

- **SUPPORT GROUP MEETINGS:**

- Contact your local Support Group in your area:
 - Website: / Phone:
 - Contact: / Meeting Information:

To find a support group in your area, contact the United Ostomy Associations of America at www.ostomy.org/Find_a_Support_Group.html or by phone at 800-826-0826.

- **GO TO THE MEETING WHEN YOU ARE UP FOR A TRIP OUTSIDE THE HOUSE! THIS IS THE MOST HELPFUL THING YOU CAN DO – OSTOMATES HELPING OSTOMATES!**

- If there is no support group in your area, then go to www.ostomy.org/Membership.html and join UOAA as an Individual Member. This will give you access to people, materials and help that you'll need to be a successful ostomate.

- **OSTOMY PATIENT VISITOR REQUEST:**

Schedule time to meet a Certified Patient Visitor from your local support group (contact information above). Assistance in obtaining an ostomy visitor is also available by phoning UOAA at 800-826-0826 or by emailing ostomyvisitor@ostomy.org

- **HOME HEALTH CARE NURSE VISITS / ASK PHYSICIAN TO ORDER A HOME HEALTHCARE NURSE AGENCY THAT HAS A WOCN on staff (if in your area).**

If a home health agency is being used for a few weeks, check the WOCN website (www.wocn.org) for certified WOCNs (Wound Ostomy Continence Nurses) that work at Home Health Care agencies. Ask your physician to specifically order those agencies and request those nurses to assist you. Note: Be sure to ask your physician to write a prescription for a home healthcare RN to come to your home after you are discharged so your wounds can be monitored after discharge. The Home Health Company may have an OMS (Ostomy Management Specialist) on staff as well – but you'd have to ask.

- Also, ask if they do not have a WOCN nurse, to send an RN with ostomy care experience.
- Call the Home Health agency before the first visit and ask them to send a nurse with Ostomy experience – may need to remind them a day before each scheduled visit.

- **IN PATIENT – IN HOSPITAL / ON STAFF WOUND CARE NURSE OR OSTOMY MANAGEMENT SPECIALIST:**

Visit with a C/WOCN (Certified Wound Ostomy Continence Nurse) if one is available at the hospital you are in. If you are in an area that does not have a C/WOCN, then there may be an OMS (Ostomy Management Specialist) in your area as well.

- **FIND YOUR LOCAL WOC NURSE OR OSTOMY MANAGEMENT SPECIALIST**

- Check the WOCN web link that will show you all the CWOCNs in your area:
 - www.wocn.org/?page=Nurse_Referral
 - CONTACT THE WOCN ASSOCIATION BY WEB PAGE OR PHONE:
 - Phone: 888-224-9626 (NJ) / Web: www.wocn.org/?page=Nurse_Referral
 - CONTACT THE OMS ASSOCIATION BY WEB PAGE OR PHONE:
 - Phone: 888-929-4575 (MI) / Web: www.nawccb.org/locate-clinician



Website: www.ostomy.org phone: (800) 826-0826

Email: info@ostomy.org

P.O. Box 525
Kennebunk, ME 04043

Phone: 800-826-0826
Fax #: 888-747-9655
8am-5pm Eastern

- **WOUND CENTER PRESCRIPTION:** Get prescription from Doctor for “standing Wound Ostomy Care to Outpatient Clinic” (covered by your insurance if applicable) that HAS A CERTIFIED WOCN (CWOCN) (Wound Ostomy Continence Nurse) or Ostomy Management Specialist (OMS). This will allow you to see the nurse whenever there is a skin issue or continence issue that they can assist you with.
- **Medication information:**
If you are an **Ileostomate or Colostomate (especially ileostomate)**, be advised that **time release medications probably don't work for you** – please be sure to advise the pharmacist at your local pharmacy, or mail order pharmacy of this so they are aware of it. Educate your Pharmacist and Physician as they do not always know this.
- **SUPPLIES:**
Order a product catalog from your medical supplier, so you can see the different products out there and what assortment you have to choose from. A WOCN can assist you in your area. Be sure to use a supplier which is approved by your insurance company.
- **From Hospital staff:** Find out how many ostomy supplies you'll be sent home with. Sometimes, the hospital policy is to give patients just a few pouches. If so, have your nurse write down the manufacturer and stock numbers of the products you're using.
- Also, ask about being enrolled in one of the discharge programs that are sponsored by ostomy manufacturers – such as the Secure Start Program by Hollister in the US (888-808-7456) (not an endorsement – informational only).
- **FREE OSTOMY SAMPLES from the Manufacturers:**
Contact vendors for Samples (before leaving hospital if possible) so they are at home waiting for you. Either YOU or a family member can contact the manufacturers to send out samples so you have multiple options to try out.
- No two ostomies are alike, so one size does NOT fit all! Experiment!
- The major manufacturers do not sell supplies directly to ostomates. They sell to medical equipment supply companies, which in turn sell to consumers.
- Manufacturers' WOCNs are nurses available to talk to you about your issues if you do not have a WOCN/OMS available in your area. They can walk you through issues you are having with your pouching system. Their services are free of charge as well.
- **PHYSICIAN OFFICE VISITS / PHONE CALLS – Issues NOTIFICATION:**
Be sure to bring your issues up with your physician. You may have to educate your physician on what you need: Ostomy supply prescription, and you may need yearly abdominal x-rays to validate that all is well with your stoma and abdominal cavity.
- **They will not always ask**, and “Don't Ask – Don't Tell” is not a good thing, especially in the beginning. All aches, pains, and skin changes need to be reported in the abdominal area, within reason and common sense.

