



HOSPICE OF THE WESTERN RESERVE

# Pediatric Caregiver Training Guide

Caring for the Physical and Emotional Needs of You and Your Child

**SECTION 5:  
CARING FOR YOUR CHILD AT HOME**



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# Caring for Your Child at Home

When a person is confined to bed, all of the body's systems must be treated with care. A child confined to bed needs help repositioning for comfort, eating and drinking, routine personal care, and maintaining good skin care and hygiene. In addition, a child confined to bed needs opportunities for play and diversion. Particular attention should be given to the psychological impact immobilization may have on them and your family. To help, place their bed near family and at the center of the room to maintain interaction with family. Keep them in a chair as much as possible.

## Helpful Hints:

Have these items on hand:

- ♦ Moist, disposable wipes
- ♦ Appropriately sized diapers (if applicable)
- ♦ Disposable gloves
- ♦ A small table or serving tray
- ♦ Several small pillows
- ♦ Skin lotion
- ♦ Extra bed linens
- ♦ Bedpan or urinal
- ♦ Absorbent pads to protect the bed

## Hospital Beds

Hospital beds can be helpful for older children, particularly those who can use the bed controls to change their positions, etc.

Hospital beds can prevent back strain if your child's own bed is low to the ground. Clean the bed as needed with a mild soap. Be sure the wheel brakes are locked at all times, especially with very active children. Your child's bed and its location are an important part of their world. Talk with them about their preferences.

Different types of mattresses can be used for additional comfort. Your hospice nurse can discuss the options with you. If using an air mattress, check the pressure every day. Be sure the air pump for an air mattress is in a safe place under the bed. Never use pins, needles or other sharps around an air mattress.

## Helping Your Child Reposition in Bed



Depending on your child's size, you may be able to gently lift them for repositioning. If not, and your child is able to assist you, allow them to help as much as they can. Raise the rail on the side you want to turn them toward and slide them close to you as you stand at the side of the bed. Gently turn them toward the side rail and pull their hips back toward you.



**If your child is unable to help with repositioning, use a lift sheet.** Raise the rail on the side you want to turn them toward and gently roll them to their side. Fan-fold a sheet tucked half-lengthwise under their back. Roll them to the other side (side rail up on that side now). Move to the opposite side (rail down so you can reach) and gently pull the sheet out. To turn side to side, pull the sheet toward you, place pillows for support. To lift to their head off the bed, use a second person, each grabbing a side of the sheet.

## Changing Bed Linens

Working from one side of the bed (side rails up on the other), gently pull up dirty linen and tuck under your child's back. Place fresh linen on the mattress and fit around the corners of the mattress. Tuck the clean linen under the dirty ones. Put the side rail up, roll your child over the "lumps" and move to the other side. Remove the dirty linen, then spread and tuck in the fresh linen.

### Helpful Hints:

- ♦ Explain to your child what you are going to do before you begin.
- ♦ Use pillows/wedges/rolled towels for back support and between the knees.
- ♦ Place bed in flattest position tolerable.

## Using a Bedpan

When assisting your child with a bedpan:

- ♦ Wearing gloves is recommended
- ♦ Roll them to one side of the bed
- ♦ Have them lift their buttocks by putting pressure on heels
- ♦ Slide the bedpan under them and have them roll back over bedpan
- ♦ Check the position of the pan
- ♦ Allow privacy but stay close
- ♦ When finished, have them roll off the bedpan
- ♦ Remove bedpan and roll them back
- ♦ Help cleanse the area if assistance is needed and pat dry
- ♦ Dispose of waste in toilet and clean bedpan
- ♦ Remove gloves and wash hands

## Using a Urinal

If your child is using a urinal:

- ♦ Wearing gloves is recommended.
- ♦ Help position your child on the side of the bed.
- ♦ Help place the penis in the urinal if needed.
- ♦ Provide privacy but stay close.
- ♦ When finished, offer tissue or dab dry.
- ♦ Dispose of waste in toilet and clean urinal.
- ♦ Remove gloves and wash hands.

### Helpful Hints:

- ♦ Explain to your child what you are going to do before you begin.
- ♦ Powder the bedpan to reduce friction.



## Helping your Child to a Chair, to Stand or to Walk

When lifting your child to carry or reposition them:

- ♦ Raise the head of the bed.
- ♦ Stand at the side of the bed and have them turn to face you.
- ♦ Swing their legs to the floor as you gently assist them to a sitting position.
- ♦ Take a moment to let them adjust to sitting up.
- ♦ Wait an additional short time if you are getting ready to walk.
- ♦ Place the chair in which they will sit at the head of the bed, facing the foot of the bed.
- ♦ Face your child and put your right foot between their knees.
- ♦ Keeping your back straight, reach under their arms and gently hug them while raising them off the bed.
- ♦ Swing toward the chair.
- ♦ To return to bed, follow the same steps in reverse.

