



Rehearsal Guide

Having an Operation

*preparing people with intellectual disability/
autism (ID/A) to successfully prepare for a
surgical procedure*

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.

PART 1: Before Surgery:

Care the day(s) before

PART 2: During Surgery:

Care the day of

PART 3: After Surgery:

Care the day(s) after

Note to Caregiver: This page can be used to document information related to instructions for care from the individual's surgical team. This may include information for before surgery, during surgery, and after surgery that can be helpful to have to review with the individual.

Section 1: Before Surgery: Introducing the Process

(Name of individual), you are going to have an operation on *(date)*.

The doctor ordered this operation to help keep you healthy.

(Name of caregiver) will go with you and stay with you while you have the *(name of surgical procedure)* completed.

This procedure will happen at *(name of location)*.



Who Will You See There?

When you go to the hospital for your operation, you will see many different people there. You probably will not know most of them.

There will be doctors, nurses, other helpers, and even some other people who are there to have an operation, too.

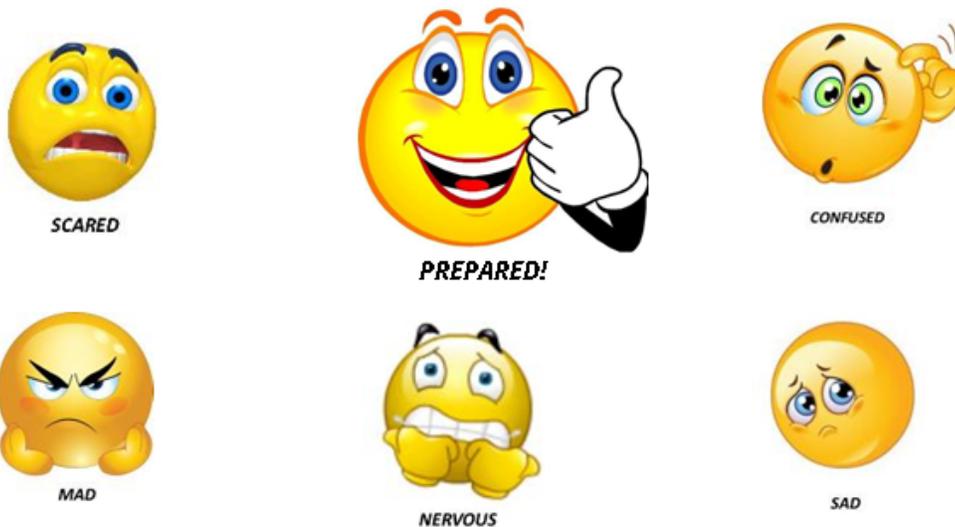


Note to Caregiver: This page contains generic pictures of various hospital personnel. It is possible sometimes to find the actual photos of a person's doctor(s) online. If able, print a copy of the person's doctor and paste it here to help familiarize the person with what his/her physician looks while reviewing this guide with the person.

How Do You Feel?

Sometimes it can make a person feel nervous when they have to go to the hospital for an operation.

How do you feel about having an operation?



What do you think will make you feel less _____?

How about we try _____ together?

This seems to make you feel better when you are _____.

Note to Caregiver: You may want to discuss your personal experiences with a similar surgical procedure. If so, do it in simple terms the person will easily understand and keep the discussion upbeat and positive.

The Day Before the Operation

The doctor may want you to do different things on the day before the operation, like not taking your medication or not eating or drinking after midnight.

Be sure to follow all directions the doctor has given you



Note to Caregiver: Explain to individual that not taking certain medications or not eating or drinking after midnight is only temporary. Explain that after operation the doctor will tell them when they can eat or drink and when to take their medications again.

Section 2: The Day of Surgery



Note to Caregiver: This section offers discussion on what the person can expect to take place the day of the operation, including what to and what not to take with them to the procedure; as well as what steps they will be asked to take at the medical facility prior to the operation.

It is advised that this section of this Rehearsal Guide be discussed with the person only after caregivers are confident the person understands the first section and appears ready to learn this new information. Again, repeated review of this section of the Rehearsal Guide is highly recommended before moving on to the third part of the guide.

Day of Your Operation: Important Things to Take

Be sure to wear comfortable, loose-fitting clothing that will be easy to put back on after your operation.

Don't forget to take things that are important for you.

What things would be important for you to take?



Note to Caregiver: Be sure to take all necessary paperwork on the day of the operation, including the person's identification, insurance cards, a list of current medications and allergies, and necessary agency forms. Bring cases for glasses, dentures, and hearing aides as needed. Ask the physician in advance if it will be necessary to bring the person's C-Pap machine if he/she is scheduled to stay overnight after the operation.

What You Can Also Take

Maybe you would like to wear your favorite jacket or hat, or carry your phone, comb, wallet, or purse with you. (*Name of caregiver*) will keep these safe for you during your operation.

What are some things you might like to take with you on the day of your operation?



What NOT to Take

What are some things that you shouldn't take with you on the day of your operation?



Note to Caregiver: Offer prompts and/or explanation as needed based on the person's responses, such as the hospital/facility says not to wear jewelry on the day of the operation, because you will have to take it all off.

