Home Management and Other Resources

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.

WATCH VIDEO

Urostomy Home Skills Program: Life with an Ostomy

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 1/3 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.
- Since urine continues to flow throughout the night, you may attach your child's urostomy pouch to the nighttime drainage bag.

BATHROOM

Your Child's Medicine

- Let your primary care doctor and pharmacist know that your child has an ostomy. Medications may need to be changed to a liquid or gel.

Bathing

- Your child may shower or bathe with or without a pouch on. Many find it easiest to change the pouch system during shower time. You can shower with the pouching system in place. The outer adhesive is waterproof, so just be sure to dry the pouch and adhesive after showering. If your child showers without a pouch on, remember that soap and water do not hurt the stoma. Since a urostomy drains often, it may work best to remove the pouch at the end of the bath or shower. This keeps urine from ending up in the tub water or on the floor of the shower.

Toilet

- A drainable pouch should be emptied when it is 1/3 to 1/2 full. Drinking water or other fluid each day can help decrease urine odor.
- 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 need a skin barrier ring and powder.

KITCHEN

Diet

Following a urostomy, there are usually no restrictions on foods or liquids. The ostomy pouch is odor-proof, so the only time you will notice an odor is when the pouch is emptied.

- Foods that increase odor
  - Asparagus, onions, garlic
- Drinks that decrease odor
  - Cranberry juice, noncaffeinated drinks
- You may have to provide foods high in folate and Vitamin B12. Liver, egg yolks, beans, potatoes (sweet and regular) Brussel sprouts, broccoli, spinach, cabbage, bananas, peaches, oranges.

DINING ROOM/CAFETERIA

- In general, your child should be able to eat as before.

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 ostomy 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 ostomy care located on the ACS web page at *https://www.facs.org/for-patients/home-skills-for-patients/ostomy/.*

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. Pre-cut 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 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 your child's activities. Heat and sweat may decrease the pouch's barrier adhesive, so you may have to check the pouch more often. Special belts or binders can help keep your child's pouch in place.
- Your child can go swimming and sit in a hot tub. You will need to make sure 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).

ADDITIONAL SUPPORT

Nurses who are certified in ostomy wound and continence care are called WOC nurses. Check with your surgeon to see if there is a WOC nurse (sometimes called ostomy nurses) that you will have access to. If you need to find an ostomy nurse, visit the WOCN resource page at wocn.org.

The United Ostomy Associations of America is a non-for-profit organization that supports people who have had or will have ostomy surgery. At their web site (ostomy.org) you will find support groups and other information.

Additional Ostomy Resources

Resources

American College of Surgeons Ostomy Home Skills Program and E-Learning Course
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 Urological Association (AUA)
auanet.org

American Pediatric Surgical Association (APSA)
apsapedsurg.org

American Pediatric Surgical Nurses Association (APSNA)
apsna.org

References

1. Parelkar SV, Shah R. Reconstruction involving gastrointestinal segments; Anatomy of gastrointestinal tract for urological reconstruction. In M. Gundeti Surgical Techniques for Pediatric and Adolescent Urology. Japee Brother Medical Publishers. New Dehli India, 2020. .
2. Schaffner, A. Pediatric ostomy surgery. *J Wound Ostomy Continence Nurs*.2010.37(5):546-8. doi:10,1097/WON.0b013e3181eded6f.
3. Steinhagen E, Colwell J, Cannon L. Intestinal Stomas—Postoperative Stoma Care and Peristomal Skin Complications. *Clin Colon Rectal Surg*. 2017 Jul; 30(3): 184–192. doi: 10.1055/s-0037-1598159. Epub 2017 May 22.
4. Freedman S, Wilan A, Boutis K, et al. Effect of Dilute Apple Juice and Preferred Fluids vs Electrolyte Maintenance Solution on Treatment Failure Among Children With Mild Gastroenteritis: A Randomized Clinical Trial. *JAMA*. 2016 May 10;315(18):1966-1974. doi: 10.1001/jama.2016.5352.
5. Browning, JD, Stephany HA. Advances in pediatric urinary diversion. *Urol Clinics of North America*. 2018. Feb:45(1):123-132. Doi:10.1016/j.ucl2017.09.013
6. WOCN, Pediatric Ostomy Care. Best Practice for Clinicians. https:// cdn.ymaws.com/member.wocn.org/resource/resmgr/document_ library/PEDIATRIC_OSTOMY_CARE-_BEST_.pdf
7. Lander, S, Radtke C, etal. Bladder augmentation in children: current problems and experimental strategies for reconstruction. Wien Med Wochenschr. 2019 169 (3) 61-70

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