



SUPPORTING FAMILY CAREGIVERS NO LONGER HOME ALONE



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Ostomy Care at Home

Educating family caregivers on stoma management and potential complications.

This article is part of a series, *Supporting Family Caregivers: No Longer Home Alone*, published in collaboration with the AARP Public Policy Institute. Results of focus groups, conducted as part of the AARP Public Policy Institute's No Longer Home Alone video project, supported evidence that family caregivers aren't given the information they need to manage the complex care regimens of family members. This series of articles and accompanying videos aims to help nurses provide caregivers with the tools they need to manage their family member's health care at home.

The articles in this new installment of the series provide simple and useful instructions that nurses should reinforce with family caregivers who perform wound care tasks. Each article also includes an informational tear sheet—*Information for Family Caregivers*—that contains links to instructional videos. To use this series, nurses should read the article first, so they understand how best to help family caregivers, and then encourage caregivers to watch the videos and ask questions. For additional information, see *Resources for Nurses*.

Family caregivers who perform medical and nursing tasks have identified wound and ostomy care as being among their most challenging responsibilities.¹ Ostomy care in particular can elicit unpleasant feelings and concern owing to the intimacy of the task, the social taboos patients or caregivers may associate with elimination, and the body image issues that may arise in some patients.

A survey of family caregivers found that they received more help with ostomy care than with any other medical or nursing task, presumably because of the higher level of complexity associated with this type of care.¹ Yet family caregivers still need more information and training in ostomy and peristomal skin care. This article and the accompanying video were developed to provide practical guidance to nurses who educate patients and family caregivers on performing ostomy and skin care at home.

PATIENT AND FAMILY ENGAGEMENT

The surgical creation of an opening in the body—an ostomy—may affect the gastrointestinal (colostomy and ileostomy) or urinary (urostomy) system. *Ostomy* and *stoma* are often used interchangeably but their meanings differ slightly: an ostomy leads to the formation of a stoma, which is the opening created in the abdominal wall through which the end of the large or small bowel or ureter protrudes.² Ostomy surgery changes a person's physical appearance and some bodily functions and can adversely affect a patient's

self-image. While the patient is still hospitalized and coping with these changes, it's important for the nurse to engage both the patient and caregiver in ostomy and peristomal skin care to ensure a successful discharge. Many patients experience stoma-related problems after returning home, and these complications are often because of a lack of knowledge and skill. Nurses must provide patients and caregivers with specialized information and resources before discharge so they'll know what to expect when they return home, are knowledgeable about the products they'll be using, are informed about how to manage an ostomy, and know when to contact a health care professional.

Before beginning stoma education and skills training, the nurse should assess the patient for pain or other discomfort. The presence of postoperative pain diminishes the patient's ability to learn and retain new information and skills. The nurse should inquire about the patient and caregiver's knowledge and concerns, which can help to ensure that the education is personalized. As the nurse teaches and watches the caregiver practice her or his skills, the nurse should pay close attention to how the patient and caregiver are responding to one another, pausing to allow them to ask questions or express concern. Because ostomy care is complex, the patient and caregiver are likely to need more than one educational session. Nurses can assure the patient and caregiver that they will become more comfortable managing the stoma with practice

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The nurse teaches the family caregiver how to change an ostomy bag. Photos courtesy of the AARP Public Policy Institute.

and that many patients and caregivers feel uncertain and awkward during initial ostomy care.

Manual dexterity—including the ability to handle the ostomy appliance clamp or spout, empty the appliance, remove and dispose of it, and apply a new one—is required in those caring for patients who've had ostomy surgery. It's equally important that the patient and caregiver learn how to properly assess the stoma and surrounding peristomal skin and are aware of the signs and symptoms of potential complications. Nurses should also provide information about recommended bathing practices, clothing, activity restrictions, medication requirements, and dietary and fluid considerations in the patient or caregiver's primary language. It's helpful to provide additional educational resources that patients and caregivers can refer to at home. These may include written instructions or links to websites that provide further support. For example, the United Ostomy Associations of America website contains useful ostomy care resources (see www.ostomy.org/Ostomy_Information.html), as does the Wound, Ostomy and Continence Nurses Society website (see www.wocn.org/page/PatientResources).

STOMA AND PERISTOMAL SKIN ASSESSMENT

Showing patients and caregivers how to assess both the stoma and the peristomal skin during each ostomy appliance change is an important part of post-surgery education. A normal stoma is pink, moist, raised slightly above the skin, and functioning properly (that is, waste is passing through it regularly).

In some people, however, the stoma may be flush with the skin.