In the Waiting Room

When you get to the hospital you will be asked to sit in the waiting room.

You will wait there 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.



When Your Name is Called

When your name is called, a nurse will ask you to follow him/her so that you can get ready for your operation.

(Name of caregiver) will be with you so you won't be alone.



Changing Into a Patient Gown

You will be asked to get undressed and to put on a patient gown before the operation. You might have to wear special slippers on your feet and a special hat to cover your hair.

The people at the hospital will put your clothes in a safe place so that you can wear them when it's time to go home.

(Name of caregiver) will be there with you to make sure you are all right.



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

Go To a Special Room

When your name is called, you will be taken to a room where nurses and doctors will talk to you.

You will be asked to lie down on a bed.

They will ask you questions, and (*name of caregiver*) will be there if you need help to answer any of these questions.



Getting Ready

A nurse will start an IV in your arm or hand and some medications may be started at this time.

You may feel a pinch, but it will go away quickly.

Remember, it's best to relax and lie still.

Close your eyes and think about your favorite things to do.

If possible, (*Name of caregiver*) will be in the room with you so that you won't be alone.



Going To the Operating Room



When it's time for your operation, the hospital staff will move you on your bed into the operating room.



Close your eyes and practice deep breathing to help you stay calm.

Note to Caregiver: Practice deep breathing with the individual.

Encourage the individual to take deep breaths while alone during the operation.

When Your Operation Starts

Once you are on the operating table, the doctor will give you medication to put you to sleep so you will not feel any pain.

The nurse will place a plastic mask over your nose and mouth so you will be able to breath during the operation.

This won't hurt a bit.

Relax and do what the doctor tells you so that you can fall asleep quickly.



Section 3: After your operation is over



Note to Caregiver: This section offers discussion on what the person can expect to after the operation is over. Including what steps they will be asked to take at the medical facility after the operation.

It is advised that this section of this Rehearsal Guide be discussed with the person only after caregivers are confident the person understands the first and second section and appears ready to learn this new information. Again, repeated review of the first two sections of the Rehearsal Guide is highly recommended before moving on to the third part of the guide.

After Surgery: When Your Operation Is Over



The doctor and nurse will wheel you on your bed into another room called the Recovery Room where you will stay until you wake up.

In The Recovery Room

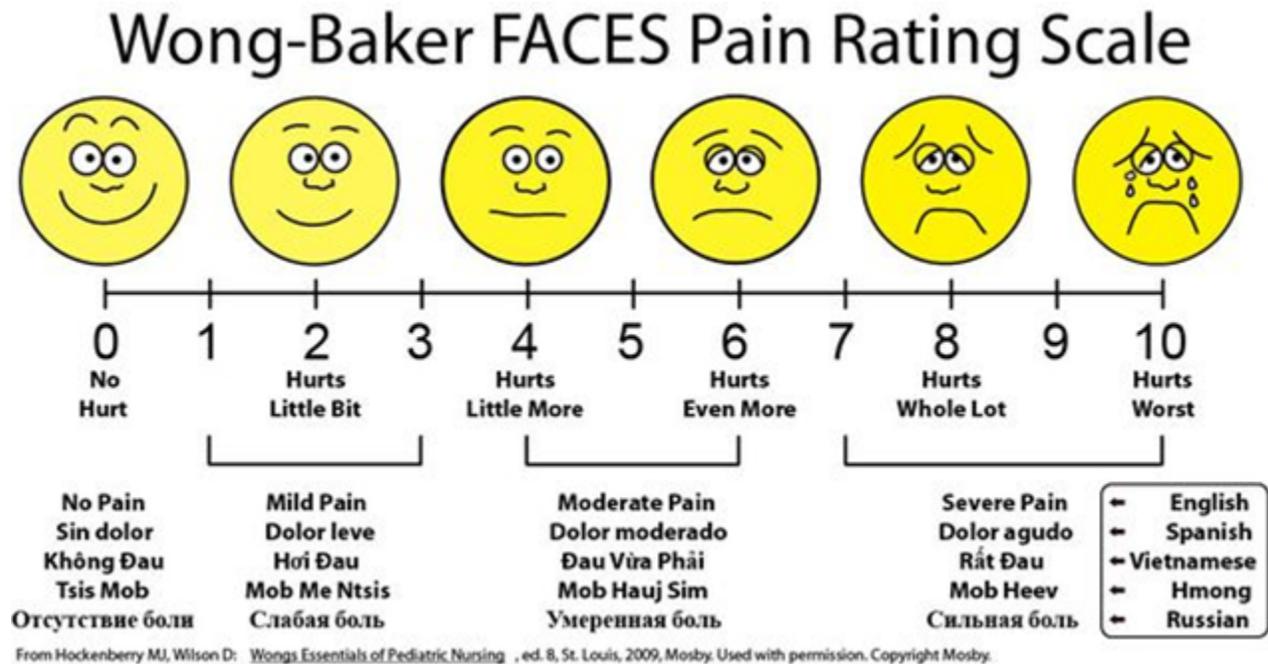
You will stay in the Recovery Room until you are wide awake again.

Nurses and doctors will check on you to make sure you are doing okay.



