

Resources to Help You Care for Your New Ostomy

Having a new ostomy can be overwhelming. This document will give you resources and tips to help you no matter how long you have your ostomy. Here are a few tips to keep in mind:

1. Learn about your ostomy (type, size), how to care for it (emptying and changing the pouch), and how to live with it day to day (nutrition, activity, working, traveling, etc.). Learn the ostomy terminology and what's normal and what isn't.
2. You will probably receive a lot of educational materials. Organize information in a way that's best for you and where you can find and use it easily. Keep notes about what you learn, highlight the most important things to know, and write down questions you have.
3. Find the support that's right for you whether it's in person, online, or by phone. It helps to talk to someone who has an ostomy and knows what you're going through.
4. Ordering supplies can take time and can be overwhelming. Sign up early for one or more of the patient support programs to get support, guidance, and some starter supplies.
5. Look at the resources in this document. They have great tips and can help you become independent and more confident in the care of your ostomy.

Learning How to Care for and Live with your Ostomy

Learning to live with and care for your ostomy is important but it takes time. It's a skill best learned when learning can be started early and repeated. There are many resources to help you learn ostomy care before and after your surgery.

The [United Ostomy Association of America](#) (UOAA) has numerous printable information guides, videos, and one page reference sheets. The UOAA is the best all-around website for people living with an ostomy. Many of the educational materials are also in [Spanish](#).

- The [Ostomy 101 Infographic](#) and [Living with an Ostomy brochure and video](#) are good resources to look at before ostomy surgery. The [Ostomy and Continent Diversion Patient Bill of Rights](#) is a tool that identifies the needs and expectations of each step of the journey.
- The [New Ostomy All in One Patient Guide](#) has information on ileostomies, colostomies, and urostomies as well as many tips for people with a new ostomy.
- The [Ostomy Diet and Nutrition](#) section has a guide with information on dehydration and a food reference chart. This section also had an Ileostomy blockage card you can print if you have an ileostomy. This document has evidence based tips on what you can do at home if you have a blockage and instructions for the ER staff on the other side.
- The [Know Your Ostomy](#) and [Know Your Pouching System](#) are educational blogs with checklists you can fill out to help you learn about your ostomy and order supplies.
- [Phoenix magazine](#) is a quarterly magazine that has stories, tips, and advice for those living with an ostomy.

[American College of Surgeons](#) has free online courses for patients and families, [Home Skills Program for Colostomy/Ileostomy Patients](#) and [Home Skills Program for Urostomy Patients](#) (expires 12/01/20). They also have their English and Spanish Ostomy Skills videos online for no cost.

Ostomy manufacturers such as [Coloplast](#), [Convatec](#), and [Hollister](#) have wonderful online educational information, tips, and booklets to download or print. Many have online videos.

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Several ostomy-related companies and personal websites have blogs and videos with tips and instructions such as [Shield Healthcare: OstomyLife](#), [Newbie Ostomy](#), and [Vegan Ostomy](#). Some of the medical supply companies, like [Shield Healthcare](#), have ostomy care info in their order catalogs.

You can also learn a lot by talking to others with an ostomy. See the next section for resources. Ask your surgeon for an ostomy nurse appointment if you need additional teaching.

Finding Support and Assistance

Some problems can be managed without seeing a nurse or doctor. This section has resources to help you troubleshoot problems and find support.

Online tools are available to help you prevent and manage challenges. [Coloplast Ostomy BodyCheck™](#) helps people with ostomies find the best pouching system for their body type. The [Peristomal Skin Assessment Guide](#) helps people troubleshoot problems with the skin around the stoma.

Online communities and discussion forums are great support resources for people with ostomies. They also give you a way to get answers for non-urgent problems. Listed below are some of the popular communities.

- Convatec's me+ community <http://meplus.convatec.com/>
- Facebook has many groups with ostomy/ostomy-related membership
- Meet an Ostomate: Forum www.meetanostomate.org/
- Ostomyland www.ostomyland.com/ostomyland/
- Ostomy Support Group on Inspire www.inspire.com/groups/ostomy/
- The United Ostomy Association of America (UOAA) has an online [discussion board](#)
- Vegan Ostomy has an [online community forum](#)

Disease specific organizations, such as, Colorectal Cancer Alliance, have online support and a buddy/mentor program.

There are in person support groups that are not only wonderful support, they can give you helpful tips for managing non-urgent problems. They usually have veteran members and ostomy nurses in attendance. There are groups in Dallas, Plano, Carrollton, Lewisville, and Ft. Worth. To find an in person or online ostomy support group go to the united ostomy association's website www.ostomy.org/support-group-finder/ or see the list on the North Texas Wound and Ostomy Nurses [website](#).

The free patient support programs offered by ostomy manufacturers can often help talk you through managing non-complex problems as well as provide support and learning resources. See the supplies section for programs and contact information.

Ostomy supply companies and manufacturers often have dedicated nurses or trained staff to assist people with ostomies by phone like [Convatec](#) and [Byram Healthcare](#). Shield Healthcare's [OstomyLife](#) has two ostomy lifestyle specialists that have blogs and videos for helpful tips on living with an ostomy. It also has "Ask Laura" for non-urgent questions.