Abnormalities of the stoma requiring medical attention include changes in color or length (for example, when the stoma protrudes further than usual from the skin) and separation of the stoma from the peristomal skin. Stomas that are black or dark maroon indicate necrosis, and those that are deep red, white, or yellow suggest trauma. The presence of any of these discolorations is considered an emergency.³ Normal peristomal skin is intact and free of any damage or rash; it should look the same as the skin on the rest of the patient's body. The junction between the stoma and the peristomal skin should also be free of separation or damage. Any abnormalities, such as rashes, redness, or skin breakdown, are usually caused by waste leaking from the stoma onto the skin, leading to irritant contact dermatitis. Such complications should be managed by a health care professional.

COMMON COMPLICATIONS

Complications can be related to the skin surrounding the stoma, as described above, or to the stoma itself.⁴ Stoma complications are varied and can include high output, ischemia, retraction, prolapse, and hernia.⁵ Family caregivers are mostly likely to encounter management issues related to peristomal skin breakdown, constipation in patients who've had sigmoid or descending colostomies, and dehydration owing to high output in patients who've had ileostomies. These complications can potentially result in ED visits or hospitalization.

Understandably, patients and caregivers may have anxiety about their ability to detect and respond appropriately when complications arise. When discussing potential complications with caregivers, nurses should include information about signs and symptoms, what to do when complications occur, and how to prevent them. They should be aware, for instance, that post-operative management of a sigmoid or descending colostomy may require colostomy irrigation to regulate bowel management and avoid constipation.⁶

Patients who've had an ileostomy are more likely to have watery stools and high output, which can lead to dehydration. Patients and caregivers should be made aware that a persistent volume output of more than 1,000 mL in a 24-hour period is considered to be high and can be an early indicator of dehydration.⁵ They can measure output using the graduated container they were given in the hospital. Needing to empty the bag more than six times a day may also be indicative of the potential for dehydration.⁵

Additional information for caregivers regarding assessment of the stoma and peristomal skin and detection and management of dehydration and blockage



Information for Family Caregivers

Assessing the Stoma and Peristomal Skin

- Wash hands and put on gloves.
- The stoma should be pink, moist, budded above skin level, and functioning.
- The peristomal skin should be free of rash and damage.
- The junction between the stoma and peristomal skin should be free of damage and separation.

Emptying the Ostomy Appliance

- Wash hands and put on gloves.
- Empty the appliance when it is one-third to one-half full.
- Have the patient sit on the toilet and open the clamp or spout of the ostomy appliance (if it has one).
- Empty the appliance into the toilet.
- Clean the end of the appliance by wiping it with toilet paper or a wipe.
- Roll up the end of the appliance and close the clamp or spout.
- Remove gloves and wash hands.

Changing the Ostomy Appliance

- Wash hands and put on gloves.
- Empty the appliance prior to changing it.
- Remove the old appliance using the “push-and-pull method,” in which you gently push the skin away from the appliance while pulling the wafer (the adhesive part of the ostomy appliance, which is attached to the skin) in the other direction. Place the used appliance in a disposable bag.
- Cleanse the skin surrounding the stoma with a wet washcloth or paper towel. Do not use creams or alcohol-containing products. Dry well.
- Assess the skin around the stoma.
- Measure the stoma using the stoma measuring guide. The stoma should be measured every time the ostomy appliance is changed during the first eight weeks after surgery, during which time the stoma size will decrease. Using the measuring guide, outline the size of the stoma on the wafer.
- Cut the wafer to match the measured size of the stoma.
- Warm the ostomy wafer by placing it under your arm and against your body for 30 seconds, or longer on cold days. (This step may be unnecessary with some appliances. Refer to the manufacturer’s recommendation.)
- Place the wafer over the stoma and against the skin. Ensure that the end of the ostomy appliance is closed.
- Dispose of any soiled materials; remove gloves and wash hands.



Recognizing Complications

Dehydration signs and symptoms.

- Losing more than 1,000 mL (approximately one quart) of liquid stool per 24-hour period
- Excessive thirst
- Dark, concentrated urine
- Weakness
- Lethargy

What to do:

- Seek medical attention.
- Have the patient drink water mixed with an electrolyte solution (it's helpful to always have commercial electrolyte-containing drinks such as Gatorade or Pedialyte available at home).

How to prevent dehydration:

- Make sure the patient avoids high-sugar beverages, which cause more fluid loss and dehydration.
- Encourage the patient to drink at least eight to 10 glasses of fluid daily.
- In patients who've had an ileostomy, include foods in their diet that are high in sodium and fiber. This helps to maintain fluid balance in the bowel.

Blockage signs and symptoms.

