

## Supplementary Online Content

Krekeler BN, Wendt E, Macdonald C, et al. Patient-reported dysphagia after thyroidectomy: a qualitative study. *JAMA Otolaryngol Head Neck Surg*. Published online March 8, 2018. doi:10.1001/jamaoto.2017.3378

Patient handout and interview guide

This supplementary material has been provided by the authors to give readers additional information about their work.

# Managing your Swallow after Thyroidectomy

## Speech-Language Pathology (000-000-0000)

Thyroidectomy may result in changes to your swallowing. Some of these changes may resolve quickly, but some may stick around for a few weeks or even several months. The good news is, there are some changes you can make to the way you eat and what you eat to help relieve some of these symptoms and to avoid uncomfortable situations, like feeling food or liquid “go down the wrong tube” or feeling like you’re choking.

### Common Swallowing Complaints following Thyroidectomy & Strategies that May Lessen these Symptoms:

1. Painful Swallowing
  - a. Avoid hard or crunchy foods
  - b. Stick to soft, easy to chew foods
  - c. Suggestions: pudding, yogurt, ice cream, soup, oatmeal
2. Difficulty Swallowing
  - a. Take small bites, chew thoroughly
  - b. Swallow several times in between bites
  - c. Eat meals slowly
3. Feeling Foods get “stuck” in Throat
  - a. Take smaller bites, chew food thoroughly
  - b. Swallow several times in between bites
  - c. Eat meals slowly
  - d. Use water or other liquid to wash food down in between bites
4. Difficulty Swallowing Pills
  - a. Use pudding or applesauce to take large/difficult to swallow pills
  - b. Take pills one at a time

\*Not all of these strategies will work for everyone, but some may help during your healing process. For any questions about these strategies, if you are experiencing coughing or choking while eating, or if there are any symptoms that concern you or cannot be managed with these strategies, please contact **Speech-Language Pathology at (000-000-0000)**. If you have a nerve injury from your surgery, it is highly recommended you make an appointment to see a speech-language pathologist as soon as possible.

**Interview Guide – Post-operative Interview**

## FACE SHEET

Date: \_\_\_\_\_

Patient #: \_\_\_\_\_

Time begin: \_\_\_\_\_

Interviewer Initials: \_\_\_\_\_

**Ask if patient has a copy of completed survey. If not completed, patient should fill it out before the interview begins. Keep the survey by you for reference during a later section of the interview.**

## INTRODUCTION:

Thank you for being willing to meet with me. My name is \_\_\_\_\_ and I am one of the interviewers on this study. And this is your second interview.

The aim of this study is to **help doctors to better understand patient’s experiences of going through thyroid cancer, surgery and treatment, and recovery.** Because this interview is about your experience, you are the expert– we are interested in what you feel and your thoughts about it.

Just to remind you: I am not a medical person. My role on the study is to interview patients at various points in time. You should know that anything you say to me is completely confidential and will only be reported to members of the study staff as aggregate data. Your name will not be used in any printed material.

**You should also know that we will not report anything you say to your doctor or to any of the clinic staff.** Clinic staff, including physicians, will only see this interview data after it has been de-identified and names have been removed. This also means that if you want your doctor to know about any of the symptoms we discuss today, you should be sure to bring them up with your doctor at your clinic visit or call the nurse after you get home.

If any questions make you uncomfortable, you can choose not to answer them and you can choose to end the interview at any time. Do you have any questions for me about the interview?

The important thing to remember in this interview is that it is about the patient experience, and YOU are the expert about your own experience. We would like to know about your experience of Thyroid cancer and recovering from surgery in your own words. Ready? Usually these interviews take about an hour. Is that ok?

We will interview you at several time points over your treatment. You might see me again or see another interviewer on the study. Great, let’s get started.

## QUESTIONS:

This first set of questions is aimed at getting at what stands out in your mind since your surgery.