- **Educate yourself, and take a written list of questions so you do not forget to ask them.** If the physician cannot answer them, contact a WOCN/OMS or call UOAA for assistance or a direction to someone who can answer your questions.
- **BE PREPARED:** You may have a few unfortunate events in the beginning. Be prepared like a good Scout. Keep a backpack or carry bag with you with change of clothing and supplies for at least 2 changes.
- **POST OPERATIVE AIR TRAVEL:** If you are traveling by airplane after your surgery, be sure to go to UOAA's Travel Tips page at www.ostomy.org/Ostomy_Travel_Tips.html which includes information on carrying scissors on the plane, full body scanners (Advanced Imaging Technology), and many useful links to the TSA (Transportation Security Administration) website. A letter from your physician describing your condition may be helpful, especially if your condition is complicated/unusual or you will be traveling outside the US.
- **UOAA TRAVEL COMMUNICATION CARD:**
www.ostomy.org/uploaded/files/travel_card/Travel_Communication_Card.pdf
This includes a **TSA Notification Card** and an additional card that may be helpful if you need to use a restroom while on board the plane. The TSA Notification Card does not exempt you from screening, but helps to communicate your condition non-verbally to TSA officers.
- Before traveling, you can phone the **TSA Cares helpline** at 855-787-2227 and you can arrange for a TSA "Passenger Support Specialist" to assist you through security screening.
- If you need to change your pouching system before a flight, try to do it at least 24 hours before departure, to ensure that the skin barrier/wafer is well sealed.
- **TRAVELING BY CAR / POST OPERATIVE**
If you drove a long distance (ex: Nevada to California) for your surgery, on the way home, bring pillows to allow you to cushion your surgical area from the seat belts. This will make the trip home a little more comfortable.
- **POST OPERATIVE MEDICATIONS:**
If your physician has prescribed a "stool softener" in the beginning after your surgery, follow directions for taking the medication.
- Anti-diarrheal meds (Imodium) and bulking agents (Metamucil, etc.) may be an option but patients should speak with doctor or WOCN first.
- **POST OPERATIVE FOOD – DO'S / DON'TS:**
Be sure to watch what you eat. There are food guides to tell you what foods produce gas, causes odors, or cause loose stools. The UOAA website has a guide at:
www.ostomy.org/uploaded/files/ostomy_info/food_ref_card.pdf
Be gentle with your food eating habits. Take it easy. Eat a soft diet initially. Gradually introduce foods to your diet in small amounts to see how your intestines will take to the foods. The intestinal tract is one of the slower healing parts of our body, especially as we get older.
- **DON'T:** Ileostomates and Colostomates (especially ileostomates): At first, avoid foods that



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may be stoma obstructive: NUTS, SEEDS, vegetables/fruit skins, or foods with skins like garlic and onions (powders ok). Re-introduce gradually in small quantities to find out what you can tolerate. Urostomates need to be careful in the beginning as well.

- All 3 surgeries involve surgery to the intestines, which means they need time to heal before exposing them to foods that can cause blockages (like green vegetables of any kind).
- DO: Foods like meatloaf, where the food has been chopped a little more finely to allow you to digest easily.
- **Abdominal blockages:**
If you are in intense intestinal pain for more than 4-5 hours, go to an Emergency Room or urgent care.

WATER: Water is important to your recovery. Drink lots of water. You need more water than an average person because it does not stay in your body as long. If you feel thirsty, then you are 2 cups (half a liter) of water behind what you should have already been drinking. Start drinking.

- Adding flavorings to the water keeps it from getting boring. Be mindful of what you add if you are also diabetic.
- Keep a container with you when you travel in your car, or other vehicle for water. Leaving the house without water can be harmful if you get dehydrated.
- Sipping vs. gulping: Take your time drinking your water. Gulping the water will not help – it will basically end up passing through too quickly, vs. allowing your system to absorb the water properly.
- **ASSESSING FLUID BALANCE:**
The first step for an ostomate in assessing fluid balance is to determine the level of their output. This can easily be done by noting the number of times that you actually empty your pouch per day and also estimating how many ounces or milliliters were in the pouch each time (that is if the output is purely fluid). If you multiply the two figures over a whole day you can get a rough estimation of your output. It is then important to make sure this that this figure is at least exceeded, if not doubled, throughout the day to replenish any fluid loss that you may have. But apart from assessing your fluid balance how can we tell if we are dehydrated?
- Some of the common symptoms of dehydration are: dry mouth, possible headache, irritability, fatigue, lack of concentration, and possible fainting spells which can cause low blood pressure. *All these symptoms can be indicative that fluid levels in the body are low.*

• **My local Affiliated Support group is:**

Support Group Name:	Phone #
Website:	Meeting Information: