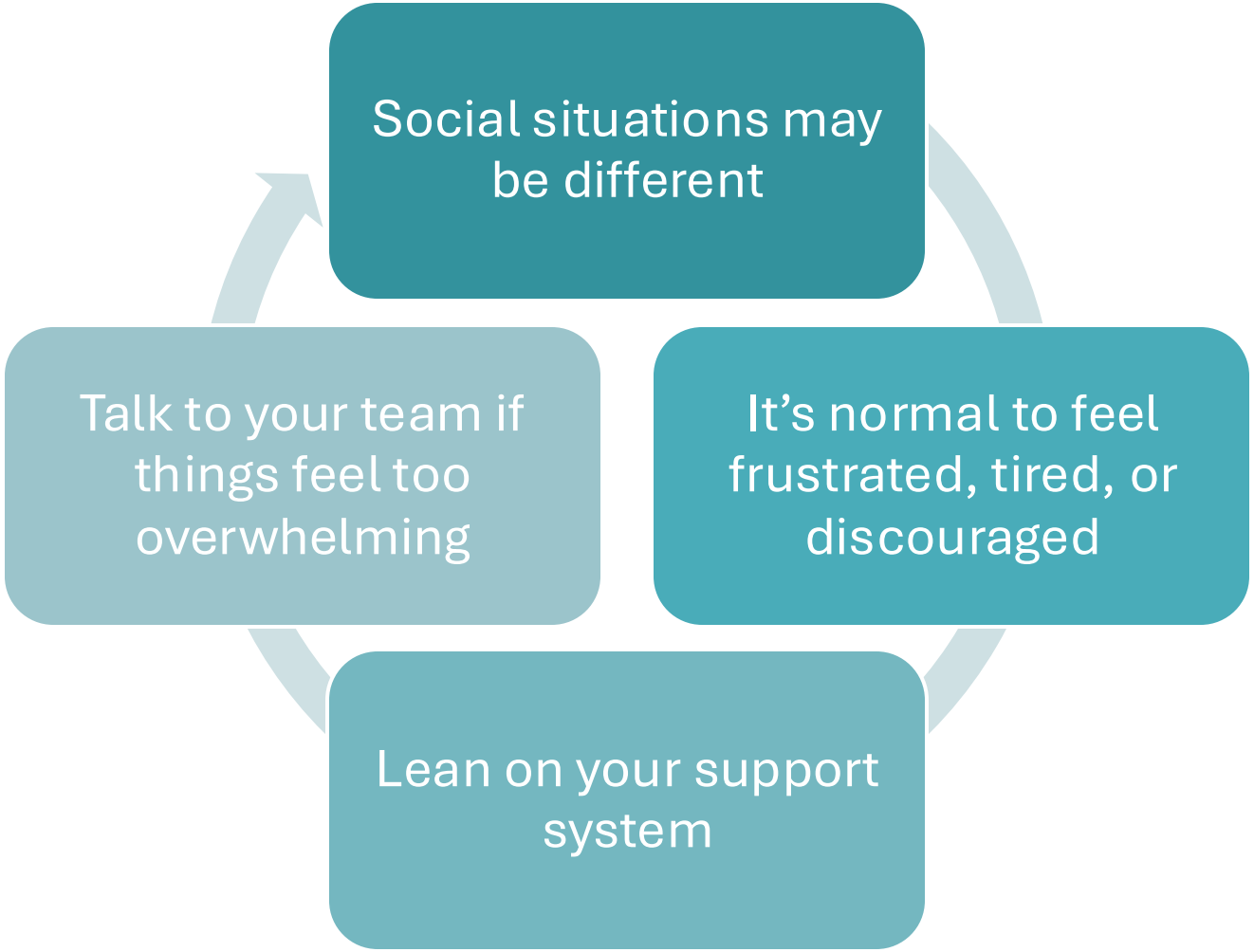
Speech & Voice

Changes depend on your specific cancer and treatment

- Hoarse or strained voice
- Fatigue when talking
- Low volume
- Reduced clarity
- Difficulty being understood
- Needing to repeat yourself

