



Cystoscopy

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

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 individual), you are going to have a test called a cystoscopy on *(insert date here)*.

The doctor ordered this test to help to keep you healthy.

(Name of caregiver) will go with you and stay with you while you have the cystoscopy completed.

This test will take place at *(name of location)*.



In The Waiting Room

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

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

Would you like to take a favorite book along to read or some of your favorite music to listen to on your headset while you wait?



Before the Cystoscopy Test

There will be people at this place who will tell you what you need to do. These people are friendly, and they are there to help you.

Before the test you will be asked to go to the bathroom to urinate (pee).



Note to Caregiver: A cystoscopy is a procedure that uses a small tube to check the urinary system. This tube is put into the urethra (the “tube” where urine leaves the body). After the procedure, this area may be tender. Use your discretion in explaining the procedure and how much information is appropriate to share. Be sure to use simple language and terms the person is familiar with to better help them understand the process and what they can expect to have happen for this procedure.

Changing Into a Patient Gown

Then, the people at the test place will tell ask you to take off your clothes and put on a patient gown before the test is done.

They will take you to the changing room to change and will tell you where you can put your clothes.

It is okay to listen to these people. (Name of caregiver) will be right there with you to assist you and make sure that you are all right.



Note to Caregiver: You may want to reassure the individual that the dressing room is private. Remember to be patient and to speak in a low, reassuring tone while assisting the individual.

Before the Test

After you have gone to the bathroom and changed into a gown, a nurse will give you some medicine to make you tired.

The medicine will help you sleep during the test.

You will not feel anything during the test because you will be asleep the whole time.



Note to Caregiver: Some providers may require an IV to be inserted before or during the test. Contact the place where the procedure will be done and ask them what to expect. If an IV will be placed before the individual goes to sleep or still in place when they wake up, you may want to prepare the individual for this step. The HCQU has an *IV Therapy Rehearsal Guide* available to review.

After You Get the Medicine

After you get the medicine, you will go to sleep.

While you are sleeping the doctor will do the test.

You won't feel anything or remember anything because you will be asleep!

Sweet Dreams!



After the Test



When you wake up the test will be over.

You slept through the whole thing!

You might still be a little bit tired after the test.

(Name of caregiver) will be sitting by your bed when you wake up.

A nurse will be there to take care of you.

Almost Done

When you wake up, the nurse will offer you something to drink.

They have pop, juice, and water.

After you are able to sit up and drink something, you will be ready to get dressed.



When You Get Home

When you get home, and for the next day or two, you might see a few things after you pee.

These are normal after this test.

- **You might see bright pink in the toilet after you pee.**
- **If you are a girl, you might see a little bit of blood on the toilet paper when you wipe after using the toilet.**
- **It might burn a little bit when you pee.**
- **You might have to pee more often than usual.**

Don't worry, all of this is normal after this test!

You can tell us if this happens, and we will help you feel better. **Be sure to drink lots of water to feel better.**



Note to Caregiver: *If the individual reports any of the symptoms above, you may want to give him/her a warm, wet washcloth and instruct them to hold it over the area where they “pee”. Encourage the person to drink more water after the test to help alleviate the side effects.*

Great Job!

I know you can do this!

Everyone is glad you are having this test done so you can stay healthy!



Note to Caregiver: *This is a good place to assess 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 cystoscopy done?” Revisit the story as often as needed to ensure the person understands and is prepared when the day of the procedure arrives.*

Additional Resources

- IV Therapy Rehearsal Guide

References

- Cleveland Clinic. (2021, April 14). Cystoscopy. Retrieved November 7, 2022, from <https://my.clevelandclinic.org/health/diagnostics/16553-cystoscopy>
- Mayo Clinic. (2021, January 5). Cystoscopy. Retrieved November 7, 2022, from <https://www.mayoclinic.org/tests-procedures/cystoscopy/about/pac-20393694>



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

**Kepro SW PA Health Care Quality Unit
(Kepro HCQU)
Hcqu.kepro.com**