Almost Done

This picture shows faces to help you tell nurses or your caregiver how much pain you may be feeling after surgery.



It is important to tell the nurse or doctor if you are having pain. The nurse can give you medication to help you feel better.

Note to Caregiver: Review the faces with the individual, explaining what each face means in terms the individual uses and is familiar with. This page can be used on the day of the surgery to help the person communicate pain and the severity. If the individual has problems with communication and has a specific way of communicating that they are in pain, tell the nursing staff so they know how to recognize this.

After Surgery: Going Home



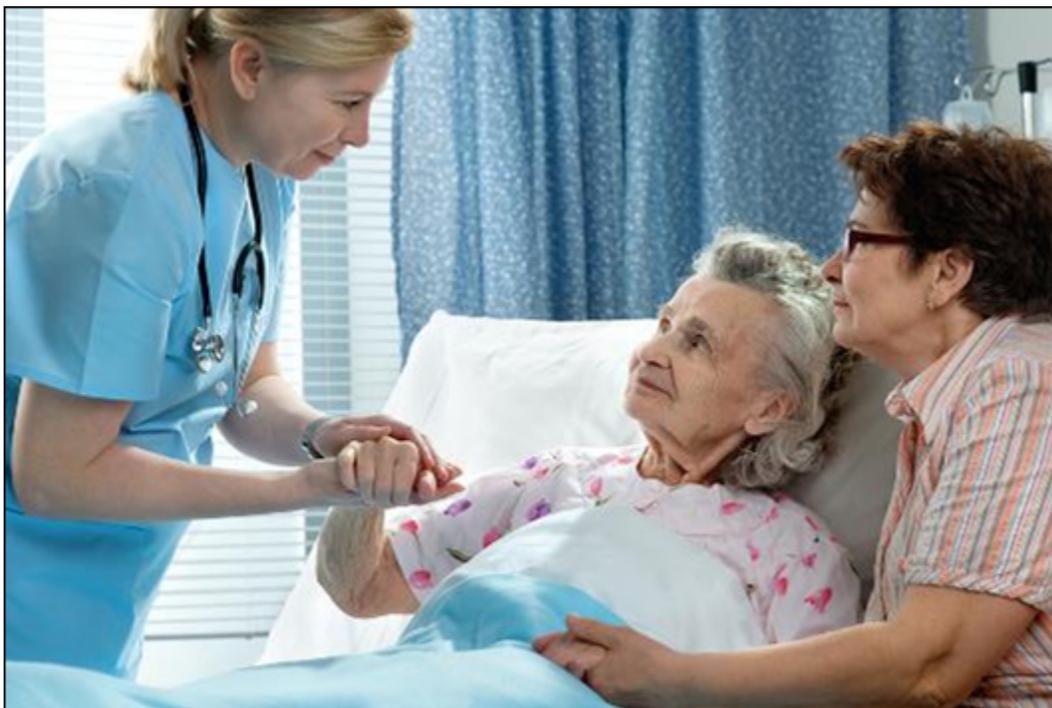
Note to Caregiver: Based on the type of operation the individual is to have and the information and instructions the doctor has given, choose which of the following operation type best suits the situation in terms of when the individual will be released from the hospital after the operation. Review the appropriate choice with the individual, taking care to stress that he/she will not be left alone and that the nurses and doctors will check on him/her often. Suggest they choose a favorite item (pillow, pajamas, blanket, photo, etc.) that they can keep with them in their hospital room.

After The Operation

In-Patient Operation

The doctor said that after the operation, you will be taken to a room in the hospital where you will stay overnight.

(Name of caregiver(s)) will be there to visit with you and make sure that you are okay. The nurses and doctors will also check on you often to make sure that you are doing well. It's important to tell them if you are not feeling well.



After The Operation

Out-Patient Operation

The doctor said that after the operation, you will be able to go home.

(Name of caregiver) and the nurse will be there to help you to get dressed. The doctor will also stop to see you and make sure that you are feeling okay.

It's important to tell the doctor and nurses if you are not feeling well so that they can help you feel better before you go home.

When you are feeling better and are dressed, a nurse will take you outside in a wheelchair so that you can get in the *(car, van)* to go home.



You'll Do Great

I know you always do the best you can!



Note to Caregiver: This is a good place 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 this (procedure/operation) done?"

Revisit the story as often as needed to ensure the person understands and is prepared when the day of the (procedure/operation) arrives.

Additional Resources

- Mshar, A. (2018, January 4). Your Child with Special Needs: Preparing for a Child's Surgery. Shield HealthCare, Inc. Retrieved on December 8, 2022, from <http://www.shieldhealthcare.com/community/grow/2018/01/04/your-child-with-special-needs-preparing-for-a-childs-surgery/>
- Resource for Integrated Care (RIC). (2014, September 2). My Health, My Life Toolkit. Retrieved on December 8, 2022, from [https://resourcesforintegratedcare.com/IDD/Care_Integration/Toolkit/My Health My Life](https://resourcesforintegratedcare.com/IDD/Care_Integration/Toolkit/My_Health_My_Life)



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

Kepro SW PA Health Care Quality Unit