

Tips for Navigating Your Patients With Ostomies

As Navigators, you're not expected to take on the role of an Ostomy nurse but you may need to assist your patients if they have or are getting an ostomy. Navigating any patient often means connecting the patient to the services they need and finding education and support resources for them. These tips are being shared to help guide you through the journey of navigating your patient with an ostomy.

General

1. Educate yourself about [ostomies](#). You don't have to be an expert but you should be familiar with the terminology if you navigate patients with ostomies.
2. Know where to go to find resources for [ostomy](#) education and support.
3. Make friends with your hospital's [Wound and Ostomy \(WOC\) Nurse\(s\)](#) and collaborate with them and the patient's surgical team.

Before Surgery

Assist your patient with pre-operative education and support.

1. Empower your patient to be proactive and begin learning about ostomy care early. They can start by looking at some of the resources listed in this document. Encourage them to ask questions until they feel comfortable with the decision to have surgery.
2. Facilitate a pre-op appointment with an Ostomy specialist for education and counseling.
3. Encourage your patient to attend a [support group](#) if there is enough time before surgery.
4. Contact the [United Ostomy Association](#) or local support groups to see if they have a Visitor program. Patients find it very helpful to speak to someone who has been through the same journey.

After Surgery

1. Make sure your patient has a consult with an Ostomy nurse. Contact the physician or ask the bedside nurse to ask for the consult. Patients are not in the hospital a long time so they need to begin learning self-care as early as possible.
2. Help the bedside nurses find resources so they can assist with teaching the patient self-management skills. The WOC nurse helps with initial teaching and management of complex problems but is not available 24/7 like the bedside nurses.
3. Patients should order [starter kits](#) (free samples for new patients) from the Ostomy manufacturers and [supplies](#) for home from DME or supply companies. Unfortunately not all hospital Case Managers/Discharge Planners assist patients with this. Home health agencies will sometimes order supplies, especially for Medicare patients. Supplies can take several days to arrive which can cause problems and anxiety for the patient. By ordering the starter kits right after surgery, patients can get samples quickly as well as the support of an ostomy professional.
4. Ostomy information can be overwhelming especially if you are also giving your patient cancer materials. Highlight the main points and break it down for them, prioritizing what they need to know now to care for their ostomy.

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5. Emotional adaptation after surgery is just as significant as physical adaptation. Encourage patients to join a face to face [support group](#), even if their ostomy is temporary. Patients with temporary ostomies still need teaching and support. They often don't want to invest the time and energy into learning but the reality is that learning for ostomy care is the same no matter how long the patient has the ostomy.
6. Facilitate a post-op appointment with an ostomy nurse for additional education and reinforcement. Many patients get home health visits but most companies do not have trained ostomy nurses. Empower patients to learn self-care and not rely on the home health nurse to teach them or do all of their ostomy care.

Along the Journey:

Patients will need ongoing support and help with managing problems. As a Navigator you can help them find resources and facilitate referrals to the services they need such as seeing an Ostomy nurse, dietitian or a mental health professional. Continue to assess their barriers and identify ways you can assist them.

Bumps in the Road

There are potential challenges that any person with an ostomy may experience. Most of these are manageable if the patient is knowledgeable and there are resources available to help.

1. If your patient has problems with their ostomy, help facilitate a visit to an ostomy nurse/clinic. This requires a provider order. There are gaps in outpatient services for people with ostomies. Not all doctors have an ostomy nurse in their office and many hospital ostomy nurses only see inpatients. **Insider's Tip:** Some hospital WOC nurses will see outpatients if their surgeon has privileges at that hospital even if the patient didn't have surgery there. See the [Ostomy Outpatient Resource Book](#).
2. If you are talking to your patient by phone about any problem related to their ostomy, see the [Ostomy Problem Guide](#) to give you guidance and help you identify serious problems and who they should contact.
3. Many companies have ostomy nurses or trained reps that can speak to patients by phone. Some patients can also get recommendations for non-urgent problems from discussion boards and online communities. See [Online and Telephone Support](#). Caution the patient that some personal and non-professional recommendations may be biased and not applicable to them.
4. There are some problems specific to cancer treatments like radiation dermatitis and mucositis. Sometimes the treatment is similar to what would normally be done for the skin. The problem arises if certain treatments need to be used under the ostomy barrier which can cause poor adherence leading to leakage of stool or urine resulting in worsening skin problems. This definitely warrants a visit with a specialist.
5. People with an ileostomy are at greater risk for dehydration. Having infections like C. diff or side effects from chemo can increase the ileostomy output so much that there's no way a patient

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can get sufficiently hydrated and they need to go to the ER. Dehydration can also lead to a [bowel obstruction](#). You can help reinforce these points with your patients.

5 Helpful Resources:

There are a lot of great resources online. Here are the ones I think are the most helpful.

1. [New Ostomy All in One Patient Guide](#) from the United Ostomy Association has information the ileostomies, colostomies and urostomies. The UOAA is the best website for people living with an ostomy.
2. [Ostomy Nutrition Guide](#) has a good section of dehydration and a food reference guide.
3. American College of Surgeons: [Ostomy Home Skills](#) has videos on ostomy care for adults and pediatrics as well as educational booklets. This is not only helpful for patients and their caretakers, but it's a great resource for nurses who will be taking care of a patient with an ostomy.
4. [American Cancer Society: Ostomies](#)
5. [North Texas Wound and Ostomy Nurses](#) is a one-stop shop of resources including the [Ostomy Outpatient Resource Book](#), [Clinical Resources](#) and [Patient resources](#). There is local information on Ostomy support groups and the Outpatient resource book has information on the available outpatient ostomy services.

Ostomy Blogs for Patients:

[Navigating the Journey: What You Should Know about Ostomies](#)) Sarah Cannon Blog

[Navigating your Ostomy Journey](#)

[The Ostomy Challenges on your Cancer Journey](#) PearlPoint Blog: pearls of Wisdom

Gwen Spector BSN, RN, COCN, CCP
GI Oncology Nurse Navigator
Sarah Cannon Institute at
Medical City Healthcare
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