



Rehearsal Guide

Cancer Treatments: Chemotherapy

Preparing individuals with intellectual disability/autism (ID/A) to successfully complete a chemotherapy 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 the treatment area. 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

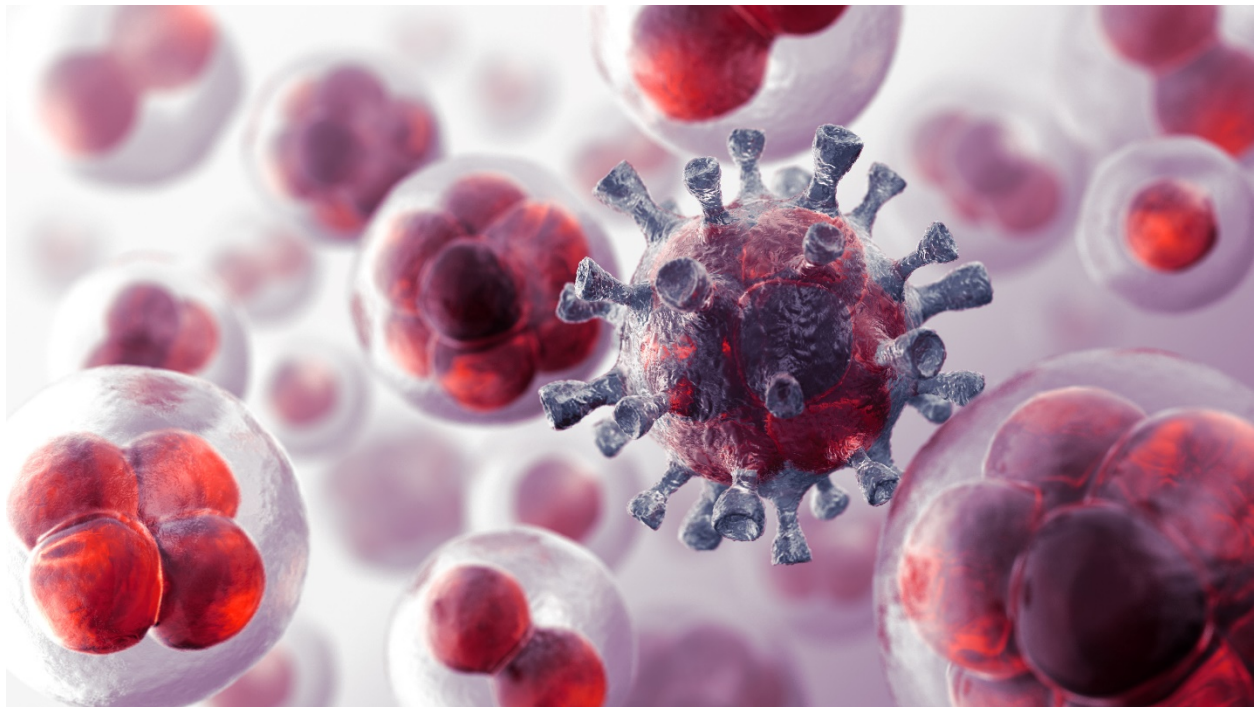
Before administering your cancer treatments your doctor may want to draw a small amount of blood from your hand or lower arm to see what your red and white blood cell counts are like. A small needle will be used to draw this blood and you may feel a little pinch.



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

Chemotherapy

Chemotherapy, also known as chemo, is a cancer treatment that uses medication to try to get rid of cancer cells. Chemo slows down or stops cancer from growing. A doctor will decide what type of chemo medication to use based on the type of cancer you have, and what other health concerns you have such as diabetes or heart disease.



There are many types of treatments that can be done at a cancer treatment center. The two cancer treatments that are most common are chemotherapy and radiation therapy.

How Is Chemo Given?

Chemo can be given in different ways. In cancer treatment centers it is typically given through a thin needle placed into a vein in your hand or lower arm. This is known as an IV. A nurse will place the needle in your arm when treatment starts. You may feel a little pinch. Chemo can also be given through a port that is inserted inside your chest. You may be at the treatment center for several minutes to several hours. It may be good to bring things of comfort with you such as a good book or magazine, a soft blanket, and headphones for music to listen to.



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

How Will I Feel During Chemo Treatments?

Chemo affects everyone differently. How you feel will depend on the type of chemo and the dose you are getting. A nurse will give you chemo medication as well as medications to help with side effects. You may feel tired or even sleepy during chemo.



How Will I Feel After Chemo?

You may experience side effects after chemo has been given. Common side effects from chemo include feeling tired, feeling sick to your stomach or throwing up, having sores in your mouth, losing your hair all over your body, and you may have some pain. Side effects can happen from chemo because it can affect your healthy cells as well as the cancer cells. Talk to the doctor or nurse about any side effects that you are having.



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 chemo is working to get rid of your cancer.



All Done!

When your chemotherapy 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!



Note to Caregiver: Take time to see how well the person understands what was presented. Ask questions such as, “Do you know what will happen when you go to see the doctor at the cancer center?” Revisit the story as often as needed to ensure the person understands and is prepared when the day of the appointment for chemotherapy arrives.

Resources

- National Institutes for Health National Cancer Institute. (2018, September). Chemotherapy and You. Retrieved on May 8, 2023, from <https://www.cancer.gov/publications/patient-education/chemotherapy-and-you.pdf>



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