



Rehearsal Guide

Swallow Test

Preparing people with intellectual disability/autism (ID/A) to successfully complete a swallow test

Introduction for Caregivers

A rehearsal guide contains realistic pictures, concrete ideas, and clear, brief instructions for guiding a person through what can be expected in a specific situation. It includes helpful suggestions for caregivers to follow to make the experience meaningful for the person and increase the likelihood of a successful outcome. This approach is beneficial when supporting people with intellectual disability/autism (ID/A) who are anxious about situations such as doctors' appointments, hospitalizations, and medical testing.

A rehearsal guide provides opportunities for the caregiver to assist the person to learn about a specific situation. It contains information on what is needed and why and explains exactly what can be expected. Such a guide is most effective when it is person-centered and used in conjunction with discussion to allow exploration of specific areas of concern. It can be a powerful tool when used as intended.

The expected result is that the person will then experience the situation in a way that supports health and well-being by being prepared and knowing what to expect. The guide can be used at all stages of the situation to facilitate a positive end result.

Thank you for taking the time to use this tool to work with self-advocates to improve their health outcomes.

How to Use This Rehearsal Guide

For best results, begin to review this rehearsal guide with the person prior to the day of the appointment. Sometimes it will help to review this material with an individual several days or weeks before an appointment; other times, it may be better to wait to review this material until just before the procedure is to take place, perhaps the day before or the morning of the procedure. Together with the individual, determine which will best suit the individual's needs and abilities in understanding the information provided; however, it is important not to wait until 5 minutes before a procedure to introduce this guide to an individual. Give the individual enough time in advance to become familiar with the procedure based on the pictures and information contained on each page and with the individual's abilities in mind.

It is best to review this guide slowly and to focus on one idea/page at a time, allowing the person to talk and/or ask questions after each idea/page is presented. A caregiver may want to share personal experiences related to having this procedure done but be sure to do so in a positive manner, depicting a positive outcome.

For Best Practices

- ✓ Allot time to review this material when the individual is alert and interested in doing so.
- ✓ Ensure that the setting is free from distraction. Based on the individual's attention span, it may be best to review one page at a time, rather than reviewing an entire guide in one sitting.
- ✓ Explain each picture and practice the suggested exercises with the individual, such as deep breathing, as they appear throughout the guide.
- ✓ On the day of the procedure, take this guide along to continue rehearsing the various steps involved in the procedure.
- ✓ Remain positive, calm, and upbeat.
- ✓ Remember to offer positive reinforcement throughout the procedure. If the procedure is not able to be completed, focus on positive aspects. If the individual seems upset, talk about it later when they are calm to find out how they felt and what could be changed or improved to have a better outcome the next time.

Introducing the Process

(Name of individual), you are going to *(name of hospital)* for a swallow test on *(date of test)*.

A swallow test means special pictures of your neck are taken while you eat and drink. These pictures are called x-rays.

(Name of caregiver) will go with you and stay with you while you see the doctor. *(Name of caregiver)* may have to wait in the waiting room when the pictures are taken. If so, *(Name of caregiver)* will be with you as soon as the test is over.

Note to Caregiver: *This rehearsal guide covers aspects of a typical swallow test. Swallow tests may vary somewhat, depending on the individual's particular swallowing difficulty and the type of procedure the doctor may use. Caregivers might try contacting the speech/language pathologist to obtain more information about the exact procedure expected. Questions to ask include: Who will be in the exam room? Is a caregiver permitted to stay with the individual during the test? Will test results be discussed immediately following the test? When using this rehearsal guide, omit or revise sections which do not apply. Though the "nickname" of this test is a "cookie swallow," please note that cookies may not be used.*

Before the Test

You may be told not to eat or drink anything for hours before the test. It helps for you to be hungry when the test begins.

You will get to eat something during the test.

Try to be patient. You will get to eat soon.



In the Waiting Room

When you first get to your appointment, you will have to wait until someone calls your name.

(Name of caregiver) will stay in the waiting room with you.

You might want to take a favorite book along to read, some of your favorite music to listen to on your headphones, or some other quiet activity to do while you wait.



Note to Caregiver: A swallow test uses x-ray. You may be permitted in the room with the individual, if desired. You would be asked to wear a special apron to protect you from radiation. If a person is pregnant, they are not permitted in the room during this test. If the individual wears dentures, they should wear them during the swallow test.

When Your Name is Called



When your name is called, a nurse will take you to a private room. The nurse may ask you to remove your clothes and to put on a gown the nurse gives you for the test.

The doctor will come and talk to you about what will happen during the test.



Note to Caregiver: Some facilities may not require the person to wear a gown. Jewelry must be removed. Consider encouraging the individual to leave earrings, necklaces, and other jewelry at home on the day of the test.

The X-Ray Machine

After you speak with the doctor, you will go to a room that has special equipment. There will be an x-ray machine and what may look like a television or computer screen.



Getting Ready

You will sit in a chair or be placed on a special table that helps you to stand next to the x-ray machine.

Sometimes these special chairs and tables have seatbelts to help you stay in place.

There will be a doctor in the room and someone to help the doctor. They will help you get into the correct position.



Getting Started

The x-ray machine is like a giant camera. It will take pictures of your neck when you swallow. These pictures appear on the computer screen for the doctor to see.

You will get to see what you look like inside as you swallow!



Getting Started



When you are ready, you will be given different foods and drinks, one at a time. You will chew and swallow.

It is important to keep the rest of your body still and not move around in the chair, because the machine will be taking pictures as you swallow.

Note to Caregiver: Rehearse this with the individual prior to the test. Ask the individual to sit in a chair and practice sitting still as you pretend to feed them different foods that they pretend to chew and swallow.

Results of Your Test

After the test, the doctor and the speech language pathologist may talk to you and *(Name of Caregiver)* about what the pictures show is happening when you swallow. They may show you a video of your test pictures.

If needed, the speech language pathologist may teach you safe ways to eat and drink.

The speech language pathologist wants to help you swallow safely.



You Can Do It!



I know you always do the best you can!

Note to Caregiver: Take time to assess how well the person understands what was presented. Ask some very brief questions such as, “Do you know what will happen when you go to have your swallow test?” Review the rehearsal guide as often as needed to ensure the person understands and is prepared when the day of the swallow test arrives.

References

- Swallowing Study. (2022, June 27). Retrieved from <https://www.uofmhealth.org/health-library/abr2463#abr2464>
- UPMC Children's Hospital of Pittsburgh. (2023). Modified Barium Swallow (Cookie Swallow). Retrieved from <https://www.chp.edu/our-services/audiology/patient-procedures/modified-barium-swallow>



For additional information regarding this guide or any of our physical or behavioral health trainings, contact:

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