



Rehearsal Guide

UPPER ENDOSCOPY

*preparing people with intellectual disability/
autism (ID/A) to successfully complete an
upper endoscopy.*

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. Review each page step by step.
- ✓ 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 the individual*, you are going to have a

test called an **upper endoscopy** on (*insert date here*) at

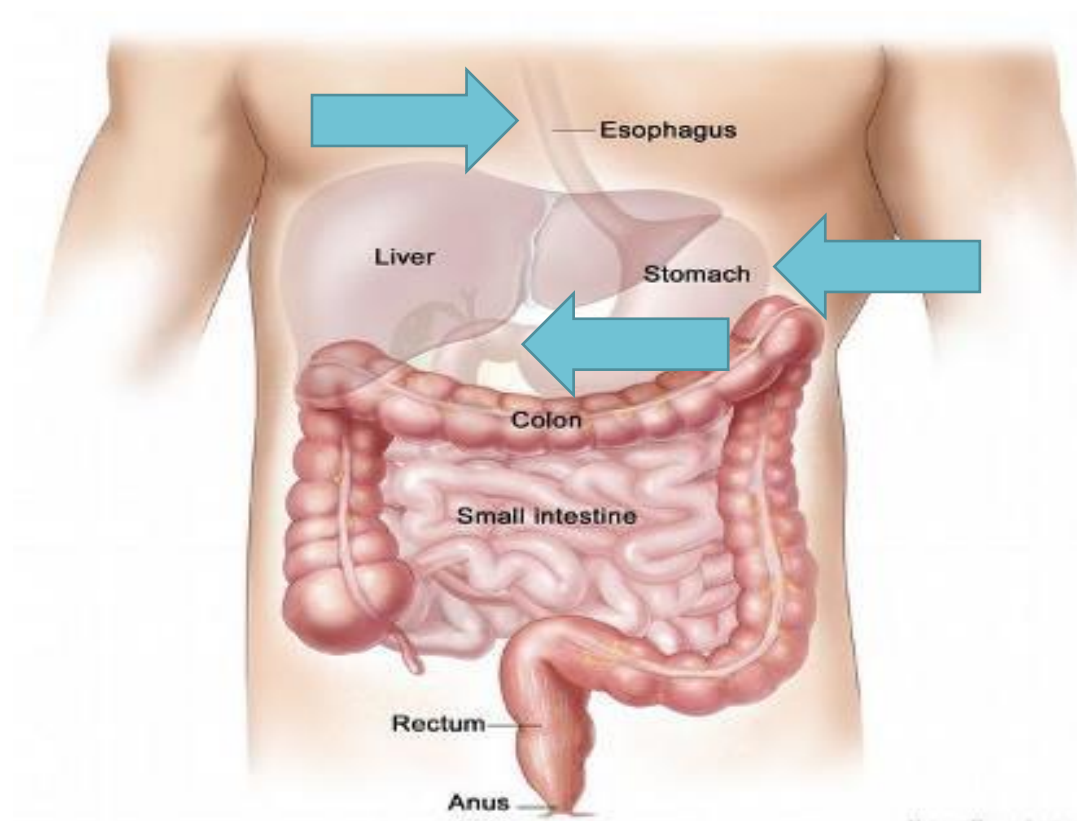
(*Name of location*).



INTRODUCING THE PROCESS

An upper endoscopy test helps your doctor see if the tube that carries food to your stomach and upper part of your small intestine is healthy. The tube that carries food to your stomach is known as the esophagus. Your stomach is the part of your body that holds and mashes up your food. The small intestine is where you get the nutrients from your food. The upper endoscopy test will take special pictures of these areas. The doctor will look at the pictures to see if they are healthy.

This picture shows parts inside a body. The arrow points to these areas.



BEFORE THE TEST

The doctor will tell you not to eat solid foods for a certain number of hours before the test, usually 8 hours. Your stomach needs to be empty and not have food in it. The doctor will see the inside of your stomach best if there is no food in it. The doctor may give you additional instructions related to your medications.



THE MORNING OF THE TEST

Do not eat before your test.

You will feel hungry, but do not eat until after the test.

Try to relax until it is time to leave for your test.

Reading a book or listening to music may be helpful.



IN THE WAITING ROOM

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

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

If you do not like to sit and wait, bring something to do. You can read, listen to music, or draw pictures while you wait. A caregiver can help you decide what to bring.



CHANGING INTO A PATIENT GOWN

People who work with the doctor will tell you what to do.

It is OK to listen to them. They are there to help you.