Contact your provider to get an appointment with an ostomy nurse if your problem can't be managed at home.

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Getting Ostomy Supplies

Tips about Getting Ostomy Supplies:

- Sign up for at least one patient support program. These programs provide support, help you choose supplies, and send samples as part of the program.
- Try different types and brands of products to see what works best for you. There's not a one size fits all in the ostomy world. You can order samples from most of the ostomy manufacturers and often from your medical supply company. You may have to change products over time as your body changes or problems occur.
- Switch companies if you don't like the company sending your supplies. Contact your insurance company to see who they contract with for ostomy supplies.
- If you are uninsured or your insurance won't cover ostomy supplies see the sections for assistance and donated and discounted supplies. You can also order samples from most Ostomy manufacturers.
- Fill out the *Know your Ostomy* www.ostomy.org/know-your-ostomy/ and *Know your Pouching System* www.ostomy.org/know-your-ostomy-pouching-system-supplies/ checklists with information from your ostomy nurse or surgeon.

Ordering Supplies

Your ostomy nurse will give you some supplies before you are discharged home. Your home health company will provide your supplies if you have Medicare part B but they are not obligated to order supplies for you if you have other insurance. Supplies will need to be ordered for home through a medical supply company. There are several companies but each may accept different insurance plans. It is recommended that you order as soon as possible. The supply company will need to get your surgeon to sign an order for your products. An abbreviated list of companies is listed below.

- Byram Healthcare www.byramhealthcare.com/ 800-308-9445 Custom Cutting program; Ostomy CareLine is staffed by WOC nurses 877-902-9726 x43312; Latino Program 866-302-4295
- CCS Medical www.ccsmed.com/ostomy.aspx 888-MEDICAL (633.4225); Spanish 800-842-6021
- Edgepark Medical Supplies www.edgepark.com/ 888-394-5375
- Liberator Medical www.liberatormedical.com/index.php 866-642-6140
- McKesson Patient Care Solutions <https://mpcs.mckesson.com/> 855-404-6727 Spanish 855-625-2580
- Shield Healthcare www.shieldhealthcare.com 800-407-8982, option 1, will sample products to help patients get the product that works the best for them and they will send an [emergency kit](#). Spanish language website is www.shieldhealthcare.com/esp/

Assistance Programs:

These companies offer up to a year of free supplies if you meet eligibility.

- Coloplast 877-781-2656
- Convatec 800-422-8811 <https://meplus.convatec.com/articles/patient-assistance-program/>.
- Hollister 888-808-7456

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Donated Supplies:

There are organizations that specifically collect donated ostomy supplies to give to people who are uninsured. There are also some charities who take donated medical supplies and may receive ostomy supplies from time to time. Members of your ostomy support group may also have extra unused supplies they want to donate.

- Kindred Box <https://kindredbox.org/> recipients only pay for shipping & handling, limited to 1 box/month
- Osto Group: www.ostogroup.org 877-678-6690 for uninsured patients, you just have to pay for shipping
- Oley Foundation: Exchange Program <http://oley.org/> sometimes has ostomy supplies; recipient has to pay for shipping; check under *Equipment Supplies/Exchange*

Discounted Supplies for Self-pay:

Many companies will give a discount if you are paying out of pocket. Here are some of the main ones that will offer supplies at a discounted rate.

- ATC Medical www.atcmedical.com/ 877-508-4013
- Best Buy Ostomy Supplies <https://bestbuymedicalsupplies.com/> 866-940-4555
- OstoStore <http://ostostore.com/> 877-396-3887
- Parthenon <https://parthenoninc.com/> 800-453-8898
- Stoma Bags www.stomabags.com/ 855-828-1444

Free Patient Support Programs:

Many manufacturers and some product suppliers offer personalized ostomy assistance services that can include support, recommendations, and samples. You do not have to order these supplies if they don't work for you. Listed below are programs from manufactures. While they provide samples, you have to order regular home supplies from a medical supply company.

- B.Braun MyOsto 833-387-6744 www.myosto-mylife.com/en.html
- Coloplast Care 888-726-7872 www.coloplastcareenroll.com/
- Convatec Starter Kit 1-877-585-0470 option 1 <http://starterkit.convatec.com/>
- Hollister Secure Start 888-808-7456 www.hollister.com/us/ostomy/ss/

Resources:

American College of Surgeons www.facs.org/education/patient-education/skills-programs/ostomy-program.
Byram Healthcare www.byramhealthcare.com/ostomy
Coloplast www.coloplast.us/Ostomy/People-with-an-ostomy/
Convatec www.convatec.com/ostomy/
Hollister www.hollister.com/en/ostomycare
Newbie Ostomy www.newbieostomy.com/
North Texas Wound and Ostomy Nurses <https://ntxwon.nursingnetwork.com/> the outpatient ostomy resource book is in the "Education and Resources" section
Ostomy 211 www.ostomy211.org/
Peristomal Skin Assessment Guide <http://psag-consumer.wocn.org/#home>
Shield Healthcare OstomyLife www.shieldhealthcare.com/community/ostomylife/
United Ostomy Association www.ostomy.org
Vegan Ostomy www.veganostomy.ca/