Tips for Caring for a Child When You are an Adult Provider

You're an adult hospice and you've had a child needing hospice or palliative services come into your care and you're not sure what to do. You've got adult care down, but your staff isn't as knowledgeable or comfortable with taking care of kids.

Some tips to help you on what to do from your pediatric palliative care/hospice colleagues in the field who care for these children every day:

First, don't panic!

You and your staff can do this!

■ Second, take a breath.

You and your staff know more than you think you do. Your skills will transfer in many ways. Let that muscle memory kick in.

- Take an inventory of your knowledge and skills, as well as equipment needs.
 - » You may wish to enlist in some pediatric sponsored skills courses such as Pediatric Advanced Life Support (PALS) for older children. PALS is offered through the <u>American</u> <u>Heart Association</u> (AHA)
 - » The NRP (Neonatal Resuscitation Program) is beneficial if you anticipate having newborns and infants in your practice. NRP can be accessed through the <u>American</u> <u>Academy of Pediatrics</u> (AAP) website

Review concurrent care in your state.

Spend a few minutes reading about <u>concurrent care in your state</u>. Unlike adults, children can receive curative treatments/care and palliative/hospice care at the same time. They do NOT have to choose one over the other.

Expand your network.

Reach out to the closest health system, clinic, service, or hospice you know cares for pediatric patients. While protecting the confidentiality of the patient, explain their case and get any counsel you may need. Ask if they're willing to be open to ongoing communications if you need a safety net while caring for the child.

If you don't have anyone close you can reach out, try the closest <u>pediatric palliative care/hospice coalition</u> to you. Most will be happy to connect you to a provider who can help answer any questions you may have.

Remember you have two patients—the child AND the family. Talk to both of them. Most children want to be involved in their care and care decisions. Children know and understand more about their disease than you might think. Talk to the patient and the family about goals of care and

goal is different situations.Use the tools at your disposal.

Like with adults, you have a lot of tools to help care for the child at your disposal. Use what makes sense, but also know for pharmacologic interventions, for example, you may need help adjusting the dosages down for the weight/height of the child. Children are not little adults. A call to a local pharmacist may be able to help here. There is a medication guide as part of the pediatric resources on the NHPCO pediatric webpages.

Additionally, there are resources for advance care planning and establishing goals of care for pediatric and adolescent patients, such as <u>My Wishes for Children</u> and Voicing Your Choices for adolescents.

You are not alone - there are many resources to assist you!

Additional Helpful Resources:

- Concurrent care specific resources
- NHPCO's Pediatric webpages
- Courageous Parents Network
- National Organization for Rare Disorders (NORD)
- NHPCO's Pediatric e-Journal has been continuously published since 2002. The e-journal is produced by the Pediatric e-Journal workgroup of the Pediatric Advisory Council. Membership is not required. Subscribe or access archived issues.

If you want additional information and support, reach out to the NHPCO Pediatric Advisory Council at pediatrics@NHPCO.org.