Your SLP will give you strategies and exercises to help

Navigating Changes



Timeline

BEFORE TREATMENT

- Baseline SLP evaluation
- Education
- Preventive exercises

DURING TREATMENT

- Symptoms may worsen
- Focus on maintaining function
- Exercises

0-3 MONTHS AFTER

- Healing phase
- Swallowing & speech may still fluctuate
- Exercises

3-12 MONTHS AFTER

- Gradual improvement
- Continued therapy can help (more exercises)

Takeaways

- Changes in swallowing, speech & voice during the first year are normal
- SLPs are here to support you before, during, and after treatment
- Focus on what you can control and take things one step at a time
- Reach out early if eating, drinking, or talking becomes difficult

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Charlotte Bayala
Alliance Ambassador
Thyroid Cancer Caregiver
Creator of The Cancer Caregiver Podcast
NW Arkansas

Announcement Specialist

The invisible labor of being a caregiver begins with communication

Communication With Your Loved One

One honest question a day:
How are you actually doing right now?

You are not just a support person.
You are a member of the care team.

- Advocacy is not overstepping.
- Bringing information to the table is not intrusive.
- Asking a clarifying question is not disruptive.

Your words matter.
Your presence matters.

Communication is one of the most profound acts of love there is.

RESOURCES

Alliance Resources:

- **Online Community Support Group**
  headandneck.org/support-community/
- **Peer-to-Peer Program, Sign Up for a Mentor**
  headandneck.org/peer-to-peer-program/
- **Financial Assistance Program**
  headandneck.org/financialassistance/
- **How do a self-exam:**
  headandneck.org/self-exam-guide/
- **Side effect resources:**
  headandneck.org/managing-side-effects/
- **Clinical Trial Finder**
  headandneck.org/hnc-resources/clinical-trials/clinical-trial-finder/

Alliance Videos:

- **What to Expect the First Year**
  https://youtu.be/2OQkPKNsIvQ?si=cn3ODT69baXmsLQ7
- **Head & Neck Cancer: The Importance of Comprehensive Rehabilitation**
  https://youtu.be/P0TNzoulars?si=4_TGvcsqiw18Xw3Z
- **Life Beyond the Diagnosis: Navigating Long-Term Survivorship of Head and Neck Cancer**
  https://youtu.be/2vQVYTp7xhQ
- **Find other videos here:**
  https://www.headandneck.org/video-directory/

RESOURCES

Other Resources:

NCCN Patient Guidelines
https://www.nccn.org/patientresources/patient-resources/guidelines-for-patients

NCCN Mobile App
https://www.nccn.org/guidelines/nccn-mobile-app

Cancer Council: Living Well After Cancer
https://www.cancercouncil.com.au/cancer-information/living-well/after-cancer-treatment/

Cancer and Careers
cancerandcareers.org/en

Triage Cancer
Triagecancer.org

MSKCC: Resources for HNC Survivors
https://www.mskcc.org/cancer-care/patient-education/resources-head-and-neck

AHNS: Cancer Survivorship
https://www.ahns.info/survivorship_intro/

UHN What to Expect During and After Your Recovery
https://www.uhn.ca/PatientsFamilies/Health_Information/Health_Topics/Documents/What_to_Expect_During_After_Head_and_Neck_Cancer_Treatment.pdf

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Questions?

Thank you for attending!

CONTACT US:

info@headandneck.org

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- Thank you for joining our 2026 AHNS/Alliance June Webinar! We value your feedback and want to hear from you.
- Webinar attendees will receive an email with a link to our feedback survey. Attendees who complete the survey will be entered for a chance to win a $50 Visa e-gift card. Only attendees who complete the survey will be eligible to win.

📌 How to Enter: Simply fill out the post-webinar survey—it's that easy.

- Your insights help us improve and continue providing valuable resources. Don’t miss this chance to share your thoughts and win!