### Helpful Hints:

- ♦ Explain to your child what you are going to do before you begin.
- ♦ Protect your back by bending your knees and lifting with your legs. Keep your back straight while reaching as little as possible.
- ♦ Be sure that the chair is stable, or wheelchair brakes are locked.

### Walkers, Shower Chairs and Benches

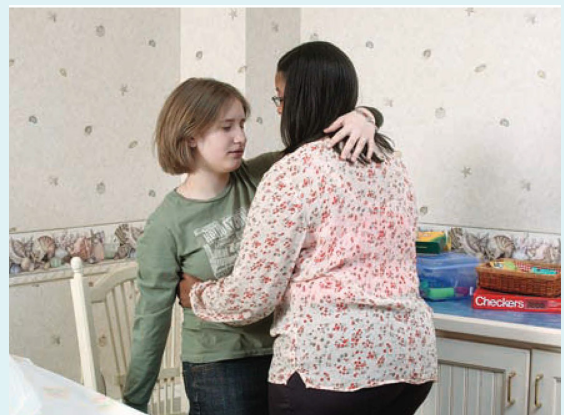
The use of assistive devices such as walkers or canes should be discussed with your hospice nurse who will be sure that you and your child are instructed in their correct use. Most equipment can be cleaned with soap and water. Be sure to dry all equipment after cleaning to prevent slips. You can protect the pads of wheelchairs to prevent soiling and stains. Keep wheelchair brakes locked when your child is not moving.



Stand at the side of the bed and have them turn to face you.



Swing their legs to the floor as you gently assist them to a sitting position.



Keeping your back straight, reach under their arms and gently hug them while raising them off the bed.

#### LEARN MORE ONLINE

For the full series of videos, please visit [hospicewr.org/caregiver-training](https://hospicewr.org/caregiver-training).

## The Physical Environment

Children who are confined to bed should be given input regarding where/how they sleep and how they interact with the day-to-day activity of the home. Allowing your child to have input in decision-making will ease boredom and feelings of isolation and helplessness. Below is a list of problems you may encounter and some positive suggestions. Your hospice nurse can offer other suggestions based on your child's needs.

### Problem:

Your child wants to sleep in their own bed, but their physical condition makes it impossible

### Helpful Hints:

- ♦ Dress up the hospital bed with bright sheets and pillows they choose.
- ♦ Make a tent over the side rails.
- ♦ Allow them to show other family members how to use their bed's controls.
- ♦ Get their input on where the bed is placed.

### Problem:

Inability to go outside or into a different room

### Helpful Hints:

- ♦ Hang mobiles, flags, kites or bright objects around the room, provide a fan for air movement.
- ♦ Change the position of their bed in the room frequently.
- ♦ Place their bed near a window if possible.
- ♦ If unable to change the position of their bed, have your child reposition in the bed (i.e., sleep with their head at the foot of the bed). Make unusual events like this into "special events".
- ♦ If possible, roll your child's bed outside when the weather is nice.

### Problem:

Feelings of isolation, boredom and/or abandonment by friends

### Helpful Hints:

- ♦ Encourage friends and family to visit and interact.
- ♦ Include your child in family-centered activities such as dinnertime, watching TV, birthday parties, etc. Have a backup setting such as a couch or reclining chair so that your child's position in the home can vary with family activities.
- ♦ Allow some privacy when friends visit. Adolescents and teenagers need private space to interact with one another.
- ♦ Encourage your child to do activities that can be done even bed bound, such as board and card games, video games and computer games.

### Problem:

Feelings of helplessness

### Helpful Hints:

- ♦ Allow your child to make as many decisions as possible (e.g., what and when to eat, what clothes to wear).
- ♦ Encourage your child to perform as much of their own personal care as possible.
- ♦ Put any items your child may need within reach so they don't need to ask for help repeatedly.



### Problem:

Struggle between independence and dependence

### Helpful Hints:

- ♦ Explain all treatments and the reasons for them.
- ♦ Provide physical assistance when necessary, but encourage your child to participate with repositioning, etc.
- ♦ Provide adequate protection for the bed linens so that any accidents or food spills are less upsetting.

### Problem:

Reaction to body image

### Helpful Hints:

- ♦ Buy clothes that fit should your child lose or gain weight due to their condition.
- ♦ Encourage your child to wear regular clothes during the day and pajamas at night.
- ♦ Provide privacy for your child when performing personal care.

### Problem:

Attention seeking behaviors

### Helpful Hint:

- ♦ Children rely on consistent rules and find comfort and security in not being treated differently. Continue to set behavior parameters whenever possible.

## Notes

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