1. How have you been since your surgery? Have you noticed any physical changes since the last time we saw you?  
**Prompts**
  - a. Any physical symptoms that you remember?
  - c. Things you were able to do or not do?
  - d. Things you didn't notice, but other people did?
  - e. Which of these were you told to expect at this point?
  - f. Which of these came as surprises?
  
2. What about the medicines that you have to take now? How do they make you feel?  
**Prompts:**
  - a. Sick to stomach, bloated, constipated?
  - b. Fatigued or jittery?
  - c. Have you mentioned any of these things to your doctor or nurse?
  - d. Why or why not?
  
3. Tell me about how your mood has been.  
**Prompts:**
  - a. Depression?
  - b. Sadness?
  - c. Irritability?
  - d. Anxiety about recurrence?

## INTERVIEWER ACTIONS, NOTES, AIMS:

**AIMS:** *to elicit any symptoms, physical, medication-related, or emotional, that come to mind WITHOUT prompting by the symptom cards.*

**NOTES:**

**QUESTIONS:**

This second set of questions looks at symptoms that other thyroid cancer patients have experienced and asks you to let us know which ones you experience and how they affect you.

**CARDS:**

4. These cards represent a range of symptoms reported by patients at various stages of recovery from Thyroid Surgery. If you don't mind, we're going to do a couple of exercises with them.

**Baseline Sort:**

5. I'd like you to take this stack of cards - It lists the symptoms we've been talking about already and some others you may not have mentioned. These cards are based on that have come up in our conversations with other Thyroid Cancer patients.
  - a. Now, please take the cards and separate them into two piles, symptoms that you have experienced since surgery, and those you have not experienced. **Note that** some of these symptoms have to do with Radioactive Iodine, so you may not have experienced them.

**INTERVIEWER ACTIONS, AIMS, AND NOTES:**

**[Bring out symptom cards, including blanks]**

**[Hand them to the patient.]**

**[Read through each pile for the tape recorder, and confirm with respondent that piles are correct. Remove the "do not have" pile and put aside. Circle the "have" symptoms on part one of the symptom checklist]**

## QUESTIONS:

**Adding symptoms:**

- b. Any symptoms not mentioned here that we should add?

**First Shuffle:**

6. Now, taking the cards of the symptoms that *have bothered* you since your surgery or bother you now, can you lay them on the in three piles: the first pile is those symptoms that bother you the most, the second pile is those that bother you a little, and the third pile is those that you experience, but do not bother you much.

- a. When did you first notice it?
- b. Can you describe it in your own words?
- c. Can you give me an example?
- d. What about these symptoms makes them the most bothersome for you?
- e. Have you mentioned it to your doctor? Do you plan to?

7. Now I want to ask you about the symptoms that affect your voice and your ability to swallow.

**Prompts:**

When did you first notice it?  
 What does it feel like?  
 Can you walk me through the experience?  
 When does it usually occur?  
 What about it bothers you?

## INTERVIEWER ACTIONS, AIMS, AND NOTES:

**[Write additional symptoms on a different colored card, reading the symptoms aloud for the tape and to confirm with the patient. Enter the new symptoms in the blank spaces in part one of the symptom checklist]**

**[Read ranking aloud for the tape and to confirm with the patient. Also mark rankings next to symptoms on checklist]**

**[Hold aside the three most bothersome – read aloud one at a time. Probe three most bothersome for dimensions and experience of symptoms.]**

**[Probe the ranking of the voice/swallow symptoms – noted in grey on the symptom checklist. Skip them if the patient indicates they have no voice/swallow symptoms, or if they have been discussed in “most bothersome” above. Probe dimensions of symptom experience and why they are ranked lower if they are in “least bothersome” or “bothers a little”]**

