



Rehearsal Guide

Cancer Treatments: Radiation Therapy

Preparing individuals with intellectual disability/autism (ID/A) to successfully complete a radiation therapy cancer treatment.

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 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 visit the *(Name of location)* cancer treatment center on *(insert date here)*.

Visiting the center will assist your body in attempting to keep your cancer from spreading to any other parts of your body.

(Name of caregiver) will go with you and stay with you while you receive your treatment.

Your visit will take place at *(name of location)*.



Note to Caregiver: This rehearsal guide covers many of the parts of typical cancer treatments. While some cancer treatments can be administered at home, many are given in cancer treatment centers. This rehearsal guide focuses on cancer treatments given at cancer treatment centers. Caregivers who know the routine of a particular cancer center can customize this rehearsal guide by rehearsing the parts that apply and skipping or changing parts that do not.

In the Waiting Room

When you first get to the cancer treatment center for your appointment, you will have to register and wait until someone calls your name.

(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 headphones while you wait?



When Your Name Is Called



When your name is called, a nurse will take you back to where your cancer treatments will occur. A nurse may first measure your height and weight. You may be asked to remove your shoes before you get on the scale.



Checking Blood Pressure and Pulse



The doctor or nurse will want to check your blood pressure by wrapping a cloth cuff around your upper arm. Try to hold still and breathe normally. You will feel a little squeeze, and then the doctor will take the cuff off. This tells the doctor how hard your blood is pumping through your body.



The doctor may hold your wrist to check your pulse. This tells the doctor how fast your heart is beating.

Taking Your Temperature

The nurse will use a thermometer to take your temperature.

This only takes a few seconds.

Some thermometers go in your mouth and under your tongue. You will need to close your mouth with the thermometer in place. Do not bite down!

Some thermometers go in your ear. Other thermometers roll across your forehead or just rest on the side of the head. With these, you don't even have to open your mouth!

All you need to do is relax!



Blood Work

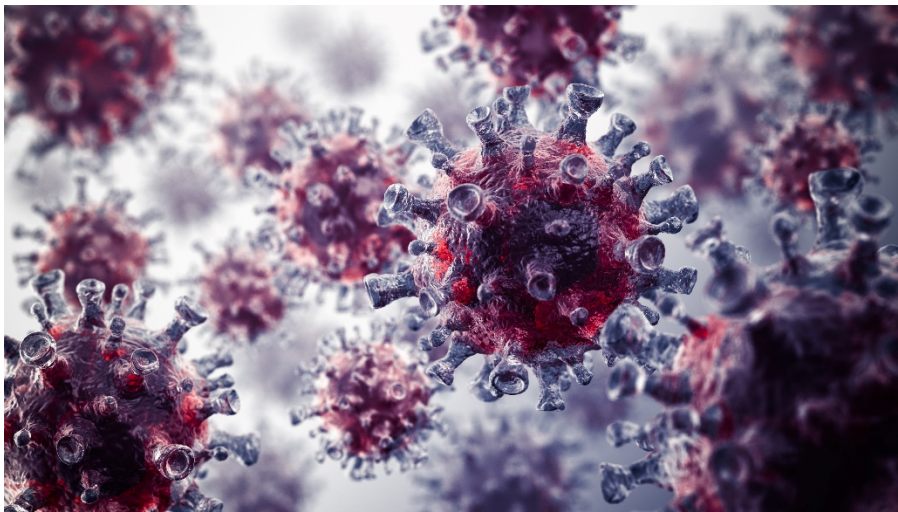
Before administering your cancer treatments your doctor may want to draw a small amount of blood from your hand or lower arm to see what your red and white blood cell counts are like. A small needle will be used to draw this blood and you may feel a little pinch.



Note to Caregiver: Instruct the individual to take deep breaths as the nurse inserts the needle into the hand or lower arm.

Radiation Therapy

Radiation therapy is a cancer treatment that uses beams of energy called radiation. These beams of energy occur in high doses and attempt to kill cancer cells or cancer growths in your body. Radiation can be done from outside your body or from inside your body.