Someone will take you to a changing room. You will be asked to take off your clothes and to put on a patient gown.

(Name of caregiver) will stay with you so you feel safe.

Someone will give you a bag; you will put your clothes in it. Someone will tell you where to put your bag of clothes.



Note to Caregiver: You may want to reassure the person that the changing room is private and his or her belongings will be safe. If needed, consider offering to hold the person's bag during the test.

GETTING READY

A person who works with the doctor will help you lie down on a bed. The person will help you lie down on your left side. The doctor will place numbing spray and a protection guard for your mouth and teeth in your mouth before you fall asleep.

(Name of caregiver) might have to wait in the waiting room while the doctor does your endoscopy test.

(Name of caregiver) will be with you when the test is over.



Note to Caregiver: Help the person practice lying down on the left side. If needed, consider calling the doctor's office or x-ray department to ask if a caregiver is permitted to be in the room until the person is asleep.

GOING TO SLEEP

When it is time for your test, someone will carefully put a small needle in your arm or hand. It will feel like a pinch. Try not to move your arm or hand. Take deep breaths to relax. A long tube will connect a bag of medicine to the needle in your arm or hand. This is an IV. The IV gets medicine into your body so you sleep during the test.



Note to Caregiver: Practice taking deep breaths with the person.

DURING THE UPPER ENDOSCOPY TEST

While you sleep, the doctor will do the test. You will not feel anything, because you will be asleep.

When you wake up, the test will be over!



AFTER THE TEST

After you wake up, you might feel tired, and your belly may feel like it is full of air.

(Name of caregiver) will be there to help you.

A nurse will be there to take care of you, too.

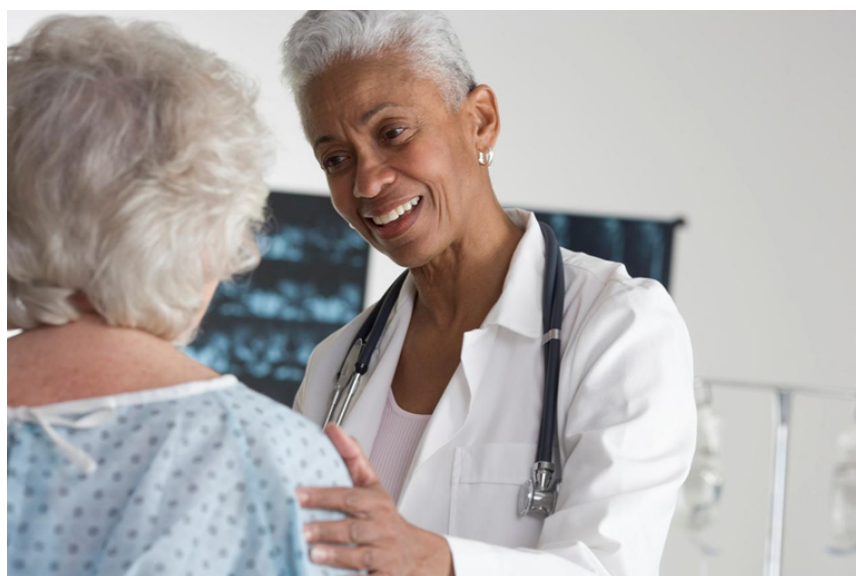


ALMOST DONE

When you are awake and able to sit up, you should not eat or drink anything until you can swallow safely. The nurse will offer you something to drink when you are ready.

Someone will bring your bag of clothes to you. You will be asked to take off the patient gown and put on your clothes. Tell them if you are not feeling well; they will let you rest until you feel better.

When you are dressed and ready, you will go home.



Note to Caregiver: This is a good time to see how well the person understood what was presented. Ask some very brief questions, such as, “Do you know what will happen when you go to have the upper endoscopy test?” Revisit this guide as often as needed to ensure the person understands and is prepared on the day of the test.

GREAT JOB! YOU CAN DO IT!

It is easy to have an upper endoscopy test.

I know you can do it! You always do a great job!



Additional Resources

- Cleveland Clinic. (2021, July 28). Upper Endoscopy. Retrieved on April 18, 2023, from <https://my.clevelandclinic.org/health/treatments/4957-upper-endoscopy-procedure>
- Mayo Clinic. (2022, August 26). Upper endoscopy. Retrieved on April 18, 2023, from <https://www.mayoclinic.org/tests-procedures/endoscopy/about/pac-20395197>



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

**Kepro SW PA Health Care Quality Unit
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