## QUESTIONS:

## INTERVIEWER ACTIONS, AIMS, AND NOTES:

**Second shuffle:**

8. Now, I'd like you to take the same cards and put them into three piles in terms of how much **they have interfered with your daily life** since your surgery. The first pile should be those that "interfere the most," the second pile should be those that interfere a little, and the third pile should be symptoms that you have but that don't interfere much with your daily life.
- Why are these the ones that interfere most? What do they interfere with?
  - Are these activities that matter to you a lot?
  - How would you rank their importance in your life?
9. Now I want to ask you about the symptoms that affect your voice and your ability to swallow.
- Prompts:**
- When did you first notice it interfering?
  - How long does it last?
  - What kinds of things does it interfere with?
  - Can you give me an example of when it interfered with something you wanted to do?
  - How important to you is the activity it interferes with?

**[Read aloud both piles for the recording and to confirm with patient. Mark rankings on symptom checklist.]**

**[Interviewer holds most interfering symptoms and reads aloud each for the tape and to ask patient to expand on and explain THE 3 MOST INTERFERING.]**

**[Probe the ranking of the voice/swallow symptoms – noted in grey on the symptom checklist – skip them if the patient indicates they have no voice/swallow symptoms, or if have been discussed in "interferes most" above. Probe dimensions of symptom experience and why they are ranked lower if they are in "least interfering" or "interferes a little"]**

10. Have you mentioned any of these issues to your doctor?

**Prompts:**

- a. Why did you choose to mention or not?
- b. What did they tell you about how long they might last?
- c. Anything you can do to make it better?
- d. How do you feel about it having talked to them?

QUESTIONS ABOUT SURVEYS:

This last set of questions is aimed at asking you to reflect on the surveys you filled out earlier, and to explore your reasons for giving the answers you did.

11. You filled out some questionnaires today. Did anything in those surveys stand out to you? Can you explain how?

**Prompts:**

- a. Any questions that raised concerns about what your continued recovery will be like?
- b. Questions that seemed confusing? Or like they just don't apply to you?
- c. Any particular health issues that you thought were relevant, but didn't come up?

**AIMS: Understanding which issues patient considers "report-worthy" or not.**

INTERVIEWER NOTES AND AIMS:

**AIMS: Get at how patient reflected on concepts in the surveys. Expand on those.**

**AIMS: Understand/operationalize "overall health" for patient.**

**[Pull out survey sheets from baseline survey and from today's survey. Turn to question 29.]**

NOTES/MARKERS:



## QUESTIONS:

12. The survey also asked about quality of life. What do you think of when you think about what *quality of life* means to you?
- Prompt:** Think about what you consider when you came up with a measurement for good quality of life.
  - [point to questionnaire] So for example today, you circled [#] on your questionnaire. What did you take into account when coming up with that number?
  - Last time you were interviewed [pre-operative] you ranked your quality of life at [#],. What do you take into account in comparing today's ranking with those other times?
13. Great! Thank you so much. We are coming to the end of our interview, but I want to ask you to take a few minutes to think about it. **Prompts:**
- Anything I missed that I should have asked?
  - Any advice you would give to another patient who is having Thyroid Surgery?
  - Advice that you would give a doctor or nurse preparing a patient to have Thyroid Surgery?

## INTERVIEWER NOTES AND AIMS:

**AIMS: Understand/operationalize "quality of life" for patient.**

**[Pull out survey sheets from baseline survey and today's survey – turn to question 30]**

**CONCLUSION:**

Thank you so much for your time and for being willing to take part in the study. Based on the study protocol, I, or one of the other interviewers, will meet with you again when you come in for your six week follow-up visit.

Are there any questions I can answer for you at this time? Great.

Let's look at your schedule for today and see what's next.

Can I help you find your way there?

END TIME: \_\_\_\_\_

**NOTES: Upload audio to I: Drive under CND study Audio – label with “Patient #, initials, visit 2, interview 2”.**

**Place this interview guide with your notes on right side of file folder. Place your marked-up symptom sheet on top of the interview guide.**