- In patients who've had a colostomy or ileostomy:
 - o thin and malodorous clear liquid stool
 - o abdominal cramping and pain
 - o reduced and concentrated urine output
 - o abdominal distension
 - o engorged stoma
- In patients who've had a urostomy: no urine


What to do:

- Notify a health care provider or go to the ED.

How to prevent blockages:

- Encourage the patient to drink at least eight to 10 glasses of fluid daily.
- Make sure the patient eats small, frequent meals and chews food well.

A family caregiver instructional video about ostomy care can be found on AARP's website:

 Caring for and Maintaining Ostomy Bags
<http://links.lww.com/AJN/A104>

For additional information and to access this video in Spanish, visit AARP's Home Alone Alliance web page: www.aarp.org/nolongeralone.

can be found on the patient tear sheet, *Information for Family Caregivers*.

EMPTYING AND CHANGING THE OSTOMY APPLIANCE

Patient and caregiver education should begin as soon as possible after surgery and while the patient is still in the hospital. After gathering the necessary supplies for emptying or changing the ostomy appliance, the nurse should advise patients and family caregivers to do the same at home, before they begin changing or emptying the appliance. In fact, caregivers may want to store these supplies—which typically include a pair of gloves, paper towels or washcloths, a basin for holding warm water, a pair of scissors, a pen or marker, new ostomy appliances, and the stoma measuring guide—together in a box or bag for easy access.⁷

Nurses can begin an educational session by providing information about when and how ostomy appliances (which are also called pouches) should be emptied and changed. There are two types of appliances: a one-piece, in which the appliance and the wafer (the circular skin barrier that adheres to the skin) are attached; and a two-piece, in which the appliance snaps onto the skin barrier. Some appliances are open-ended and have a clamp or other securement device at the end, whereas others are closed and sealed. Closed appliances are discarded after each use.²

The appliance should be emptied when it is one-third to one-half full. Encourage patients and caregivers to feel the appliance to assess how full it is and to empty it as needed. The appliance is typically changed twice a week, or sooner if there are problems with leakage or skin irritation.⁸ Be sure to allow the patient and caregiver as many opportunities as possible before discharge to express their concerns, ask questions, and practice emptying the device. After the patient and caregiver watch the nurse change the ostomy appliance, they should be able to demonstrate this for the nurse prior to discharge. The video, which can be accessed at <http://links.lww.com/AJN/A104>, shows the nurse changing the ostomy appliance while the patient is in bed, which may be easier in the days after surgery. However, the patient and caregiver should be aware that people who've had ostomy surgery typically empty and change the appliance while sitting on the toilet.

MEDICATION CONSIDERATIONS

Medication absorption may be altered in people who've had an ileostomy. Some medications, such as those with an enteric coating or in a time-release formulation, may be ineffective because they can't be absorbed.⁹ Patients and caregivers need to be aware of this and remind their pharmacist that they've had os-



After measuring the stoma using the measuring guide, the nurse cuts the wafer, the adhesive part of the ostomy appliance, which is attached to the skin.

tomy surgery each time they fill a prescription for a new medication.

It's also important that these patients and their caregivers are aware of the danger of taking a laxative, which can cause significant fluid loss and dehydration in people who've had ileostomies.⁹ Although these patients have watery and thin stools and are thus unlikely to seek a laxative, they should remind their health care providers of the need to avoid these medications.

BATHING AND ACTIVITY


After the postsurgery recovery period has passed, ostomy patients can take a shower or bath with or without the ostomy appliance.¹⁰ Soap and water will not harm the external tissues of the stoma if it is well rinsed and dried, and water will not flow inside it. After bathing with the wafer and/or pouch on, it is helpful to dry the wafer with a towel or hair dryer to prevent moisture-related skin damage.

People with stomas can swim with their ostomy appliance in place, as the appliance is designed to maintain adhesion in water.^{10,11} The appliance should be emptied before swimming to reduce the likelihood of leakage, and the patient should avoid using heated therapy pools, which may increase the likelihood of infection.¹¹

Most patients do not need to modify their clothing after ostomy surgery. However, an ostomy above the waistline can make it difficult to wear a belt or tuck in a shirt. With a well-secured appliance, patients can participate in sports but should use caution when playing sports that require a significant amount of body contact. After the postoperative period, which typically lasts a few weeks, patients are physically able to return to their previous levels of physical and sexual activity. However, they and their partners may



Resources for Nurses

 Caring for and Maintaining Ostomy Bags^a
<http://links.lww.com/AJN/A112>

AJN's resource page for supporting family caregivers includes previous articles and videos in this series.
<http://links.lww.com/AJN/A81>

