

Home Management and Other Resources

SAMPLE

Overview

There's more to having an ostomy than changing pouches. You and your child will have to make a few other adjustments. Let's go over the different areas of your home management and find out how to accomplish some everyday activities.

BEDROOM

Dressing

- ▶ Modern pouches lie pretty flat against the body. Even though the pouch is very obvious to you and your child, it usually cannot be seen under most clothes. Emptying the pouch when it's one-third full will keep it from bulging. There are also specially designed underwear and support belts to help secure the pouch. Bicycle pants or spandex may help during periods of increased activity.

Sleeping

- ▶ When infants and children lie on their stomachs to sleep, the pressure of the body on a full pouch may cause leakage and soil the bed linens.
 - This problem may be prevented by emptying the pouch right before your child goes to bed. It may also be helpful to limit foods and fluids a few hours before bedtime. If your child is wearing closed-end pouches during the day, switch to the longer drainable pouch at night.

BATHROOM

Your Child's Medicine

- ▶ Some changes may need to be made to medications. Let your primary care doctor and pharmacist know that your child has an ostomy. With an ileostomy, coated tablets and extended-release medications may come out whole into the pouch or pass through too quickly to be fully absorbed. Medications may need to be changed to a liquid or gel.

Bathing

- ▶ One may take a bath or shower with or without the pouch on. Many parents find it easiest to change the pouch system during shower or bath time. Remove the entire pouch and barrier prior to the bath or shower. Clean and inspect the skin, then apply the new barrier and pouch. Since an ileostomy drains often, it may work best to remove the pouch at the end of the bath or shower, which keeps stool from ending up in the tub water or on the floor of the shower. Remember that soap and water do not hurt the stoma. Avoid lotions and oils on the peristomal skin.

Toilet

- ▶ A drainable pouch should be emptied when it is 1/3 to 1/2 full. Pouch deodorant can help decrease stool odor.
- ▶ If your child has a disposable pouch, he or she will need to have a supply of disposable waste bags in the bathroom. The soiled pouch will need to be placed in a sealed bag and then thrown in the trash.

Changing a Pouch

- ▶ Keep supplies that you will need to change the entire pouching system together in one location. You will need washcloths or gauze pads, mild soap, a measuring guide, scissors, a new pouch, and a pen. If desired, you may also need skin barrier paste, skin barrier powder, and pouch deodorant.

KITCHEN/DIET

Ileostomy/Colostomy

- ▶ Once you have been given the OK by your surgeon, your child can return to eating a well-balanced diet. As you add new foods, you will see the effect they have on the ostomy output. A dietician can work with you to help with your child's food adjustment.
- ▶ Foods that can cause gas:
 - Carbonated beverages, broccoli, cabbage, beans, onions, Brussels sprouts, cucumbers
 - The ostomy pouch is odor-proof, so the only time an odor will be noticeable is when you empty the pouch
- ▶ Odor-producing foods:
 - Fish, eggs, garlic, beans, turnips, cheese, cabbage
- ▶ Foods that thicken stool:
 - Pudding, creamy peanut butter, baked apples/ applesauce, pasta, rice, cheese, bread, potatoes
- ▶ Foods that can cause blockage if not chewed well:
 - Nuts, celery, coconut, mushrooms, raw crunchy vegetables, dried fruits, popcorn
- ▶ High-fiber foods that can decrease constipation and keep stools soft:
 - Beans (brown, black, kidney, pinto, lentils, lima, soybeans), avocados, fiber-rich cereal, oats, brown rice, turnip greens, wheat pasta, fruit (raspberries, grapefruit, pears, papaya, apples with skin), potatoes with skin, sweet potatoes, and yams



DINING ROOM/CAFETERIA

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- ▶ In general, your child should be able to eat as before. You may hear noise coming from your child's ileostomy/colostomy during digestion. Usually the noise is barely heard by anyone else. Eating slowly and eating less may decrease the digestive sounds.



OUTDOORS

Returning to School

- ▶ Children can return to school as soon as they are ready, usually 2 to 4 weeks after the operation. Initially, it may be helpful to go to school for only a half day. Speak with your child's surgeon about activities your child wants to participate in. There may be some activity restrictions. If your child will be away from school for more than 2 weeks, talk with your social worker to arrange for a teacher to come to your home.
- ▶ There should be no difficulty with the pouch while your child is at school. Your child will need to have extra supplies (pouches and zip-top bags for pouch disposal) and possibly a change of clothes.
- ▶ Be prepared for what you will tell the people you meet about your child's operation. Tell them as much or as little as you want them to know. You can simply say that your child has had abdominal surgery.
- ▶ Ask your WOC nurse or surgeon for guidelines to send to your child's nurse/school. This should include who they should go to for help with their ostomy and pouch change. A school nurse or administrator can take the online training for pediatric ostomy care located on the ACS Pediatric Colostomy/Ileostomy web page under "Professional Resources."

Traveling

- ▶ You may travel as normal with a little extra planning.
- ▶ Be sure to take extra supplies, since they may not be available while traveling. Take the phone number of where you can get your products, just in case you have to order more in an emergency.
- ▶ For airline travel, pack supplies in your carry-on luggage. Precut the pouches at home, as scissors will not be allowed in a carry-on bag. You should also have a note from your surgeon identifying that your child needs the pouching system. This note is also good to have in case you need a private area if airport security has to do an extended search. If you use pouch deodorants, cream, or powder, these products will need to be placed in a sealed plastic bag.
- ▶ For road trips, check the location of your child's seat belt to make sure it is not putting pressure on the pouch. If the seat belt is on the pouch, move it below or above the pouch. Do not keep extra pouches in areas of extreme heat, such as the back rear window or trunk of your car. If your child uses disposable pouches, remember that you will need zip-top bags to dispose of the pouches.

Exercise and Activity

- ▶ Speak with your child's doctor or nurse about activities your child would like to participate in. Heat and sweat may decrease the pouch's barrier adhesive, so you may have to check the pouch more often. Special belts or binders are available to keep your child's pouch in place.
- ▶ Your child can go swimming and sit in a hot tub. You will need to make sure the pouch is supported while swimming, and that a good seal is maintained. Suggestions include wearing a swimsuit with a high waistline and extra support, using a closed-end mini pouch, and checking the skin barrier to make sure there is a good seal. Support belts specially made for added security during swimming are available.



Family Discussion

- ▶ Your family and dear friends will want to understand more about your child's operation. Some things you may want to talk about include who should know about the ostomy, who else needs to learn how to provide care, and what to do if someone notices a pouch leak (for example, a signal system or code word).
- ▶ Family and caregivers, including school nurses can review the skills to care for your child's ostomy at facs.org/ostomy.

Additional Ostomy Resources

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Resources

American College of Surgeons

Surgical Patient Education Program

facs.org/ostomy | 1-800-621-4111

Wound, Ostomy and Continence Nurses Society (WOCN®)

wocn.org | 1-888-224-9626

United Ostomy Associations of America (UOAA)

ostomy.org | 1-800-826-0826

American Society of Colon and Rectal Surgeons (ASCRS)

fascrs.org

American Pediatric Surgical Association (APSA)

apsaped surg.org

American Pediatric Surgical Nurses Association (APSNA)

apsna.org

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