



Rehearsal Guide

Hemodialysis

*preparing people with intellectual disability /
autism (ID/A) to successfully complete
hemodialysis*

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 go to your dialysis appointment on *(insert date here)* at *(Name of location)*.



Note to Caregiver: Prior to first appointment, it may be helpful to visit the dialysis center and meet their staff. This may help to alleviate some of the fears that the individual will be facing.

IF YOU ARE NERVOUS

Remember, (*Name of the individual*), will be with you during your appointment at the dialysis center.

Deep breaths may help you relax, so let's practice deep breathing.



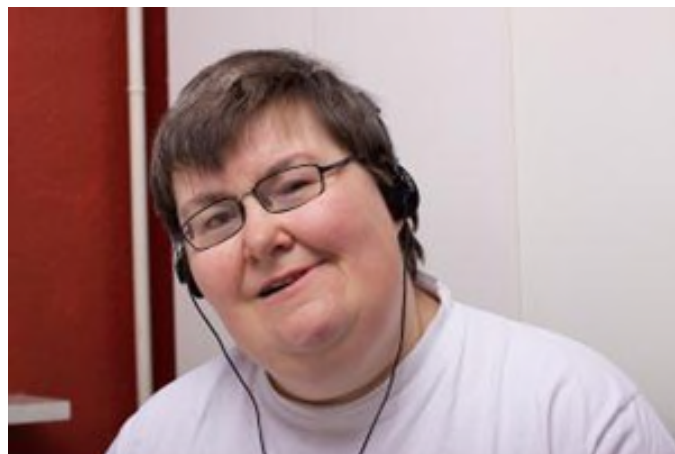
Note to Caregiver: Practice deep breathing with the individual. Encourage the individual to take a slow deep breath with you now and as needed before the procedure.

IN THE WAITING ROOM

When you first get to your appointment, you may have to wait until someone calls your name.

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

Take your favorite book to read or your favorite music with headphones to listen to while you wait.



INTRODUCING THE PROCEDURE

(*Name of the individual*), the nurse will be connecting the tubing to your (*Type of Access- Port, Central line, AV Fistula*). The machine will clean your blood because your kidneys are sick and can no longer do the job of cleaning your blood like they should. The machine that your tubing will be connected to is called a Dialysis Machine.



CLEANING THE ACCESS AREA

The area of your body where your tubing is connected must be cleaned prior to being connected to the dialysis machine.



CONNECTING TO THE ACCESS SITE

A nurse will be connecting one to two needles into the access site. It will be uncomfortable for a few seconds. You can ask for numbing medication for your skin to help with the needle stings. Everything will be taped in place until the end of the treatment.



Note to Caregiver: You may want to reassure the individual that it only hurts for a short time and to stay very still when the needle is inserted. Be patient and speak in a low, reassuring tone of voice.

THE TREATMENT

The treatment takes about 4 hours from start to finish. You can take along your favorite book, a portable video game system with headphones, or favorite music with headphones. You can also watch TV.

(Name of the caregiver), will stay with you during the treatment.



You will usually have treatments 3 times a week. Ask your caregiver to check mark the days of your treatment:

- **Monday**
- **Tuesday**
- **Wednesday**
- **Thursday**
- **Friday**
- **Saturday**
- **Sunday**

Note to Caregiver: *You may want to let the individual know that although they have a schedule, things sometimes change due to illness and holidays, so they may not always stay on that schedule.*

WHEN YOUR TREATMENT IS DONE

When all your blood has been cleaned, the nurse will take the catheter out of your chest or arm.

It might hurt a little when the nurse takes the catheter out of your chest or arm.

(Name of the individual), will be right there with you.

The nurse will put a bandage over where the catheter was. It may be a band aid or a bigger bandage.



AFTER TREATMENTS

Dialysis treatments should make you feel better as they clean out your blood. However, you may feel very tired the day of and day after your treatment. It is best to plan for a relaxing day after the procedure. If you are not feeling any better or feeling worse let your caregiver know right away so that they can let your doctor know.



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 dialysis?” Revisit this guide as often as needed to ensure the person understands and is prepared when the day of the treatment.

GREAT JOB! YOU CAN DO IT!

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



Additional Resources

- Davita Kidney Care. (n.d.). What is Hemodialysis? Retrieved on November 11, 2022, from <https://www.davita.com/treatment-services/dialysis/in-center-hemodialysis/what-is-hemodialysis>
- Mayo Clinic. (2021, August 19). Hemodialysis. Retrieved on November 11, 2022, from <https://www.mayoclinic.org/tests-procedures/hemodialysis/about/pac-20384824>
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). (2018, January). Retrieved on November 11, 2022, from <https://www.niddk.nih.gov/health-information/kidney-disease/kidney-failure/hemodialysis>



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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