^aFamily caregivers can access this video, which is available in English or Spanish, as well as additional information and resources, on AARP's Home Alone Alliance web page: www.aarp.org/nolongeralone.

need emotional and psychological support as they adjust to an altered sexual experience, since ostomy surgery can affect both sexual function and body image.¹²

Patients who've had an ostomy can travel without restrictions. Travel cards that detail a patient's care needs in various languages can be downloaded from the World Council of Enterostomal Therapists website (see www.wcetn.org/index.php?option=com_content&view=article&id=83:country-travel-cards&catid=19:default&Itemid=154). These cards can be used at security checkpoints to validate the stoma appliance and help the patient or caregiver communicate the patient's medical and ostomy care needs while traveling.

DIETARY AND FLUID RECOMMENDATIONS

Eating a balanced diet to maintain good health is essential after ostomy surgery. Patients usually follow a liquid or low-fiber and low-residue diet following surgery, after bowel sounds have returned. Typically, they transition to a regular diet after edema resolves, approximately six to eight weeks after surgery.^{9,10}

Patients and caregivers should be told to introduce new foods slowly to assess their effect on ostomy management.⁹ Many common foods and drinks, for instance, can affect the consistency, color, and frequency of stool and urine production; the production of gas; and odor.^{3,10} Using a well-fitted appliance, eating regularly, and avoiding foods that produce gas (such as beans, dairy products, and onions) can help to prevent the dislodgment of the appliance and any associated embarrassment.⁹ In addition, some appliances are designed to filter odors, and odor-eliminating drops can also be added to the ostomy appliance.

Maintaining adequate hydration is very important for patients who've had ostomy surgery. They should have a daily fluid intake of at least 48 to 64 ounces.⁹ Caffeinated beverages such as coffee or tea can adversely affect hydration, because they can cause an increased output of urine and salt.⁹ The United Ostomy Associations of America recommends that

patients counter this fluid loss by increasing their water intake when drinking caffeinated beverages.¹²

Eating regularly and not skipping meals helps to prevent the occurrence of watery stools and gas.⁹ Patients should eat a variety of foods from all food groups, avoiding those known to bother the patient (such as dairy products if lactose intolerant) or increase the likelihood of a blockage, such as popcorn, mushrooms, and nuts.⁹ ▼

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REFERENCES

- Reinhard SC, et al. *Home alone: family caregivers providing complex chronic care*. Washington, DC: AARP Public Policy Institute; 2012 Oct. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.
- United Ostomy Associations of America, Inc. *What is an ostomy?* n.d. http://www.ostomy.org/What_is_an_Ostomy.html.
- Prinz A, et al. Discharge planning for a patient with a new ostomy: best practice for clinicians. *J Wound Ostomy Continence Nurs* 2015;42(1):79-82.
- Jemec GB, Nybaek H. Peristomal skin problems account for more than one in three visits to ostomy nurses. *Br J Dermatol* 2008;159(5):1211-2.
- Kwiat M, Kawata M. Avoidance and management of stomal complications. *Clin Colon Rectal Surg* 2013;26(2):112-21.
- Wound, Ostomy and Continence Nurses Society Guideline Development Task Force. WOCN Society clinical guideline: management of the adult patient with a fecal or urinary ostomy—an executive summary. *J Wound Ostomy Continence Nurs* 2018; 45(1):50-8.
- Carmel J, et al., editors. *Wound, Ostomy and Continence Nurses Society core curriculum. Ostomy management*. Philadelphia: Wolters Kluwer; 2016.
- Colwell JC. Postoperative nursing assessment management. In: Carmel J, et al., editors. *Wound, Ostomy and Continence Nurses Society core curriculum. Ostomy management*. Philadelphia: Wolters Kluwer; 2016. p. 113-9.
- Pasia M. *Ostomy nutrition guide*. Kennebunk, ME: United Ostomy Associations of America; 2017. http://www.ostomy.org/uploaded/files/ostomy_info/OstomyNutritionGuide.pdf?direct=1.
- Goldberg MT. Patient education following urinary/fecal diversion. In: Carmel J, et al., editors. *Wound, Ostomy and Continence Nurses Society core curriculum. Ostomy management*. Philadelphia: Wolters Kluwer; 2016. p. 132-9.
- Skaros S, et al. Stomas, ostomies, and appliances: implications for aquatic therapy. *Aquatic Therapy Journal* 2006; 9(2):3-7.
- Turnbull G. *Intimacy after ostomy surgery*. Kennebunk, ME: United Ostomy Associations of America; 2009. http://www.ostomy.org/uploaded/files/ostomy_info/uooa_sexuality_en.pdf?direct=1.