Getting Ready for Treatment

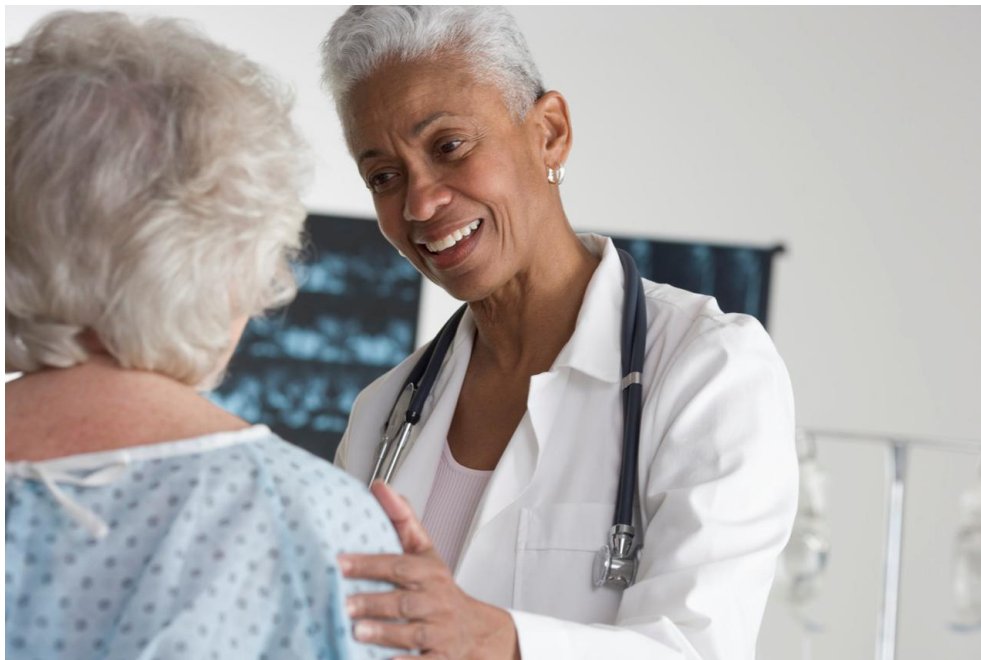
Before receiving treatment, your care team will explain what will happen, mark the area on your body that will be treated with a marker or a small tattoo, and ask you to practice staying very still on the table where you will receive treatment. It is OK to follow their directions and try to stay as still as possible. (*Name of caregiver*) will help you practice laying still at home so you can be ready for the treatment.



Photo by [National Cancer Institute](#) on [Unsplash](#)

Radiation From Outside Your Body

Some radiation can be done from outside of your body from a machine that will be aimed at the area where your cancer is. The machine can be very noisy but does not touch your body. It will only be given in the area where your cancer is located. Treatment may occur daily for several days, or for several weeks. This depends on the type of cancer you have and what the goal is for treating it.



Note to Caregiver: Help the individual prepare for radiation by visiting the treatment center prior to treatment occurring.

Radiation Inside Your Body

When you receive radiation inside your body, it is placed inside the body or near the cancer. It can be done in liquid form by drinking or swallowing a pill, or through an IV. It can also be done in solid form with seeds or ribbons as well.



Note to Caregiver: Practice with the person asking questions of the doctor such as, "What is this medicine for?" or "How does this medicine work?"

How will I feel after my radiation treatments?

After radiation, some side effects may occur as a result of radiation treatments, because high doses of radiation not only kill bad cancer cells but also healthy good cells in the area. Side effects can be different for each person. Common side effects are feeling tired, skin changes like dryness, peeling, or blisters, diarrhea, hair loss, and sores in the mouth and throat.



Note to Caregiver: Encourage the individual to report nausea/vomiting, hair loss, mouth sores, pain, and any other side effects to the nurse and doctor.

How Do I Know If My Cancer Treatments Are Working?

The doctor will do medical tests such as blood work or imaging tests that look at pictures of the inside your body from the outside. These tests can assist the doctor in knowing if the radiation treatments are helping.



All Done!

When your radiation therapy is completed, the doctor may give you a prescription for medication or other tests. The doctor may make some suggestions.

Make sure you understand the instructions before you leave.



Great Job! I Know You Can Do It!



Resources

- Mayo clinic. (2023, April 20). Radiation Therapy. Retrieved on June 16, 2023, from <https://www.mayoclinic.org/tests-procedures/radiation-therapy/about/pac-20385162>
- National Institutes for Health National Cancer Institute. (2021, April). Radiation Therapy and You: Support for People with Cancer. Retrieved on May 8, 2023, from <https://www.cancer.gov/publications/patient-education/radiation-therapy-and-you.pdf>
- Unsplash. 2010. Photo on Unsplash from the National Cancer Institute. Retrieved on June 16, 2023, from <https://unsplash.com/photos/ITZUfrst5fM>



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

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